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'A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic

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3 'A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland
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5 during the COVID-19 pandemic
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Abstract

Objectives: To investigate the experiences and views of practitioners in UK and Ireland concerning changes in bereavement care during the COVID-19 pandemic.

Design: Online survey using a snowball sampling approach.

Setting: Practitioners working in hospitals, hospices, care homes and community settings across the UK and Ireland.

Participants: Health and social care professionals involved in bereavement support.

Interventions: Brief online survey distributed widely across health and social care organisations.

Results: 805 respondents working in hospice, community, and hospital settings across the UK and Ireland completed the survey between 3rd August and 4th September 2020.

Changes to bereavement care practice were reported in: the use of telephone, video and other forms of remote support (90%); supporting people bereaved from non-COVID conditions (76%), from COVID-19 (65%), and people bereaved before the pandemic (61%); funeral arrangements (61%); identifying bereaved people who might need support (56%); managing complex forms of grief (48%) and access to specialist services (41%). Free-text responses demonstrated the complexities and scale of the impact on bereaved people and on health and social services, practitioners and their relationships with bereaved families.

Conclusions: The pandemic has created major challenges for the support of bereaved people: increased needs for bereavement care, transition to remote forms of support, and the stresses experienced by practitioners, among others. The extent to which services are

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3 able to adapt, meet the escalating level of need and help to prevent a “tsunami of grief”
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6 remains to be seen. The pandemic has highlighted the need for bereavement care to be
7
8 considered an integral part of health and social care provision.
9

10
11 **Keywords:** bereavement care, grief, COVID-19 pandemic
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17 **Strengths and limitations of this study**

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19
20 • This national survey of health and social care professionals is the first to identify the
21
22 major impact of the pandemic on bereavement care in the UK.
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- 25
26 • 805 responses from across the UK and Ireland were received from a wide range of
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28 professional roles and settings supporting the generalisability of the data.
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- 31
32 • Due to the snowball sampling approach, it is not possible to calculate a response
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34 rate.
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38 • While there was consistency in responses across settings, further research is needed
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40 to investigate the settings and bereaved populations where support needs are
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42 highest.
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Introduction

Bereavement care is a significant component of the work of a wide range of health and social care professionals, yet it is often unrecognised and considered a low priority in health care policy and practice. The global COVID-19 pandemic has brought to the fore the importance of end of life and bereavement care. The scale of the impact of the COVID-19 pandemic on those bereaved is now becoming apparent: it is estimated that for every COVID death nine people are affected by bereavement (1). Deaths from COVID-19 are characterised by factors that may increase the risk of complicated and prolonged grief responses (2-4) including; sudden and unexpected deaths, deaths in intensive care units, patient isolation and severe symptoms including breathlessness at the end of life (5-8). Social distancing measures have had a major impact on those bereaved from all causes, not only from COVID-19. These essential measures restricted visiting in hospitals, care homes and hospices, preventing loved ones saying goodbye and leaving some to die alone. Viewing the deceased person's body and funeral proceedings were severely curtailed. Bereaved people may feel especially isolated and unable to access the benefits of social support (9). People bereaved prior to the pandemic are also affected, with social isolation and interrupted bereavement care intensifying feelings of grief (10). Evidence is limited on the ways in which the pandemic is impacting on the experience of bereavement. A recent review found that pandemics may cause multiple losses, both directly related to the death itself and symbolic losses to individual and societal bereavement practices (11). Rituals related to the management and disposal of bodies have significance across a range of religious and cultural communities and the disruptions caused by pandemics may impact bereavement outcomes (12-14). Harrop et al. (15) reviewed the

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3 evidence regarding system-level responses to mass bereavement events, including natural
4
5 and human-made disasters as well as pandemics; they found limited research of low quality.
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9 At present, it is not clear what forms of support are appropriate or effective during and
10
11 following pandemics (16). To support practitioners and policy-makers, we surveyed
12
13 practitioners in the United Kingdom (UK) and Ireland concerning changes in their
14
15 bereavement care practice during the COVID-19 pandemic.
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18 19 20 21 22 **Methods**

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25 An online survey (see Appendix 1) was developed in Survey Monkey based on the literature,
26
27 stakeholder consultation and the authors' clinical and academic experience. The study was
28
29 reviewed by the University of Cambridge Psychology Research Ethics Committee
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31 (PRE.2020.094).
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36 After a local pilot, an email with the survey link was sent between 3 August and 4
37
38 September 2020 to members of a wide range of organisations: Association for Palliative
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40 Medicine of Great Britain and Ireland, UK Queen's Nursing Institute, Royal College of
41
42 General Practitioners, Hospice UK, National Association of Funeral Directors, National
43
44 Bereavement Alliance, Association of Hospice and Palliative Care Chaplains, UK Board of
45
46 Health Care Chaplains, College of Health Care Chaplaincy, Dying Matters, Association of
47
48 Directors of Adult Social Services in England, Care Association Alliance, National Care
49
50 Association, Care Provider Alliance, The Cremation Society, British Psychological Society and
51
52
53 a national network of Patient and Public Involvement (PPI) leads. Participants were
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3 encouraged to forward the survey link to interested colleagues, seeking a snowball sample
4
5 of practitioners.
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9 Responses were anonymous unless respondents supplied their name and email address in
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11 the optional final field to indicate interest in further research. After initial questions seeking
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13 demographic data concerning respondents' geographical areas of work, professional roles,
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15 work settings and involvement in bereavement care, the main question addressed changes
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17 in bereavement care practice (if any) during the COVID-19 pandemic. These included
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19 identifying bereaved people who might need support, restrictions regarding funeral
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21 arrangements, supporting people bereaved from COVID, and from non-COVID conditions,
22
23 supporting people bereaved before the pandemic, managing complex forms of grief, use of
24
25 telephone, video or other remote support and access to specialist services for the bereaved.
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27 Details regarding changes in practice were invited in free text. A final optional question
28
29 invited further comments on supporting bereaved people during the pandemic.
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36 *Data analysis*

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38 The Checklist for Reporting Results of Internet E-Surveys was followed (17). Descriptive
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40 statistics were used for demographic and categorical response data. Analysis of free-text
41
42 replies was undertaken by CP and JH. Following a thematic analysis approach, themes were
43
44 developed inductively from the data by coding responses and allocating them to thematic
45
46 categories (18). These themes were refined in consultation with SB.
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51 *Patient and Public Involvement*

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53 The Cambridge Palliative and End of Life Care Patient and Public Involvement group were
54
55 involved throughout the development, dissemination and analysis of the survey. Following a
56
57 meeting in April 2020 where priority areas for bereavement research were discussed, RL
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1
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3 joined the project advisory group to ensure that PPI perspectives were included throughout,
4 especially development of the survey instrument. A second PPI group meeting in September
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6
7
8 2020 discussed the survey findings, identified key recommendations for practice, advised
9
10 concerning dissemination strategy and suggested avenues for further research.
11
12

13 **Results**

14 *Respondents*

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17 Eight hundred and five survey responses were received between 3rd August and 4th
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21
22 September 2020 from a wide range of health, social care and bereavement professionals
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24
25 (Table 1): Nurses (176, 22%); Bereavement Counsellors, Support Workers or Volunteers
26
27 (173, 21%); Chaplains (115, 14%); Doctors (98, 12%); Health and Social Care Managers (54,
28
29 7%); Social Workers or Social Care Workers (52, 6%); Allied Health Professionals (35, 4%);
30
31
32 Psychologists, Psychotherapists and Counsellors (30, 4%); Bereavement Service Managers
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34 and Coordinators (29, 4%); Administrators (27, 3%); and Funeral Directors/Celebrants (19,
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37 2%).
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Table 1. Current professional role

| Professional role | No. of respondents |
|---|--|
| Nurse | 176 (22%) |
| - <i>Palliative care specialist nurse</i> | 103 |
| - <i>Community nurse</i> | 51 |
| - <i>Other nurse</i> | 22 |
| Bereavement counsellor, support worker or volunteer | 173 (21%) |
| Chaplain | 115 (14%) |
| Doctor | 98 (12%) |
| - <i>Palliative care doctor</i> | 65 |
| - <i>General Practitioner</i> | 28 |
| - <i>Other doctor</i> | 5 |
| Health and social care management | 54 (7%) |
| Social worker/Social care worker | 52 (6%) |
| Allied Health Professionals | 35 (4%) |
| Psychologists, psychotherapists and counsellors | 30 (4%) |
| Bereavement service manager or co-ordinator | 29 (4%) |
| Administration | 27 (3%) |
| Funeral Director/Celebrant | 19 (2%) |
| Total | 808 (three respondents identified two job roles) |

Responses were received from across the UK and Ireland (Figure 1) from practitioners working in Hospice (37%), Primary Care and Community (32%), Hospital (25%), and Care Home (6%) settings. Participants were involved in a range of bereavement care provision: emotional support and listening (18%), pre-bereavement support prior to death (15%), support immediately after a death (15%), providing information on support services (13%), referring for specialist support (10%), clinical assessment of support needs (8%), bereavement counselling (8%), practical arrangements of certificates and funerals (7%), specialist psychological / psychiatric support (2%) and prescribing medication (2%).

Changes in bereavement care practice

Respondents reported major changes in their personal provision of bereavement care and/or changes in their area across all the listed categories. Examples from thematic analysis of the explanatory free text are shown in Table 2.

The greatest change was to the use of telephone, video and other forms of remote support, reported by 90% of respondents. Prior to the pandemic telephone and video had been used rarely but were now the primary mode of support.

Practitioners reported changes in skills required to support people bereaved by COVID-19 (65%) and non-COVID conditions (76%). Regardless of cause of death it was emphasised that the support provided was largely consistent, as all families had experienced similar restrictions prior to and after a death.

Support for people bereaved before the pandemic also experienced significant change (61%) as many bereavement services had been suspended and/or had shifted to online or telephone formats.

The impact of restrictions regarding funeral arrangements (61%) and difficulties identifying bereaved people who might need support (56%) were frequently reported, exacerbated by reduced opportunities for in-person interaction.

Less changes in managing complex forms of grief (48%) and access to specialist services (41%) were reported, although many were unsure of changes in these areas.

