2023

Irish Hospice Foundation: Time to Reflect Survey

ECNE Research, LLC©

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Executive Summary

The COVID-19 pandemic was an unprecedented crisis that suddenly disrupted society. The establishment of various restriction measures to mitigate the spread of the virus was difficult to process and transformed the way in which we experienced dying, death, and bereavement. COVID-19 brought a profound loss of life with death statistics broadcasted several times a day across all forms of news outlets and social media. Every individual was forced to contemplate the fragility of human life every day, sometimes several times a day. As a result, COVID-19 had a lasting impact on us all and contributed to a silent epidemic of grief.

The 'Time to Reflect' survey was commissioned by Irish Hospice Foundation to elucidate the experiences and perceptions of the Irish population in relation to dying, death, and bereavement and the impact of COVID-19. A total of 2259 participants completed the 'Time to Reflect' national survey from November 2021 to February 2022. Participants were invited to share their (a) perspectives of death, dying and bereavement (b) personal experiences of death, dying and bereavement and (c) general information about themselves. This study is the first of its kind to capture the specific challenges and experiences of the Irish population in relation to grief and bereavement during the pandemic.

Most participants were aged between 45 and 54 years old, female and lived in rural areas. Over half of the participants reported experiencing the death of someone close to them during the pandemic. Hospitals were the most frequent place of death and approximately 22% of deaths were confirmed or suspected COVID-19 infection. Most participants reported that the pandemic changed their views about dying, death and bereavement with the participants reporting a greater awareness of grief and loss due to COVID-19. Almost three quarters of participants reported the pandemic prevented their loved one from having the death they would have wished for. Over 86% of participants agreed that their experience of a loved one's death was negatively affected by COVID-19. Less than 20% of bereaved participants were able to spend time with their loved one before they died and over half of participants were not present with their loved one when they died. These negative experiences were attributed to COVID-19 public health restrictions and the strain on healthcare workers and settings. Restrictions on funerals and mourning rituals were also cited as having an impact on the grief experience of bereaved individuals with participants emphasizing the need to grieve properly including attending funerals and having an opportunity to say goodbye.

Healthcare workers were also negatively impacted from the trauma of witnessing so many deaths across all age groups and the restrictions that limited human contact. One in five of the participants were healthcare workers and they recalled the difficulty of watching loved ones of their patients who were not permitted to visit their loved ones. Healthcare worker participants described working on the frontline as a harrowing and traumatic experience. They described the moral struggle of not being able to provide patients with the quality of care they required. Both family members and healthcare workers referred to situations in which a patient died completely alone without family or staff present, and the pervasive impact that had on them.

Findings from the brief grief questionnaire found that 14% of participants exhibited signs of prolonged grief disorder, which is less than findings from similar studies in other countries.

Participants highlighted three main priorities for future end-of-life care in Ireland:

1. Ensuring that people are supported to die with dignity, free from pain in a calm and comfortable place of their choosing.
2. Better home-based support for people at the end of their life.
3. Ensuring every person has equal access to palliative care wherever they live and whatever their age.

There is concern globally regarding the detrimental impact of COVID-19 on the grieving process and the provision of bereavement support, particularly considering the public health measures and restrictions placed on society during the pandemic. Several authors have indicated that there is likely to be long-standing consequences on dying, death, and bereavement due to the profound loss of human life. Others have suggested that the impact may not be as extensive as originally anticipated. There is consensus regarding the need for continued research on the topic and close monitoring of people who have been bereaved to identify those most at-risk of developing prolonged grief disorders or other complications, and to intervene early. Several recommendations are made in this report in terms of health system measures, health policy, and future research. Recommendations include the need to facilitate family visiting in healthcare settings and provide opportunities to family members to say goodbye to their loved ones. Furthermore, health services should be equipped with additional bereavement support services for patients, families, and staff. Screening and early intervention for those experiencing prolonged grief disorders or complicated grief should be incorporated into health policy and practices.

The society-wide implementation of strict COVID-19 prevention measures proved to be detrimental to the dying, death, and bereavement experience. Accordingly, in the event of future pandemics, careful consideration is needed when imposing restrictions that can significantly hinder the grief experience.

Scope of Project

The project was conducted in two key phases. Phase one consisted of a scoping review of the literature on the topic of COVID-19 and its impact on dying, death, and bereavement. The review sought to elucidate the impact of lockdown measures, changes to health service procedures, rules on funerals and gatherings, number of deaths during the pandemic, and short and long-term impacts of COVID-19 on grief and bereavement. Furthermore, survey research that investigated the impact of the pandemic on grief and bereavement was reviewed. The search was limited from 2020-2023.

Phase two of the project presented survey data collected by Irish Hospice Foundation between November 2021 and February 2022. A survey was administered to individuals over the age of 18 years (N=2259), to explore perspectives and experiences of dying, death, and bereavement in Ireland during the pandemic.

Phase 1: Scoping Review of the Literature

The aim was to conduct a scoping review of academic and grey literature to gather up-to-date information on the number of deaths, impact on grief and bereavement, lockdown measures and other public measures during the pandemic. The methods used to conduct the review of the literature are provided in Appendix 1. A summary of the key findings is provided below.

Two key themes emerged from the literature review as follows:

- Exponential increase in global interest in the impact of COVID-19 on grief and bereavement
- Findings of survey research exploring impact of COVID-19 on dying, death, and bereavement

Exponential Increase in Global Interest in the Impact of COVID-19 on Grief and Bereavement

A total of 145 papers were sourced that focused on the impact of COVID-19 on grief and bereavement globally. The volume of publications is reflective of the increased focus and interest in this topic. Figure 1 below provides an overview of the number of publications per year. The number of publications doubled from 2020 to 2021 with a similar number published in 2022.

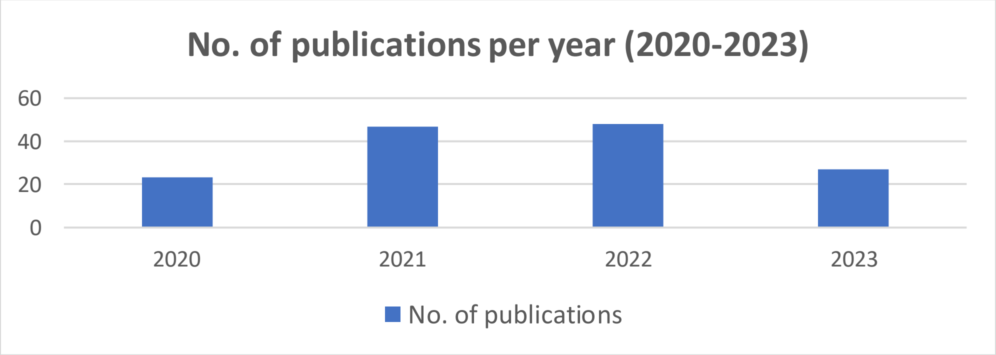


FIGURE 1 PUBLICATIONS FOCUSED ON GRIEF AND BEREAVEMENT DURING COVID-19 (2020-2023)

This prior research was conducted in many countries, which emphasizes the global impact of COVID-19 and the similar experiences of individuals all over the world, due to restrictions placed on healthcare and bereavement support services. Figure 2 below presents a heat map, which illustrates in which countries most of the prior research was conducted.

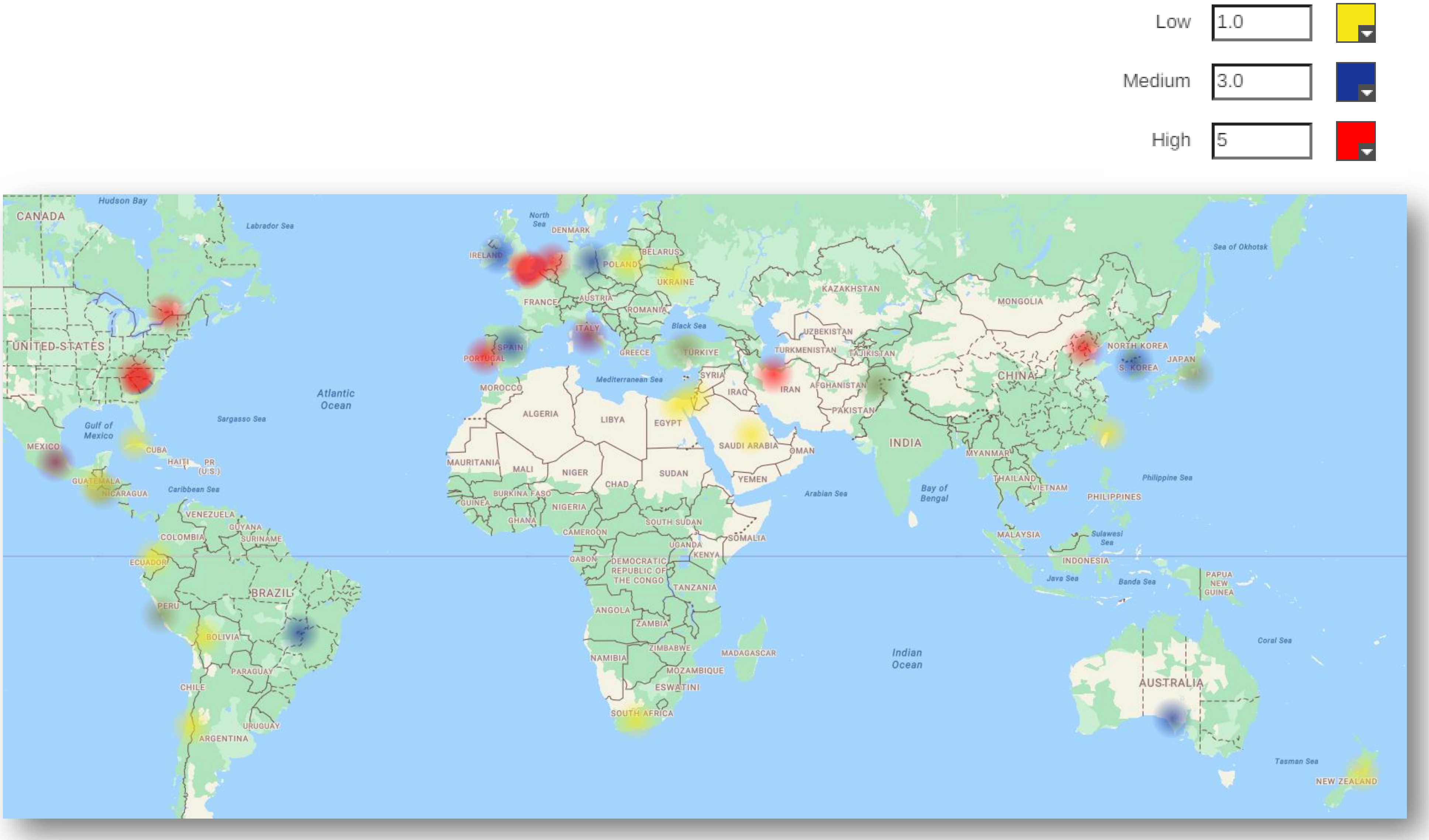


Figure 2 Countries Where Studies Were Conducted on the Impact of COVID-19 on Grief and Bereavement

In terms of research design, the studies utilized a range of study designs. The most common design used was a quantitative survey or cross-sectional design. The second most common type of papers were literature review or discussion papers, which synopsized the impact of COVID-19 and cautioned about long-term psychosocial impacts of restrictions during the pandemic. The remainder of the studies were mostly qualitative and there were 5 randomized controlled trials (RCTs) conducted. See Figure 3 below for a summary of study designs.

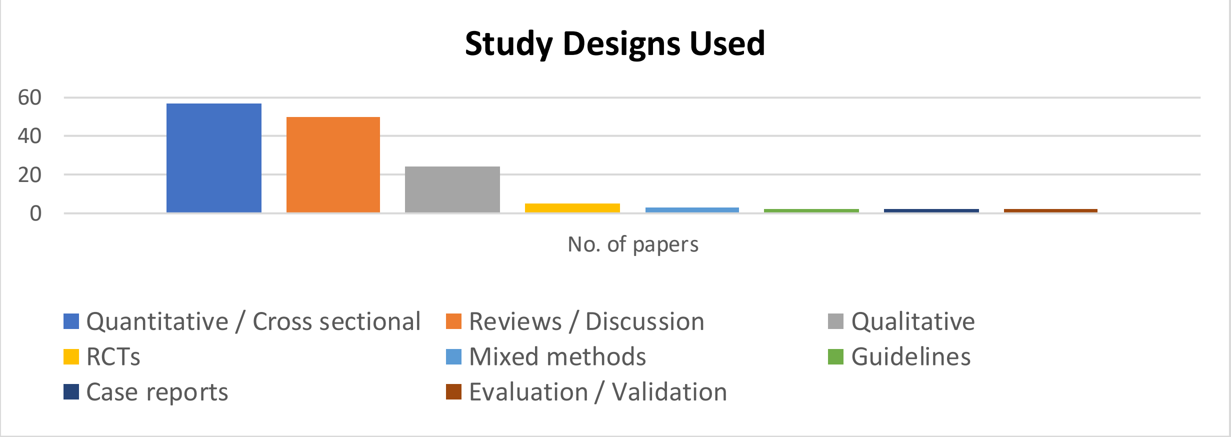


Figure 3 Overview of Design / Methodology of Included Studies

A range of populations were included in prior research examining the impact of COVID-19 on dying, death, and bereavement. A total of 84,097 participants were included across all studies. Most of the studies recruited bereaved family members who lost a loved one during the pandemic (N=19,779) apart from one population study that recruited a large sample of older adults (51,383). An overview of the included samples is provided in Figure 4 below.

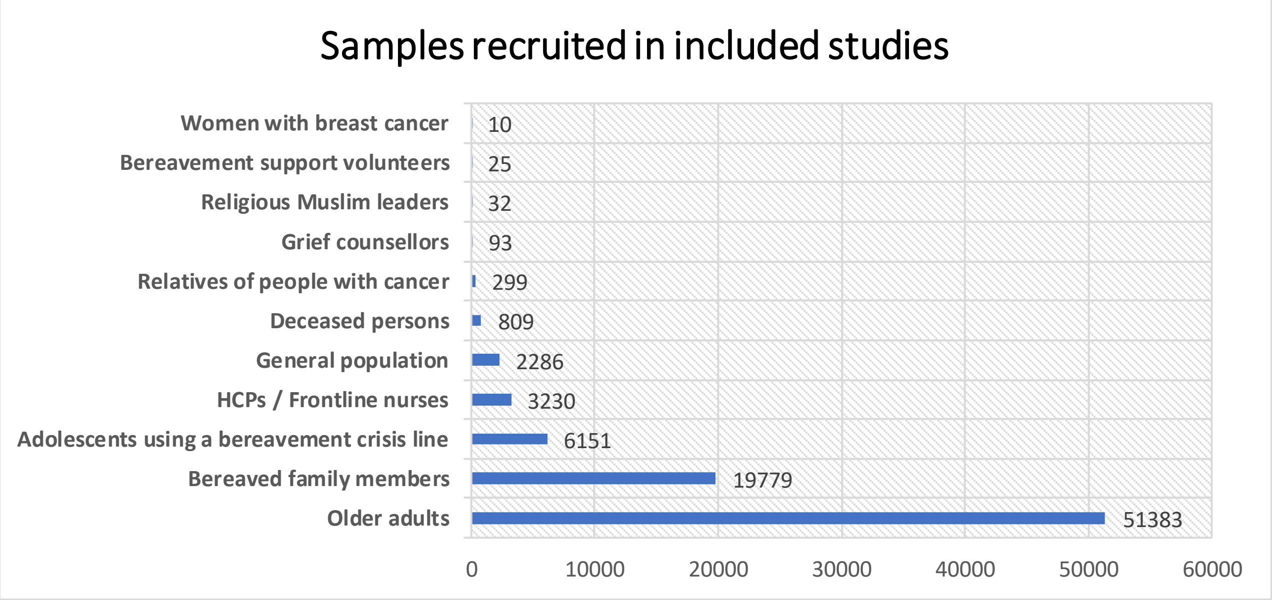


Figure 4 Overview of Samples in Included Studies

Summary

In summary, there has been an exponential increase in the number of studies focused on the impact of COVID-19 on grief and bereavement. Most of these prior studies have taken place in Europe, the USA, Canada, Iran, and China. A variety of research designs have been used but most studies have been quantitative or review / discussion papers. Almost all the studies recruited individuals who had lost a family member during COVID-19. It can be concluded from this summary analysis that there is concern on a global level regarding the detrimental impacts of COVID-19 on the grieving process and the provision of bereavement support, particularly considering the public health measures and restrictions placed upon societies globally. The next section presents further details on the findings of prior survey research that examined the impact of COVID-19 on grief and bereavement.

Findings of Survey Research Exploring Impact of COVID-19 on Dying, Death, and Bereavement

A total of 32 survey studies were sourced that explored the impact of COVID-19 on dying, death, and bereavement. Findings of these prior studies highlighted the impact of COVID-19 on bereaved individuals and the impact on healthcare workers and patient care.

Impact on Bereaved Individuals

COVID-19 impacted the bereavement experience and evidence indicates similar impacts were noted globally. For example, the pandemic caused bereaved individuals to feel more isolated due to an inability to connect with family or attend in-person support groups. Strategies identified to improve the bereavement experience included improving communication with families, safe facilitation of family visiting in healthcare settings, and strengthening the bereavement support sector through the provision of greater resourcing and expansion of support services. Specific recommendations were made in terms of the need to develop best practices for funeral practices and other similar rituals, that provide opportunities for remembrances, and enhanced social support for those who are grieving.

Several authors indicated that there is likely to be long-standing consequences on dying, death, and bereavement due to the profound loss of human life during COVID-19. Other authors suggested that the impact may not be as extensive as originally anticipated. All authors agreed that there is a need for continued research on the topic and close monitoring of people who have been bereaved to identify those most at-risk of developing Prolonged Grief Disorders (PGD) or other complications, and to intervene early. Risk factors for developing prolonged grief disorder or complicated grief included those who lost a partner, child, or parent; shared a close relationship with the deceased; or lost a person due to COVID-19.

One study found that non-white participants had significantly higher PGD scores than white participants. Studies also showed that children and young people faced additional strains and challenges associated with pandemic bereavement, and resources and initiatives that facilitate supportive communication within family and school settings, adequate resourcing of school and community-based specialist bereavement/mental health services, and increased information and signposting to available support are important. Similarly, evidence suggests that bereaved older adults need additional mental health support, as COVID-19 deaths have lingering mental health implications for them.

In terms of the provision of bereavement care and support services, it was reported that the pandemic created major challenges, which if left unaddressed may lead to significant physical and mental health morbidity and create a further burden on health and social care services. Therefore, it is imperative that bereavement support services become a high priority in the health policy agenda.

