Journal of grief and responses to death

The impact of Covid-19 on bereavement care in Ireland: A national survey of bereavement care providers

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Keywords: Covid, bereavement, grief, care

Implications for practice

- Following the pandemic bereavement care organisations face many challenges, and particularly services in the voluntary sector are feeling the pressure.
- Basic standards exist for the charity sector in Ireland (set by the Irish Charity Regulator), there are no bereavement-specific guidelines or standards for community-based bereavement organisations. Developments in this area may increase both public confidence and referrer (eg GP) confidence in a bereavement care pathway.
- Funding and support for the community-based organisations should be stabilised and multiannual, allowing for development and continuity of support.

- Initiatives which strengthen the transparency of level 2 bereavement support services and underpin their vital role in bereavement care, such as the development of core competencies, should be considered.
- Professional psychotherapy and psychology services should be accessible, trained and readily available as part of a bereavement care pathway. While all bereaved people will not need this type of service, a sufficiently resourced public health model means service must be available when required.
- Some service additions which arose in response to Covid restrictions, such as online support, have proved valuable additions to service provision beyond Covid.
- Covid created an opportunity to raise awareness of death, dying and bereavement, such as the national bereavement campaign.
 These initiatives should continue beyond Covid.

Abstract

Objectives: To a) describe bereavement care providers' experience of demand and type of need for bereavement care during the first year of the pandemic; b) describe the self-assessed impact on care providers of providing bereavement care through the pandemic; c) identify service adaptations and challenges currently faced.

Methods: Data was collected via an online survey of Irish bereavement service workers (n=199) during the 2021 level 5 restrictions enforced due to the Covid-19 pandemic.

Results: 47% of respondents noted an increase in the demand for their bereavement support service, with many reporting higher levels of distress and more complex needs among service users. 47% reported an increase in the emotional impact of the work, their increased need for support from their employer and the increased pressure they felt due to the service user volume and needs. Many service providers altered their service provision and/or developed new services to meet the changing pattern of needs and restrictions in the way they could provide their service. The positive changes and opportunities resulting from the pandemic were also noted, some of which they intended to continue post-pandemic.

Conclusion: The pandemic and related restrictions shone a light on the way we die and grieve in Ireland. Bereavement care is not represented in health and social policy in an integrated way. With the current focus on bereavement, now may be the time to develop a national policy for bereavement care, which should provide direction for service provision and pathways, alongside public education to meet bereavement needs.

Introduction

Public health models for bereavement support have been proposed in several countries as a guide for identifying bereavement needs and for mapping the appropriate informal, community, organised and professional responses (NICE, 2004; Bonanno et al, 2008; Schut et al, 2001; Aoun, 2014; Aoun et al, 2020.

These models recognise that all bereaved people have needs; for compassion, for information and for the support of those around them. However, some factors can indicate that bereaved people need additional support; these include personal factors (mental health, resilience, attachment style), the type of relationship (eg parent to a child who

died), or factors relating to the death, including cause of death or its suddenness (Burke & Neimeyer, 2013).

According to the public health model a proportion of people will be at risk for difficult outcomes and require extra support (up to 30% of bereaved people according to Aoun et al, 2015). For some of these, community and voluntary peer groups are well placed to provide such support, offering a space to share experience, to learn about grief, to be listened to, while some people will require more structured coping interventions, such as those provided through counselling. For a small but significant proportion of bereaved people (9.8% according to Lundorf et al, 2017) grief is experienced as persistently debilitating; these people experience 'paralysis' or social dysfunction due to grief and require specialised support. This indicates prolonged grief disorder as outlined in the ICD-11 (WHO, 2021).

In Ireland, such public health models have been developed for childhood bereavement (Jones et al, 2015) and adult bereavement (Irish Hospice Foundation, 2020). Approximations of the proportions of bereaved people requiring support range from 30% accessing community/volunteer-based or peer grief support and 10% requiring referral to mental health professionals (Aoun et al, 2014; Lundorf et al, 2017). Nevertheless, loss and bereavement are generally absent from social and health policies, appearing primarily in suicide prevention and palliative care health policies.

The Covid-19 pandemic has brought bereavement to a more central position in the attention of media, health professionals and researchers. The nature of Covid-19 deaths (unexpected, isolated, ICU environment) and the impact of restrictions on funerals, rituals, and support for all deaths during this period result in predictions of disrupted grieving for the medium and longer-term (Mayland et al, 2020). A US study estimated that nine people were impacted by every Covid-19 death (Verdery et al, 2020). Importantly, children are identified as among the bereaved, highlighting the need to understand grief reactions and appropriate supports at different points in the life cycle.