Table 2. Bereavement care changes during COVID-19

| Changes to | Yes | No | Unsure | Illustrative comment examples |
|--|-----------|-----------|-----------|--|
| Identifying bereaved people who might need support | 437 (56%) | 291 (37%) | 59 (7%) | <p>We've been unable to see as many family members face-to-face as we normally would, so it's been harder for us to identify people. (#58 Hospice Social Worker)</p> <p>More difficult to assess those who need support with distancing and limited visiting. This influenced our ability to form relationships with relatives and identify their needs. (#104 Palliative Medicine Doctor)</p> <p>as a clinical team we were much more proactive, checking every bereaved family/carer and doing it twice and taking longer periods of time to make sure it was as right as it could be, impacting hours worked. (#802 Quality Improvement Lead)</p> |
| Restrictions regarding funeral arrangements | 446 (61%) | 181 (25%) | 108 (15%) | <p>Families will talk to us about how unfair they feel the restrictions are regarding funerals, especially if their loved one did not die from Covid 19. (#267 Hospital Bereavement Manager)</p> <p>The bereaved have found it very difficult not being involved in the physical process of collecting death certificates, taking them to the registrar, then physically going to the funeral directors - these rituals are part of a process. (#766 Citizens Advice Administrator)</p> <p>Bereaved relatives don't come back and collect the death certificate -it gets scanned to the registry office We do an online cremation form which we email to the funeral directors. We do not need to see the patient after death and don't go to funeral directors. Part 2 GPs are not needed (#545 Palliative Medicine Doctor)</p> |

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| 5 | Supporting people | 500 | 189 | 85 (11%) |
| 6 | bereaved from COVID | (65%) | (24%) | Sudden, more unexpected deaths, different bereavement response and reactions. Disbelief. Practical questions about how long they should self-isolate for after the death if they visited the hospital. (#74 Palliative Medicine Doctor) |
| 7 | | | | |
| 8 | | | | Visiting restrictions have meant much less face to face contact. For example I |
| 9 | | | | have talked with a spouse in the car park at social distance (#153 Palliative |
| 10 | | | | Medicine Doctor) |
| 11 | | | | |
| 12 | | | | |
| 13 | | | | |
| 14 | | | | There was a lot of anger about having Covid on the death certificate if they had |
| 15 | | | | been suffering from a long term illness prior (#572 Hospice Bereavement |
| 16 | | | | Counsellor) |
| 17 | | | | |
| 18 | | | | |
| 19 | Supporting people | 586 | 157 | 33 (4%) |
| 20 | bereaved from non- | (76%) | (20%) | Very challenging at first as we did not know how to support the bereaved as |
| 21 | COVID conditions | | | events were folding at a high and fast speed. Every case was treated as though it |
| 22 | during the pandemic | | | was Covid-19. Lots of gaps and lessons to be learned as some non-Covid patients |
| 23 | | | | were just classified as Positive patients. (#141 Chaplain) |
| 24 | | | | |
| 25 | | | | I have found families who have lost a member during the pandemic feel their |
| 26 | | | | loss is not as big as that of people dying of COVID. Or as important. (#234 |
| 27 | | | | Hospice Social Worker) |
| 28 | | | | |
| 29 | | | | |
| 30 | | | | it is hard to differentiate between COVID and non-COVID deaths. The death may |
| 31 | | | | not be certified as COVID related, but the bereaved person experience may well |
| 32 | | | | be impacted by the COVID restrictions. (#440 Service Manager/Head of |
| 33 | | | | Department) |
| 34 | | | | |
| 35 | | | | |
| 36 | Supporting people | 468 | 214 | 84 (11%) |
| 37 | already experiencing | (61%) | (28%) | Pandemic caused relapse to clients who were beginning to look forward and |
| 38 | | | | manage their grief, necessitating offering extra support (#127 Hospice |
| 39 | | | | Bereavement Counsellor) |
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bereavement when
the pandemic started

Many clients receiving counselling have refused offers of telephone, preferring to wait until 'normal services resume'. (#682 Hospice Social Worker)

We are beginning to see more extreme reactions from people who were bereaved before the pandemic and who had begun to find ways of living in their altered world, but who now find that most of the outlets that they were using to help themselves are now closed to them. (#271 Hospice Social Worker)

Managing complex forms of grief 356 (48%) 256 (34%) 135 (18%)

These are just more difficult cases to tackle, and the isolation - not having been able to visit a loved one in hospital who's subsequently died - exacerbates this. (#7 General Practitioner)

We have at times entered territory/topics that are new and we do not have the answers to. (#526 Hospice Family Services Manager)

Increase in referrals regarding this (#540 Assistant Psychologist)

Use of telephone, video or other remote support 704 (90%) 52 (7%) 22 (3%)

We were not using video call before covid and rarely offering counselling by phone, but this is now primary to our service (#40 Hospice Bereavement Service Manager)

Learning about the different "platforms" has needed energy to understand. New data protection has also been needed in relation to information stored on phones. (#293 Community Nurse)

It is more difficult picking up on subtleties of the consultation remotely, touch is obviously not possible either- everything is now done remotely for mental health in general practice (#444 General Practitioner)

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3 Access to specialist 301 292 134 (18%)
4 services for the (41%) (40%)
5 bereaved
6

7 These have reduced enormously and people have been left without an
8 accessible service (#378 Counselling and Bereavement Services Manager)

9 Services like Cruse Bereavement Care have been so inundated that families do
10 not get seen to as quickly as they normally would. Also, we usually advise that if
11 families are struggling with their grief then they should visit their GP to get a
12 referral to a counselling service, of course, GP's have been restricting
13 appointments so this has become very challenging as to where we can sign post
14 bereaved families to. (#158 Medical Examiners Officer)

15 Limited access as specialist services such as psychological support staff were
16 redeployed (#104 Palliative Medicine Doctor)
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Impacts on bereavement care practice: analysis of free text responses

Analysis of respondents' free text comments identified three key areas impacted by the pandemic: health and social care services; clinicians and their relationships with bereaved families; and bereaved peoples' experience. These are explained below with illustrative quotes: further detail is shown in Table 3.

1) The impact on health and social care services

Services faced initial challenges adapting to changing national government guidelines. Some bereavement services were suspended due to staff being furloughed or redeployed, particularly specialist services. Volunteer support in hospitals and hospices was reduced due to visiting restrictions. Associated with an increase in deaths, for some services this led to increased waiting lists: *'we had 600% increase in deaths for a 3-week period. Dealing with the backlog of bereavement support was challenging'* (#15 Palliative Medicine Doctor).

Bereavement care fell to a wide range of staff members, including some with limited experience of or training in supporting bereaved people who had to rapidly develop the required communication skills: *'Doctors, in particular F1 and F2, have really developed ... bereavement skills'* (#66 End of Life ANP).

Some reported that prior insufficient existing resources created even greater challenges, with concern that the pandemic would worsen the situation and add new difficulties due to the complex grief reactions: *'We didn't have a sufficient bereavement service pre covid'* (#512 Nurse).

Adapting care to online or telephone formats was particularly challenging with limited access to the equipment needed and staff training to use them: *'staff didn't know about*

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2
3 *them, hadn't been shown how to use them, which apps to use and how to log in' (#74*
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5 Palliative Medicine Doctor). Changes were needed to governance processes and
6
7 confidentiality agreements to accommodate the additional ethical and privacy
8
9 considerations of online and remote work.
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13 However, these changes also served to increase opportunities for bereavement support.

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15 Whereas previous procedures had stipulated a waiting period before offering bereavement
16
17 support or relied on self-referral, many were adopting a proactive approach due to
18
19 heightened awareness of the bereaved relatives need for support and increased social
20
21 isolation following a death, whether from COVID-19 or from other causes: *'For families of*
22
23 *patients who die in hospital, we are making contact sooner and by phone to "debrief" in*
24
25 *more detail' (#311 General Practitioner). Services supporting children and young people at*
26
27 times reported these groups to have been more receptive to online support than usual
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29 methods.
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35 Hospices and hospital teams reported widening access to their bereavement support to
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37 patients from across the local community or hospital, whereas this had previously only been
38
39 available to relatives known to the services. Some of these wider services were specifically
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41 for those bereaved from COVID-19: *'We wouldn't normally deal with people that have been*
42
43 *bereaved...we changed the service to meet the needs of those bereaved following a covid*
44
45 *death' (#483 Palliative Care Day Services Manager).*
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51 Collaborative efforts were described, bringing together local agencies such as hospices,
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53 district hospitals, and charities. New services had been developed, often telephone
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55 helplines or online support that would offer compassionate support and information on
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57 local and national services. Other innovations included allowing families to email pictures to
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3 place in patients' rooms, providing bereaved families with mementoes such as knitted
4 hearts, sending condolence cards, and arranging for the return of the deceased's property.
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6 Some of these service adaptations, particularly online support, were reported to be long-
7
8 term changes.
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15 Many respondents also reported a lower rate of uptake from bereaved people than they
16 had anticipated in the initial stages of the pandemic, although more recently referrals had
17 increased and were expected to increase further. Some feared being overwhelmed by
18 demand: *'We are really only seeing those who have been bereaved in Jan/Feb so far, so*
19 *there may be many more to come'* (#129 Community Listening Service Coordinator).
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30 2) *The impact on clinicians and their relationships with bereaved relatives*

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33 Changes to services impacted on how practitioners interacted with and built relationships
34 with bereaved people. The reduced ability to meet face to face was repeatedly raised and
35 reported to impact on all stages of a bereaved person's journey.
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41 Restrictions on visiting meant practitioners had less, or no, opportunities to see family
42 members before the death to assess their potential bereavement support needs. Following
43 the death, collection of death certificates, visits to registry offices and appointments with
44 funeral directors were all arranged online or by telephone: these had previously been ways
45 for bereaved families to meet professionals, ask questions and discuss the death: *'family*
46 *would come back to the unit to collect the death certificate face to face the following day*
47 *which allows time to sit and talk to them about their needs, and this no longer happens'*
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58 (#111 Palliative Medicine Doctor).
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3 Emotional support was reported to have been significantly disrupted. Physical distancing,
4 the use of personal protective equipment (PPE) and use of remote support was restricting
5 non-verbal communication such as facial expressions and body language which were felt to
6 be important in developing trusting relationships: *'The use of staff PPE has made*
7 *communication more complex, limiting non-verbal communication and making staff and*
8 *families feel uncomfortable'* (#368 Clinical Psychologist).

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19 *'it has felt as though we are dealing with them at arm's length whereas we would be there*
20 *to hold their hands, give them a hug as needed'* (#16 Palliative Medicine Doctor).

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24 Associated with this sense of moral injury were reports of a broader emotional impact on
25 practitioners who described finding remote support more demanding on emotional reserves
26 and attention. Conversations were described as more difficult as practitioners had been
27 unable to develop relationships with families, and the bereaved needed more information
28 and support as they had been unable to visit and see how their family member changed
29 over time: *'It relies on clinicians to paint a visual picture of what is happening, which is a*
30 *new skill and also relies on clinicians taking the time to have these conversations'* (#117
31 Palliative Medicine Doctor). Respondents described such work as 'draining' and difficult to
32 manage, alongside their own emotional strains during the pandemic, including their own
33 experiences of loss and feelings of grief.

3) *The impact on bereaved people*

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Many respondents expressed grave concerns over the long-term impacts on bereaved
people, highlighting the inability or restrictions on being with the dying patient as having a
profound impact in bereavement. Family members were reported to feel guilty that they

1
2
3 had not been able to be with the dying person and say 'goodbye', and frustrated that they
4
5 had been unable to ensure their loved one's wishes were respected at the end of life:

6
7
8 *'Many people who died were denied opportunity to die in their preferred place of care /*
9
10 *preferred place of death and died in alternative makeshift community hospital environments*
11
12 *that were less than person centred and suboptimal environments to receive their care in last*
13
14 *days' (#215 GP).*

15
16
17
18
19 Not being able to 'see the journey' of the dying patient meant bereaved families often had
20
21 questions following a death, with reports of increased queries from family members about
22
23 the care received, including anger at restrictions and feelings of unfairness, leading to
24
25 difficulties in accepting the death: *'Families feel cheated and robbed of a relative who*
26
27 *normally would be still alive if not for the virus' (#234 Social Worker).*

28
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31
32 Restrictions around returning the deceased person's belongings and viewing the body,
33
34 particularly for COVID-19 patients and restricted funeral arrangements were reported to
35
36 have caused significant distress and exacerbated feelings of unfairness.

37
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39
40 While those bereaved from COVID-19 and non-COVID conditions were similarly affected by
41
42 the restrictions, specific challenges related to COVID-19 were reported. Some respondents
43
44 described relatives' anger at having COVID-19 on the death certificate, commenting that the
45
46 disease *'seemed to have a "stigma" for some' (#233 Bereavement Specialist Liaison Nurse).*

47
48
49 This sense of stigma was thought to exacerbate peoples' feelings of having failed to protect
50
51 their family member from COVID-19.