Impact on Healthcare Workers and Patient Care

Evidence shows that healthcare staff working on the frontlines during the COVID-19 pandemic experienced a significant number of patient deaths and they faced diverse unknowns related to the treatment of patients with

COVID-19. They initially did not know how to treat the disease correctly and felt overwhelmed and confused by the constantly changing protocols and procedures. In one study conducted with nurses, almost 60% of participants were found to be suffering from complicated grief. Nurse participants who were floor nurses working in a COVID-19 intensive care unit, had more than 10 years clinical experience, and had worked in COVID-19 wards for more than two years, were more likely to experience complicated grief. Complicated grief can result in significant health problems and burnout among nurses. Similarly, one study conducted with midwives revealed that the COVID-19 pandemic impacted their ability to provide optimal care and support to bereaved parents. Furthermore, the use of Personal Protective Equipment (PPE), such as facemasks, was described as a significant barrier to providing compassionate care. Visitor restrictions and support on discharge were also highlighted as impacting on the provision of healthcare with clinicians being conscious of providing added support to compensate for restrictions and lack of support. Social isolation associated with COVID-19 restrictions was also highlighted by healthcare workers as potentially leading to a more complex and prolonged grieving process for patients.

Several recommendations were made by authors to address and improve the experience of healthcare workers. Authors proposed that governments, health authorities, and managers should support healthcare workers in pandemic settings to reduce the adverse impact on their health and well-being. The need for supportive interventions at the organizational level was highlighted including support and resources to help staff cope with the emotional toll of working with the bereaved during the COVID-19 pandemic. It was recommended that training programmes should be implemented to enhance the coping skills of staff, and organizations should promote self-care and provide opportunities for staff to debrief and process their emotions related to their work with the bereaved. Other self-care and grief management strategies identified included the provision of opportunities for healthcare workers on the frontlines to take a brief and simple pause after hearing about or witnessing a patient's death; investment in grief support resources for staff; development of interventions to help healthcare workers prepare for loss and support them in their grief over the deaths of patients and co-workers from COVID-19; and ensuring the continuity of spiritual and religious activities as well as social support for patients and their families.

Conclusion to Literature Review

In summary, a total of 32 survey studies examined the impact of COVID-19 on grief and bereavement (please refer to Appendix 1 for further details on the literature review). There was a consistent focus across all studies with most examining the impact on bereaved persons or healthcare workers, while other studies focused on establishing the reliability and validity of pandemic-specific measures. Many of the studies assessed for signs of prolonged grief disorder or complicated grief in various samples and almost all raised concerns about the severity of grief observed, which was reported to exceed pre-pandemic or expected levels of complicated and prolonged grief. Many authors called for extensive screening to identify those at risk and intervene early. A strong recurring theme in the literature was also the need for more investment and funding for bereavement support services and psychotherapy interventions to address the inevitable grief epidemic. Three of the survey studies were conducted in Ireland. One of the studies described the implementation and evaluation of a national bereavement helpline that was implemented by Irish Hospice Foundation in response to the pandemic; another explored the experiences and perceptions of midwives providing perinatal bereavement care during COVID-19; and the third study examined bereavement care provision in the UK and Ireland with a sample of people working in hospice, community, and hospital settings only. Therefore, a national Irish survey is warranted to elucidate the specific challenges and experiences of the Irish population in relation to grief and bereavement during the pandemic.

Phase 2: Time to Reflect Survey

The second phase of this project presented the findings of a national survey administered by Irish Hospice Foundation (IHF) to adults all over Ireland from November 2021 to February 2022. The goal was to explore the perspectives and experiences of dying, death, and bereavement in Ireland during the pandemic.

Survey Aims

The survey had four main objectives:

1. To examine attitudes of Irish people towards dying, death, and bereavement.
2. To examine people's experiences of dying, death, and bereavement.
3. To explore if and how the COVID-19 pandemic affected people's experiences of dying, death, and bereavement.
4. To explore if any positive experiences have emerged through the pandemic in relation to new practices and rituals in the field of end-of-life care and mourning.

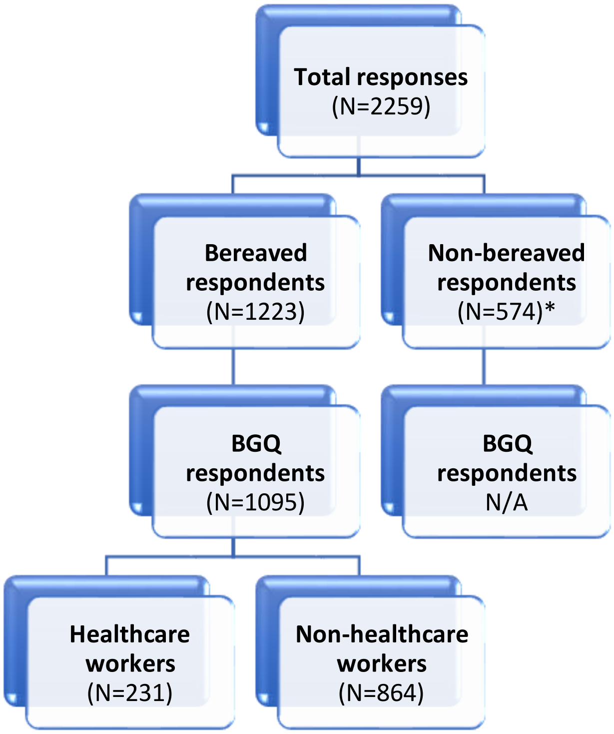
Survey Methods

Data were collected via a survey tool, between November 2021 and February 2022, which was 18 months after the declaration of the pandemic and stay-at-home mandates, and one year after the COVID-19 vaccination was made available for vulnerable patients. Many restrictions remained in place including face mask mandates and hospital visiting restrictions. Furthermore, the peak of the death rate in Ireland for COVID-19 was a year prior to the commencement of the survey, making this an appropriate time to reflect on the past collective experience.

The survey was delivered in both digital forms (via Survey Monkey) and paper forms. Individuals over 18 years old in Ireland during the survey period were recruited by purposive, non-probability-based sampling. The survey was disseminated by IHF through different platforms including IHF events, social media, network connections, and relevant programmes. IHF contacted Spun Out, Focus Ireland, Sing Ireland and Irish Men's Shed for greater visibility of the study. Promotion of the survey was also made within hospitals via the End-of-Life Care Coordinators Networks and postering within the acute hospital sector. Additionally, direct contact was made with some organizations in the older person sector and Pavee Point, a national non-governmental organization that advocates and supports the rights of the travelling community in Ireland. Paper versions of the survey were also distributed to individuals in nursing home settings.

Survey Instrument

The Time to Reflect survey comprised 38 questions across three sections. The first section of the survey (Section A) examined perspectives on dying, death, and bereavement since the pandemic began. Participants who indicated they were bereaved during this time proceeded to Section B, which focused on understanding participants personal experience before and after the death of their loved one. The final section of the survey (Section C) collected demographic and wellbeing information from bereaved and non-bereaved participants. Survey responses were predominately presented in the form of Likert scales (i.e., responses ranging from strongly disagree to strongly agree, or from yes to does not apply, or from not a lot to a lot). Open-ended questions were also asked throughout the survey to give participants the opportunity to provide additional information that could not be collected through quantitative questions. This predominantly included thoughts and experiences on dying, death, and bereavement, during COVID-19. Bereaved participants were also invited to complete the 'Brief Grief Questionnaire' (BGQ). The BGQ is a validated questionnaire for screening for Prolonged Grief Disorder and comprises five statements (Shear et al., 2006). Figure 5 below provides an overview of the survey flow and participant response rates.



** Not equal to total no. of responses due to missing data for this question.*

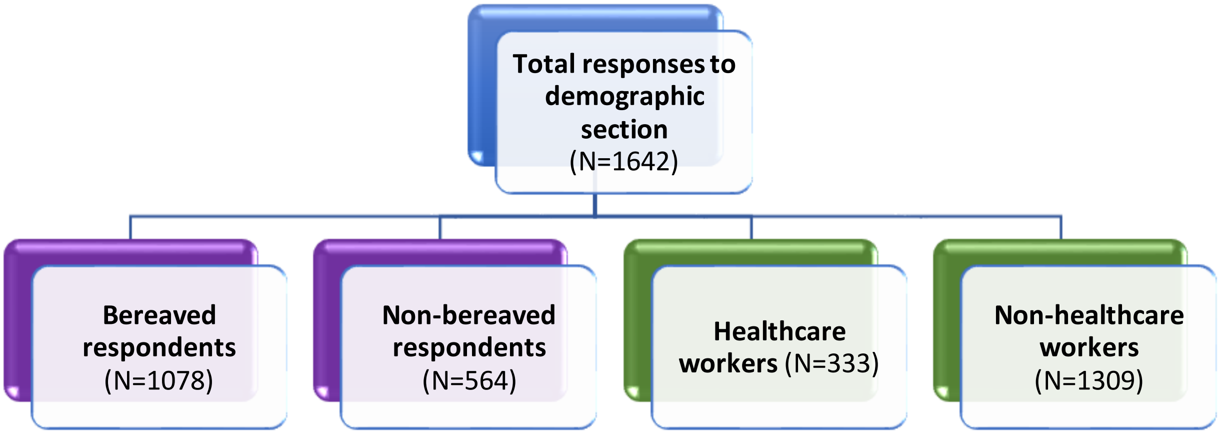


FIGURE 5 SURVEY FLOW AND RESPONSE RATES

Ethical Considerations

Participants were provided with an information leaflet prior to completing the survey and contact details of the study team were also provided if participants had any questions or queries about the study. Participation in the study was voluntary and participants could opt out if they wished to. Ethical approval to carry out the study was granted by the Royal College of Surgeons Ireland (REC Approval No: 202105022).

IHF acted as the data controller when managing the data and was responsible for the protection, storing, and analysis of the survey. The anonymity of participants was prioritized when storing and analyzing survey data.

Data Analysis

Data were analyzed using IBM SPSS 27. Descriptive and inferential statistics were used in the analysis. Responses to the five BGQ questions were computed into total scores ranging from 0 to 10. BGQ total scores were grouped into three categories for statistical analysis; prolonged grief disorder (PGD) not indicated (0-4), Sub-threshold of PGD indicated (5-7), and PGD indicated (8-10). Data derived from the open-ended survey questions were analyzed thematically (Braun and Clarke, 2006). Specifically, the researchers familiarized themselves with the data by reading and documenting initial ideas. The relevant text was then imported into NVivo 12 where the researcher assigned multiple codes using an open and axial coding approach. Next, codes were refined and grouped into potential themes along with relevant data/excerpts. An in-depth discussion then took place with IHF to further review the themes and sub-themes, before reaching a collective agreement on the identification and definition of themes and sub-themes. Finally, chosen themes and sub-themes were selected for report inclusion coupled with compelling and relevant excerpts from the open-ended questions.

Results

The results are presented in the following order:

- Demographic Information
- Health and Wellbeing of Participants
- Results from Bereaved Participants
- Perceptions of Dying, Death, and Bereavement
- End-of-Life Care during COVID-19
- Healthcare Workers' Experience of End-of-Life Care during COVID-19
- Bereaved Participants' Experience of Dying and Death
- Funerals and Mourning Rituals
- Experience of Bereavement and Grief
- Likelihood of Prolonged Grief as Measured by the Brief Grief Questionnaire (BGQ)
- Future Priorities for End-of-Life Care in Ireland.

Demographic Information

It should be noted that 617 of the overall 2259 participants did not provide any demographic information. For those that did provide demographic information (N=1642), the largest age group of participants were aged between 45 and 54 years old (N=456, 27.8%) and were female (N=1106, 67.4%) (see Table 1). Most participants were white Irish ethnicity (N=1521, 92.6%) and lived with their families (N=1186, 73%) in rural areas (N=526, 32%). Almost half of participants (N=784, 47.9%) were married or in a civil partnership. Most of the participants were not healthcare workers (N=1464, 81.5%).

Table 1. Demographic Characteristics of Total Study Sample

	All Participants	
Variable	N	%
Age		
18-24	130	7.9%
25-34	201	12.2%
35-44	264	16.1%
45-54	456	27.8%
55-64	294	17.9%
65-74	237	14.4%
75+	38	2.3%
Unknown	22	1.4%
Total	*1642*	*100%*

Gender		
Male	525	32.0%
Female	1106	67.4%
Other/Non-binary	8	0.5%
Prefer not to say	3	0.2%
Total	*1642*	*100%*
Ethnicity		
White Irish	1521	92.6%
Irish Traveller	1	0.1%
Black Irish	2	0.1%
Any other white background	83	5.1%
Any other black background	1	0.1%
Asian Irish	6	0.4%
Any other Asian background	12	0.7%
Other	16	1.0%
Total	*1642*	*100%*
Relationship Status		
Single, never married	415	25.4%
Civil partnership or married	784	47.9%
Cohabiting with a significant other	253	15.5%
Separated or divorced	92	5.6%
Widowed	93	5.7%
Total	*1637*	*100%*
Geographic Location		
Urban	389	23.7%
Suburban	379	23.1%
Town	348	21.2%
Rural	526	32.0%
Total	*1642*	*100%*
Living Circumstances		
Living alone	274	16.9%
Living with family	1186	73.0%
Living in shared accommodation	81	5.0%
Living in a care or residential setting	1	0.1%
Living in direct provision	0	0%
Homeless	4	0.2%
Other	78	4.8%
Total	*1624*	*100%*
Healthcare Worker		
No	1464	81.5%
Yes	333	18.5%
Total	*1797*	*100%*

Bereaved vs Non-Bereaved Participants

A total of 1078 (88.1%) of 1223 bereaved participants completed the demographic section of the survey. Most bereaved participants were female (N=753, 69.9%) and aged between 45 and 54 years old (N=322, 29.9%). Over 90% (N=1008) were Irish and resided in rural areas across Ireland (N=329, 32.4%). Almost half of bereaved participants were either married or in a civil partnership (N=514, 47.8%) and 72.5% (N=773) either lived with family or other people. Bereaved individuals responding to the survey were slightly older than non-bereaved individuals (49 years old, SD + 14.9, p<0.03). Most bereaved participants (N=990, 80.9%) and non-bereaved participants (N=474, 82.6%) were not healthcare workers. Statistically significant differences were noted between the bereaved and non-bereaved group in terms of age and gender (see Table 2).

Table 2. Comparison of Demographic Variables for Bereaved vs Non-Bereaved Participants

Variable	Bereaved During Pandemic					
	Yes		No			
	n	%	n	%	X^2	p
Age					**33.36**	**<.001***
18-24*	73	6.8%	57	10.1%		
25-34*	115	10.7%	86	15.2%		
35-44	178	16.5%	86	15.2%		
45-54*	322	29.9%	134	23.8%		
55-64*	209	19.4%	85	15.1%		
65-74*	135	12.5%	102	18.1%		
75+	27	2.5%	11	2.0%		
Unknown*	19	1.8%	3	0.5%		
Total	*1078*	*100%*	*564*	*100%*		
Gender					**8.95**	**.030***
Male*	318	29.5%	207	36.7%		
Female*	753	69.9%	353	62.6%		
Other/Non-binary	5	0.5%	3	0.5%		
Prefer not to say	2	0.2%	1	0.2%		
Total	*1078*	*100%*	*564*	*100%*		
Ethnicity					**7.43**	**.385**
White Irish	1008	93.5%	513	91.0%		
Irish Traveller	1	0.1%	0	0.0%		
Black Irish	1	0.1%	1	0.2%		
Any other white background	45	4.2%	38	6.7%		
Any other black background	1	0.1%	0	0.0%		
Asian Irish	4	0.4%	2	0.4%		
Any other Asian background	9	0.8%	3	0.5%		
Other (please specify)	9	0.8%	7	1.2%		
Total	*1078*	*100%*	*564*	*100%*		
Relationship Status					**3.03**	**.552**
Single, never married	265	24.6%	150	26.7%		
Civil partnership or married	514	47.8%	270	48.1%		
Cohabiting with a significant other	167	15.5%	86	15.3%		
Separated or divorced	62	5.8%	30	5.3%		
Widowed	68	6.3%	25	4.5%		
Total	*1076*	*100%*	*561*	*100%*		
Geographic Location					**3.10**	**.376**

Urban	243	22.5%	146	25.9%		
Suburban	259	24.0%	120	21.3%		
Town	227	21.1%	121	21.5%		
Rural	349	32.4%	177	31.4%		
Total	*1078*	*100%*	*564*	*100%*		
Healthcare Worker					**.687**	**.407**
No	990	80.9%	474	82.6%		
Yes	233	19.1%	100	17.4%		
Total	*1223*	*100%*	*574*	*100%*		

*Note. P- values computed based on chi-square tests. The level of significance was set to 0.05. *denotes significant differences.*

The next section focuses on demographic comparisons between healthcare workers and the other survey participants.

Healthcare Workers vs Other Survey Participants

Of the 1642 participants who responded to these demographic questions, 333 of them or one in five were healthcare workers (N=333, 20.3%). Table 3 provides further comparative information in terms of age, gender, ethnicity, relationship status, geographic location, and bereavement status of healthcare workers vs other survey participants. Most of the healthcare workers group and the other survey participants group were aged between 45 and 54 years old (N=120, 36% and N=336, 25.7% respectively). Over 82% of healthcare workers were female (N=276) and over 63% of other survey participants (N=830) were female. Most of the healthcare worker participants (N=311, 93.4%) and other survey participants (N=1210, 92.4%) were white Irish ethnicity and either married or in a civil partnership (N=175, 52.6% of healthcare workers; and N=609, 46.7% of other survey participants). Over 40% of healthcare workers (N=141) and almost 30% of the other survey participants (N=385) lived in a rural location. Most participants in both groups had experienced bereavement (N=233, 70% of healthcare workers; N=990, 67.6% of the other survey participants). Statistically significant differences were noted between the healthcare worker and other survey participant group in terms of age, gender, ethnicity, relationship status, and geographical location.

Table 3. Comparison of Demographic Variables for Healthcare Workers vs Other Survey Participants

	Healthcare Worker					
	Yes		**No**			
Variable	**N**	**%**	**N**	**%**	X^2	**P**
Age					**70.35**	**<.001***
18-24*	11	3.3%	119	9.1%		
25-34	45	13.5%	156	11.9%		
35-44	63	18.9%	201	15.4%		
45-54*	120	36.0%	336	25.7%		
55-64*	77	23.1%	217	16.6%		
65-74*	12	3.6%	225	17.2%		
75+*	2	0.6%	36	2.8%		
Unknown	3	0.9%	19	1.5%		
Total	*333*	*100%*	*1309*	*100%*		
Gender					**46.58**	**<.001***
Male*	57	17.1%	468	35.8%		
Female*	276	82.9%	830	63.4%		
Other/Non-binary	0	0.0%	8	0.6%		
Prefer not to say	0	0.0%	3	0.2%		

Total	*333*	*100%*	*1309*	*100%*		
Ethnicity					**20.82**	**.004***
White Irish	311	93.4%	1210	92.4%		
Irish Traveller	0	0.0%	1	0.1%		
Black Irish	1	0.3%	1	0.1%		
Any other white background*	9	2.7%	74	5.7%		
Any other black background	0	0.0%	1	0.1%		
Asian Irish	3	0.9%	3	0.2%		
Any other Asian background*	7	2.1%	5	0.4%		
Other (please specify)	2	0.6%	14	1.1%		
Total	*333*	*100%*	*1309*	*100%*		
Relationship Status					**14.58**	**.006***
Single, never married	83	24.9%	332	25.5%		
Civil partnership or married	175	52.6%	609	46.7%		
Cohabiting with a significant other	44	13.2%	209	16.0%		
Separated or divorced	24	7.2%	68	5.2%		
Widowed*	7	2.1%	86	6.6%		
Total	*333*	*100%*	*1304*	*100%*		
Geographic Location					**21.60**	**<.001***
Urban	73	21.9%	316	24.1%		
Suburban*	59	17.7%	320	24.4%		
Town	60	18.0%	288	22.0%		
Rural*	141	42.3%	385	29.4%		
Total	*333*	*100%*	*1309*	*100%*		
Bereaved					**.687**	**.407**
No	100	30.0%	474	32.4%		
Yes	233	70.0%	990	67.6%		
Total	*333*	*100%*	*1464*	*100%*		

Note. P- values computed based on chi-square tests. The level of significance was set to 0.05. *denotes significant differences.