Crises, including pandemics, create collective stress and potential trauma – for the public experiencing the event and for the workers supporting them. While research on the bereavement experience arising from such events in the past is scarce (Mayland et al, 2020), there are indications that many of those impacted by crisis maintain resilience (Bonanno, 2008). However, the experience of being bereaved through Covid-19 is similar in profile to an unnatural bereavement, such as suicide or homicide (Eisma et al, 2020), and current studies are showing elevated levels of more disrupted grief or prolonged grief disorder (Tang et al, 2021, Breen et al, 2021).

The effectiveness of natural social support is emphasised in public health bereavement models, yet it is primarily social support that was impacted by Covid-19 restrictions. In addition, organised peer and community bereavement support services, counselling, and psychotherapy, usually provided face-to-face in a group or individual settings, were forced to withdraw from physical contact.

Pearce et al (2021) surveyed end-of-life healthcare professional bereavement care providers and identified significant shifts in the way bereavement care was adapted and provided through the pandemic. Implications for staff support and training and for integrating bereavement into mainstream health and social care were discussed. While the study claims to speak to bereavement care provision in the UK and Ireland, only 15 of the 805 respondents were based in the Republic of Ireland.

This study seeks to:

- a) describe bereavement care providers' (adult and children services) experience of demand and type of need for bereavement care during the first year of the pandemic
- b) to describe the self-assessed impact on care providers of providing bereavement care through the pandemic, and
- c) to identify the adaptations these services made, and challenges currently faced.

Methods

Research design

This quantitative study used an online survey to collect data from bereavement service providers across Ireland, drawing on two similar studies in the UK (A Penny and L Selman (personal communication); Sutton *et al*, 2022). The survey was supplemented with questions reflecting the concerns of Irish services as identified by

stakeholders National Bereavement Forum and Childhood Bereavement Network (2020). As well as gathering quantitative evidence related to the change to services, open-ended questions were used to gain further insight by allowing respondents to describe what they experienced in their own words. Statistical analysis was undertaken by author AR while MK undertook the qualitative analysis of open-ended responses. The author group engaged in the discussion of the initial findings, and all were involved in preparing the journal publication.

The study met the criteria for a low-risk study review by the UCD Human Research Ethics Committee – Humanities (HREC-HS). All low risk studies are subject to a research ethics compliance review but not a full committee review (reference number: HS-E-21-167-Holme). Written consent was used by asking participants to read participant information and indicate their consent to participate before they proceeded to the survey.

Participants

The survey was open for six weeks during April and May of 2021, when Ireland experienced level 5 restrictions due to the Covid-19 pandemic. Those providing bereavement support in Ireland, at any level of care (eg provision of information, support groups to counselling) and in any setting (eg hospital, hospice or in the community) were contacted through email requests to be eavement networks, to publicly identifiable organisations and through social media and invited to complete the survey.

Measures

The survey consisted of 37 questions; 26 closed questions (some included optional comment boxes) and 11 open questions. There were six sections: 1) the impact of the pandemic on bereavement service provision (6 questions); 2) the impact of the pandemic on their service users (2 questions); 3) the impact on their staff and volunteers (3 questions); 4) the challenges they face (9 questions); 5) what supports would be of help (3 questions). Eleven of the 37 questions obtained information about the organisation the respondent worked with and their role within the organisation (eg a local or national service, target service users, if bereavement was the main or minor focus of their role).

Data analysis

The quantitative data were analysed using IBM SPSS (version 14). Descriptive statistics were calculated for closed questions and content analysis was used to categorise and quantify the replies in the opened ended texts. Response categories, a set of replies that can be grouped because they are part of the same topic, were identified for each of the open-ended questions and their occurrence within the text calculated. Many respondents used the open-ended questions as an opportunity to provide a reflective and detailed description of their experience as frontline workers and their concerns for their service users.

Results

Sample

In total 199 participants responded, with 159 of those also providing information about their service structure (eg target service user, local or national service) and their role within the organisation (eg bereavement a main or minor part of their role) (Table 1).

Respondents indicated a wide range of bereavement support provisions, including support before and at the time of death (eg memory-making activities), after-death supports at level 1 (eg information about the grief process), at level 2 (eg bereavement support group), at level 3 (eg counselling) and level 4 (eg specialist bereavement intervention) (Table 2).