52
53
54
55 Respondents suggested that the focus on COVID deaths had adversely impacted on the
56
57 bereavement experiences of those whose loved one had died of other conditions who may
58
59 *'feel their loss is not as big as that of people dying of COVID. Or as important' (#234 Hospice*
60

1
2
3 Social Worker). In some cases, funding was allocated only for those who had been bereaved
4
5 by COVID-19, which *'could create inequality of service provision'* (#40 Hospice Bereavement
6
7 Service Manager).
8
9

10
11 Those bereaved prior to the pandemic were also impacted. Some were reported to find it
12
13 difficult to move from face-to-face to online support and preferred to wait until in-person
14
15 support would resume. Lockdown restrictions were described as a *'second bereavement'*
16
17 (#776 Bereavement Support Co-ordinator) as historical bereavements resurfaced during the
18
19 pandemic leading to increased demand for services. An overall climate of increased
20
21 loneliness, social isolation, fear and anxiety amongst communities was perceived to be
22
23 heightening existing mental health difficulties related to bereavement.
24
25
26
27

28
29 Respondents reported many unknown impacts of the pandemic on bereaved people and
30
31 how these would be managed when services *'were already patchy and not fit for purpose*
32
33 *prior to the COVID-19 pandemic'* (#9 Palliative Medicine Doctor). Concerns were raised over
34
35 a large and *'invisible cohort of people'* (#611 Palliative Medicine Doctor) who may not access
36
37 support or for whom support will be restricted, leading to greater unmet need: *'There may*
38
39 *be a silent epidemic of grief that we have not yet picked up on'* (#9 Palliative Medicine
40
41 Doctor).
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Table 3. Impacts of the pandemic on bereavement care practice

| Theme | Illustrative quotes |
|---|---|
| <p>1. Impact on services</p> | <p>Before COVID there needed to be an improvement in specialist bereavement services. The generic support provided by staff has become more difficult to provide - particularly during the height of covid in the community setting when only essential visits were being done face to face. There still needs to be better access to bereavement services. Furthermore, there is no access to chaplaincy in the community setting which should be considered. (#582 Palliative Medicine Doctor)</p> <p>As team leader of a small team of nurses providing a Hospice at Home service countywide. Prior to Covid -19 we had already identified there is a gap in follow up bereavement support for families of the patients who we have nursed. It is not something we have the capacity to do. (#670 Community Nurse)</p> <p>The staff adapted very professionally and quickly to ensure there were no gaps in sessions for those needing the service... We did have to write a whole new service protocol and generate new confidentiality statements and counselling contracts as the staff working with online platforms had to set out new boundaries for counselling and support, having looked into these boundaries, it was a bit scary at first because you have to protect the staff who can see into people homes and personal space and ensure there are no interruptions during the session with IT breaking down etc. However, now 5 months on from lockdown, we do find that the challenges and most clients engage well. (#475 Head of Information and Supportive Care Services)</p> |
| <p>2. Impact on clinicians and relationships with patients</p> | <p>It has brought many challenges for both client and counsellor. Much of what happens in the counselling session is about reading body language and facial expressions. This has proven nearly impossible. Also it is much more difficult to build an empathic trusting relationship when there is a phone or computer in between client and counsellor. It has been harder to reach young bereaved people as not always appropriate to do telephone or video work. (#554 Hospice Bereavement counsellor)</p> <p>I found it really, really emotionally taxing. It is not in my normal day job to be having conversations. I found preparing patients and relatives for intubating knowing that may be the beginning of their grief journey incredibly hard. (#407 Respiratory physiotherapist)</p> <p>This has been a difficult time for both the bereaved and staff. The bereaved have a reduced, non face to face service. The staff feel powerless and are restricted from doing the job they are passionate about. That said a great deal of</p> |

1
2
3 learning has been going on and staff have been imaginative in finding new approaches. (#418 Palliative care Specialist
4 Nurse)
5

6
7 **3. Impact on bereaved
8 people**

I feel it's the isolation that is causing the greatest emotional and mental anguish. That, and the fact that many people
9 saw their loved ones poorly at home, then taken to hospital, never to be seen again. This leaves very deep scars. So I feel
10 peer support is fundamental to help bereaved families feel and share their story with others and, have a chance to hear
11 someone's else story. Grief is unique to every individual but community spirit helps heal, through a sense of belonging
12 and walking with people who understand your pain. (#617 Bereavement support worker/volunteer)

13
14 The experience of grief is far more complex given majority of loved ones have been mostly separated from the dying
15 person during the illness and even during most of the dying process... Families have experienced more complex guilt for
16 feeling somehow they may have failed in their duty to shield vulnerable loved ones from the infection or that they
17 couldn't be united with their loved ones during the illness (#215 General Practitioner)

18
19 I have concerns that some bereavements may be more complex due to visiting restrictions - families may not have been
20 able to say goodbye as they wished or had less time with their loved one. Some have changed their preferred place of
21 death based on visiting restrictions. Some people dislike virtual support and prefer face to face, so it is likely that despite
22 efforts, bereavement support has not been as high quality as it was. (#690 Palliative Care Doctor)
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Discussion

Evidence on the impact of the COVID-19 pandemic on the experience of bereavement is emerging. This first study of UK bereavement care practice during the pandemic reveals significant changes in the delivery of support and the ways in which services have adapted to address the more complex needs of bereaved families. Bereavement care has undergone major change in both acute and community settings, affecting bereaved people, clinicians, support workers and the wider health and social care system. Increased need for bereavement care has challenged practitioners as they have taken on new responsibilities and skills and shifted to remote and electronic working. The potential for prolonged and complicated grief responses is particularly concerning (19, 20).

The large number of replies from across the UK and Ireland and the wide range of professional roles and settings represented support the generalisability of the data. Anonymity encouraged detailed and honest responses. Due to snowball sampling it is not possible to calculate a response rate. While there was consistency in responses across settings, further research is needed to investigate the settings and bereaved populations where support needs are highest.

As the world enters the next wave of the pandemic, urgent consideration is needed of ways to ensure optimal support: bereavement can have a significant impact on morbidity and mortality, yet bereavement care often remains an afterthought in clinical priorities (21). This study highlights that bereavement care is a significant component of health and social care across a wide range of settings and clinical roles, although many practitioners feel poorly equipped to manage bereavement (22-24).

1
2
3 Practitioners indicated remote delivery of some bereavement support may be implemented
4 long term; however, further research on the efficacy of remote support for bereavement is
5
6 long term; however, further research on the efficacy of remote support for bereavement is
7
8 required. Trusting relationships and compassionate communication between staff and
9
10 bereaved families are critical to bereavement care (25). This is challenging to ensure
11
12 through remote and online routes, creating additional burdens of time and emotional
13
14 resources for an already overstretched and exhausted workforce. The emotional and
15
16 personal impact on practitioners highlighted in this study is a particular area of concern (26,
17
18 27).

19
20
21
22
23 Bereavement service provision has for many years been highly variable across the UK (28).
24
25 While it was heartening that many respondents reported the development of new and
26
27 expanded services, it is unclear how sustainable these will be in the longer-term. The
28
29 markedly reduced income of many charities during the pandemic is concerning for future
30
31 provision of bereavement and palliative care (29). Given the increasing need for
32
33 bereavement support highlighted during the pandemic, it is imperative that policymakers,
34
35 funders, health, social care and community services work together to develop a sustainable
36
37 model of resourcing at local, regional and national levels.

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43 In the early stages of the pandemic, physical health needs were understandably prioritised.
44
45 However, there is now a need to also focus on the mental health needs of the population,
46
47 including the needs of the many people bereaved over the course of the ongoing pandemic.
48
49 Our study highlights the need for a proactive approach, offering support for all those
50
51 bereaved whether from COVID-19 or other conditions (6, 15) (see Box 1. Recommendations
52
53 for bereavement care practice and policy).
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3 All bereaved people are currently facing the double problem of both experiencing difficult
4 and traumatic deaths and also having limited access to support from family, friends and
5
6 services. Respondents indicated a high level of unmet support needs of bereaved people,
7
8 with concerns of subsequent significant physical and psychological morbidity.
9
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12
13 While many bereaved people adjust to their loss with informal support of family, friends and
14
15 community, the three-tiered “public health model of bereavement support” is designed to
16
17 guide professionals to identify those who need support from services and identify the
18
19 minority at risk of complicated and prolonged grief responses (30).
20
21

22
23
24 The increased number of people at risk of prolonged and complicated grief responses may
25
26 lead to a temporary revision of this model (8, 31). However, bereavement care practitioners
27
28 and service providers are advised to acknowledge that most bereaved people will not
29
30 benefit from specialist mental health intervention and should therefore tailor their support
31
32 accordingly.
33
34

35
36
37 To address the potential ‘silent epidemic of grief’, it is also important to build public
38
39 awareness of the availability and accessibility of bereavement support services. Speaking
40
41 about grief remains an area of public discomfort, and it is important practitioners encourage
42
43 bereaved people to view grief as a ‘valid’ reason to seek help from health and community
44
45 services (32, 33).
46
47

48
49
50 This study highlights the profound impact of the pandemic on bereaved people, yet much
51
52 remains unknown about how individuals, communities, and the health and social care
53
54 system will respond. While further research is urgently needed in this area, we already know
55
56 that action is needed now to ensure equity of provision across ethnic groups, ages and
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3 marginalised groups and equity of care for all bereaved people whether from COVID, from
4
5 other conditions or those bereaved prior to the pandemic.
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Box 1. Recommendations for bereavement care practice and policy

- Improved resources for existing bereavement services to enable coordination between local, regional and national networks and encourage a sustainable model of bereavement care.
- Developing a proactive approach to supporting those bereaved during this period and making services accessible for all
- Enabling regular communication with families prior to a death and after to ensure families have opportunities to ask questions and receive reassurance
- Draw on existing resources to help with difficult conversations around end-of-life and the immediate period of bereavement (26)
- Where possible, find ways for families to be with dying loved ones
- Integrating assessment of bereaved families' needs into communication to help identify and signpost those who might require further support
- Training in bereavement care to be integrated into medical, nursing and other health care professional training
- Acknowledging the challenges on staff and encourage brief training for those who feel unequipped to manage needs of grieving families

Conclusion

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50 Bereavement care is a central aspect of the work of a wide range of health and social care
51
52 professionals yet remains a low priority within health care policy. The COVID-19 pandemic
53
54 has highlighted this important area of patient care, creating both major challenges to
55
56 bereavement support provision and opportunities for practitioners and policy-makers to
57
58 address this neglected area of clinical care. Bereavement is one of the long-term impacts of
59
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3 COVID-19: if left unaddressed it may lead to significant physical and mental health morbidity
4
5
6 and create a further burden on health and social care services.
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10 11 12 **Figure legend**

13
14
15 Figure 1. Geographical location
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21 **Contributor and guarantor information**

22 23 24 **Contributors**

25
26
27 CP and SB designed and co-led the study: RL, MS, NZ-C, CH, AL contributed to the study
28
29 design; CP, JH and SB conducted the data analysis; CP, JH and SB drafted the paper: all the
30
31 authors reviewed and commented on the draft paper and have approved this final version.
32
33
34 CP and SB are the guarantors. The corresponding author attests that all listed authors meet
35
36 authorship criteria and that no others meeting the criteria have been omitted.
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10 **Competing interests declaration**

11
12
13
14 All authors have completed the ICMJE uniform disclosure form
15
16 at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the
17
18 submitted work; no financial relationships with any organisations that might have an
19
20 interest in the submitted work in the previous three years; no other relationships or
21
22 activities that could appear to have influenced the submitted work.
23
24
25