Geographic Locations

Table 4 provides further comparative information in terms of age, gender, ethnicity, relationship status, geographic location, and bereavement status of those living in rural vs other areas. Across all geographic location groups, most participants were aged between 45 and 54 years old, female, and white Irish ethnicity. Most participants were either married or in a civil partnership across each geographical location category. Over 60% of all participants, regardless of geographic location, had been bereaved during the pandemic. Statistically significant differences were noted between the various geographic location groups in terms of age, gender, and healthcare worker status.

Table 4. Comparison of Demographic Variables Based on Geographic Location of Participants

	Geographic Location									
Variable	**Urban**		**Suburban**		**Town**		**Rural**			
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**X^2**	**p**

Age									**57.60**	**<.001***
18-24	30	7.7%	27	7.1%	36	10.3%	37	7.0%		
25-34*	71	18.3%	39	10.3%	37	10.6%	54	10.3%		
35-44	76	19.5%	63	16.6%	63	18.1%	62	11.8%		
45-54	97	24.9%	92	24.3%	96	27.6%	171	32.5%		
55-64	61	15.7%	78	20.6%	53	15.2%	102	19.4%		
65-74	48	12.3%	62	16.4%	51	14.7%	76	14.4%		
75+*	1	0.3%	15	4.0%	9	2.6%	13	2.5%		
Unknown	5	1.3%	3	0.8%	3	0.9%	11	2.1%		
Total	*389*	*100%*	*379*	*100%*	*348*	*100%*	*526*	*100%*		
Gender									**23.96**	**.004***
Male*	151	38.8%	125	33.0%	109	31.3%	140	26.6%		
Female*	237	60.9%	251	66.2%	234	67.2%	384	73.0%		
Other/Non-binary	1	0.3%	1	0.3%	4	1.1%	2	0.4%		
Prefer not to say	0	0.0%	2	0.5%	1	0.3%	0	0.0%		
Total	*389*	*100%*	*379*	*100%*	*348*	*100%*	*526*	*100%*		
Ethnicity									**31.17**	**.071**
White Irish	360	92.5%	356	93.9%	315	90.5%	490	93.2%		
Irish Traveller	0	0.0%	0	0.0%	1	0.3%	0	0.0%		
Black Irish	0	0.0%	2	0.5%	0	0.0%	0	0.0%		
Any other white background	15	3.9%	15	4.0%	22	6.3%	31	5.9%		
Any other black background	0	0.0%	0	0.0%	0	0.0%	1	0.2%		
Asian Irish	2	0.5%	2	0.5%	2	0.6%	0	0.0%		
Any other Asian background	6	1.5%	3	0.8%	3	0.9%	0	0.0%		
Other (please specify)	6	1.5%	1	0.3%	5	1.4%	4	0.8%		
Total	*389*	*100%*	*379*	*100%*	*348*	*100%*	*526*	*100%*		
Relationship Status									**19.74**	**.072**
Single, never married	115	29.6%	85	22.5%	92	26.4%	123	23.5%		
Civil partnership or married	161	41.5%	184	48.8%	163	46.8%	276	52.7%		
Cohabiting with a significant other	68	17.5%	62	16.4%	51	14.7%	72	13.7%		
Separated or divorced	22	5.7%	20	5.3%	27	7.8%	23	4.4%		
Widowed	22	5.7%	26	6.9%	15	4.3%	30	5.7%		
Total	*388*	*100%*	*377*	*100%*	*348*	*100%*	*524*	*100%*		
Bereaved during Pandemic									**3.10**	**.376**
Yes	243	62.5%	259	68.3%	227	65.2%	349	66.3%		
No	146	37.5%	120	31.7%	121	34.8%	177	33.7%		
Total	*389*	*100%*	*379*	*100%*	*348*	*100%*	*526*	*100%*		
Healthcare Worker									**21.60**	**<.001***
No*	316	81.2%	320	84.4%	288	82.8%	385	73.2%		
Yes*	73	18.8%	59	15.6%	60	17.2%	141	26.8%		
Total	*389*	*100%*	*379*	*100%*	*348*	*100%*	*526*	*100%*		

Note. P- values computed based on chi-square tests. The level of significance was set to 0.05. *denotes significant differences.

Health and Wellbeing of Participants

All survey participants were invited to rate their overall health and wellbeing status. Findings showed that of the 1635 that responded to these questions most participants (N=1259, 76.9%) rated their general health as good and 66.3% (N =1078) rated their mental health as good. Almost half of participants (N =736, 45%) reported moderate financial wellbeing (see Table 5).

Table 5. Health and Wellbeing of All Survey Participants

Variable	All Participants N	 %
Health Status		
Bad	73	4.5%
Fair	305	18.6%
Good	1259	76.9%
Total	*1637*	*100%*
Mental Health Status		
Bad	149	9.2%
Fair	400	24.6%
Good	1078	66.3%
Total	*1627*	*100%*
Financial Well-being		
Finding it difficult	151	9.2%
Just about getting by	298	18.2%
Doing Alright	736	45%
Living Comfortably	450	27.5%
Total	*1635*	*100%*

Bereaved vs Non-Bereaved Participants

Means and standard deviations were calculated for general health status, mental health status, and financial well-being of bereaved participants compared with non-bereaved participants (see Table 6). Participants who had not experienced bereavement during the pandemic were found to have a slightly higher mean general health status, mental health status, and financial well-being score than those who had been bereaved during the pandemic. This finding was statistically significant for general health status with bereaved participants having a lower score (M = 4.02, SD = 0.86) than non-bereaved participants (M = 4.11, SD = 0.86, p = 0.040).

Table 6. Health and Wellbeing of Bereaved vs Non-Bereaved Participants

	Bereaved During Pandemic							
	Yes			No				
Variable	**N**	**M**	**SD**	**N**	**M**	**SD**	**t**	**p**
Health Status	1076	4.02	.86	561	4.11	.86	**-2.05**	**.040***
Mental Health Status	1068	3.77	.95	559	3.86	.97	**-1.69**	**.090**
Financial Well-being	1075	3.85	.99	560	3.93	.97	**-1.42**	**.155**

Note. P-values were computed using independent samples t-tests and the level of significance was set to 0.05. *denotes significant differences.

Healthcare Workers vs Other Survey Participants

Means and standard deviations were calculated for general health status, mental health status, and financial well-being of healthcare workers compared with other survey participants (see Table 7). Healthcare workers were found to have a higher mean general health status, mental health status, and financial well-being score than other survey participants. This finding was statistically significant for general health status with other survey participants having a lower score (M = 3.99, SD = 0.88) than healthcare workers (M = 4.29, SD = 0.75, p < 0.001) and it was also significant for mental health status (M = 4.04, SD = 0.87 for healthcare workers vs M = 3.74, SD = 0.97 for other survey participants, p < 0.001).

Table 7. Health and Wellbeing of Healthcare Workers vs Other Survey Participants

	Healthcare Worker							
	Yes			**No**				
Variable	**N**	**M**	**SD**	**N**	**M**	**SD**	**t**	**p**
Health Status	333	4.29	.75	1304	3.99	.88	**-5.70**	**<.001***
Mental Health Status	332	4.04	.87	1295	3.74	.97	**-5.12**	**<.001***
Financial Well-being	333	3.98	.97	1302	3.85	.99	**-2.23**	**.024**

Note. P-values were computed using independent samples t-tests and the level of significance was set to 0.05. *denotes significant differences.

Geographic Location

Means and standard deviations were calculated for general health status, mental health status, and financial well-being based on the geographic location of participants (see Table 8). For general health status, those living in a town had the lowest mean score (M = 3.86, SD = 0.89) and this was significantly different from the three other categories (i.e., urban, suburban, and rural) (p < 0.001). Participants living in urban areas had the lowest mental health status scores (M = 3.78, SD = 0.95) but this was not significantly different from the other categories. Mental health status scores for participants living in a town vs suburban were significantly different (p = 0.032) and for participants living in a rural area vs a town (p<0.001). Those living in a town or in urban or rural areas had similar mean financial well-being scores and these were lower than the mean score for participants living in suburban areas. Financial well-being scores were significantly different for those living in a town compared with those living in suburban areas (p = 0.001).

Table 8. Comparisons of Health and Wellbeing Based on Geographic Location

	Geographic Location													
	Urban			**Suburban**			**Town**			**Rural**				
Variable	**N**	**M**	**SD**	**N**	**M**	**SD**	**N**	**M**	**SD**	**N**	**M**	**SD**	**F**	**p**
Health Status	388	4.11	.83	377	4.10	.83	348	3.86	.89	524	4.11	.87	**7.42**	**<.001***
Mental Health Status	385	3.78	.95	374	3.83	.95	346	3.90	1.0	522	3.90	.91	**5.71**	**<.001***
Financial Well-being	388	3.88	.95	377	4.00	.95	348	3.88	1.0	522	3.88	.93	**4.60**	**<.001***

Note. P-values were computed using Analysis of Variance (ANOVA) with follow-up pairwise comparisons. The level of significance was set to 0.05. *denotes significant differences.

Results from Bereaved Participants

Experiences of Bereavement

Over half of the participants (N=1223, 54.1%) reported experiencing the death of someone close to them during the pandemic and over 40% of these (N=478) reported losing more than one person during this period. Meanwhile, 82.9% of participants (N=1872) knew of either a friend or colleague who experienced bereavement. Of those who experienced a bereavement, over half lost someone in 2021 (N=623, 56.1%), while 41.2% of participants (N=457) lost someone in 2020, and 2.7% of participants (N=30) were bereaved during 2022. Most participants reported the death of their father (N=172) or mother (N=160). Forty-one participants reported losing their spouse or partner during COVID-19, and 13 lost their son or daughter. A total of 37.9% of participants (N=448) reported that the death of their loved one was unexpected or sudden.

Place of Death

Over 60% of participants (N=719, 63.9%) indicated the place of death of their loved one. Hospitals were the most frequent place of death (N=250, 34.8%), followed by home (N=217, 30.2%), and nursing homes (N=125, 17.4%).

Table 9. Place of Death Reported by Participants

Variable	N	%
In their own home	217	30.2%
In a nursing home	125	17.4%
In a hospice	85	11.8%
In my home or the home of another member of my family	11	1.5%
In another kind of residential or care home	12	1.7%
In a hospital	250	34.8%
I don’t know	6	0.8%
Prefer not to say	2	0.3%
Somewhere else (please specify)	11	1.5%
Total	**719**	**100%**

Cause of Death

Confirmed COVID-19 infection and suspected COVID-19 infections were reported to be the primary cause of death in 14.1% and 1.4% of reported cases respectively. Cancer was reported as the main cause of death (N=331, 29.1%). Other causes of death reported by participants included cardiac conditions, stroke, pregnancy complications, suicide, and accidents (see Table 10 below).

Table 10. Primary Cause of Death Reported by Participants

Variable	N	%
Cancer	**331**	**29.1%**
Cardiac condition (e.g., Heart attack, Heart failure, or other disease of the heart or circulatory system)	**198**	**17.4%**
Confirmed COVID-19 infection	**160**	**14.1%**
Dementia	**86**	**7.6%**

Respiratory disease (e.g., Chronic Obstructive Pulmonary disease (COPD), Chronic bronchitis, Cystic Fibrosis)	**55**	**4.8%**
Unknown or Inconclusive	**44**	**3.9%**
Suicide	**41**	**3.6%**
Accident	**32**	**2.8%**
Stroke	31	2.7%
Age-Related, Unspecified	27	2.4%
Nervous system disorder (e.g., Motor Neuron Disease, Multiple Sclerosis, Parkinson's Disease)	26	2.3%
Sepsis	23	2.0%
Suspected COVID-19 infection	16	1.4%
Other (e.g., pneumonia, organ failure, renal disease etc.)	66	5.9%
Total	1,136	100.0%

The next section presents findings on perceptions of dying, death, and bereavement of survey participants since the pandemic.

Perceptions of Dying, Death, and Bereavement

In this section of the survey, all participants (N=2259) were asked about their views on dying, death, and bereavement since the pandemic began including whether they have given more thought to their own end-of-life wishes. All survey participants were invited to complete this section, regardless of their bereavement status.

Results showed that most participants (N=930, 41.2%) reported that the pandemic changed their views about dying, death, and bereavement quite a lot or a lot, and a further 26.8% (N=603) reported that the pandemic changed their views on the topic a bit. Most participants also indicated that they have spoken about dying and death 'more than usual' or 'a lot more than usual' since the beginning of the pandemic (N=1250, 55.7%). Similarly, participants reported a greater awareness of grief and loss due to COVID-19 (N=1512, 67.3%). Yet, less than half of participants (N=1049, 46.8%) reported that they had given more thought to their own end-of-life wishes (see Table 11).

Table 11. Perceptions of Dying, Death, and Bereavement since the COVID-19 Pandemic

		Responses N (%)				
	N	**Not at all**	**Not much**	**A bit**	**Quite a lot**	**A lot**
COVID-19 changed my views about dying, death and bereavement	2248	341 (15.2%)	374 (16.6%)	603 (26.8%)	648 (28.8%)	282 (12.5%)
	N	**A lot less than usual**	**Less than usual**	**About the same as usual**	**More than usual**	**A lot more than usual**
I have spoken more about death and dying since the pandemic	2245	55 (2.4%)	63 (2.8%)	877 (39.1%)	966 (43.0%)	284 (12.7%)
	N	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Because of the pandemic I have	2247	96 (4.3%)	154 (6.9%)	485 (12.6%)	902 (40.1%)	610 (27.1%)

greater awareness of grief and loss						
Because of the pandemic I have given more thought to my own end-of-life wishes	2243	138 (16.2%)	344 (15.3%)	712 (31.7%)	753 (33.6%)	296 (13.2%)

Bereaved vs Non-Bereaved Participants

Perceptions of dying, death, and bereavement were compared for bereaved participants and non-bereaved participants (see Table 12). Almost half of bereaved participants (N=599, 49.1%) reported the pandemic changed their views on dying, death, and bereavement a lot or quite a lot. Meanwhile, only 26.4% (N=151) of non-bereaved participants reported that the pandemic changed their views a lot or quite a lot. Over 60% of bereaved participants (N=753, 61.9%) reported that they had spoken about death and dying more than usual or a lot more than usual since the pandemic while 42.1% (N=241) of non-bereaved participants reported the same trend. Almost three-quarters of bereaved participants (N=897, 73.6%) agreed or strongly agreed that they had a greater awareness of grief and loss because of the pandemic in contrast to 57.3% of non-bereaved participants (N=329). Similarly, more bereaved participants (N=622, 51.1%) agreed or strongly agreed that they had given more thought to their own end-of-life wishes because of the pandemic in comparison to 37.5% of non-bereaved participants (N=214).

Table 12. Perceptions of Dying, Death, and Bereavement – Comparisons between Bereaved and Non-Bereaved Participants

	Bereaved during the pandemic	**N**	**Responses N (%)**				
			Not at all	**Not much**	**A bit**	**Quite a lot**	**A lot**
COVID-19 changed my views about dying, death and bereavement*	Yes	1219	162 (13.3%)	164 (13.5%)	294 (24.1%)	401 (32.9%)	198 (16.2%)
	No	573	110 (19.2%)	120 (20.9%)	192 (33.5%)	127 (22.2%)	24 (4.2%)
		N	**A lot less than usual**	**Less than usual**	**About the same as usual**	**More than usual**	**A lot more than usual**
I have spoken more about death and dying since the pandemic*	Yes	1216	29 (2.4%)	25 (2.1%)	409 (33.6%)	547 (45.0%)	206 (16.9%)
	No	573	15 (2.6%)	18 (3.1%)	299 (52.2%)	220 (38.4%)	21 (3.7%)
		N	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Because of the pandemic I have greater awareness of grief and loss*	Yes	1218	48 (3.9%)	58 (4.8%)	215 (17.7%)	486 (39.9%)	411 (33.7%)
	No	574	25 (4.4%)	61 (10.6%)	159 (27.7%)	247 (43.0%)	82 (14.3%)
Because of the pandemic I have given more thought to my own end-of-life wishes*	Yes	1219	54 (4.4%)	158 (13.0%)	385 (31.6%)	431 (35.4%)	191 (15.7%)
	No	570	43 (7.5%)	117 (20.5%)	196 (34.4%)	163 (28.6%)	51 (8.7%)

Note. P-value computed based on chi-square test and level of significance was set to 0.05. *denotes significant differences where p<0.001.

Healthcare Workers vs Other Survey Participants

Perceptions of healthcare workers on dying, death, and bereavement were evaluated (see Table 12). Over 70% of healthcare workers (N=241, 72.6%) reported that the pandemic changed their views on dying, death, and bereavement a lot or quite a lot. Over half of healthcare workers (N=197, 59.7%) reported that they had spoken about death and dying more than usual or a lot more than usual since the beginning of the pandemic and over 70% (N=237, 71.4%) agreed or strongly agreed that they had a greater awareness of grief and loss because of the pandemic. Almost half of healthcare workers (N=163, 49.1%) agreed or strongly agreed that they had given more thought to their own end-of-life wishes because of the pandemic.