Demand for bereavement support and type of needs

Most of the 199 respondents experienced a change in the demand for their service during the first year of Covid (76%, 151); 47% noted an increase in service demand at some stage over the first year, 36% noted an increase from March to December 2020 and 41% noted an increase from January to April 2021). Only 16% noted no change in their service. Nearly one-third (30%) of respondents reported that they were operating a waiting list for bereavement care.

Almost all respondents (91%, 181) noted a different pattern of need among new bereaved clients compared with before the pandemic. Higher levels of distress associated with the death were reported

by 58% and nearly a third (31%) identified more complex needs or higher levels of risk. Less available support from family and friends was evident for almost half (46%). Changes in help-seeking, such as delaying accessing support until restrictions ease, were noted (41%) while a contrasting pattern showed a proportion of respondents noting clients sought support sooner after the death (22%). The period of time clients engaged with the service increased according to 24%, and some (23%) reported more practical issues arising for service users, such as financial concerns

Open-ended responses elaborated on respondents' experiences (N=151). The overwhelming response was the sense of isolation in grief for service users (N=74, 49%), due to the lack of contact with families and friends and feeling left alone to cope with their grief.

'People are having to grieve alone in their own bubble, the old community supports are not available, and this is taking its toll on people...'

'Bereavement is happening in silence. A neighbour does not know a neighbour has died until weeks later. This will have a big impact on communities and families.'

'The sense of loss can sometimes feel like it didn't happen due to not having friends and family attend funeral. The support is different. It is very isolating. It's like the bereaved are in one bubble and everyone else is in another. Everyone is just carrying on with their own lives. Sense of community is not there for the bereaved because of Covid physical restrictions.'

A lack of closure (N=41, 27%) due to limited goodbye rituals, lack of access to hospital/nursing home visits at the end of life made it harder to process what happened.

'The need for closure is greater as many young people were unable to attend the funeral of a loved one due to restricted numbers so if it was a grandparent or an uncle/aunt etc they had to watch the service online or [with] a close friend.'

'Due to restrictions on visiting those bereaved often have not had as much contact with their loved one as they would have pre Covid. As a result often those bereaved have not physically seen their loved ones deterioration over time.'

Some reported a heightened anxiety and trauma among service users (N=27 18%)

Table 1: Bereavement service and participant information (n=159)					
		%	N		
Sector	NGO	58	92		
	Statutory	25	39		
	Private sector	16	26		
	Other	1	2		
National or local service provision	National	31	51		
	Local/CHO/county level	56	112		
	Other	2	4		
Target service user (relationship	All bereaved people	70	112		
to deceased)	Bereaved parents	21	34		
	Siblings	18	28		
	Bereaved children and young people	14	22		
	Widow(ers)	9	14		
	Other	9	15		
Target service user (cause of	Following all cause of death	66	105		
death)	Palliative care/chronic illness	12	19		
	Suicide	12	19		
	Pregnancy loss	7	11		
	Still birth or neonatal death	7	11		
	Homicide	4	7		
	Road traffic collision	3	4		
	Other	9	14		
Age group of service users	Both adults and children/young people	49	78		
	Adults only	37	59		
	Children and young people only	6	9		
Organisation	Counselling/psychotherapy service	21	34		
	National bereavement charity	14	22		
	Hospital	12	19		
	Family resource centre	11	18		
	Hospice	9	15		
	Local bereavement charity	7	11		
	National or local charity (not bereavement specific)	6	9		
	Health Service Executive	4	7		
	School/college	3	4		
	Childcare facility	1	1		
	Other	12	19		
The focus of bereavement in the participant's role	Main focus of my role	22	35		
the participant's role	Forms a significant part of my role	43	68 45		
	Forms a minor part of my role	28 7	45 11		
Destining and the latest	I do not provide any bereavement support				
Participant's role in the organisation	Counsellor/psychotherapist/psychologist/psychiatrist	26 19	40 30		
o.gailiaddoi1	Manager/coordinator Social worker/social care worker	19	21		
	CEO/chair/board member	12	19		
	Bereavement volunteer	9	14		
	Bereavement midwife	4	6		
	Community development worker	3	4		
	Teacher/special needs assistant	1	1		
	Chaplain	1	1		
	Other	14	23		