26 **Data sharing**

27
28
29 Anonymised data will be shared on request.
30
31

32 **Transparency statement**

33
34
35
36 The lead author/manuscript guarantor affirms that this manuscript is an honest, accurate,
37
38 and transparent account of the study being reported; that no important aspects of the study
39
40 have been omitted; and that any discrepancies from the study as planned (and, if relevant,
41
42 registered) have been explained.
43
44
45

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47
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52
53 the NIHR, or the Department of Health and Social Care.
54
55
56

57 **Dissemination to participants and related patient and public communities**

1
2
3 The published results of the study will be sent to all collaborating organisations who will be
4
5 invited to disseminate the findings amongst their members. The published results will also
6
7 be shared with patient and public communities via the Cambridge Palliative and End of Life
8
9 Care PPI group, a national network of PPI leads, local news outlets and social media.
10
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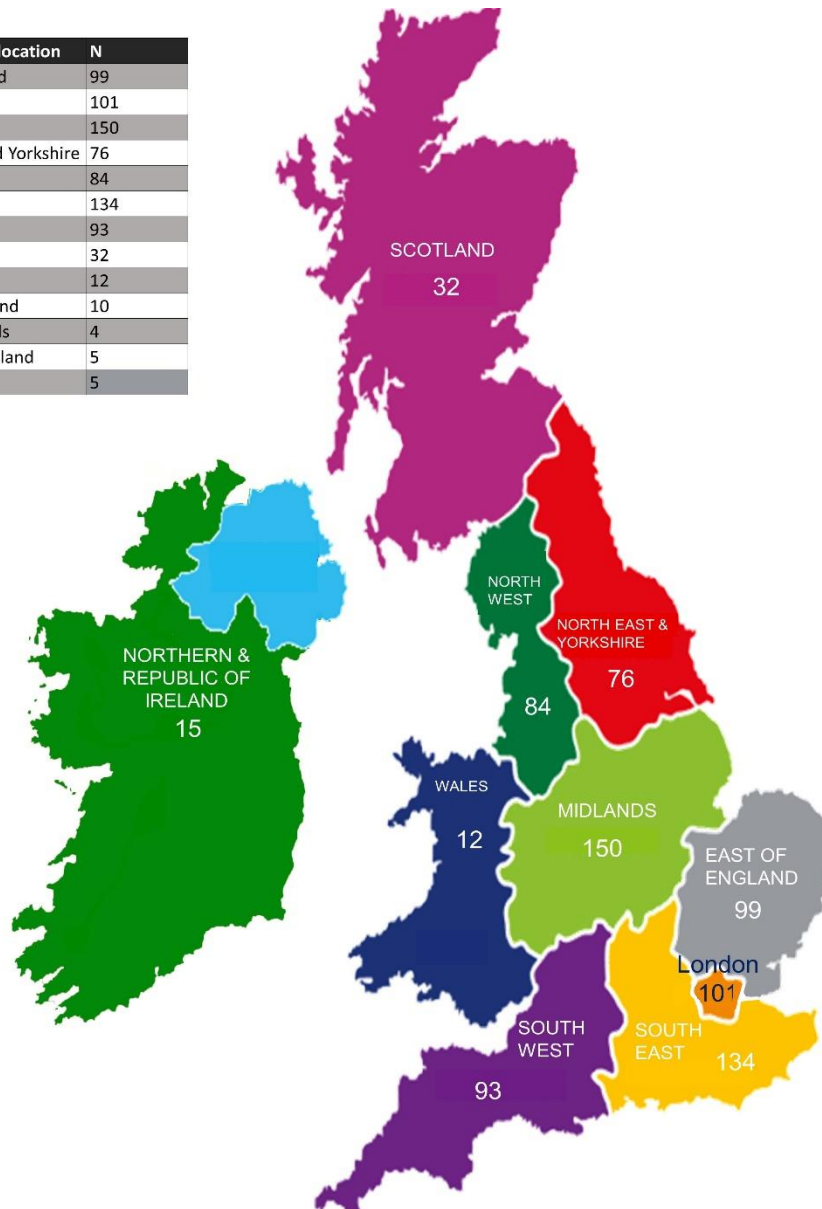
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Figure 1. Geographical location

| Geographical location | N |
|--------------------------|-----|
| East of England | 99 |
| London | 101 |
| Midlands | 150 |
| North East and Yorkshire | 76 |
| North West | 84 |
| South East | 134 |
| South West | 93 |
| Scotland | 32 |
| Wales | 12 |
| Northern Ireland | 10 |
| Channel Islands | 4 |
| Republic of Ireland | 5 |
| Nationwide | 5 |



Online Appendix. Text of the online survey

Bereavement care during the COVID-19 pandemic

The current COVID-19 pandemic has been a particularly difficult time for people experiencing bereavement and has changed the ways in which professionals are seeking to support them. In order to help each other in our care of bereaved people at this difficult time, we have developed a brief questionnaire which will take less than five minutes to complete.

We would be grateful if you could complete this in the near future (closing date Friday September 4th) so that we can analyse and circulate the results as soon as possible. We will send the results by email to everyone who responds and aim to publish a journal paper in the near future.

Please feel free to forward the survey link to your colleagues: it would be helpful to have a good number of responses from across the UK.

There are no right or wrong answers. We look forward to hearing from you.


Stephen and Caroline


Prof. Stephen Barclay sigb2@medschl.cam.ac.uk and Dr Caroline Pearce cmp89@medschl.cam.ac.uk


This research aims to identify the changes in the ways that professionals are providing bereavement support during the pandemic. It is funded by the NIHR School for Primary Care Research and has been reviewed by the University of Cambridge Psychology Research Ethics Committee. By responding to this survey, you consent to take part in this study: you can withdraw at any time by closing the survey without pressing the final “submit” button. Any participant identifiable data will be stored in a University secure data hosting server and destroyed after 12 months: all anonymised data will be stored for ten years on university password-protected computers. For general information about how our University uses personal data, please see: <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>

If you have any questions about the study please contact Prof. Stephen Barclay sigb2@medschl.cam.ac.uk

| | |
|--|--|
| Q1 - In what area of the country do you work? (tick one box) | East of England Greater London Midlands North East North West South East South West Scotland Wales Ireland Other (please specify) |
| Q2 - What is your current professional role? (Tick one box) | General Practitioner Community Nurse Bereavement Counsellor Bereavement support worker / volunteer Chaplain Funeral Director Social Worker Care Home Manager Social Care Worker Clinical Psychologist Palliative Medicine doctor Palliative Care Specialist Nurse Other (please specify) |
| Q3 - In what setting(s) do you work? (Tick as many as apply) | Care Home Community Hospice Hospital Other (please specify) |
| Q4 - In what aspects of care for bereaved people are you involved? (Tick as many as apply) | Providing support immediately after a death Practical arrangements of certificates and funerals Providing information on support services Emotional support and listening Clinical assessment of support needs Bereavement counselling Referring for specialist support Provision of specialist psychological / psychiatric support Prescribing medication Pre-bereavement support prior to death |

|  | Checklist for Reporting Results of Internet E-Surveys (CHERRIES) | |
|---|---|--|
| <i>Item Category</i> | <i>Checklist Item</i> | <i>Explanation</i> |
| Design | | |
| | Describe survey design | p.5-6. Target population consisted of practitioners involved in bereavement care working in the UK. A snowball sampling approach was used. |
| IRB (Institutional Review Board) approval and informed consent process | IRB approval | p. 5. The study was reviewed by the University of Cambridge Psychology Research Ethics Committee. |
| | Informed consent | p.6, Appendix 1. Participants were informed of the survey objectives, purpose of survey responses and estimated length of time to complete the survey before completing the survey. Information on data storage was provided. (see Appendix 1) |
| | Data protection | Appendix 1. If provided, personal contact information was stored separately from the survey responses on a password protected computer. |
| Development and pre-testing | Development and testing | p. 5. The survey was developed using Survey Monkey. A pilot survey was conducted to assess usability and technical functionality with three participants. |
| Recruitment process and description of the sample having access to the questionnaire | Open survey versus closed survey | p.5-6. Open survey: key organisations were targeted but sharing to relevant colleagues was encouraged. |
| | Contact mode | p.5-6. Initial contact with participants was made via email. |
| | Advertising the survey | The survey was advertised by relevant health and social |

|  | Checklist for Reporting Results of Internet E-Surveys (CHERRIES) | |
|---|---|--|
| <i>Item Category</i> | <i>Checklist Item</i> | <i>Explanation</i> |
| | | organisations via their mailing lists, social media and webpages. Organisations are listed on p 5-6. |
| Survey administration | Web/E-mail | p.5-6. Survey was sent out via email with a link to a web-based survey. Data capture was automated through the platform host, Survey Monkey. |
| | Context | The survey was not posted on a website. |
| | Mandatory/voluntary | Appendix 1. Voluntary survey |
| | Incentives | Appendix 1. No incentives were offered. |
| | Time/Date | 3 rd August - 4 th September 2020 |
| | Randomization of items or questionnaires | p.5-6. Questions and items were not randomized. |
| | Adaptive questioning | Not applicable |
| | Number of Items | Appendix 1. Eight items in total on one page |
| | Number of screens (pages) | One page |
| | Completeness check | Appendix 1. Completeness checks were not performed during the survey. Mandatory questions had non- response options ("Unsure" or "other"). Questions enforced one option or multiple options where relevant. |
| | Review step | Appendix 1. Responses were editable before submitting the survey. |
| Response rates | Unique site visitor | The survey could only be completed once from the same device. |
| | View rate (Ratio of unique survey visitors/unique site visitors) | Not applicable. |

| | | |
|---|---|--|
|  | Checklist for Reporting Results of Internet E-Surveys (CHERRIES) | |
| Item Category | Checklist Item | Explanation |
| | Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors) | Not applicable |
| | Completion rate (Ratio of users who finished the survey/users who agreed to participate) | Not applicable – Submission of survey included agreement to participate |
| Preventing multiple entries from the same individual | Cookies used | Survey Monkey uses cookies to prevent multiple responses from the same device. |
| | IP check | SurveyMonkey records respondent IP addresses in backend logs and deletes them after 13 months. Multiple responses from the same device were not permitted. |
| | Log file analysis | No other techniques were used |
| | Registration | Not applicable |
| Analysis | Handling of incomplete questionnaires | p.6. All respondents completed the mandatory questions and so were included in the analysis. |
| | Questionnaires submitted with an atypical timestamp | p. 6. Not cut off point was imposed for excluding responses to be analysed. |
| | Statistical correction | p.5-6. No weighting was applied to the data analysis. |

BMJ Open

'A silent epidemic of grief': a survey of bereavement care provision in the United Kingdom and Ireland during the COVID-19 pandemic

| | |
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| | |

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3 'A silent epidemic of grief': a survey of bereavement care provision in the United Kingdom
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6 and Ireland during the COVID-19 pandemic
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Abstract

Objectives: To investigate the experiences and views of practitioners in the United Kingdom and Ireland concerning changes in bereavement care during the COVID-19 pandemic.

Design: Online survey using a snowball sampling approach.

Setting: Practitioners working in hospitals, hospices, care homes and community settings across the UK and Ireland.

Participants: Health and social care professionals involved in bereavement support.

Interventions: Brief online survey distributed widely across health and social care organisations.

Results: 805 respondents working in hospice, community, and hospital settings across the UK and Ireland completed the survey between 3rd August and 4th September 2020.

Changes to bereavement care practice were reported in: the use of telephone, video and other forms of remote support (90%); supporting people bereaved from non-COVID conditions (76%), from COVID-19 (65%), and people bereaved before the pandemic (61%); funeral arrangements (61%); identifying bereaved people who might need support (56%); managing complex forms of grief (48%) and access to specialist services (41%). Free-text responses demonstrated the complexities and scale of the impact on bereaved people and on health and social services, practitioners and their relationships with bereaved families.