Table 13. Healthcare Worker Perceptions of Dying, Death, and Bereavement

		Responses N (%)				
	N	**Not at all**	**Not much**	**A bit**	**Quite a lot**	**A lot**
COVID-19 changed my views about dying, death and bereavement	332	45 (13.6%)	46 (13.9%)	77 (23.2%)	115 (34.6%)	49 (14.8%)
	N	**A lot less than usual**	**Less than usual**	**About the same as usual**	**More than usual**	**A lot more than usual**
I have spoken more about death and dying since the pandemic	330	2 (0.6%)	7 (2.1%)	124 (37.6%)	154 (46.7%)	43 (13%)
	N	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Because of the pandemic I have greater awareness of grief and loss	332	9 (2.7%)	23 (6.9%)	63 (19%)	135 (40.7%)	102 (30.7%)
Because of the pandemic I have given more thought to my own end-of-life wishes	332	12 (3.6%)	50 (15.1%)	107 (32.2%)	109 (32.8%)	54 (16.3%)

Survey Participant Reflections

Throughout the survey, participants were provided the opportunity to respond to free-text questions whereby they could indicate their reflections and thoughts on their experiences and views of dying, death, and bereavement during the pandemic. Thematic analysis was used to identify common themes from the open-ended question responses among participants. The following three themes emerged in relation to perceptions of dying, death, and bereavement care during the pandemic:

- Greater Cognisance of Life and Death

- Self-Reflection of End-of-Life Wishes
- Reflecting on the Dying Experience

Greater Cognisance of Life and Death

Some participants highlighted how the pandemic reminded them of the fragile nature of life and they became more aware of their own mortality:

> *"During the pandemic, because of experiences of death and loss around me and in the world, I happened to start a research project on this topic. Now, I have mortality awareness more than before, and I sense that my life choices have started changing based on the inevitability of death."*

Another participant commented on the fragility of life:

> *"COVID-19 has brought death into sharp focus, we have a much more acute understanding as to the delicate nature of life, and what it means to be able to celebrate life through our traditional funerals and wakes."*

Participants discussed an inward shift towards existential questions:

> *"When you see people who are young, fit, and death being the last thing on their mind, passing and in some cases, leaving young families behind it does make you think that this could easily happen to me. And, if it did what would the impact on others be? And have I got all my affairs taken care of, what would others have to deal with on top of grief?"*

Self-Reflection on End-of-Life Wishes

One main positive outcome of the pandemic reported by participants was self-reflection about their end-of-life wishes. Participants expressed how the onset of COVID-19 led to thoughts about funerals, creating wills, and the impact their death will have on their families. Moreover, participants voiced speaking more about death and dying with those close to them:

> *"I have made a will; I have made a living wishes document and myself and my siblings and parents have had honest discussions about this. Covid forced us to have these conversations in our family."*

One participant spoke of how they would like their funeral to be an enjoyable experience and took into consideration the importance of end of life preparation to ensure their family does not have to deal with anything:

> *"I don't want my children to have to sort anything, they will have enough to deal with at the time. I want it to be fun. I have been making videos and will continue to document the good, the bad and the ugly of the pandemic. To try and capture for my grandchildren who are not yet born how it felt to live through this unprecedented time."*

Another participant voiced that they completed Irish Hospice Foundation's 'Think Ahead' form and recognised the importance of making your end-of-life wishes known to family:

> *"I'm in my 50s. My parents are in their 80s and 70s and very healthy, thank God. I've given and spoken to them both about the' Thinking Ahead' document, and the importance of making their wishes known. I'm going to fill out my own care plan and 'Thinking Ahead' form in the next two months."*

Reflecting on the Dying Experience

COVID-19 did stimulate reflection on the current healthcare system, structures, and changes required in the future. Collectively, participants stressed the need for more choice and autonomy around the dying experience. One participant recalled his uncle taking his own life and expressed the desire for dying with dignity in Ireland:

> *"My uncle was terminally ill & took his life. He just didn't want the pain & struggle & knew his wife wouldn't be able to care for him. If he was a dog, we could have chosen peace & dignity for him. We really need to address dying with dignity in Ireland. Our whole experience as a family & mid covid lock down restrictions was horrendous."*

Similarly, another participant insisted on the need for more autonomy or potentially the establishment of assisted dying laws in Ireland:

> *"Under strict guidelines, one should have the [option] to choose their time of death if they so wish. i.e., if one is given a terminal diagnosis, with 6 months to live, if they choose to end their life, their wish should be permitted."*

The next section presents findings that related to the provision of end-of-life care as reported by survey participants.

End-of-Life Care during COVID-19

More than one third of participants (N=603, 36.8%,) provided care to someone during the pandemic. Nearly 80% of participants who reported caring for someone else during the pandemic were women, and over half were healthcare workers (55.2%, N=333).

Only half of participants reported that their loved one received the level of care they needed at end of life (N=391, 54.2%) and that the spiritual / religious needs of their loved one was met at end of life (N=386, 53.6%). Over 70% of participants (N=507) reported that the pandemic completely or partly prevented their loved one from having the death they would have wished for. Almost half of participants (N=492, 43.5%), felt that their loved one did not die in the place they would have liked, and other participants reported that their loved one was not surrounded by the people they would have liked to be around them at the time (N=344, 30.5%) (see Table 14).

Table 14. End-of-Life Care During the COVID-19 Pandemic

		Responses N (%)				
	N	**Yes**	**Somewhat or partly**	**No**	**Don't know**	**Does not apply**
They had the level of care I think they needed when dying	722	391 (54.2%)	199 (27.6%)	91 (12.6%)	38 (5.3%)	3 (0.4%)
They had their spiritual/religious needs met at the end of their life	720	386 (53.6%)	113 (15.7%)	80 (11.1%)	96 (13.3%)	45 (6.3%)
COVID-19 prevented them from having the death I think they would have wanted	721	350 (48.5%)	157 (21.8%)	153 (21.2%)	37 (5.1%)	24 (3.3%)
They died where I think they wanted to die	1131	377 (33.3%)	124 (11.0%)	492 (43.5%)	93 (8.2%)	45 (4.0%)
They were surrounded by people I think they wanted when they were dying	1128	440 (39.0%)	245 (21.7%)	344 (30.5%)	36 (3.2%)	63 (5.6%)
COVID-19 prevented them from having the death I wished for them	1130	497 (44.0%)	195 (17.3%)	256 (22.7%)	49 (4.3%)	133 (11.8%)

Survey Participant Reflections

The following themes emerged from analysis of free-text open questions in relation to end of life care during COVID-19:

- Lack of Proper Care
- Frustration with COVID-19 Restrictions
- Strain on Healthcare Settings

Lack of Proper Care

Participants expressed that care was not as good as it should be, and this was attributed to the emphasis that was placed on COVID-19. For example, one survey participant recalled watching her daughter die and highlighted the lack of care and compassion shown from hospital staff:

> *"I'm not a stupid woman. I am aged 77 years now, but to my very unprofessional and non-medical observation, I was watching my sweet daughter being " PUT DOWN" like a dog! I will forever have nightmares about this. When the staff removed the oxygen tubes from her throat, she only 'lived' for 10 minutes. It was the worst time of my life... cruel to her family watching her die and definitely not what I expected."*

Another participant described how her uncle passed away during the pandemic and how medical staff did not attend to his medical needs throughout the night. Consequently, this experience added an extra layer of grief for her and her relatives:

> *"My uncle passed away in hospital, earlier this year with Covid. I was able to attend the funeral (12 people). His daughter and sons are still grieving hugely. He passed away alone. No one had checked on him all night and he was found the following morning. This is a huge grief for his children."*

Similarly, another participant reflected on the experience of her mother being left alone in a hospital room for a two-week period and the lack of care she was given by healthcare staff:

> *"My mother was left alone in a single room for over 2 weeks while cancer raged in her body. This was the experience as she approached the end of life. Nobody wanted this. Staff could barely take the time to charge her phone for us to speak to her despite knowing she could not communicate with family any other way. We are all hurt and traumatized by the way we were excluded from spending time with her, and her transfer to hospice care was delayed by Covid"*

Frustration with COVID-19 Restrictions

Participants emphasized their frustration with COVID-19 restrictions with many participants regarding them as inhumane. For example, one participant reported the wrongdoing of the restrictions, and the cruelty of seeking permission to visit a dying loved one:

> *"I'm left with only a feeling of anger, a sense that everything was done wrong, cancelled procedures due to Covid etc., then asking permission from guards to travel to see a dying sibling was immensely cruel, some would say okay, but others not so accommodating."*

Another participant understood the rationale of the COVID-19 restrictions in place but outlined the difficulty in deferring a sad occasion:

> *"We all understand that the restrictions were essential, but it meant that these opportunities were lost. It's possible to defer a holiday, or the celebration of a happy occasion, but not a sad one."*

Furthermore, another participant reported their frustration and unfairness with some COVID-19 restrictions:

> *"[I] missed the spontaneity of people dropping in or being able just to drop in to visit someone. [I] found myself getting very angry about stupid rules...like numbers allowed to stand at a football game but not at a graveside. I found myself getting very angry at the establishment quite often."*

Strain on Healthcare Settings

Participants reported witnessing the stress faced by healthcare workers during the pandemic and the need for better support for healthcare workers. For example, one participant emphasized the need for sufficient training for healthcare staff:

> *"Healthcare staff are so burned out and as a result the lack of empathy can be staggering. Staff need to be much better supported in order to provide a caring health service. This doesn't just mean tokenistic supports for staff but sufficient staffing, so they get breaks, so they have reflective practice, so they're trained in considering what the person they're interacting with is going through etc."*

Another participant referred to their experience as a visitor in a hospital during the pandemic and reported witnessing the poor management of public hospitals and the distress healthcare staff experienced during this time:

> *"Because she died in a public ward, we could only gather as a family in the corridor, not around her bed (which was cramped, 1-2 people at most). This should not be the case. Public hospitals are so poorly managed and so lacking in facilities. The staff were very good, but clearly overworked and traumatized."*

One participant recalled witnessing the distress nursing home staff felt and how they were burnt out and overwhelmed with seeing large cases of death:

> *"It was terrible to see young staff at the nursing home cry, the foreign staff did not think they would see their own children again and they were exhausted and overcome with so much death in that terrible month."*

Healthcare Workers' Experience of End-of-Life Care during COVID-19

Healthcare workers described their specific experiences of providing end-of-life care in free-text open responses. The following two themes emerged:

- Emotional Impact
- Lack of Normalcy

Emotional Impact

Participants who were healthcare workers discussed the negative feelings they endured during the pandemic and the hardships experienced by their patients. Some recalled the difficulty of watching loved ones of their patients who were not permitted to enter the hospital due to restriction measures and how families were often disappointed with them:

> *"Working frontline, it often was harrowing. Watching family members outside in the rain looking in as their loved one dies inside with one member of the family only present. Relatives were often difficult to cross with us, [which worsened] the absolute misery we were feeling."*

Similarly, another healthcare worked described the sadness of watching a patient's family witnessing the end-of-life of their father through a hospital window:

> *"As a healthcare worker, the impact of patients not being able to physically see their loved ones is one of the hardest parts of my nursing career. To see a family looking in a window, viewing their dying father was so traumatic and heart breaking. It is a moment in time I will never forget."*

One healthcare worker warned of the long-term detrimental effects, both emotional and psychological, that will affect the nation because of the pandemic:

> *"I saw husbands watch their wife's funeral on an iPad as they were [COVID] positive and couldn't get to the funeral. A daughter who had just had a baby several hours earlier watched her mother being buried on an iPad. The fall out of all the deaths over the last 29 months will have a long and negative effect on us all."*

Lack of Normalcy

Healthcare worker participants described the emotional difficulty they experienced, which was particularly due to the increased number in deaths, social restrictions, and overall strain on healthcare settings:

> *"I'm a healthcare worker who's been in an acute hospital in COVID wards and I've seen more deaths in the last 20 months than ever before. The lack of human contact for so many, the need for PPE and lack of normalcy for those dying was so hard to deal with."*

Another participant reported the difficulty of being unable to provide patients with the quality time they deserved and the effect this had on their wellbeing:

> *"As a nurse, I might've had 10-12 patients at a time where the majority of patients were very unwell, so unfortunately, I didn't have the time to give them the time they deserved. You could be with one sick patient for up to an hour and go to the next and they could've been lying there dead, for who knows how long. It's impossible not to blame yourself. You felt like you failed your patient and their families."*

Furthermore, another healthcare worker who worked during all waves of the pandemic reported the limited support available for staff and limited opportunity to debrief with peers:

> *"Working as an ICU nurse during all waves. Wave 1 and 3 have traumatised me because of the high mortality rate including all age groups. Lack of family visiting was difficult at the beginning of the pandemic. Lack of support for staff, lack of debriefing."*

Bereaved Participants' Experience of Dying and Death

The next section presents findings on the experience of dying and death of a loved one as reported by survey participants. Over 86% of participants (N=976) agreed that their experience of a loved one's death was negatively affected by COVID-19. Less than 20% of bereaved participants (N=223, 19.6%) were able to spend time with their loved one before they died and over half of participants (N=717, 63.7%) were not present with their loved one when they died. Some participants reported not receiving the support they needed from professionals involved in the end-of-life care of their loved one (N=246, 21.8%) (see Table 15).

Table 15. Experiences Before the Death of a Loved One

		Responses N (%)				
	N	**Yes**	**Somewhat or partly**	**No**	**Don't know**	**Does not apply**
My experience around the time of their death	1130	718 (63.5%)	258 (22.8%)	115 (10.2%)	14 (1.2%)	25 (2.2%)

was negatively affected by COVID-19						
I was able to spend the time I wanted with them before they died	1135	223 (19.6%)	189 (16.7%)	641 (56.5%)	2 (0.2%)	80 (7%)
I was with them at time they died	1126	267 (23.7%)	34 (3.0%)	717 (63.7%)	5 (0.4%)	103 (9.1%)
The professionals involved in the end of their life gave me the support I needed	1128	273 (24.2%)	217 (19.2%)	246 (21.8%)	29 (2.6%)	363 (32.2%)

Survey Participant Reflections

The following two themes emerged in relation to bereaved participants' experience of dying and death:

- Lonely and Powerless
- Denied the Opportunity to Say Goodbye

Lonely and Powerless

Participants reported the feelings of loneliness and powerlessness that occurred throughout the pandemic:

> *"The distance between people really highlighted to me how isolating it can be. I live alone and I struggle with my own emotions. I missed the support of family and friends. I missed the comfort of a hug or a chat over a shared cup of tea."*

One participant recalled the lonely experience she had following a miscarriage including the lack of social contact, limited support, and difficulty engaging in recreational activities:

> *"During the third lockdown, I experienced a miscarriage, and I found the experience completely devastating. Working from home alone, without social outlets, in isolation, little opportunity for distraction or exercise, counselling conducted remotely, a lack of support from my GP who was under huge strain…already. Challenging experience of grief was compounded by the circumstances in which I found myself."*

Another participant mentioned the loneliness experienced following the burial of a loved one:

> *"When you bury a loved one during a pandemic, like I did... and you turn away from their grave and go home to an empty house, no memorial gathering, no extended family and friends to share the loss or share a memory. It's by far the loneliest of times. Something as a nation we wouldn't be used too."*

Denied the Opportunity to Say Goodbye

When describing the impact of COVID-19, participants expressed how the implementation of capped visiting numbers in hospital and nursing home settings meant some participants were unable to say goodbye to their loved ones and as a result, some patients died alone:

> *"My brother-in-law died suddenly and unexpectedly from a late diagnosis of cancer. His wife and his children could not sit with him or comfort him but could only look through the glass. Only in his last minutes when he was already in a coma were they allowed at his bedside. They never really got to say goodbye, even worse, they never got to comfort him, tell him they loved him, while he could still hear them. None of us got to say goodbye. There has to be a better way."*

Another participant spoke of how strictly hospital staff adhered to the restrictions and denied family members any opportunity to visit their loved ones:

> *"I lost my mum to Covid-19, 2 years previously (April 2020). She went into hospital with an infection. We were restricted from visiting her for 3 months. Around every corner, every effort was made to keep us out of the hospital."*

The implementation of restricted visits in hospital settings was undoubtedly difficult for many people. One participant expressed being unable to be with her grandmother when she died and the effect that this had:

> *"My Nan got a stroke and was in hospital, she got 3 more strokes afterwards. She was 10 days in hospital altogether before she passed away. I had stressed to the hospital staff that I lived nearly 2 hours from the hospital and if anything happened to her to please ring me. They rang and said she had a turn, I said I'd leave, and they told me not to. By the time I got to the hospital my beautiful grandmother was gone at 94. She had died on her own. I will never forgive myself."*

Funerals and Mourning Rituals

Over 20% of participants were unable to attend the funeral of their loved one (N=262, 23.5%) and almost 70% of participants (N=765, 68.6%) reported that family and friends were excluded from funerals due to COVID-19 restrictions. Almost half of participants stated they were unable to have the funeral or ritual they would have liked for their loved one (N=531, 47.5%). However, most participants (N=608, 54.6%) felt that a funeral remained a source of comfort for them in their grieving. Over half of participants stated that people in their community had found other ways to honour the person who had died (N=601, 53.6%) and a similar number (N=608, 54.6%) stated that even with restrictions, some aspects of the funeral were a comfort to them (see Table 16).

Table 16: Impact of COVID-19 on Funerals and Mourning Rituals

		Responses N (%)			
	N	**Yes**	**Somewhat or partly**	**No**	**Does not apply**
I was unable to attend their funeral in person because of the COVID-19 restrictions	1116	262 (23.5%)	68 (6.1%)	697 (62.5%)	89 (8%)
Some family and/or close friends were excluded from the funeral because of the COVID-19 restrictions	1115	765 (68.6%)	147 (13.2%)	158 (14.2%)	45 (4.0%)
We were able to have the funeral service or ritual we wanted for them	1119	215 (19.2%)	342 (30.6%)	531 (47.5%)	31 (2.8%)
People in the community still found meaningful ways to honour them on the day of their funeral	1121	601 (53.6%)	353 (31.5%)	131 (11.7%)	36 (3.2%)
Even with restrictions, some aspects of the funeral were a comfort to me	1114	608 (54.6%)	310 (27.8%)	145 (13.0%)	51 (4.6%)

<u>Survey Participant Reflections</u>

The above quantitative results were supported and reiterated in the open-text responses from participants. The following three themes emerged in relation to funerals and mourning rituals:

- Altered Funeral Structures and Restrictions
- Lost Opportunities to Grieve

- Difficulty Supporting Others

Altered Funeral Structures and Restrictions

Many participants mentioned difficult experiences due to the restrictions that were placed on funerals. The capped attendance numbers, social distancing, and overall new arrangements of funerals made the bereavement experience even more difficult for family members, leaving them in a state of shock:

> *"She was lifted by the funeral director and buried two hours later. We left clothes but it is my belief that they did not dress her. They didn't tell us, and we didn't ask. I believe that she was placed in a bag, and it was put into a coffin. We walked to the church; kind neighbours lined the route but only the immediate family were allowed into the graveyard. The gate was closed. We were not permitted to carry the coffin. The priest quickly said a few prayers. It was over in a matter of minutes. Almost no one spoke to us as we walked home in shock."*

One participant reported the difficulty in choosing who could attend funerals and indicated how the funeral did not meet their expectations:

> *"It was like a lottery trying to decide who would and wouldn't attend. We were able to have time with our loved one in a funeral home; however only a very limited family were able to come and say goodbye. I found this very difficult as it is certainly not the type of funeral we would have intended."*

Another participant highlighted the grief and pain that is still present due to the restricted funeral arrangements during the pandemic:

> *"We never left her side throughout her 9-month battle but were robbed of those last precious times. We got no funeral. 10 of us. We couldn't carry her coffin or bring up gifts. We had to drive our own cars and pick coffins over WhatsApp messages. I look back over it and it was so surreal. We weren't surrounded by family and friends and now 18 months later I feel my mom is just forgotten by everyone and they have moved on and I think we just feel stuck in that grief and devastation."*

Lost Opportunities to Grieve

Participants emphasized the need to grieve properly, which required access to support, the ability to attend traditional funerals, and the opportunity to say goodbye. However, COVID-19 hindered these activities, which are essential components of the grieving process:

> *"Having lost a loved one during the pandemic and adhering to restrictions in place for the funeral reinforces the need to be able to grieve appropriately. Not being able to have a wake, meet and greet people freely and share a cup of tea were significant losses."*

Another participant compared the death of her mother before the pandemic with her father's death during the pandemic and highlighted how the removal of traditional grieving rituals disrupted and impacted the grieving process:

> *"It didn't change my views so much on dying and death, but I probably didn't understand the importance of 'rituals' in the aftermath of the death of a loved one until they were taken away. My mother's death from cancer almost 5 years ago was a drawn-out lingering process but we had time to process it every step of the way. Covid robbed us of that when it came to our father's death."*

Another participant also emphasised how the removal of traditional mourning rituals or norms could have long-term detrimental effects for many people:

> *"During the pandemic as we couldn't attend funerals it was extremely lonely for families to go home to their respective households alone without this step of the grieving process. I believe that grief is delayed in these circumstances and that as a country we will have a lot of people grieving once we get through this time and employers, friends etc. may not be mindful that people need time. This could potentially cause or aggravate some form of depression."*

Difficulty Supporting Others

Survey participants frequently referred to the difficult and heart-breaking experience of being unable to extend their support to family and friends during the pandemic due to preventive measures in place and fear of contracting or passing on COVID-19. For example, one participant recalled the following experience:

> *"A friend's Dad passed at the beginning of the pandemic, and I found it hard to know what to do e.g., could I go to the house or funeral? In the end I went to the house but felt awkward because I couldn't shake hands, hug, or even stand next to the coffin to pay respects."*

Another participant who was a healthcare worker described the heartbreak of not being able to comfort her family at a funeral during the pandemic in fear of placing her family members at risk of COVID-19:

> *"I'll never forget watching my 86-year-old aunt sob silently and without being able to physically comfort her for fear I'd place her at risk as I'm a nurse working in a hospital with Covid patients."*

Moreover, another participant emphasized the difficulty of being unable to comfort his wife at a funeral due to the restrictions placed on funeral arrangements during the pandemic:

> *"When my wife's grandmother died, funeral attendance was capped at 10 so I had to sit in the car and watch the funeral via livestream, so I was unable to hold her hand and give her comfort during the mass and this was very difficult."*

The next section of the report discusses the experiences of bereavement and grief amongst survey participants.