Table 2: Type of bereavement support provided (n =159)					
		%	N		
Pre and at the time of death	Pre death/bereavement support eg memory-making activities	36	57		
	Immediate post death support eg bereavement suites,				
	memory-making	35	55		
	Bereavement home visits	25	40		
Level 1	Grief information (website or written)	30	80		
	Remembrance events/services	44	70		
	Bereavement helpline/support line	27	43		
	Public bereavement information events	21	33		
	Drop -in support eg bereavement cafés	11	18		
	Social groups eg walking groups for bereaved	5	8		
	Online bereavement forum	3	5		
Level 2	Bereavement support group	32	51		
	One-to-one support with a trained volunteer	24	38		
	One-to-one support – volunteers without bereavement specific training	8	13		
Level 3	General counselling/psychotherapy	47	75		
Level 4	Specialist bereavement intervention, involving mental health service	24	38		
	Other	16	25		

'Last year, after the first lockdown, I saw an unprecedented number of older people (over 80), suffering from anxiety for the first time in their lives, finding it hard to readjust to life after lockdown. I am seeing much more people who are presenting with trauma alongside their grief, exacerbated by loneliness and isolation.'

From respondents working in maternity services (n= 10), there was a particular concern for maternity sector service users, partners not being present for appointments, in particular scans and when receiving difficult news or test results.

'Some parents are finding out devastating news about their baby and they are completely on their own. Mothers are in hospitals getting their scans alone, we have fathers who feel they have not had the chance to be a part of their baby's life, they weren't at one scan, and mothers who feel they are grieving completely alone as no one got the chance to meet their baby.'

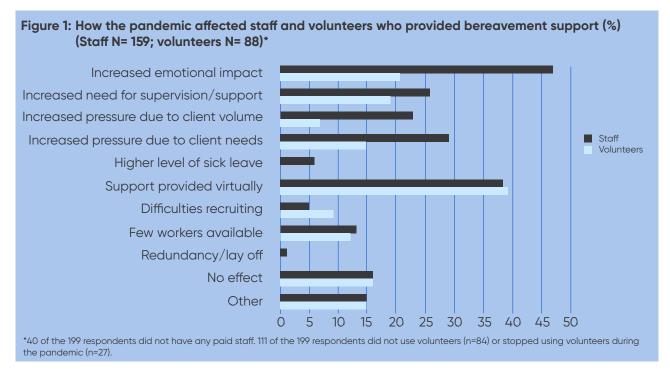
'More awareness of the impact of grief' was noted as a potential positive outcome (n=2).

'It has people speaking more openly about grief and has created a greater awareness in the importance of seeking support if necessary'.

Impact on care providers (staff and volunteers) providing bereavement care through the pandemic

Of the 199 respondents, 80% stated their service employed staff (N=159) and 44% used volunteers (N=88). Of the 88 respondents whose service used volunteers, almost a quarter reported that they stopped using volunteers during the pandemic (23%, n=27). Both staff and volunteers providing bereavement support during the pandemic were affected, although a higher proportion of staff seemed to experience an increase in the emotional impact, an increase in pressure due to the volume of clients or needs of clients, and the need for supervision and support when compared to volunteers (see Figure 1 for details). Nearly half of the respondents noted an increase in the emotional impact on staff (47%). The fact that support had to be provided virtually impacted both staff and volunteers, and the need for supervision is noted. Figure 1 details the areas in which both staff and volunteers were impacted. A similar proportion of respondents indicated that they did not know the impact on volunteers and staff, 9% and 8%, respectively.

One respondent gave some insight into the impact on their staff which encapsulated many concerns highlighted by respondents overall.



'Due to staff being stretched further and delays with Covid, staff are generally dealing with a much higher stress level both personally and from service users who are, understandably, upset about certain services. It can be disheartening for staff, given they have all been overworked with this past year. I think because of Covid closing down everything, people have not been taking holidays. Everyone is waiting until we can go somewhere or do something. For this reason no one is getting to switch off.'

Services' adaptations and challenges experienced

Only 9% (N=19) did not make any change to their service during the first 14 months of the pandemic. Most (63%) made changes to their existing service provision, 27% developed new services, and 7% ceased providing services. Of those who reported an increase in service demand (57%, 114), many signposted to local services (44%), increased their service provision (35%) or started a waiting list (29%).

New service: 'Relatives of all patients who die in our organisation receive a phone call from a medical social worker (MSW) following the death for emotional and practical supports. In addition, all relatives (nominated person) receive a bereavement information pack. Prior to C-19 this was only provided to relatives of patients going for post-mortem as the MSW post is solely funded to support the PM process.'