Conclusions: The pandemic has created major challenges for the support of bereaved people: increased needs for bereavement care, transition to remote forms of support, and the stresses experienced by practitioners, among others. The extent to which services are

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2
3 able to adapt, meet the escalating level of need and help to prevent a “tsunami of grief”
4
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6 remains to be seen. The pandemic has highlighted the need for bereavement care to be
7
8 considered an integral part of health and social care provision.
9

10
11 **Keywords:** bereavement care, grief, COVID-19 pandemic
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17 **Strengths and limitations of this study**

- 18
19
20 • This national survey of health and social care professionals is the first to identify the
21
22 major impact of the pandemic on bereavement care in the UK.
23
24
- 25
26 • 805 responses from across the UK and Ireland were received from a wide range of
27
28 professional roles and settings.
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- 30
31 • Due to the snowball sampling approach, it is not possible to calculate a response
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33 rate.
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- 35
36 • While there was consistency in responses across settings, further research is needed
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38 to investigate the settings and bereaved populations where support needs are
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40 highest.
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Introduction

Bereavement care is a significant component of the work of a wide range of health and social care professionals, yet it is often unrecognised and considered a low priority in health care policy and practice. The global COVID-19 pandemic has brought to the fore the importance of end of life and bereavement care. The scale of the impact of the COVID-19 pandemic on those bereaved is now becoming apparent: it is estimated that for every COVID death, nine people are affected by bereavement (1). Deaths from COVID-19 are characterised by factors that may increase the risk of complicated and prolonged grief responses (2-4) including; sudden and unexpected deaths, deaths in intensive care units, patient isolation and severe symptoms including breathlessness at the end of life (5-8). Social distancing measures have had a major impact on those bereaved from all causes, not only from COVID-19. These essential measures restricted visiting in hospitals, care homes and hospices, preventing loved ones saying goodbye and leaving some to die alone. Viewing the deceased person's body and funeral proceedings were severely curtailed. Bereaved people may feel especially isolated and unable to access the benefits of social support (9). People bereaved prior to the pandemic are also affected, with social isolation and interrupted bereavement care intensifying feelings of grief (10). Evidence is limited on the ways in which the pandemic is impacting on the experience of bereavement. A review found that pandemics may cause multiple losses, both directly related to the death itself and symbolic losses to individual and societal bereavement practices (11). Rituals related to the management and disposal of bodies have significance across a range of religious and cultural communities and the disruptions caused by pandemics may impact bereavement outcomes (12-14). Harrop et al. (15) reviewed the

1
2
3 evidence regarding system-level responses to mass bereavement events, including natural
4 and human-made disasters as well as pandemics. The authors found limited research of low
5 and human-made disasters as well as pandemics. The authors found limited research of low
6 quality, but identified several consistent messages for improving bereavement support
7 provision during and after the pandemic including adopting a proactive support model,
8 central coordination of locally delivered services, and training in core competencies specific
9 to COVID-19 for those delivering support.
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18 At present, however, it is not clear what forms of support are appropriate or effective
19 during and following pandemics (16). To support practitioners and policy-makers, we
20 surveyed practitioners in the United Kingdom (UK) and Ireland concerning changes in their
21 bereavement care practice, including the target group, mode, and content of delivery during
22 the COVID-19 pandemic.
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34 **Methods**

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37 A descriptive cross-sectional online survey (see Appendix 1) was developed in Survey
38 Monkey. Initial development of survey was carried out by CP and SB, following consultation
39 with a patient and public involvement (PPI) group (detailed below) and discussions with
40 stakeholders including hospice and hospital chaplaincy staff. The study was developed in
41 parallel with a literature review of bereavement care, which had provided the team with up-
42 to-date knowledge of the evidence base and an established network of stakeholders. All
43 authors contributed to the development of the survey drawing on their clinical, research,
44 and lived experience in bereavement care respectively. Literature concerning the potential
45 impact of COVID-19 on bereavement care also informed the content of the survey questions
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3 (2-4, 6-8, 11, 15). . The study was reviewed by the University of Cambridge Psychology
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5
6 Research Ethics Committee (PRE.2020.094).
7

8 *Patient and Public Involvement*

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10
11 The Cambridge Palliative and End of Life Care Patient and Public Involvement group were
12
13 involved throughout the development, dissemination and analysis of the survey. Following a
14
15 meeting in April 2020 where priority areas for bereavement research were discussed, RL
16
17 joined the project advisory group to ensure that PPI perspectives were included throughout,
18
19 especially development of the survey instrument. A second PPI group meeting in September
20
21 2020 discussed the survey findings, identified key recommendations for practice, advised
22
23 concerning dissemination strategy and suggested avenues for further research.
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29 *Study procedure*

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32 Health and social care organisations based in the UK were approached based on their
33
34 professional involvement in supporting bereaved people. After a local pilot involving three
35
36 respondents, the following organisations distributed an email with the survey link between
37
38 3 August and 4 September 2020 to their members and/or professional networks via email
39
40 lists, member newsletters and/or social media: Association for Palliative Medicine of Great
41
42 Britain and Ireland, UK Queen's Nursing Institute, Royal College of General Practitioners,
43
44 Hospice UK, National Association of Funeral Directors, National Bereavement Alliance,
45
46 Association of Hospice and Palliative Care Chaplains, UK Board of Health Care Chaplains,
47
48 College of Health Care Chaplaincy, Dying Matters, Association of Directors of Adult Social
49
50 Services in England, Care Association Alliance, National Care Association, Care Provider
51
52 Alliance, The Cremation Society, British Psychological Society and a national network of
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54 Patient and Public Involvement (PPI) leads.
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3 Participants were encouraged to forward the survey link to interested colleagues, seeking a
4
5 snowball sample of practitioners.
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9 Responses were anonymous unless respondents supplied their name and email address in
10
11 the optional final field to indicate interest in further research. After initial questions seeking
12
13 demographic data concerning respondents' geographical areas of work, professional roles,
14
15 work settings and involvement in bereavement care, the main question addressed changes
16
17 in bereavement care practice (if any) during the COVID-19 pandemic. These included
18
19 identifying bereaved people who might need support, restrictions regarding funeral
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21 arrangements, supporting people bereaved from COVID, and from non-COVID conditions,
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23 supporting people bereaved before the pandemic, managing complex forms of grief, use of
24
25 telephone, video or other remote support and access to specialist services for the bereaved.
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30 Details regarding changes in practice were invited in free text. A final optional question
31
32 invited further comments on supporting bereaved people during the pandemic.
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36 *Data analysis*

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38 The Checklist for Reporting Results of Internet E-Surveys was followed (17). Descriptive
39
40 statistics were used for demographic and categorical response data. Analysis of free-text
41
42 replies was undertaken by CP and JH. Following a thematic analysis approach, themes were
43
44 developed inductively from the data by coding responses and allocating them to thematic
45
46 categories (18). CP conducted preliminary coding of the free text data and developed an
47
48 initial coding structure which categorised codes into overarching themes. A second author
49
50 (JH) independently analysed a proportion (25%) of the free text responses using the initial
51
52 coding structure, allocating quotes to the relevant theme. The coding framework was then
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revised in an iterative process through discussions with SB, until consensus on the final themes was reached.

Results

Respondents

Eight hundred and five survey responses were received between 3rd August and 4th September 2020 from a wide range of health, social care and bereavement professionals (Table 1).

Table 1. Current professional role

| Professional role | No. of respondents |
|---|--|
| Nurse | 176 (22%) |
| - <i>Palliative care specialist nurse</i> | 103 |
| - <i>Community nurse</i> | 51 |
| - <i>Other nurse</i> | 22 |
| Bereavement counsellor, support worker or volunteer | 173 (21%) |
| Chaplain | 115 (14%) |
| Doctor | 98 (12%) |
| - <i>Palliative care doctor</i> | 65 |
| - <i>General Practitioner</i> | 28 |
| - <i>Other doctor</i> | 5 |
| Health and social care management | 54 (7%) |
| Social worker/Social care worker | 52 (6%) |
| Allied Health Professionals | 35 (4%) |
| Psychologists, psychotherapists and counsellors | 30 (4%) |
| Bereavement service manager or co-ordinator | 29 (4%) |
| Administration | 27 (3%) |
| Funeral Director/Celebrant | 19 (2%) |
| Total | 808 (three respondents identified two job roles) |

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2
3 Responses were received from across the UK and Ireland (Figure 1) from practitioners
4 working in Hospice (37%), Primary Care and Community (32%), Hospital (25%), and Care
5 Home (6%) settings. Participants were involved in a range of bereavement care provision:
6 emotional support and listening (88%), pre-bereavement support prior to death (72%),
7 support immediately after a death (72%), providing information on support services (65%),
8 referring for specialist support (51%), bereavement counselling (40%), clinical assessment of
9 support needs (38%), practical arrangements of certificates and funerals (34%), prescribing
10 medication (11%) and specialist psychological / psychiatric support (10%).
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23 *Changes in bereavement care practice*

24 Respondents reported major changes in their personal provision of bereavement care
25 and/or changes in their area across all the listed categories. These changes are presented in
26 Table 2, along with examples from the thematic analysis of the explanatory free text.
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35 The greatest change to bereavement support was in the mode of delivery and the use of
36 telephone, video and other forms of remote support, reported by 90% of respondents. Prior
37 to the pandemic, telephone and video had been used rarely but were now the primary
38 mode of support.
39
40
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45

46 Practitioners reported changes in skills required to support people bereaved by non-COVID
47 conditions (76%) and COVID-19 (65%). Support for people bereaved before the pandemic
48 also experienced significant change (61%) as many bereavement services had been
49 suspended and/or had shifted to online or telephone formats.
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57 Regardless of cause of death, it was emphasised that the support provided was largely
58 consistent, as all families had experienced similar restrictions prior to and after a death.
59
60

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3 Frequently reported were the impact of restrictions on funeral arrangements (61%), and
4
5 reduced opportunities for in-person interaction also produced difficulties when identifying
6
7 bereaved people who might need support (56%).
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11 Less changes in managing complex forms of grief (48%) and access to specialist services
12
13 (41%) were reported, although many were unsure of changes in these areas.
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For peer review only

Table 2. Bereavement care changes during COVID-19

| Changes to | Yes | No | Unsure | Illustrative comment examples |
|--|-----------|-----------|---------|---|
| Use of telephone, video or other remote support | 704 (90%) | 52 (7%) | 22 (3%) | <p>We were not using video call before covid and rarely offering counselling by phone, but this is now primary to our service. (#40 Hospice Bereavement Service Manager)</p> <p>Learning about the different "platforms" has needed energy to understand. New data protection has also been needed in relation to information stored on phones. (#293 Community Nurse)</p> <p>It is more difficult picking up on subtleties of the consultation remotely, touch is obviously not possible either- everything is now done remotely for mental health in general practice. (#444 General Practitioner)</p> |
| Supporting people bereaved from non-COVID conditions during the pandemic | 586 (76%) | 157 (20%) | 33 (4%) | <p>Very challenging at first as we did not know how to support the bereaved as events were folding at a high and fast speed. Every case was treated as though it was Covid-19. Lots of gaps and lessons to be learned as some non-Covid patients were just classified as positive patients. (#141 Chaplain)</p> <p>I have found families who have lost a member during the pandemic feel their loss is not as big as that of people dying of COVID. Or as important. (#234 Hospice Social Worker)</p> <p>it is hard to differentiate between COVID and non-COVID deaths. The death may not be certified as COVID related, but the bereaved person experience may well be impacted by the COVID restrictions. (#440 Service Manager/Head of Department)</p> |