Experience of Bereavement and Grief

Over 60% of participants (N=691) stated that the pandemic made their grieving process more difficult, and over half of respondents (N=580, 53.6%) stated that, despite the restrictions, their family and friends found meaningful ways to support them in their grief. Almost 40% of participants (N=396) did not get the support they needed after the death of a loved one because of restrictions (see Table 17).

Table 17. Experiences After the Death of a Loved One

		Responses N (%)				
	N	**Strongly agree**	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**
The Impact of COVID-19 made my grief more difficult	1086	280 (25.8%)	411 (37.8%)	253 (23.3%)	83 (7.6%)	59 (5.4%)
Even with restrictions, my family and friends have found meaningful ways to support me in my grief	1082	79 (7.3%)	501 (46.3%)	325 (30%)	127 (11.7%)	50 (4.6%)
I didn't get the support I needed after the death because of the COVID-19 restrictions	1080	128 (11.9%)	268 (24.8%)	389 (36.0%)	220 (20.4%)	75 (6.9%)

Yet, most bereaved participants (N=496) reported that they did not require extra support from a professional or support service. For those that did require support services, most sought help from a counsellor, psychotherapist, or private psychologist (N=138) or from a GP (N=100). Some participants (N=80) wanted to get support but did not know where to go (see Figure 6 below).

Survey Participant Reflections (N = 815)

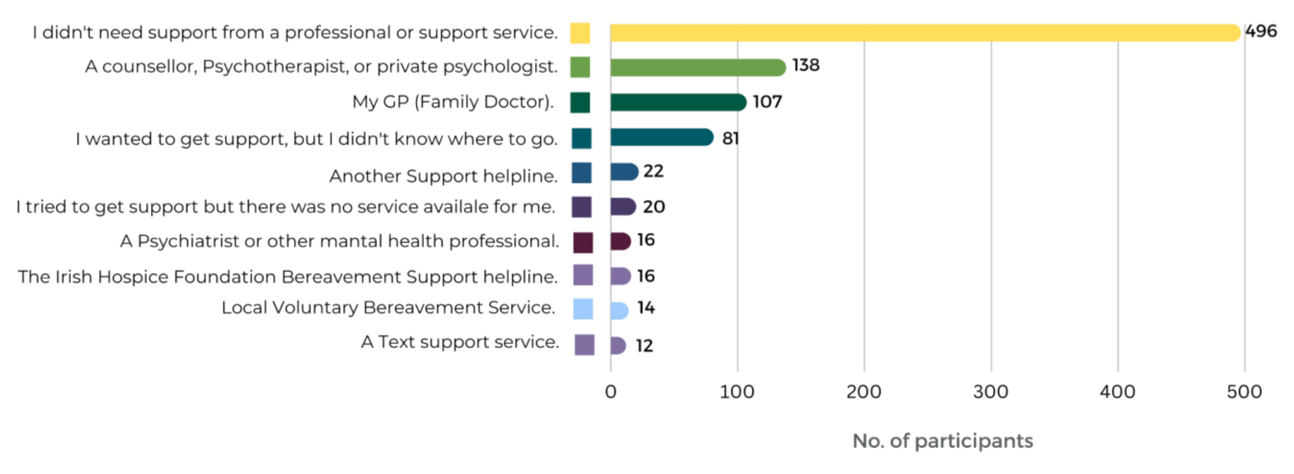


FIGURE 6 BEREAVEMENT SUPPORT SERVICES ACCESSED DURING THE COVID-19 PANDEMIC

The above quantitative results were supported and reiterated in the open-text responses from participants. The following themes emerged:

- Limited Bereavement Support During the Pandemic
- Importance of Community Support

Limited Bereavement Support During the Pandemic

Participants expressed a lack of bereavement support during the pandemic. This was presented as a lack of support given by a professional or difficulty accessing support while grieving. For instance, one participant recalled their experience of visiting their GP to get support following a bereavement and explained how limited emotional support was given:

> *"Even if a death occurred prior to the pandemic, for the most part the Covid has had a knock-on effect to those who were grieving when it started. When I went to see my GP as I thought I needed help, he said "of course you don't feel right, you lost both your parents. Keep losing weight" – nothing was offered to help i.e., counselling etc."*

Another participant shared the experience of paying a counsellor for support during the pandemic, but the service provided did not meet her expectations:

> *"I lost a family member who I was very close to in recent times and cannot cope with the loss. I have searched for proper grief counselling without success. All help lines are only open for a few hours during the day whereas those of us who live alone find the evening and night-time the worst to deal with. There is no proper grief counselling for people like me. I paid a so-called counsellor €140 and all he told me was "you are a strong woman you can work it out for yourself". I am disgusted with the lack of grief counselling particularly for the older generation."*

Another participant explained how the nurses were very caring towards her mother in hospital but mentioned the disappointment of no support being offered to herself or her siblings when it was needed:

> *"At no time were myself or my siblings offered any numbers for support afterwards etc. when we could have done with it. I cannot fault the care the nurses gave to my mom. They were super. Just an observation on the afterwards care for ourselves and the follow up."*

Importance of Community Support

During the pandemic, social distancing and reduced social contact made it difficult for people to offer support to bereaved individuals. Subsequently, the way in which support was exchanged differed immensely to pre-pandemic times and participants emphasized the value of extending traditional support to grieving individuals:

> *"I think the restrictions make it difficult for someone living after a bereavement – the same support networks can't be there in person. I think that makes the aftermath more difficult – having people around for a while afterwards can help processing, and even help with practical things afterwards – people could do with support then too as the emotions are likely to arise fresh again e.g., dealing with business issues, wills etc."*

Similarly, another participant spoke of not being able to show support due to restrictions on household visits and funeral attendance:

> *"A relative died during the pandemic but not from Covid 19. The family did not have the benefit of the community being able to attend the mass and could not call to houses. Then I realized how important all that is when there is a death."*

The pandemic reinforced the importance of community support and participants reported how they came to realise the importance of community support:

> *"The need to be able to share a death with your community was something I took for granted. Having sadly been at a number of close relatives' funerals, I see that the funerals with restricted numbers do not permit a family to hear lovely stories about the deceased or feel the support of the community."*

The value of connection and togetherness as a vital part of the grieving process was highlighted by another participant:

> *"I didn't realise how important it is to have the support of relatives/community when a person dies, but when that is diminished, it can be a difficult process. Irish people have historically been good at grieving and coming together at a difficult time, and when we could not do that, it made it harder."*

Likelihood of Prolonged Grief Disorder as Measured by the Brief Grief Questionnaire

The Brief Grief Questionnaire (BGQ) was used to screen for Prolonged Grief Disorder (PGD) among participants who indicated they experienced a bereavement during the pandemic. PGD includes intense feelings of grief that are long-lasting and can interfere with everyday life. Scores between 0 and 4 indicated no PGD. Scores between 5 and 7 meant a possible sub-threshold of PGD was detected, while scores 8 or higher indicated signs of PGD.

Overall BGQ Scores

Overall results from the BGQ (N=1095) demonstrated relatively high scores across all statements with a mean score of 3.95 (SD = 2.86). Most participants' (N=653, 59.7%) had a total score between 0 and 4 on the BGQ, indicating no symptoms of PGD, while 26.1% of participants (N=286) scored between 5 and 7 on the BGQ, indicating a sub-threshold of PGD. The remaining participants (N=156, 14.2%) scored between 8 and 10, indicating that they were experiencing symptoms of PGD (see Table 18).

Table 18. BGQ Scores for Bereaved Participants

Variable	Bereaved N = 1095

	n	*%*
BGQ Category		
No PGD indicated (0-4)	653	59.6
Sub-threshold PGD indicated (5-7)	286	26.1
PGD indicated (8-10)	156	14.2

Note. BGQ – Brief Grief Questionnaire; PGD – Prolonged Grief Disorder

<u>BGQ Individual Item Responses</u>

Individual responses to each item of the BGQ demonstrated that over 60% of participants (N=674) reported having trouble accepting the death of their loved one. Almost three-quarters of participants (N=762, 70.1%) reported that grief was interfering with life. Additionally, over 60% (N=666) were having bothersome images or thoughts and almost half of participants (N=522, 47.9%) were avoiding activities that remind them of the person they lost during the pandemic. More than half of participants (N=585, 53.9%) expressed feeling cut off or distant from others (see Table 19).

Table 19. Responses to Individual Items in the Brief Grief Questionnaire

		Responses N (%)		
	N	**Not a lot**	**Somewhat**	**A lot**
Trouble accepting this person's death	1092	418 (38.3%)	436 (39.9%)	238 (21.8%)
Grief interfering with life	1087	325 (29.9%)	529 (48.7%)	233 (21.4%)
Having bothersome images or thoughts	1087	421 (38.7%)	406 (37.4%)	260 (23.9%)
Avoiding doing things that remind them of the person	1090	568 (52.1%)	353 (32.4%)	169 (15.5%)
Feeling cut off or distant from others	1086	501 (46.1%)	369 (34%)	216 (19.9%)

<u>BGQ Scores for Healthcare Workers</u>

BGQ total scores were compared for bereaved participants who were also healthcare workers as opposed to those who were not healthcare workers (see Table 20). Most participants 63.6% (N=147) of healthcare workers and 58.6% (N=506) of non-healthcare workers had a total score between 0 and 4 on the BGQ, indicating PGD was not present . No statistically significant difference was found when comparing healthcare workers vs other survey participants.

Table 20. BGQ Scores for Healthcare Workers vs Non-Healthcare Workers

	Healthcare Worker					
	No		**Yes**			
Variable	**N = 864**		**N = 231**			
	n	***%***	***n***	***%***	**X^2 (2)**	***p***
BGQ Total						
No PGD indicated (0-4)	506	58.6%	147	63.6%	2.11	.348
Sub-threshold PGD indicated (5-7)	230	26.6%	56	24.2%		
PGD indicated (8-10)	128	14.8%	28	12.2%		

Note. P-value computed based on chi-square test and level of significance was set to 0.05.

BGQ Scores Based on Geographic Location

BGQ total scores were compared for bereaved participants located in urban, suburban, rural areas and towns (see). Most participants in all locations had a total score between 0 and 4 on the BGQ, indicating PGD was not present. No statistically significant difference was found when comparing responses based on geographic location.

Table 21. BGQ Scores Based on Geographic Location

Variable	Geographic Location									
	Urban N = 242		Suburban N = 257		Town N =227		Rural N = 348			
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	X^2 *(6)*	*p*
BGQ Category										
No PGD indicated (0-4)	143	59.1%	167	65.0%	122	53.7%	206	59.2%	11.31	.079
Sub-threshold PGD indicated (5-7)	72	29.8%	59	23.0%	63	27.8%	86	24.7%		
PGD indicated (8-10)	27	11.1%	31	12.0%	42	18.5%	56	16.1%		

Note. P-value computed based on chi-square test; BGQ – Brief Grief Questionnaire; PGD – Prolonged Grief Disorder

BGQ Scores and Cause of Death

No statistically significant differences in BGQ scores were found based on the cause of death of the participants loved one (see Table 22). Participants whose loved one died from cancer had higher indications of PGD (N=56, 36.1%) than other causes of death. Over 12% (N=20) of participants whose loved one died from COVID-19 (N=19) had indications of PGD.

Table 22. BGQ Scores and Cause of Death

Cause of Death	BGQ Category							
	No PGD indicated N= 648		Sub-threshold PGD indicated N = 281		PGD indicated N = 155			
	N	*%*	*N*	*%*	*N*	*%*	X^2 **(70)**	***p***
Cancer	185	28.5%	76	27.0%	56	36.1%	87.68	.075
Cardiac condition (e.g., Heart attack, Heart failure, or other disease of the heart or circulatory system)	118	18.2%	53	18.9%	22	14.2%		
Confirmed COVID-19 infection	84	13.0%	48	17.1%	19	12.3%		
Dementia	56	8.6%	20	7.1%	5	3.2%		

Respiratory disease (e.g., Chronic Obstructive Pulmonary disease (COPD), Chronic bronchitis, Cystic Fibrosis)	34	5.2%	13	4.6%	5	3.2%
Unknown or Inconclusive	25	3.9%	12	4.3%	2	1.3%
Age-Related, Unspecified	24	3.7%	2	0.7%	0	0.0%
Accident	18	2.8%	6	2.1%	8	5.2%
Suicide	17	2.6%	11	3.9%	9	5.8%
Stroke	15	2.3%	9	3.2%	6	3.9%
Nervous system disorder (e.g., Motor Neuron Disease, Multiple Sclerosis, Parkinson's Disease)	14	2.2%	7	2.5%	5	3.2%
Suspected COVID-19 infection	10	1.5%	3	1.1%	1	0.6%
Sepsis	10	1.5%	6	2.1%	7	4.5%
Organ Failure	10	1.5%	2	0.7%	0	0.0%
Pneumonia	5	0.8%	3	1.1%	2	1.3%
Non-COVID 19 Infection	4	0.6%	1	0.4%	0	0.0%
Homicide	2	0.3%	2	0.7%	0	0.0%
Epilepsy	2	0.3%	1	0.4%	0	0.0%
Diabetes-Related Complication	2	0.3%	1	0.4%	0	0.0%
Congenital Disease	2	0.3%	0	0.0%	0	0.0%
Death due to perinatal or pregnancy complications	1	0.2%	0	0.0%	0	0.0%
Miscarriage	1	0.2%	1	0.4%	1	0.6%
Medical Procedure	1	0.2%	0	0.0%	1	0.6%
Abdominal Complications	1	0.2%	0	0.0%	1	0.6%
Renal Disease	1	0.2%	1	0.4%	1	0.6%
Fall-Related Complication	1	0.2%	1	0.4%	1	0.6%
Bowel Ischemia	1	0.2%	0	0.0%	0	0.0%
Blood Disorder	1	0.2%	0	0.0%	0	0.0%
Post-Operative Complication	1	0.2%	0	0.0%	0	0.0%
Liver Disease	1	0.2%	0	0.0%	0	0.0%
Mitochondrial encephalomyopathy, lactic acidosis and stroke-like episodes (MELAS)	1	0.2%	0	0.0%	0	0.0%

Anaphylaxis	0	0.0%	0	0.0%	1	0.6%
Protein-losing enteropathy (PLE)	0	0.0%	0	0.0%	1	0.6%
Loneliness	0	0.0%	0	0.0%	1	0.6%
Sarcoidosis	0	0.0%	1	0.4%	0	0.0%
Rectal Bleed	0	0.0%	1	0.4%	0	0.0%

Note. P-value computed based on chi-square test and level of significance was set to 0.05.

BGQ Scores and Place of Death

No statistically significant differences in BGQ scores were found based on the place of death of the participant's loved one (see Table 23). More participants whose loved one died in a hospice (N=16, 19.5%) had indications of PGD compared with participants whose loved one died in other settings.

Table 23. BGQ Scores and Place of Death

	BGQ Category							
	No PGD indicated (0-4)		Sub-threshold PGD (5-7)		PGD indicated (8-10)			
Place of Death	*N*	*%*	*N*	*%*	*N*	*%*	*X² (16)*	*p*
Own home (N=207)	140	67.6%	45	21.7%	22	10.6%	18.88	.275
Hospital (N=245)	139	56.7%	75	30.6%	31	12.6%		
Nursing home (N=121)	82	67.8%	30	24.8%	9	7.4%		
Hospice (N=82)	47	57.3%	19	23.2%	16	19.5%		
Other (N=32)	20	62.5%	9	28.1%	3	9.3%		

Note. P-value computed based on chi-square test and level of significance was set to 0.05.

BGQ Scores and Relationship to Deceased

A statistically significant association was found between BGQ scores and participants' relationship to the deceased (see Table 24). Indicators of PGD were more prevalent in participants who lost a parent, extended family member. a spouse, in-law, or a child compared with those who lost other family members.

Table 24. BGQ Scores and Relationship to Deceased

	BGQ Category							
	No PGD indicated N = 639		Sub-threshold PGD indicated N = 279		PGD indicated N = 152			
Relationship	*N*	*%*	*N*	*%*	*N*	*%*	X² (22)	p
Parent/Step Pparent (N = 323)*	165*	25.8%	85	30.5%	73*	48.0%	137.59	<.001

Grandparent (N = 88)	56	8.8%	21	7.5%	11	7.2%
Sibling (N = 67)	32	5.0%	21	7.5%	14	9.2%
Client/Resident/Patient (N =35)	25	3.9%	9	3.2%	1	0.7%
Friend (N = 145)*	86	13.5%	49*	17.6%	10*	6.6%
Other (N =20)	15	2.3%	3	1.1%	2	1.3%
Extended Family Member (N = 177)*	130*	20.3%	38*	13.6%	9*	5.9%
In-law (N = 95)*	65*	10.2%	24	8.6%	6*	3.9%
Son or Daughter (N = 14)*	4*	0.6%	4	1.4%	6*	3.9%
Spouse/Partner (N =39)*	6*	0.9%	14*	5.0%	19*	12.5%
Neighbour (N = 35)	26	4.1%	8	2.9%	1	0.7%
Colleague (N = 32)*	29*	4.5%	3*	1.1%	0	0.0%
Total	639	100.0%	279	100.0%	152	100.0%

Note. P-value computed based on chi-square test; * **indicates** significant differences; Bonferroni correction applied to reduce Type I error.