Made changes to existing provision: 'We had to change our service to online, this was new to many of our clients and really didn't work so well for some of our older clients. So we reverted to mobile phone contact.'

Service ceased: 'It was very sad to abandon our successful and important service especially at this very difficult time for families. We were clearly directed to do so as the organisation deemed it unsafe.'

The most common challenge reported by respondents (N=199) was the difficulty in accessing physical spaces for meeting service users in-person (27%). Some had difficulty in accessing specialist supports, such as mental health service (23%), felt challenged because of their difficulty meeting the demand for their service (13%) or being unable to meet the client's needs (12%). In relation to service providers, access to bereavement training specific to the pandemic (19%), maintaining staff and volunteers' motivation (13%), lack of volunteers available to work (8%) and being able to provide sufficient support and supervision (8%) were also seen as challenges for services.

Of the 53 respondents in management positions, many (32%) were concerned about the emotional isolation of staff working from home and were worried about burnout and the mental health of frontline staff. They were understaffed and felt under pressure, which was compounded by having to redeploy staff to respond to demand.

'Staff support was challenging in terms of supporting them as they were managing their own anxieties whilst holding and containing their clients and their families also.'

'I feel like we haven't been able to get the team together for any sort of social event in so long and I worry about the teams mental health....

One must be passionate about this line of work in order to be effective and I do not want work to be something endured by any of the team so I feel it is imperative that we make our conditions better for all.'

Some (24%) felt the level of change management during the pandemic was significant; all work processes and procedures had to be adapted to new ways of working safely.

'The volume of changes required to work processes and procedures was very demanding in a dynamic situation that required constant review and attention.'

Others (25%) highlighted concern about not reaching those who were not able or suitable for online, especially children and more vulnerable groups, such as non-literate, those experiencing mental health issues, etc.

'Many people are not fully literate and can only work face-to-face.'

Another issue mentioned by those in a management role was the impact on fundraising and pressures from the lack of core funding.

Most (61%) participants felt the pandemic had led to some positive changes or opportunities for their bereavement services. These included enhanced access to support (64/122) for example, remote supports were accessible irrespective of location, no travel time and associated costs were involved.

'Online has made it more possible for people at attend a bereavement group online. Some of the reasons being ease of accessibility (location/distance from where they live would have be prohibitive). Less time taken up with travel etc.'

Remote supports were seen as an addition to service provision, not a replacement going forward.

'I do think some people liked being able to talk to the counsellor from their own home, this is an area we will look into when this pandemic is over.' 'Working online has certainly challenged us but for many being in their homes and indeed us in ours has allowed for a normality it the relationship....seeing their pets, they ours... photos of the deceased at hand, memorials such as trees that many planted in their gardens all have enriched the relationship.'

'There has been a greater emphasis on online resources which is accessible to all age ranges. However the inability to meet people face to face and support their grief in person in a safe and therapeutic space has been denied. There is a clear need for in person contact and communication.'

The restrictions brought about by Covid created an opportunity to provide service through a new virtual medium (N=16), such as online or phone.

'Covid-19 has prompted our much greater use of social media platforms to support, engage with, inform and provide guidance and support to our clients and other stakeholders.'

'It is part of our strategy to have online bereavement support available for parents. Covid-19 fasttracked us.'

Having to use virtual mediums forced respondents to learn new digital skills, acquire additional skills and be creative (N=12), which allowed them to offer their normally face-to-face support in a virtual format.

'As volunteers with a bereavement service, we have received training in telephone contact with clients. Training in Zoom and WhatsApp is on the way also.'

Covid also created an opportunity to raise awareness of death, dying and bereavement (N=8).

'There is so much more awareness to the impacts of grief. People seem to be speaking about it more and are feeling that it is acceptable to do that.'

'Covid-19 brought the bereavement community together which supported ideas and opportunities.'

Limitations

The data presented represents the views of 199 individual bereavement care providers at one point in time during the first 14 months of the pandemic. The sample represents at least 104 discrete individual organisations (124 of the 199 respondents provided their organisation's name). However, only 53 held management positions, so

the extent to which respondents were best placed to give an organisational view of the bereavement challenges may be limited. The results presented here are an overview of experiences across the whole continuum of bereavement care provision, and a limitation is that the individualised needs of specific sectors or levels of care are not explored further.