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|----|------------------------|-------|-------|-----------|--|
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| 5 | Supporting people | 500 | 189 | 85 (11%) | Sudden, more unexpected deaths, different bereavement response and |
| 6 | bereaved from COVID | (65%) | (24%) | | reactions. Disbelief. Practical questions about how long they should self-isolate |
| 7 | | | | | for after the death if they visited the hospital. (#74 Palliative Medicine Doctor) |
| 8 | | | | | |
| 9 | | | | | Visiting restrictions have meant much less face to face contact. For example I |
| 10 | | | | | have talked with a spouse in the car park at social distance. (#153 Palliative |
| 11 | | | | | Medicine Doctor) |
| 12 | | | | | |
| 13 | | | | | |
| 14 | | | | | There was a lot of anger about having Covid on the death certificate if they had |
| 15 | | | | | been suffering from a long term illness prior. (#572 Hospice Bereavement |
| 16 | | | | | Counsellor) |
| 17 | | | | | |
| 18 | | | | | |
| 19 | Supporting people | 468 | 214 | 84 (11%) | Pandemic caused relapse to clients who were beginning to look forward and |
| 20 | already experiencing | (61%) | (28%) | | manage their grief, necessitating offering extra support (#127 Hospice |
| 21 | bereavement when | | | | Bereavement Counsellor) |
| 22 | the pandemic started | | | | |
| 23 | | | | | |
| 24 | | | | | Many clients receiving counselling have refused offers of telephone, preferring |
| 25 | | | | | to wait until 'normal services resume'. (#682 Hospice Social Worker) |
| 26 | | | | | |
| 27 | | | | | |
| 28 | | | | | We are beginning to see more extreme reactions from people who were |
| 29 | | | | | bereaved before the pandemic and who had begun to find ways of living in their |
| 30 | | | | | altered world, but who now find that most of the outlets that they were using to |
| 31 | | | | | help themselves are now closed to them. (#271 Hospice Social Worker) |
| 32 | | | | | |
| 33 | Restrictions regarding | 446 | 181 | 108 (15%) | Families will talk to us about how unfair they feel the restrictions are regarding |
| 34 | funeral arrangements | (61%) | (25%) | | funerals, especially if their loved one did not die from Covid 19. (#267 Hospital |
| 35 | | | | | Bereavement Manager) |
| 36 | | | | | |
| 37 | | | | | |
| 38 | | | | | The bereaved have found it very difficult not being involved in the physical |
| 39 | | | | | process of collecting death certificates, taking them to the registrar, then |
| 40 | | | | | |
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physically going to the funeral directors - these rituals are part of a process.
(#766 Citizens Advice Administrator)

Bereaved relatives don't come back and collect the death certificate - it gets scanned to the registry office. We do an online cremation form which we email to the funeral directors. We do not need to see the patient after death and don't go to funeral directors. Part 2 GPs are not needed. (#545 Palliative Medicine Doctor)

| | | | | |
|--|--------------|--------------|---------|---|
| Identifying bereaved people who might need support | 437 (56%) | 291 (37%) | 59 (7%) | We've been unable to see as many family members face-to-face as we normally would, so it's been harder for us to identify people. (#58 Hospice Social Worker) |
|--|--------------|--------------|---------|---|

More difficult to assess those who need support with distancing and limited visiting. This influenced our ability to form relationships with relatives and identify their needs. (#104 Palliative Medicine Doctor)

As a clinical team we were much more proactive, checking every bereaved family/carer and doing it twice and taking longer periods of time to make sure it was as right as it could be, impacting hours worked. (#802 Quality Improvement Lead)

| | | | | |
|---------------------------------|--------------|--------------|-----------|--|
| Managing complex forms of grief | 356 (48%) | 256 (34%) | 135 (18%) | These are just more difficult cases to tackle, and the isolation - not having been able to visit a loved one in hospital who's subsequently died - exacerbates this. (#7 General Practitioner) |
|---------------------------------|--------------|--------------|-----------|--|

We have at times entered territory/topics that are new and we do not have the answers to. (#526 Hospice Family Services Manager)

Increase in referrals regarding this (#540 Assistant Psychologist)

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2
3 Access to specialist
4 services for the
5 bereaved
6

301
(41%)

292
(40%)

134 (18%)

These have reduced enormously and people have been left without an accessible service. (#378 Counselling and Bereavement Services Manager)

7 Services like Cruse Bereavement Care have been so inundated that families do
8 not get seen to as quickly as they normally would. Also, we usually advise that if
9 families are struggling with their grief then they should visit their GP to get a
10 referral to a counselling service, of course, GP's have been restricting
11 appointments so this has become very challenging as to where we can sign post
12 bereaved families to. (#158 Medical Examiners Officer)

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15 Limited access as specialist services such as psychological support staff were
16 redeployed. (#104 Palliative Medicine Doctor)
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Impacts on bereavement care practice: analysis of free text responses

A total of 3543 free text comments were received in response to Q5 and Q6. Analysis of respondents' free text comments identified three key areas impacted by the pandemic: health and social care services; clinicians and their relationships with bereaved families; and bereaved peoples' experience. These are explained below with illustrative quotes: further detail is shown in Table 3.

1) The impact on health and social care services

Services faced initial challenges adapting to changing national government guidelines. Some bereavement services were suspended due to staff being furloughed or redeployed, particularly specialist services. Volunteer support in hospitals and hospices was reduced due to visiting restrictions. Associated with an increase in deaths, for some services this led to increased waiting lists: *'we had 600% increase in deaths for a 3-week period. Dealing with the backlog of bereavement support was challenging'* (#15 Palliative Medicine Doctor).

Bereavement care fell to a wide range of staff members, including some with limited experience of or training in supporting bereaved people who had to rapidly develop the required communication skills: *'Doctors, in particular F1 and F2, have really developed ... bereavement skills'* (#66 End of Life Advanced Nurse Practitioner).

Some reported that prior insufficient existing resources created even greater challenges, with concern that the pandemic would worsen the situation and add new difficulties due to the complex grief reactions: *'We didn't have a sufficient bereavement service pre covid'* (#512 Nurse).

1
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3 Adapting care to online or telephone formats was particularly challenging with limited
4
5 access to the equipment needed and staff training to use them: *'staff didn't know about*
6
7 *them, hadn't been shown how to use them, which apps to use and how to log in'* (#74
8
9 Palliative Medicine Doctor). Changes were needed to governance processes and
10
11 confidentiality agreements to accommodate the additional ethical and privacy
12
13 considerations of online and remote work.
14
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16

17
18 However, these changes also served to increase opportunities for bereavement support.
19
20 Whereas previous procedures had stipulated a waiting period before offering bereavement
21
22 support or relied on self-referral, many were adopting a proactive approach due to
23
24 heightened awareness of the bereaved relatives need for support and increased social
25
26 isolation following a death, whether from COVID-19 or from other causes: *'For families of*
27
28 *patients who die in hospital, we are making contact sooner and by phone to "debrief" in*
29
30 *more detail'* (#311 General Practitioner). Services supporting children and young people at
31
32 times reported these groups to have been more receptive to online support than usual
33
34 methods.
35
36
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38

39
40 Hospices and hospital teams reported widening access to their bereavement support to
41
42 patients from across the local community or hospital, whereas this had previously only been
43
44 available to relatives known to the services. Some of these wider services were specifically
45
46 for those bereaved from COVID-19: *'We wouldn't normally deal with people that have been*
47
48 *bereaved...we changed the service to meet the needs of those bereaved following a covid*
49
50 *death'* (#483 Palliative Care Day Services Manager).
51
52
53

54
55 Collaborative efforts were described, bringing together local agencies such as hospices,
56
57 district hospitals, and charities. New services had been developed, often telephone
58
59
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1
2
3 helplines or online support that would offer compassionate support and information on
4
5 local and national services. Other innovations included allowing families to email pictures to
6
7 place in patients' rooms, providing bereaved families with mementoes such as knitted
8
9 hearts, sending condolence cards, and arranging for the return of the deceased's property.
10
11
12 Some of these service adaptations, particularly online support, were reported to be long-
13
14 term changes.
15
16

17
18
19
20 Many respondents also reported a lower rate of uptake from bereaved people than they
21
22 had anticipated in the initial stages of the pandemic, although more recently referrals had
23
24 increased and were expected to increase further. Some feared being overwhelmed by
25
26 demand: *'We are really only seeing those who have been bereaved in Jan/Feb so far, so*
27
28 *there may be many more to come'* (#129 Community Listening Service Coordinator).
29
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34 35 2) *The impact on clinicians and their relationships with bereaved relatives*

36
37
38 Changes to services impacted on how practitioners interacted with and built relationships
39
40 with bereaved people. The reduced ability to meet face to face was repeatedly raised and
41
42 reported to impact on all stages of a bereaved person's journey.
43
44

45
46 Restrictions on visiting meant practitioners had less, or no, opportunities to see family
47
48 members before the death to assess their potential bereavement support needs. Following
49
50 the death, collection of death certificates, visits to registry offices and appointments with
51
52 funeral directors were all arranged online or by telephone: these had previously been ways
53
54 for bereaved families to meet professionals, ask questions and discuss the death: *'family*
55
56 *would come back to the unit to collect the death certificate face to face the following day*
57
58
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1
2
3 *which allows time to sit and talk to them about their needs, and this no longer happens'*
4
5
6 (#111 Palliative Medicine Doctor).
7

8
9 Emotional support was reported to have been significantly disrupted. Physical distancing,
10
11 the use of personal protective equipment (PPE) and use of remote support was restricting
12
13 non-verbal communication such as facial expressions and body language which were felt to
14
15 be important in developing trusting relationships: *'The use of staff PPE has made*
16
17 *communication more complex, limiting non-verbal communication and making staff and*
18
19 *families feel uncomfortable'* (#368 Clinical Psychologist).
20
21
22

23
24 *'it has felt as though we are dealing with them at arm's length whereas we would be there*
25
26 *to hold their hands, give them a hug as needed'* (#16 Palliative Medicine Doctor).
27
28

29
30 Associated with this sense of moral injury were reports of a broader emotional impact on
31
32 practitioners who described finding remote support more demanding on emotional reserves
33
34 and attention. Conversations were described as more difficult as practitioners had been
35
36 unable to develop relationships with families, and the bereaved needed more information
37
38 and support as they had been unable to visit and see how their family member changed
39
40 over time: *'It relies on clinicians to paint a visual picture of what is happening, which is a*
41
42 *new skill and also relies on clinicians taking the time to have these conversations'* (#117
43
44 Palliative Medicine Doctor). Respondents described such work as 'draining' and difficult to
45
46 manage, alongside their own emotional strains during the pandemic, including their own
47
48 experiences of loss and feelings of grief.
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54 3) *The impact on bereaved people*

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3 Many respondents expressed grave concerns over the long-term impacts on bereaved
4 people, highlighting the inability or restrictions on being with the dying patient as having a
5 profound impact in bereavement. Family members were reported to feel guilty that they
6 had not been able to be with the dying person and say 'goodbye', and frustrated that they
7 had been unable to ensure their loved one's wishes were respected at the end of life:
8
9

10
11 *'Many people who died were denied opportunity to die in their preferred place of care /*
12 *preferred place of death and died in alternative makeshift community hospital environments*
13 *that were less than person centred and suboptimal environments to receive their care in last*
14 *days' (#215 General Practitioner).*
15

16
17 Not being able to 'see the journey' of the dying patient meant bereaved families often had
18 questions following a death, with reports of increased queries from family members about
19 the care received, including anger at restrictions and feelings of unfairness, leading to
20 difficulties in accepting the death: *'Families feel cheated and robbed of a relative who*
21 *normally would be still alive if not for the virus' (#234 Social Worker).*
22
23

24
25 Restrictions around returning the deceased person's belongings and viewing the body,
26 particularly for COVID-19 patients and restricted funeral arrangements were reported to
27 have caused significant distress and exacerbated feelings of unfairness.
28
29

30
31 While those bereaved from COVID-19 and non-COVID conditions were similarly affected by
32 the restrictions, specific challenges related to COVID-19 were reported. Some respondents
33 described relatives' anger at having COVID-19 on the death certificate, commenting that the
34 disease *'seemed to have a "stigma" for some' (#233 Bereavement Specialist Liaison Nurse).*
35
36

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38 This sense of stigma was thought to exacerbate peoples' feelings of having failed to protect
39 their family member from COVID-19.
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3 Respondents suggested that the focus on COVID deaths had adversely impacted on the
4 bereavement experiences of those whose loved one had died of other conditions who may
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7
8 *'feel their loss is not as big as that of people dying of COVID. Or as important'* (#234 Hospice
9
10 Social Worker). In some cases, funding was allocated only for those who had been bereaved
11
12
13 by COVID-19, which *'could create inequality of service provision'* (#40 Hospice Bereavement
14
15 Service Manager).