BGQ Scores and Time Spent with the Deceased Before they Died

Table 25 displays the chi-square results to determine if associations were found between respondents being able to spend the time with their loved one before they died and their BGQ category. The results showed no differences between being able to spend time and BGQ category.

Table 25. BGQ Scores and Time Spent with the Deceased Before they Died

	I was able to spend the time I wanted with them before they died									***p***
	Yes		**No**		**Somewhat or partly**		**Don't know**			
	n	***%***	***n***	***%***	***n***	***%***	***n***	***%***	X^2 *(6)*	
BGQ Category										
No PGD indicated (0-4)	123	55.9%	362	59.2%	99	53.7%	1	50.0%	8.31	.216
Sub-threshold PGD indicated (5-7)	58	26.4%	172	28.2%	45	25.0%	1	50.0%		
PGD indicated (8-10)	39	17.7%	77	12.6%	36	20.0%	0	0.0%		

Note. P-value computed based on chi-square test; Bonferroni correction applied to reduce Type I error.

Table 26 shows BGQ category based on whether the respondent was with the person when they died. The chi-square test results were significant (p < .001). Specifically, there were lower rates of PGD for those that were not with the person (10.4%) relative to those that were with the person (25.8%).

Table 26. BGQ scores and Being with the Deceased at the Time they Died

	I was with them when they died									p
	Yes		No		Somewhat or partly		Don't know			
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*X² (6)*	
BGQ Category										
No PGD indicated (0-4)*	118	44.7%	432	62.7%	20	58.8%	2	50.0%	47.48	<.001
Sub-threshold PGD indicated (5-7)	78	29.5%	185	26.9%	6	17.60%	2	50.0%		
PGD indicated (8-10)*	68	25.8%	72	10.4%	8	23.5%	0	0.0%		

Note. P-value computed based on chi-square test; * indicates significant differences between Yes and No column values.

BGQ Scores and Access to Support during COVID-19 Pandemic

A statistically significant association was found between BGQ scores and participants' access to support during the pandemic (see Table 27). Bereaved participants were asked to rate their level of agreement with the following statement: 'I didn't get the support I needed because of COVID-19 restrictions'. A higher percentage of those who agreed or strongly agreed with the statement had indications of PGD and sub-threshold PGD.

Table 27. BGQ Scores and Access to Support during COVID-19 Pandemic

	BGQ Category						
Response to: *"I didn't get the support I needed because of COVID-19 restrictions"*	No PGD indicated (0-4)		Sub-threshold PGD (5-7)		PGD indicated (8-10)		
	n	*%*	*n*	*%*	*n*	*%*	*p*
Strongly Agree (N=128)	34	26.6%	41	32.0%	53	41.4%	< 0.05
Agree (N=268)	121	45.1%	103	38.4%	44	16.4%	
Disagree (N=220)	171	77.7%	38	17.3%	11	5.0%	
Strongly Disagree (N=75)	52	69.3%	14	18.7%	9	12.0%	

Note. P-value computed using independent samples t-tests and level of significance was set to 0.05.

BGQ Scores and Experience of Death

Chi-square tests were conducted to determine if associations were found between respondents reporting that COVID-19 prevented the person from having the death they would have wished for and their BGQ category. Respondents that felt COVID-19 prevented the person from having the death they would have wished for had significantly higher rates of sub-threshold PGD relative to those who did not feel that way (see Table 28 below).

Table 28. BGQ Scores and COVID-19 Preventing the Death the Respondent would have Wished for the Deceased

	Covid-19 prevented them from having the death I would have wished for them									p
	Yes		No		Somewhat or partly		Don't know			
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*X^2 (6)*	
BGQ Category										
No PGD indicated (0-4)*	244	50.8%	166	66.7%	123	66.1%	33	75.0%	32.67	<.001
Sub-threshold PGD indicated (5-7)*	155	32.3%	45	18.1%	44	23.7%	9	20.5%		
PGD indicated (8-10)	81	16.9%	38	15.3%	19	10.2%	2	4.5%		

Note. P-value computed based on chi-square test; * indicates significant differences between Yes and No column values.

BGQ Scores and Ability to have a Funeral or Ritual

Table 29 shows the chi-square results comparing the ability to have the desired funeral or ritual for the death of the loved one and BGQ category. There were no differences between those who did and those who did not have the desired funeral and BGQ category (p = .491).

Table 29. BGQ Scores and the Ability to Have the Funeral or Ritual the Respondent Wanted for the Deceased

	We were able to have the kind of funeral or ritual we wanted for them									p
	Yes		No		Somewhat or partly		Don't know			
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*X^2 (6)*	
BGQ Category										
No PGD indicated (0-4)*	126	60.9%	293	56.3%	209	62.4%	0	0.0%	3.41	.491
Sub-threshold PGD indicated (5-7)*	52	25.1%	147	28.3%	82	24.5%	0	0.0%		
PGD indicated (8-10)	29	14.0%	80	15.4%	44	13.1%	0	0.0%		

Note. P-value computed based on chi-square test

Future Priorities for End-of-Life Care in Ireland

All survey participants (N=2259) were asked to select three top priorities from a list of seven for future end-of-life care in Ireland. The following were the top priorities for end-of-life care in Ireland as reported by survey participants:

1) Ensuring that people are supported to die with dignity, free from pain in a calm and comfortable place of their choosing (N=1547, 68,4%)
2) Better home-based supports for people at the end of their life (N=1113, 49.2%)

3) Ensuring every person has equal access to palliative care wherever they live and whatever their age (N=1042, 46.1%).

A summary of all seven priorities is provided in Figure 7 below.

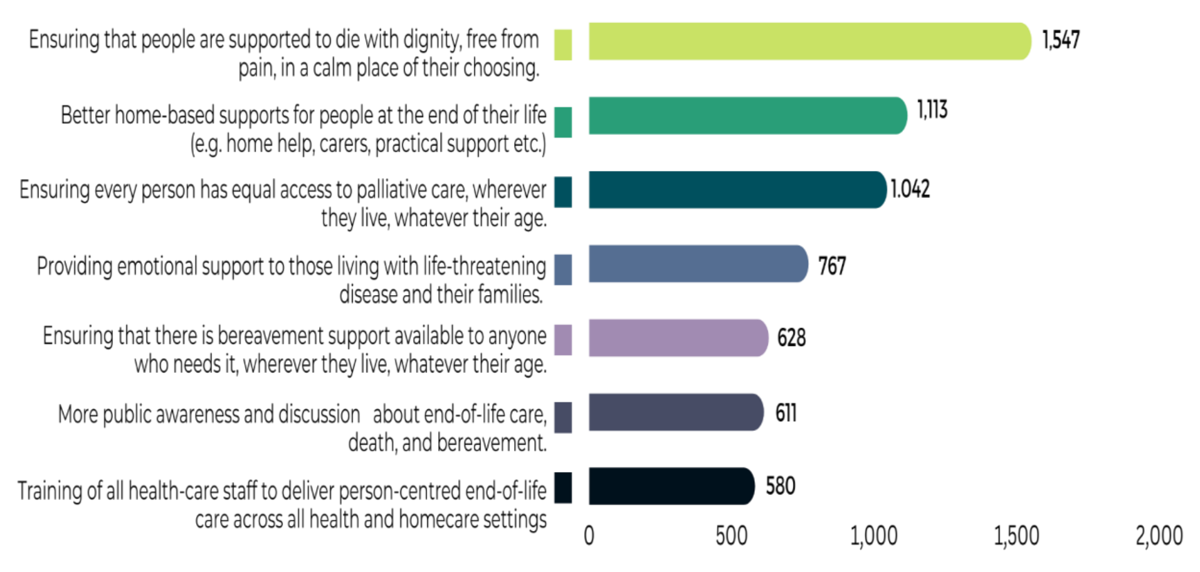


FIGURE 7 FUTURE PRIORITIES FOR END-OF-LIFE CARE IN IRELAND

Conclusion

In conclusion, the purpose of this survey was to understand the impact of COVID-19 on perceptions and attitudes towards dying, death, and bereavement among the population in Ireland and to learn more about their bereavement experience during this time.

The survey was conducted 18 – 22 months after the first COVID-19 case was reported in Ireland and a year after the first vaccination campaign was launched in the country. Public health restrictions were still in place at the time the survey was disseminated, and quite rigorous restrictions remained in place until the end of 2021 before beginning to ease in early 2022. Restrictions on hospital, nursing home and hospice visits and funeral arrangements predominantly remained in place.

The results of this 'Time to Reflect' survey provide valuable insights into the provision of end-of-life care during the pandemic, the experiences of families and their dying loved ones and the difficult and very emotive circumstances healthcare staff had to work and live in. The findings also highlight the significant impact of restriction measures on funerals and mourning rituals, and experiences of grief, loss, and bereavement. Conclusions are categorised based on the following headings:

- Impact of COVID-19 on General Attitudes to Dying, Death, and Bereavement
- Impact of COVID-19 and Restrictions on Grieving
- Impact of COVID-19 Restrictions on Healthcare
- Impact of COVID-19 on Bereavement Support
- Impact of COVID-19 on Healthcare Workers

Impact of COVID-19 on General Attitudes to Dying, Death, and Bereavement

Findings of the 'Time to Reflect' survey highlighted that COVID-19 impacted general attitudes and perceptions of dying, death, and bereavement. Most participants reported that their views about dying, death, and bereavement had changed due to COVID-19 and that they have spoken about dying and death more since the beginning of the pandemic. Most participants also reported a greater awareness of grief and loss due to COVID-19. This increased awareness of dying, death, and bereavement was even more pronounced for those who had experienced a bereavement and for healthcare workers. These findings can be explained by the increased focus on dying and death by the general public during COVID-19. For example, some studies highlighted the salience of sudden deaths reported by the media and the dehumanizing effects of death statistics (Torrens-Burton et al. 2022, Donovan et al. 2023). The general public were faced with updates on the number of deaths in every available news outlet several times a day along with nationwide campaigns focused on 'flattening the curve' or in other words, reducing the death toll. This inevitably led to a hyperfocus on dying and death.

The finding that healthcare workers also exhibited a shift in their perceptions and awareness of dying, death, and bereavement is not surprising. Prior literature showed that nurses working on the frontlines during COVID-19 experienced a significant number of patient deaths, which led to stress and frustration for many (Williams et al. 2022). The shift in perceptions amongst survey participants who were healthcare workers was elaborated on in the qualitative comments, which highlighted the trauma of witnessing so many deaths across all age groups and the impact of restrictions on human contact at such a critical time.

Impact of COVID-19 and Restrictions on Grieving

The literature review suggested that COVID-19 related bereavement was more severe than natural losses but similar to the bereavement experience from unnatural losses (e.g., suicide, accidents). Findings of the 'Time to Reflect' survey indicated that PGD was present amongst 14% of participants, which aligns with or is less than prior studies conducted during the pandemic. A recently published study in the UK reported that 34.6% of participants had PGD indications 13 months post bereavement and 28.6% at 25 months post bereavement (Harrop et al. 2023). In this Irish data, while indications of PGD at 14% are lower than proportions reported elsewhere, the relatively large sub-threshold levels on the BGQ show one in four bereaved people may need closer monitoring.

The survey shows no statistically significant differences in indications of PGD (as measured by the BGQ) based on cause of death. In terms of COVID-19 deaths, 16.7% of participants whose loved one died from COVID-19 or suspected COVID-19 had indications of PGD. The survey did support an association between closeness of a relationship to the deceased and PGD scores. A statistically significant association was noted between the loss of a parent, spouse, or child, and indications of PGD. This aligns with the literature review that closeness of the relationship to the deceased affects the severity of grief experienced by a bereaved individual. Higher PGD scores were also associated with those who self-reported that they did not get the support they needed because of COVID 19 restrictions (41% of those above the threshold for PGD responded that they did not get adequate bereavement support).

Results of this survey found that there were significantly lower rates of PGD for participants who were not with their loved ones when they died compared with those who were with their loved ones. This is an interesting finding given the literature points to the importance of saying goodbye in the grieving process. These participants would have had the opportunity to say goodbye and be at their loved one's side when they died and yet, they had a higher rate of PGD. One explanation is that those with indications of PGD may have had a particularly close relationship to the deceased. Another explanation may be the particularly difficult circumstances that their loved one may have died in. If the person was in a care setting, families and staff would have been wearing PPE, contact would have been very limited, and the family member may only have been allowed access to the person in their final hours.

Results also showed that participants who felt that COVID-19 had prevented their loved one from having the death they would have wished for had significantly higher rates of sub-threshold PGD than those who did not feel that way. These findings highlight the impact that the end-of-life care experience can have on the bereaved and their likelihood to experience PGD.

It was evident from the literature that altered funeral structures and mourning rituals had a major impact on experiences of grief during COVID-19. Participants in this survey struggled with the loss of rituals due to the limitations in the number of people attending funerals and the introduction of safety protocols during the pandemic. This finding aligns with previous research that suggests a lack of mourning rituals and the inability to say goodbye to loved ones during the pandemic was traumatic and contributed to feelings of shock and anger among bereaved individuals. The survey further showed that funerals remained a source of comfort for participants in their grieving. Despite many participants finding ways to honour the individual who died, they felt as though they had lost an opportunity to grieve when they were denied the chance to have the traditional aspects of a funeral. Overall the survey demonstrated that in responding to future public health emergencies policy makers should pay close attention to the longer-term impact that bereavement can have on people and ensure that grieving rituals are maintained where possible.

Impact of COVID-19 and Restrictions on Healthcare

The visiting restrictions in place across the country caused a major disruption in the normal functioning of hospitals and nursing homes during the pandemic. Findings of the 'Time to Reflect' survey emphasise the struggle of bereaved participants, who were often denied the opportunity to be present at their loved one's bedside in the last moments of their life. The findings also highlight the emotional burden faced by healthcare workers particularly the added emotional burden of often being the only communication channel between the dying patient and their family, as well as caring for them. Participants discussed how these experiences gave rise to feelings of guilt, remorse, and moral suffering, which was also captured in the literature.

Quantitative and qualitative survey findings revealed relatively poor experiences in the delivery of end-of-life care. The results suggest that even though bereaved individuals thought the level of care was appropriate, they felt their loved ones did not have the death experience they would have wanted. A common experience highlighted in the results was a patient dying after a prolonged hospital admission without the companionship of their families. Both family members and healthcare workers highlighted the distress associated with patients not being able to receive high quality end-of-life care. Qualitative comments from both family members and healthcare workers referred to situations in which a patient died completely alone without family or staff present. Many participants highlighted the lasting impact of these negative experiences on them.

These results reflect the studies in the literature review which found that bereaved participants who reported that their loved one died in a hospital or nursing home were more likely to report poorer end-of-life care experiences with visiting restrictions and place of death as contributing factors.

In terms of place of death, hospitals were reported as the most frequent place of death followed by a person's own home and then a nursing home. This is aligned with another recent report on dying and death in Ireland (Matthews et al. 2021), which found that hospitals were the most common place where people died based on data collected from 2013 to 2018. Likewise, the second and third most common places where people died were at home and in a long stay residential care setting (Matthews et al. 2021). However, it should be noted that the survey responses show a slight rise in the numbers of people dying at home and a slight decrease in the numbers who died in hospitals and hospice care during COVID-19.

The restrictions and measures put in place during COVID-19 resulted in poorer end-of-life experiences for both dying patients and their families. The lessons learnt should prompt policy makers and public health officials preparing for future pandemics to include alternative arrangements and provide resources to sustain and support the delivery of end-of-life care and family visiting arrangements.

Impact of COVID-19 on Bereavement Support

Over one in three bereaved people felt they did not get the support they needed at the time of the death and in general following the death due to COVID 19 restrictions. However, the survey also found that participants often did not seek formal support from a professional or support service, which is consistent with prior literature that highlights the fact that informal support is commonly used and sought by the bereaved. The survey highlighted that members of the Irish community sought ways to extend their support to those in their communities who were bereaved. This is aligned with the literature, which also found that bereaved individuals reported positive bereavement support from their community, family, and friends during the pandemic despite restriction measures, including extending support via telecommunication, and moving in with a relative after a family loss.

Despite communities finding new ways of providing support to bereaved individuals, the grieving process was incredibly challenging and bereaved participants reported feelings of loneliness and difficulty sourcing help through their GPs in the qualitative data. Similarly, Harrop et al. (2021) found that bereaved participants reported difficulty in getting appointments with their GP, a lack of support from their GP, and feelings of isolation due to restrictions on socialization. A recently published Irish survey of the impact of COVID-19 on bereavement care in Ireland (Roberts et al. 2021) highlighted that almost half of bereavement service worker participants reported an increase in demand for bereavement support services and many reported more complex needs among service users.

Impact of COVID-19 on Healthcare Workers

Consistent with the literature, this survey showed that healthcare workers were greatly impacted by their traumatic experiences during the pandemic, evidently suggesting that support should be in place for healthcare workers, as they cope in the aftermath. Other research that explored healthcare workers' mental health during the pandemic found that those who experienced burnout or had high compassion satisfaction[1] were more likely to experience secondary traumatic stress (Yu et al., 2022). Possible explanations for this could be that healthcare workers had to quickly adapt to very demanding workloads, constantly changing information, new working procedures, insecure employment, and the very real threat of putting themselves and their loved ones at risk of contracting COVID-19 (Smallwood and Willis, 2021).

However, this survey showed that healthcare workers exhibited statistically significant higher mean scores of self-reported general health and mental health and higher financial wellbeing scores compared to non-healthcare workers. In addition, healthcare workers showed lower incidences of sub-threshold PGD and PGD scores and higher incidences of non PGD scores compared to non-healthcare workers. This suggests a resilience and protective component to PGD for healthcare workers compared to non-healthcare workers, despite a high proportion of healthcare workers experiencing a bereavement during the pandemic.

Nonetheless, there is a need to ensure that sufficient supports are in place for healthcare workers who have endured traumatic experiences during COVID-19 and are under ever increasing demands in the current healthcare climate. This is emphasized in the literature (Williams et al. 2022) and recommendations to address the grief experience of healthcare workers included:

- Educators should provide education related to self-care, resilience, and grief management strategies.
- Healthcare systems should develop interventions to help staff prepare for loss and support them in their grief over the deaths of patients and co-workers from COVID-19.
- Healthcare systems should provide opportunities for staff on the frontlines to take a brief and simple pause after hearing about or witnessing a patient's death to mourn the loss and invest in grief support resources for staff.
- Regular debriefing sessions should be provided for staff to enable them to reflect on their experiences caring for individuals diagnosed with COVID-19, which may assist in processing their grief.
- Healthcare systems should implement occupational safety precautions which is critical in preventing long-term disability of workers affected by COVID-19.
- Public health officials should ensure the continuity of spiritual and religious activities as well as social support for patients and their families during the pandemic and provide training for healthcare staff on this topic.

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[1] *Compassion satisfaction is defined as the pleasure one derives from being able to do one's work well*

Recommendations

Based on the findings of the literature review and the 'Time to Reflect' Survey, recommendations are made in the following areas:

1. Health System Measures to Enhance Bereavement Support
2. Health Policy
3. Future Research

Health System Measures to Enhance Bereavement Support

Considering that this research highlighted the need to address poor access to bereavement support services, high levels of stress among healthcare workers, and insufficient choice regarding personal health decisions, some potential solutions/recommendations are identified in Table 30.