Discussion

It is encouraging that the sample reflects support services representing each of the levels of the public health model of bereavement care (levels 1 to 4 on the pyramids for childhood and adult bereavement (Jones *et al*, 2015; IHF, 2020). In addition, the support described is focused on bereavement through a range of circumstances (from miscarriage through to chronic illness and suicide), for both adults and children, in acute and community settings and across a continuum of pre-death to post-death support.

The non-governmental organisation sector makes up over half of the respondents, and this probably reflects the service pattern in Ireland, particularly for parental bereavement and suicide bereavement, where level 2 community charities are set up by founders who have had personal experience of these types of loss. Level 2 supports are relevant to upwards of 30% of bereaved people, and they should be a visible and accessible support in communities (Aoun, 2015). However, while basic standards exist for the charity sector in Ireland (set by the Irish Charity Regulator), there are no bereavement-specific guidelines or standards for community-based bereavement organisations. Developments in this area may increase both public confidence and referrer (eg GP) confidence in a bereavement care pathway. Their core role requires that funding and support for these community and peer organisations should be stabilised and multi-annual, allowing for development and continuity of support in this aftermath of the peak of Covid-19. It is worth noting that 50% of those overseeing the financial operations of bereavement services had concerns for the future.

Overall, the respondents report increased demand and more intense patterns of bereavement need that correspond with the projections in the literature (Mayland *et al*, 2020; Diolaiuti *et al*, 2021) and with the contemporary research on

bereavement during Covid-19 (Breen et al, 2022; Eisma et al, 2020). However, access to specialist bereavement services was cited as a significant challenge for almost one-quarter of respondents. In addition, recent (although pre-pandemic data) Irish research on complicated grief has identified skills and knowledge deficits and a gap in the translation of research to practice education among level 3 and level 4 providers (Dodd et al, 2022a; Dodd et al, 2022b). A functioning public health model requires tertiary and specialist care to be available based on need.

The pandemic has highlighted the need for us all to make space for grief, other people's and our own (Selman et al, 2021). Concern has been shown about the severe impact of the pandemic on healthcare professionals, and their roles in supporting not only patients dying from Covid-19 but also the patients' grieving families (Stroebe & Schut, 2021). Many bereavement care providers in this study expressed an increased need for supervision, and many reported increased pressures due to service user needs and volume. This has also been reported in other countries, such as the UK (Pearce et al, 2021; Sutton et al, 2022). Research shows that this increase in demand and pattern of bereavement in response to Covid will continue (Mayland et al, 2020; Diolaiuti et al, 2021). Reactions of caring professionals need consideration. Services' ability to meet the demand and the needs of service users and to support their staff and volunteers requires sustained or additional resources.

Respondents reported that the pandemic presented a wide range of challenges for their service but it also resulted in many positive changes and opportunities. Some commented that they intend to keep some of these new service developments and resources, such as providing some element of remote support along with in-person support and the development of level 1 supports, such as information for all bereaved families. The adaptations reported showed great flexibility; overall, these findings align with Pearce et al (2021). The pandemic also allowed for opportunities for service providers, such as enhanced collaboration both within and outside the organisation, access to more training opportunities, learning more skills due to the changing nature of the delivery of the supports (eg face-to-face to remote support) and increasing the amount of support provided (ie able to see more service users due to less travel time).

Recommendations and future directions

The pandemic and related restrictions have shone a light on the way we die and grieve in Ireland. It has highlighted the public health context for mourning and bereavement. Currently, bereavement care is not represented in health and social policy in an integrated way, appearing primarily in suicide and palliative care national policy (Department of Health, 2015; Department of Health and Children, 2001). The survey results reported here, in the context of the public health model of bereavement care, represents an opportunity to promote public and community engagement and professional development in this area. While the research was conducted in the context of bereavement during the pandemic, the public health model provides direction for ongoing development of bereavement care - in usual as well as crisis times.

Our research identifies some tentative priorities for development and for future research. With respect to development, initiatives which strengthen the transparency of level 2 bereavement support services and which underpin their vital role in bereavement care should be considered. These may include the development of core competences and/or bereavement care standards frameworks. Similarly, professional psychotherapy and psychology services should be accessible, trained and readily available as part of a bereavement care pathway.

Research involving service providers' views is an important element of development. Ongoing audit and research incorporating a stronger cohort of service manager – and commissioners of these services – would be indicated for the future.

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