16
17
18 Those bereaved prior to the pandemic were also impacted. Some were reported to find it
19
20
21 difficult to move from face-to-face to online support and preferred to wait until in-person
22
23 support would resume. Lockdown restrictions were described as a *'second bereavement'*
24
25 (#776 Bereavement Support Co-ordinator) as historical bereavements resurfaced during the
26
27 pandemic leading to increased demand for services. An overall climate of increased
28
29 loneliness, social isolation, fear and anxiety amongst communities was perceived to be
30
31 heightening existing mental health difficulties related to bereavement.
32
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34

35
36 Respondents reported many unknown impacts of the pandemic on bereaved people and
37
38 how these would be managed when services *'were already patchy and not fit for purpose*
39
40 *prior to the COVID-19 pandemic'* (#9 Palliative Medicine Doctor). Concerns were raised over
41
42 a large and *'invisible cohort of people'* (#611 Palliative Medicine Doctor) who may not access
43
44 support or for whom support will be restricted, leading to greater unmet need: *'There may*
45
46 *be a silent epidemic of grief that we have not yet picked up on'* (#9 Palliative Medicine
47
48 Doctor).
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Table 3. Impacts of the pandemic on bereavement care practice

| Theme | Illustrative quotes |
|---|---|
| <p>1. Impact on services</p> | <p>Before COVID there needed to be an improvement in specialist bereavement services. The generic support provided by staff has become more difficult to provide - particularly during the height of covid in the community setting when only essential visits were being done face to face. There still needs to be better access to bereavement services. Furthermore, there is no access to chaplaincy in the community setting which should be considered. (#582 Palliative Medicine Doctor)</p> <p>As team leader of a small team of nurses providing a Hospice at Home service countywide. Prior to Covid -19 we had already identified there is a gap in follow up bereavement support for families of the patients who we have nursed. It is not something we have the capacity to do. (#670 Community Nurse)</p> <p>The staff adapted very professionally and quickly to ensure there were no gaps in sessions for those needing the service... We did have to write a whole new service protocol and generate new confidentiality statements and counselling contracts as the staff working with online platforms had to set out new boundaries for counselling and support, having looked into these boundaries, it was a bit scary at first because you have to protect the staff who can see into people homes and personal space and ensure there are no interruptions during the session with IT breaking down etc. However, now 5 months on from lockdown, we do find that the challenges and most clients engage well. (#475 Head of Information and Supportive Care Services)</p> |
| <p>2. Impact on clinicians and relationships with patients</p> | <p>It has brought many challenges for both client and counsellor. Much of what happens in the counselling session is about reading body language and facial expressions. This has proven nearly impossible. Also it is much more difficult to build an empathic trusting relationship when there is a phone or computer in between client and counsellor. It has been harder to reach young bereaved people as not always appropriate to do telephone or video work. (#554 Hospice Bereavement Counsellor)</p> <p>I found it really, really emotionally taxing. It is not in my normal day job to be having conversations. I found preparing patients and relatives for intubating knowing that may be the beginning of their grief journey incredibly hard. (#407 Respiratory Physiotherapist)</p> <p>This has been a difficult time for both the bereaved and staff. The bereaved have a reduced, non face to face service. The staff feel powerless and are restricted from doing the job they are passionate about. That said a great deal of</p> |

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learning has been going on and staff have been imaginative in finding new approaches. (#418 Palliative Care Specialist Nurse)

3. Impact on bereaved people

I feel it's the isolation that is causing the greatest emotional and mental anguish. That, and the fact that many people saw their loved ones poorly at home, then taken to hospital, never to be seen again. This leaves very deep scars. So I feel peer support is fundamental to help bereaved families feel and share their story with others and, have a chance to hear someone's else story. Grief is unique to every individual but community spirit helps heal, through a sense of belonging and walking with people who understand your pain. (#617 Bereavement support worker/volunteer)

The experience of grief is far more complex given majority of loved ones have been mostly separated from the dying person during the illness and even during most of the dying process... Families have experienced more complex guilt for feeling somehow they may have failed in their duty to shield vulnerable loved ones from the infection or that they couldn't be united with their loved ones during the illness (#215 General Practitioner)

I have concerns that some bereavements may be more complex due to visiting restrictions - families may not have been able to say goodbye as they wished or had less time with their loved one. Some have changed their preferred place of death based on visiting restrictions. Some people dislike virtual support and prefer face to face, so it is likely that despite efforts, bereavement support has not been as high quality as it was. (#690 Palliative Care Doctor)

Discussion

Evidence on the impact of the COVID-19 pandemic on the experience of bereavement is emerging. This first study of UK bereavement care practice during the pandemic reveals significant changes in the delivery of support and the ways in which services have adapted to address the more complex needs of bereaved families. Bereavement care has undergone major change in both acute and community settings affecting bereaved people, clinicians, support workers and the wider health and social care system. Increased need for bereavement care has challenged practitioners as they have taken on new responsibilities and skills and shifted to remote and electronic working. The potential for prolonged and complicated grief responses is particularly concerning (19, 20).

The large number of replies from across the UK and Ireland and the wide range of professional roles and settings represented support the potential generalisability of the data. Anonymity encouraged detailed and honest responses. However, due to snowball sampling it is not possible to calculate a response rate or appraise the representativeness of the sample. While there was consistency in responses across settings, further research is needed to investigate the settings and bereaved populations where support needs are highest. The survey instrument was self-developed as a rapid response to understand the impact of the pandemic on bereavement services and was not subjected to psychometric testing.

As the world enters the next wave of the pandemic, urgent consideration is needed of ways to ensure optimal support: bereavement can have a significant impact on morbidity and mortality, yet bereavement care often remains an afterthought in clinical priorities (21). This study highlights that bereavement care is a significant component of health and social care

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2
3 across a wide range of settings and clinical roles although practitioners may at times feel
4
5 poorly equipped to manage bereavement (22-24).
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9 Practitioners indicated remote delivery of some bereavement support may be implemented
10
11 long term; however, further research on the efficacy of remote support for bereavement is
12
13 required. Trusting relationships and compassionate communication between staff and
14
15 bereaved families are critical to bereavement care (25). This is challenging to ensure
16
17 through remote and online routes, creating additional burdens of time and emotional
18
19 resources for an already overstretched and exhausted workforce. The emotional and
20
21 personal impact on practitioners highlighted in this study is a particular area of concern (26,
22
23 27).
24
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28
29 Bereavement service provision has for many years been highly variable across the UK (28).
30

31 While it was heartening that many respondents reported the development of new and
32
33 expanded services, it is unclear how sustainable these will be in the longer-term. The
34
35 markedly reduced income of many charities during the pandemic is concerning for future
36
37 provision of bereavement and palliative care (29). Given the increasing need for
38
39 bereavement support highlighted during the pandemic, it is imperative that policymakers,
40
41 funders, health, social care and community services work together to develop a sustainable
42
43 model of resourcing at local, regional and national levels.
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49 In the early stages of the pandemic, physical health needs were understandably prioritised.

50
51 However, there is now a need to also focus on the mental health needs of the population,
52
53 including the needs of the many people bereaved over the course of the ongoing pandemic.

54
55 Respondents indicated a high level of unmet support needs of bereaved people, with
56
57 concerns of subsequent significant physical and psychological morbidity. Service adaptations
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1
2
3 reported in this study propose the potential benefits of a proactive approach during this
4
5 period, offering support for all those bereaved whether from COVID-19 or other conditions
6
7
8 (6, 15) (see Box 1. Implications for bereavement care practice and policy).
9

10
11 To address the potential ‘silent epidemic of grief’, it is also important to build public
12
13 awareness of the availability and accessibility of bereavement support services to encourage
14
15 bereaved people to view grief as a ‘valid’ reason to seek help from health and community
16
17 services (30, 31). While many bereaved people adjust to their loss with informal support of
18
19 family, friends and community, the three-tiered “public health model of bereavement
20
21 support” may help to guide professionals to identify those who need support from services
22
23 and those at risk of complicated and prolonged grief responses (32).
24
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28
29 This study highlights the profound impact of the pandemic on bereaved people, yet much
30
31 remains unknown about how individuals, communities, and the health and social care
32
33 system will respond. While further research is urgently needed in this area, we already know
34
35 that action is needed now to ensure equity of provision across ethnic groups, ages and
36
37 marginalised groups and equity of care for all bereaved people whether from COVID, from
38
39 other conditions or those bereaved prior to the pandemic.
40
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44
45 **Box 1. Implications for bereavement care practice and policy**

- 46
47 • Improved resources for existing bereavement services to enable coordination
48
49 between local, regional and national networks and encourage a sustainable model
50
51 of bereavement care.
- 52
53 • Developing a proactive approach to supporting those bereaved during this period
54
55 and making services accessible for all
- 56
57 • Enabling regular communication with families prior to a death and after to ensure
58
59 families have opportunities to ask questions and receive reassurance
60

- Where possible, find ways for families to be with dying loved ones
- Integrating assessment of bereaved families' needs into communication to help identify and signpost those who might require further support
- Training in bereavement care to be integrated into medical, nursing and other health care professional training
- Acknowledging the challenges on staff and encourage brief training for those who feel unequipped to manage needs of grieving families

Conclusion

Bereavement care is a central aspect of the work of a wide range of health and social care professionals yet remains a low priority within health care policy. The COVID-19 pandemic has highlighted this important area of patient care, creating both major challenges to bereavement support provision and opportunities for practitioners and policy-makers to address this neglected area of clinical care. Bereavement is one of the long-term impacts of COVID-19: if left unaddressed it may lead to significant physical and mental health morbidity and create a further burden on health and social care services.

Figure legend

Figure 1. Geographical location

Contributor and guarantor information

Contributors

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2
3 CP and SB designed and co-led the study; RL, MS, NZ-C, CH, AL contributed to the study
4 design; CP, JH and SB conducted the data analysis; CP, JH and SB drafted the paper: all the
5 authors reviewed and commented on the draft paper and have approved this final version.
6
7
8 CP and SB are the guarantors. The corresponding author attests that all listed authors meet
9
10 authorship criteria and that no others meeting the criteria have been omitted.
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45 **Competing interests declaration**

46
47 All authors have completed the ICMJE uniform disclosure form
48 at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the
49 submitted work; no financial relationships with any organisations that might have an
50 interest in the submitted work in the previous three years; no other relationships or
51 activities that could appear to have influenced the submitted work.
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Data sharing

Anonymised data will be shared on request.