Issue	Recommendation(s)
Traumatic experience for bereaved persons	❖ Facilitate supportive communication that meets the needs of the dying person and their family ❖ Enable continual family visiting in healthcare settings where possible ❖ Provide opportunities to family members to say goodbye to their loved one ❖ Ensure that family members can say goodbye after a death by means of funerals and rituals
Limited access to bereavement support	❖ Equip health services with additional bereavement support services that can be made available to patients and families ❖ Provide training to healthcare workers on social emotional skills to support bereaved families ❖ Expand or establish online and face-to-face bereavement support groups, particularly across rural communities
Traumatic experience for healthcare workers	❖ Ensure that healthcare workers can freely access wellness programmes and counselling ❖ Provide healthcare workers with opportunities and space to debrief and process their emotions and grief related to their work with the bereaved ❖ Provide regular debriefing opportunities to healthcare workers and opportunities to take a brief pause at work when they experience a patient death – this will enable them to reflect on the experience, mourn the loss, and better process their grief
Lack of choice regarding personal health decisions	❖ Advocate for the importance of discussing preferences for health treatment with patients and families early in the onset of illness ❖ Expand continuing education for healthcare professionals to cover dialogues regarding dying, death, bereavement and spiritual wellbeing among patients and their families

Health Policy and Practice

The findings of this report are beneficial for public health practitioners, healthcare workers, family carers, policymakers, and the general public. The literature review highlighted that there is concern globally regarding the detrimental impact of COVID-19 on the grieving process and the provision of bereavement support, particularly considering the public health measures and restrictions placed on society during the pandemic. Several authors have indicated that there is likely to be long-standing consequences on dying, death, and bereavement due to the profound loss of human life, and that the increase in pathological grief will become a worldwide public health concern, calling it a silent epidemic of grief (Eisma et al. 2021, Eisma and Tamminga 2022, Pearce et al. 2021). Others have suggested that the impact may not be as extensive as originally anticipated (Lenferink and Boelen 2023).

There is consensus regarding the need for continued research on the topic and close monitoring of people who have been bereaved to identify those most at-risk of developing prolonged grief disorders or other complications, and to intervene early. Screening and early intervention for those experiencing prolonged grief disorders or complicated grief should be incorporated into health policy and practices. Other recommendations from the literature include the need to find innovative ways for healthcare workers to connect with and support bereaved persons during a public health crisis (Helton et al. 2020) and the need to ensure continuity of spiritual and religious activities, as well as social support for patients and their families during a public health crisis.

These recommendations from the literature were further supported by the survey findings in which participants emphasised the need to grieve properly, which required access to support, the ability to attend traditional funerals, and the opportunity to say goodbye. The survey findings give insights into perspectives and experiences of dying, death, and bereavement during COVID-19, which can be used to facilitate open conversations on the topic. Furthermore, understanding the end-of-life care experiences of individuals as reported by their loved ones can highlight any gaps in the healthcare system that need more attention. The results of this report can be used to inform future public health responses to similar scenarios.

Future Research

There is consensus in the literature that further research on the long-term impacts of COVID-19 is warranted and this research should include large population-based samples, as well as studies that focus on specialised groups (e.g., older adults, children, and young people). Further research monitoring the severity of grief amongst different groups, in particular those in Ireland who were at the sub threshold of prolonged grief disorder would also be beneficial to inform public health responses and practices to support those at-risk. More studies that explore the impact on healthcare workers is also warranted to help identify coping strategies and necessary supports for healthcare workers and workplaces in the event of future global health crises.

Limitations

The survey was cross-sectional in nature and collected data among participants at one point in time. Therefore, a cohort study that follows participants over a period of time may yield different findings because views and perceptions may change. The study had limited representation of younger age groups, male participants, and non-Irish ethnic background residing in Ireland. Future research with diverse populations is warranted. Another limitation of the study was the sensitive nature of the survey questions relating to dying, death, and bereavement. This may have impacted the missing data throughout the survey responses.

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Appendix 1 - Scoping Review of the Literature (Phase 1)

The aim was to conduct a scoping review of academic and grey literature to gather up-to-date information on the number of deaths, impact on grief and bereavement, lockdown measures and other public measures during the pandemic.

Research Questions

The review questions were as follows:

1. What impact did COVID-19 have on grieving and bereavement?
2. How did public lockdown and isolation measures impact on grief and bereavement care?

Search Methods

A scoping review of the literature was conducted using the following electronic database:

- **PubMed**: this database comprises more than 34 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full text content from PubMed Central and publisher web sites.

Search Terms and Selection Criteria

A combination of the following key search terms was used: bereavement, grief, pandemic, funerals, rituals, impact, lockdown, and public health measures. Boolean operators (e.g., AND, IF, NOT) were used to broaden or narrow the search. The search was limited by publication year (2020-2023) and language (English).

The search strategy was built around the following key search concepts / strings:

- Concept 1 = Bereavement
- Concept 2 = COVID-19

An overview of the key search terms used is provided in Table 31 **Error! Reference source not found.**below:

Table 31. Search Concepts / Strings		
Concept 1	Bereavement	Bereavement OR grief OR death OR dying
Concept 2	COVID-19	COVID-19 OR “coronavirus pandemic” OR pandemic

The search concepts were combined as follows:

- Concept 1 AND 2

The PICO framework was used to guide inclusion / exclusion criteria (see Table 32).

Table 32. PICO Framework Guiding the Selection Criteria	
Population	**All**
Intervention	Bereavement support and care
Comparator	N/A
Outcomes	Impact of pandemic

Search Results

Searches in the academic databases resulted in 145 included articles. An overview of the search process and results is provided in the PRISMA flow diagram in **Error! Reference source not found.** below. A summary analysis was conducted on the 145 total included papers and a more in-depth analysis was conducted on the subset of 32 papers that pertained specifically to survey research.

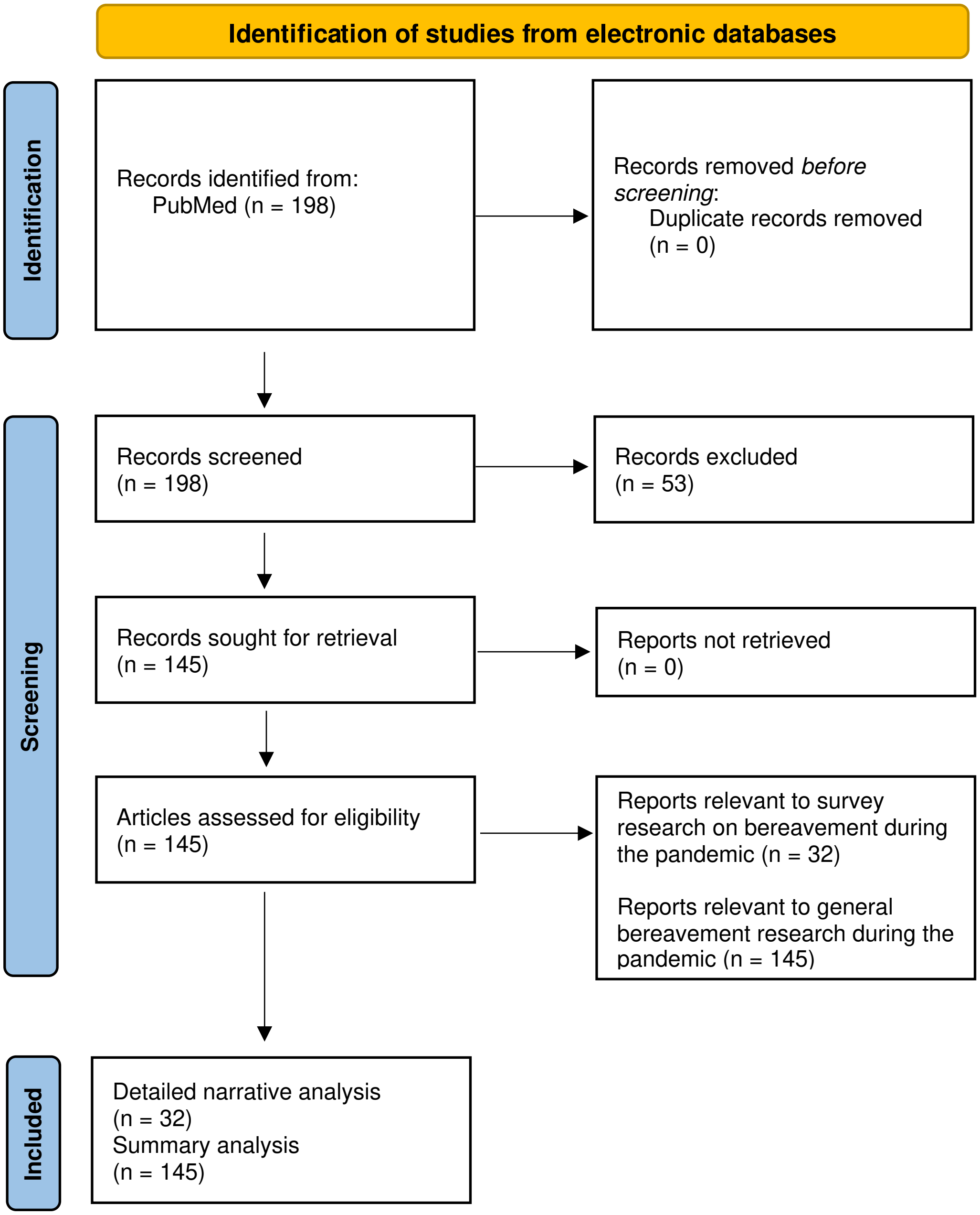

FIGURE 8 PRISMA FLOW DIAGRAM

Two key themes emerged from the literature review as follows:

- Exponential increase in global interest in the impact of COVID-19 on grief and bereavement
- Findings from survey research exploring impact of COVID-19 on dying, death, and bereavement

Exponential Increase in Global Interest in the Impact of COVID-19 on Grief and Bereavement

A total of 145 papers were sourced in this review that focused on the impact of COVID-19 on grief and bereavement globally. The volume of publications is reflective of the increased focus and interest in this topic. Figure 1 below provides an overview of the number of publications per year. The number of publications doubled from 2020 to 2021 with a similar number published in 2022.

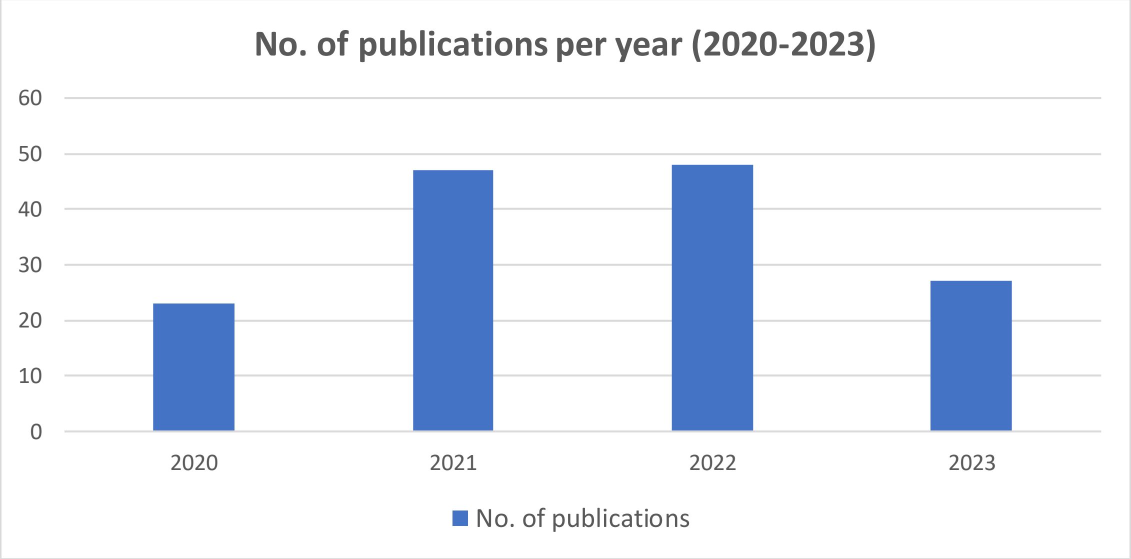

FIGURE 1 PUBLICATIONS FOCUSED ON GRIEF AND BEREAVEMENT DURING COVID-19 (2020-2023)

This prior research was conducted in many countries, which emphasizes the global impact of COVID-19 and the similar experiences of individuals all over the world, due to restrictions placed on healthcare and bereavement support services. Figure 22 below presents a heat map, which illustrates in which countries most of the prior research was conducted.

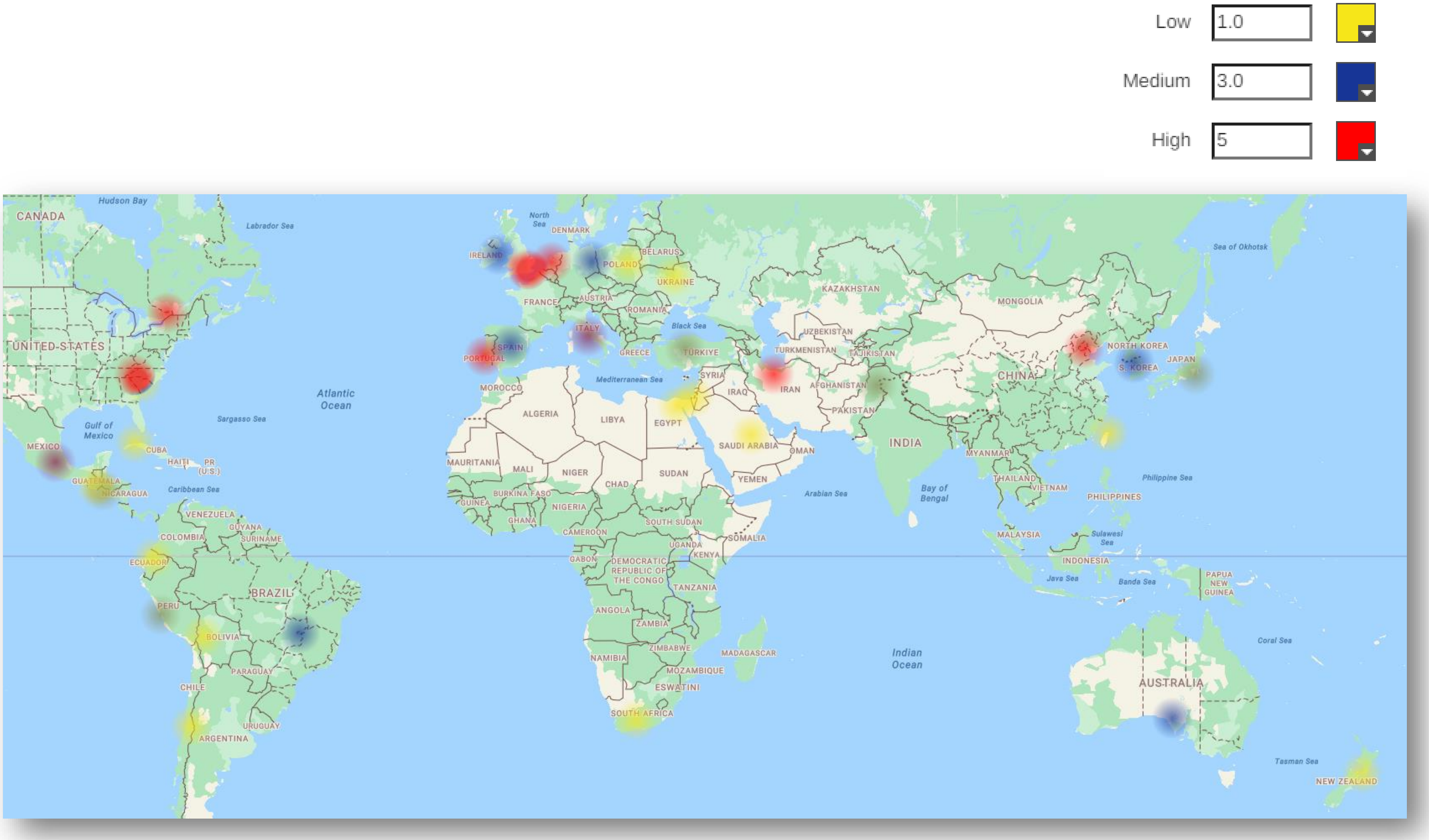

Figure 2 Countries Where Studies Were Conducted on the Impact of COVID-19 on Grief and Bereavement

In terms of research design, the studies utilized a range of study designs. The most common design used was a quantitative survey or cross-sectional design. The second most common type of papers were literature review or discussion papers, which synopsized the impact of COVID-19 and cautioned about long-term psychosocial impacts of restrictions during the pandemic. The remainder of the studies were mostly qualitative and there were 5 randomized controlled trials (RCTs) conducted. See Figure 3 below for a summary of study designs.

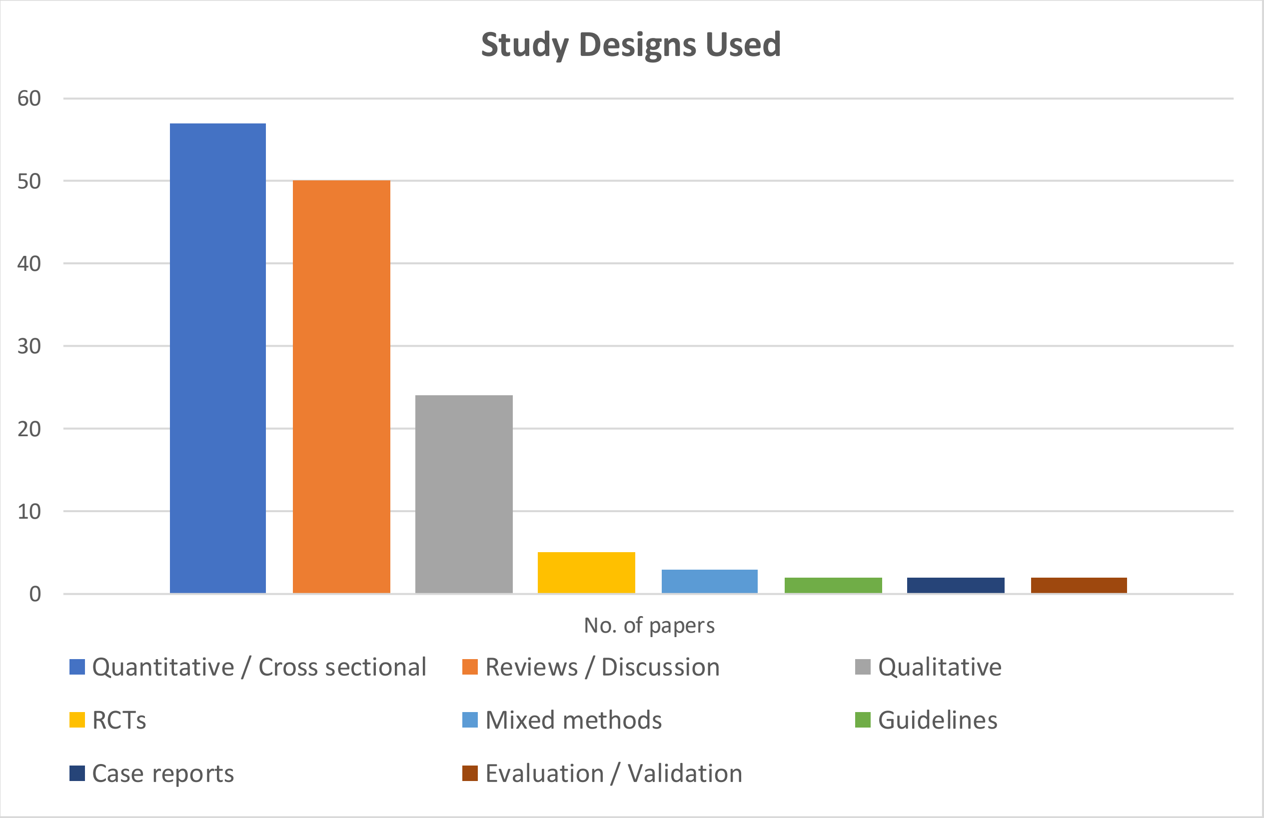

FIGURE 3 OVERVIEW OF DESIGN / METHODOLOGY OF INCLUDED STUDIES

A range of populations were included in prior research examining the impact of COVID-19 on dying, death, and bereavement. A total of 84,097 participants were included across all studies. Most of the studies recruited bereaved family members who lost a loved one during the pandemic (N=19,779) apart from one population study that recruited a large sample of older adults (51,383). An overview of the included samples is provided in Figure 4 below.