Transparency statement

The lead author/manuscript guarantor affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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Dissemination to participants and related patient and public communities

The published results of the study will be sent to all collaborating organisations who will be invited to disseminate the findings amongst their members. The published results will also be shared with patient and public communities via the Cambridge Palliative and End of Life Care PPI group, a national network of PPI leads, local news outlets and social media.

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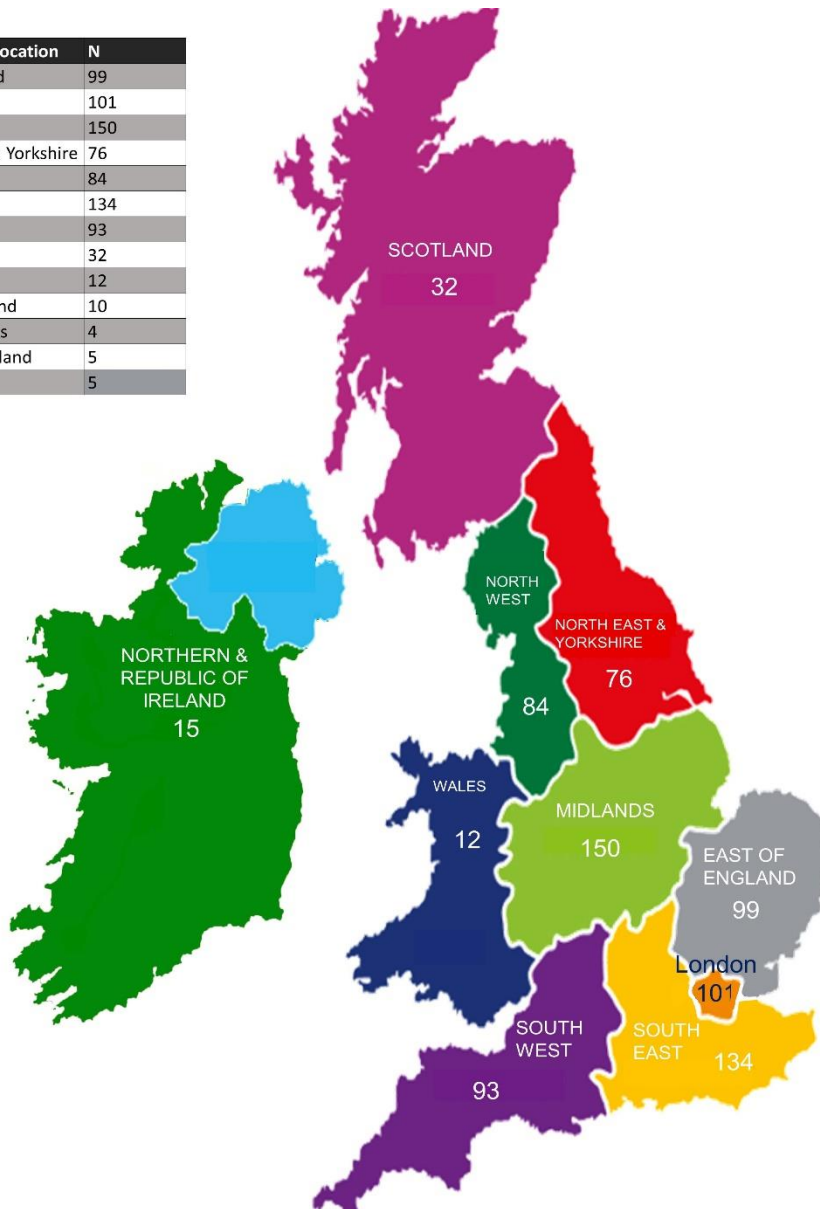
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Figure 1. Geographical location

| Geographical location | N |
|--------------------------|-----|
| East of England | 99 |
| London | 101 |
| Midlands | 150 |
| North East and Yorkshire | 76 |
| North West | 84 |
| South East | 134 |
| South West | 93 |
| Scotland | 32 |
| Wales | 12 |
| Northern Ireland | 10 |
| Channel Islands | 4 |
| Republic of Ireland | 5 |
| Nationwide | 5 |



Online Appendix. Text of the online survey

Bereavement care during the COVID-19 pandemic

The current COVID-19 pandemic has been a particularly difficult time for people experiencing bereavement and has changed the ways in which professionals are seeking to support them. In order to help each other in our care of bereaved people at this difficult time, we have developed a brief questionnaire which will take less than five minutes to complete.

We would be grateful if you could complete this in the near future (closing date Friday September 4th) so that we can analyse and circulate the results as soon as possible. We will send the results by email to everyone who responds and aim to publish a journal paper in the near future.

Please feel free to forward the survey link to your colleagues: it would be helpful to have a good number of responses from across the UK.

There are no right or wrong answers. We look forward to hearing from you.

Stephen and Caroline

Prof. Stephen Barclay sigb2@medschl.cam.ac.uk and Dr Caroline Pearce cmp89@medschl.cam.ac.uk


This research aims to identify the changes in the ways that professionals are providing bereavement support during the pandemic. It is funded by the NIHR School for Primary Care Research and has been reviewed by the University of Cambridge Psychology Research Ethics Committee. By responding to this survey, you consent to take part in this study: you can withdraw at any time by closing the survey without pressing the final "submit" button. Any participant identifiable data will be stored in a University secure data hosting server and destroyed after 12 months: all anonymised data will be stored for ten years on university password-protected computers. For general information about how our University uses personal data, please see: <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>


If you have any questions about the study please contact Prof. Stephen Barclay sigb2@medschl.cam.ac.uk


| | |
|--|--|
| Q1 - In what area of the country do you work? (tick one box) | <ul style="list-style-type: none"> East of England Greater London Midlands North East North West South East South West Scotland Wales Ireland Other (please specify) |
| Q2 - What is your current professional role? (Tick one box) | <ul style="list-style-type: none"> General Practitioner Community Nurse Bereavement Counsellor Bereavement support worker / volunteer Chaplain Funeral Director Social Worker Care Home Manager Social Care Worker Clinical Psychologist Palliative Medicine doctor Palliative Care Specialist Nurse Other (please specify) |
| Q3 - In what setting(s) do you work? (Tick as many as apply) | <ul style="list-style-type: none"> Care Home Community Hospice Hospital Other (please specify) |
| Q4 - In what aspects of care for bereaved people are you involved? (Tick as many as apply) | <ul style="list-style-type: none"> Providing support immediately after a death Practical arrangements of certificates and funerals Providing information on support services Emotional support and listening Clinical assessment of support needs Bereavement counselling Referring for specialist support Provision of specialist psychological / psychiatric support Prescribing medication Pre-bereavement support prior to death |

Online Appendix. Text of the online survey

| | |
|---|--|
| | Other (please specify) |
| Q5 - In the light of the COVID-19 pandemic, have you made changes in the ways you care for the bereaved and / or have there been adaptations to services in your locality regarding: | Identifying bereaved people who might need support Restrictions regarding funeral arrangements Supporting people bereaved from COVID Supporting people bereaved from non-COVID conditions |
| Please click on one of the Yes / No / Unsure buttons to the right of each issue. | Supporting people bereaved before the pandemic Managing complex forms of grief Use of telephone, video or other remote support |
| Please provide details of change or other comments (Free text box for replies) | Access to specialist services for the bereaved |
| Q6 - Do you have any further comments on supporting bereaved people during the COVID-19 pandemic? (Free text box for replies) | |
| Q7 - Further research 1. We are planning a further study in which we would like to talk with some recently bereaved people through telephone interviews. If you would be interested in approaching people for that research, please give your contact details and we will get back in touch with you: | |
| Name | Email |
| Q8 - Further research 2. Colleagues in Bristol and Cardiff are undertaking a more detailed survey of bereavement service provision during the pandemic. If you might be interested in taking part in their research, please give your contact details below and we will forward information about that study | |
| Name | Email |
| Thank you for completing this survey. Please forward the link to your colleagues and others who might be interested in taking part. | |

|  | Checklist for Reporting Results of Internet E-Surveys (CHERRIES) | |
|---|---|--|
| <i>Item Category</i> | <i>Checklist Item</i> | <i>Explanation</i> |
| Design | | |
| | Describe survey design | p.5-6. Target population consisted of practitioners involved in bereavement care working in the UK. A snowball sampling approach was used. |
| IRB (Institutional Review Board) approval and informed consent process | IRB approval | p. 5. The study was reviewed by the University of Cambridge Psychology Research Ethics Committee. |
| | Informed consent | p.6, Appendix 1. Participants were informed of the survey objectives, purpose of survey responses and estimated length of time to complete the survey before completing the survey. Information on data storage was provided. (see Appendix 1) |
| | Data protection | Appendix 1. If provided, personal contact information was stored separately from the survey responses on a password protected computer. |
| Development and pre-testing | Development and testing | p. 5. The survey was developed using Survey Monkey. A pilot survey was conducted to assess usability and technical functionality with three participants. |
| Recruitment process and description of the sample having access to the questionnaire | Open survey versus closed survey | p.5-6. Open survey: key organisations were targeted but sharing to relevant colleagues was encouraged. |
| | Contact mode | p.5-6. Initial contact with participants was made via email. |
| | Advertising the survey | The survey was advertised by relevant health and social |

|  | Checklist for Reporting Results of Internet E-Surveys (CHERRIES) | |
|---|---|--|
| <i>Item Category</i> | <i>Checklist Item</i> | <i>Explanation</i> |
| | | organisations via their mailing lists, social media and webpages. Organisations are listed on p 5-6. |
| Survey administration | Web/E-mail | p.5-6. Survey was sent out via email with a link to a web-based survey. Data capture was automated through the platform host, Survey Monkey. |
| | Context | The survey was not posted on a website. |
| | Mandatory/voluntary | Appendix 1. Voluntary survey |
| | Incentives | Appendix 1. No incentives were offered. |
| | Time/Date | 3 rd August - 4 th September 2020 |
| | Randomization of items or questionnaires | p.5-6. Questions and items were not randomized. |
| | Adaptive questioning | Not applicable |
| | Number of Items | Appendix 1. Eight items in total on one page |
| | Number of screens (pages) | One page |
| | Completeness check | Appendix 1. Completeness checks were not performed during the survey. Mandatory questions had non- response options ("Unsure" or "other"). Questions enforced one option or multiple options where relevant. |
| | Review step | Appendix 1. Responses were editable before submitting the survey. |
| Response rates | Unique site visitor | The survey could only be completed once from the same device. |
| | View rate (Ratio of unique survey visitors/unique site visitors) | Not applicable. |

|  | Checklist for Reporting Results of Internet E-Surveys (CHERRIES) | |
|---|---|--|
| <i>Item Category</i> | <i>Checklist Item</i> | <i>Explanation</i> |
| | Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors) | Not applicable |
| | Completion rate (Ratio of users who finished the survey/users who agreed to participate) | Not applicable – Submission of survey included agreement to participate |
| Preventing multiple entries from the same individual | Cookies used | Survey Monkey uses cookies to prevent multiple responses from the same device. |
| | IP check | SurveyMonkey records respondent IP addresses in backend logs and deletes them after 13 months. Multiple responses from the same device were not permitted. |
| | Log file analysis | No other techniques were used |
| | Registration | Not applicable |
| Analysis | Handling of incomplete questionnaires | p.6. All respondents completed the mandatory questions and so were included in the analysis. |
| | Questionnaires submitted with an atypical timestamp | p. 6. Not cut off point was imposed for excluding responses to be analysed. |
| | Statistical correction | p.5-6. No weighting was applied to the data analysis. |