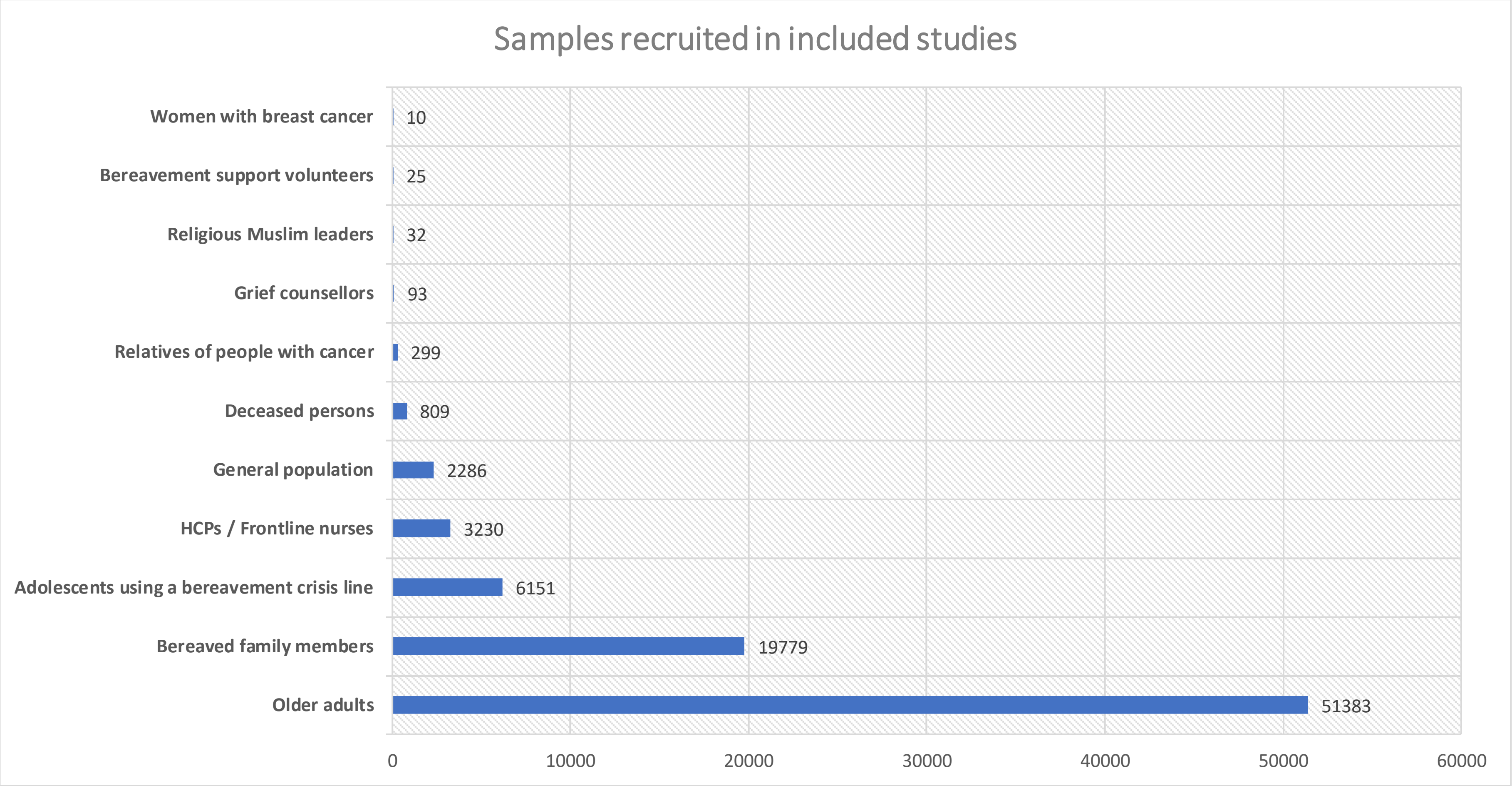

Figure 4 Overview of Samples in Included Studies

Summary

In summary, there has been an exponential increase in the number of studies focused on the impact of COVID-19 on grief and bereavement. Most of these prior studies have taken place in Europe, the USA, Canada, Iran, and China. A variety of research designs have been used but most studies have been quantitative or review / discussion papers. Almost all the studies recruited individuals who had lost a family member during COVID-19. It can be concluded from this summary analysis that there is concern on a global level regarding the detrimental impacts of COVID-19 on the grieving process and the provision of bereavement support, particularly considering the public health measures and restrictions placed upon societies globally. The next section presents further details on the findings of prior survey research that examined the impact of COVID-19 on grief and bereavement.

Findings of Survey Research Exploring Impact of COVID-19 on Grief and Bereavement

A total of 32 survey studies were sourced that explored the impact of COVID-19 on grief and bereavement. The studies are presented according to the following themes and sub-themes with key findings highlighted under each theme:

- Impact on Bereaved Individuals
    - Grief Experience and Response
    - Severity of Grief
    - Risk Factors for Prolonged Grief Disorder / Complicated Grief
    - Bereavement Support
    - Children and Young People
    - Older Adults
- Impact on Healthcare Workers and Patient Care
    - Grief Experience and Response
    - Challenges to Providing Care
- Reliability and Validity Studies of Measures of Healthcare Related Grief
    - Grief Support in Healthcare Scale (GSHCS)
    - Pandemic Grief Scale (PGS)

Impact on Bereaved Individuals

Grief Experience and Response

In the USA, Helton et al. (2020) examined the ways in which COVID-19 affected the bereavement experiences of parents whose children died of cancer before the pandemic (N=15) using a qualitative design with semi-structured interviews. Parents who had previously participated in a survey-based study on the early grief experience of parents of children who died of cancer were invited to complete the interviews. The interviews focused on examining the current support for parents and other family members within the first several years after the child's death, and participants were asked how COVID-19 had impacted their life and bereavement. Fifteen of 33 eligible parents completed the interview; 14 were white and non-Hispanic, five were males. COVID-19 was addressed in 13 interviews, in which parents identified multiple and variable ways that COVID-19 had affected their bereavement experience. Many parents reported feeling more isolated because of the inability to connect with family or attend in-person support groups, whereas others acknowledged their experience had made them uniquely positioned to cope with the uncertainty of the current situation. Clinicians must find innovative ways to connect with and support bereaved parents during challenging times of a public health crisis.

Similarly, in the UK, Torrens-Burton et al. (2022) described the experiences of people bereaved during the COVID-19 pandemic and generated a rich understanding of the challenges they faced. Qualitative data from two independent nationwide online surveys to describe the experiences of people bereaved during the pandemic (N=881) were analyzed. Six main themes were identified: troubled deaths; mourning, memorialization, and death administration;

mass bereavement, the media, and the ongoing threat of the pandemic; grieving and coping; work and employment; and support from the health and social care system. The authors concluded that the findings demonstrated the profound and far-reaching impact the pandemic had on the lives of people who have been bereaved. Several recommendations were made for improving the experiences of people bereaved during the pandemic and for any future pandemics. The recommendations included reducing trauma associated with death experiences by improving communication with and involvement of families, and safe facilitation of family visiting in healthcare settings, where possible. Strengthening the bereavement support sector was also highlighted by the provision of greater resourcing and expansion of national support, regional services in areas with long waiting lists and strategies to improve awareness of bereavement support options. Furthermore, it was recommended that best practice recommendations are developed, promoted, and adhered to in terms of funeral options during times of social restrictions and that opportunities are providing for remembrances, greater respect, and listening to the bereaved. The authors further concluded that this would require media recognition of the dehumanizing effects of death statistics; the need to give voice to stories of the bereaved and provide more supportive narratives; and inclusive consultation with those recently bereaved to ensure lessons are learned for future pandemics.

Similar findings were noted in a study in India that evaluated the impact of COVID-19 on grief, death, mourning, and coping in the Kashmiri population (Majid et al. 2022). A purposive sample of 89 people from district Bandipora and Srinagar of Kashmir were included. Of the 89 participants, 37 participants had lost a family member to COVID-19, while 52 participants lost a family member due to reasons other than COVID-19 infection. Participants with a family member who died from COVID-19 infection had significantly higher pandemic grief levels (M=10.00, SD=5.08) compared with participants whose family member died of other causes (M=3.75, SD=3.11) ($p<0.001$). Male participants were also found to have significantly higher levels of pandemic grief (M=7.44, SD=5.59) than female participants (M=4.59, SD=3.51) ($p<0.001$). Qualitative findings revealed that most participants (N=71), whose loved one died from COVID-19 were not able to visit family to offer condolence or attend the funeral due to the restrictions on public gathering (mourning) and the majority (N=78) were not given the chance to meet their loved ones who were dying. This affected the mental well-being of most participants who were bothered by the fact that their loved one died alone, and who also felt guilty that they were not able to take care of their loved ones when they needed them most. Restrictions on performing the religious-cultural rituals at the time of death also affected the participants. The authors concluded that the findings emphasized the importance of social support for those who are grieving and the need for in-person interactions, which can never be replaced by telephone or virtual communication.

In the USA, Grace (2021) examined how COVID-19 bereavement was associated with depressive symptoms and binge drinking in a sample recruited using a quota-based approach to approximate the racial-ethnic, sex, income, and educational composition of the American population based on U.S. Census Bureau estimates (N=2000). The study also explored how the loss of a close tie to COVID-19 affects mental health, particularly among essential workers. Results showed that even after adjustment for non-random exposure to COVID-19 bereavement, the loss of a loved one to COVID-19 was still robustly associated with depressive symptoms and binge drinking. Furthermore, the strength of these relationships varied across different segments of society, as the associations between COVID-19 bereavement and depressive symptoms and binge drinking were accentuated among essential workers relative to other respondents. The author concluded that profound loss of human life due to COVID-19 will have consequences for mental health that reverberate for years to come and stated that it will be crucial to identify those most at-risk for developing prolonged grief and substance use disorders, and to dedicate sufficient resources to assisting these individuals as they navigate the grieving process.

Another study in the UK sought to investigate whether the removal of psychosocial and formal support had an adverse effect upon the mental health and well-being of bereaved persons – Donovan et al. (2023) explored the impact of COVID-19 and lockdown on people who have experienced sudden bereavement because of an epilepsy-related death using an online, qualitative, and quantitative survey. People who had experienced an epilepsy-related death between 1980-2020 were recruited (N=275). A total of 84% of participants reported a bereavement following a sudden death of a person aged under 40, with 22% aged 19 and under. Most participants (77%) reported they had been thinking more about the person who died compared to before the COVID-19 outbreak and 54% had experienced more distressing flashbacks to the time of death. Additionally, 61% reported more difficulties falling asleep and staying asleep and 88% of participants reported that the outbreak and response measures had negatively impacted their mental health. A third of participants (33%) were taking medication for a diagnosed mental health condition at the time of the study. Four main themes emerged from the qualitative data that captured the negative experiences of COVID-19: 'Family', 'Lifestyle', 'Personal Well-being' and 'Health Services and Shielding Populations'. The 'Personal Well-being' theme was inextricably linked to grief symptoms including 'reflection on the death', 're-exposure to feeling', 'grief', 'salience of sudden deaths in the media' and 'inability to commemorate anniversaries and rituals'. The authors concluded that the study highlighted the impact of the disruption caused by the pandemic on the grief management of those bereaved by epilepsy-related death. Furthermore, the authors proposed that grief is not static, and its management is connected to the psychosocial and formal support structures that were disrupted during the pandemic. The removal of these supports had an adverse effect upon the mental health and well-being of many bereaved.

Severity of Grief

In the UK, Selman et al. (2022) determined the factors associated with higher levels of grief and support needs among people bereaved during COVID-19 (N=711). An open web survey design was disseminated via social and mainstream media, voluntary sector associations and bereavement support organizations, including organizations representing ethnic minority communities. Participants were mostly female (N=628, 88.6%) and the average age was 49.5 years (SD=12.9). A total of 311 deaths (43.8%) were from confirmed or suspected COVID-19 and the mean age of deceased persons was 72.2 years (SD=16.1). Almost 30% of participants (N=197) exhibited severe vulnerability. Grief and support needs were significantly higher for those with closer relationships to the deceased vs those who had more distant relationships ($p<0.001$). Grief and support needs were also significantly higher for those with reported social isolation and loneliness ($p<0.001$). Other factors associated with significantly higher grief and support needs were place of death ($p<0.05$) and health professional support post-death ($p<0.05$). The three most common grief and support needs were:

- Dealing with my feelings about the way my loved one died (60%)
- Expressing my feelings and feeling understood by others (53%)
- Feelings of anxiety and depression (53%)

Restricted funeral arrangements were also found to result in higher levels of grief and support needs. Interestingly, other pandemic-related problems such as being unable to visit, spend time with or say goodbye to a friend or relative prior to their death were found to generally have a small effect on levels of grief and perceived support needs. Cause of death was found to have some effect on levels of grief and perceived support needs with participants whose relative died from COVID-19 reporting slightly higher grief and support needs than those whose relative died from non-COVID-19 circumstances. The authors concluded that the levels of grief observed in this sample were higher than pre-pandemic studies and this may be due to stressors universally experienced during the pandemic. Several recommendations were made including the need for further investment in statutory, voluntary, and community bereavement support services, and the need for compassionate community-based initiatives in bereavement to strengthen, support, and learn from communities' own approaches to informal bereavement support. Furthermore, it was recommended that future restrictions on funerals and other group mourning social practices must be considered carefully. The quality of care and support provided to bereaved people immediately after a death must be prioritized and adequately resourced across care settings in the pandemic context.

In the USA, Breen et al. (2022) examined whether dysfunctional grief symptoms, disrupted meaning, risk factors, and functional impairment differ between people bereaved from COVID-19 and from other natural or violent causes during COVID-19. The study also investigated the mediating role of disrupted meaning in the relationship between risk factors and functional impairment and dysfunctional grief symptoms. A sample of 409 participants (67.73% male;

M = 37.54 years) completed an online survey in June 2021. There were no statistically significant differences between the three groups on any of the outcome variables; all three groups manifested clinical levels of functional impairment equal to or greater than bereaved groups diagnosed with complicated or prolonged grief disorder prior to the pandemic. Disrupted meaning partially mediated the relationship between risk factors on the one hand and functional impairment and dysfunctional grief symptoms on the other. Findings indicated that deaths *during* COVID-19, rather than deaths *from* COVID-19, may precipitate symptoms of significant clinical concern.

Edwards et al. (2023) conducted a prospective survey among community hospital next-of-kin (N=123) to evaluate the effects of COVID-19 on grief. Severity of grief was measured using PG-13-R among those bereaved during the pandemic and compared to pre-pandemic controls. Grief severity and demographics were compared across three periods based on the time of relatives' death: pre-pandemic (November 2019-March 2020), early pandemic (March 2020-June 2020), and mid-pandemic (July 2020-October 2020). No statistical differences were noted in unadjusted PG-13-R score, individual PG-13-R questions, and demographic characteristics across the three periods. In adjusted analyses, COVID-19-related death was associated with an increased PG-13-R score while hospice use was associated with a decline in the PG-13-R score. The authors concluded that COVID-19-related deaths may lead to a higher risk for PGD, consistent with COVID-19 grief studies globally.

Extensive research on grief severity and reactions has been conducted in the Netherlands. One study by Eisma and Tamminga (2020) examined grief reactions to non-COVID-19 deaths during the pandemic using a large cross-sectional survey design with a sample of bereaved adults in the Netherlands (N=1600). The study aimed to test two hypotheses: (i) reported grief levels would be higher during the pandemic than before it; and (ii) experiencing a recent loss during the pandemic would elicit more severe grief reactions than experiencing a recent loss before the pandemic. Most participants were female (78%) and the mean age of participants was 45.26 years. Over 45% of participants (N=731) had experienced a loss before the pandemic, and 54% of participants (N=869) had experienced a loss during the pandemic. Results showed that grief severity was not significantly different during the pandemic compared to before the pandemic among all bereaved persons. Individuals who experienced a recent loss during the pandemic had higher levels of grief severity compared to those who experienced a recent loss before the pandemic. The difference in grief severity between those who experienced a recent loss during the pandemic and those who experienced a recent loss before the pandemic remained significant even after controlling for relevant loss-related variables. Time since loss was the only variable that differed between the groups, but it did not explain the group differences in grief severity. The study suggests that the pandemic had a small but robust negative effect on psychological adjustment after non-COVID-19-related deaths during the pandemic. The researchers predicted that the more severe acute grief responses during the pandemic may eventually lead to a higher prevalence of PGD and persistent complex bereavement disorder (PCBD) in the general bereaved population.

Another study by Eisma and Tamminga (2022) examined acute grief reactions in people bereaved due to COVID-19 (N=99) and compared them with grief among people who have experienced unnatural (N=161) and natural loss (N=1006). Results showed that COVID-19 deaths were more often parental deaths and less often child deaths (compared with other deaths). COVID-19 deaths were also more often unexpected and characterized by an inability to say goodbye appropriately. Additionally, results showed that COVID-19 deaths yielded higher grief levels than natural deaths, but not unnatural deaths. This is aligned with findings from another study by Eisma et al. (2021), which compared grief levels among people recently bereaved due to COVID-19 (N=49), natural loss (N=1182), and unnatural loss (N=210). Results also showed that people who experienced COVID-19-related bereavement reported more severe grief than people who experienced natural losses, but the grief response was similar to people who experienced an unnatural loss. Furthermore, results of Eisma et al. (2021) reported that COVID-19 bereavement yielded higher symptom levels of PGD, and persistent complex bereavement disorder (PCBD) compared to natural bereavement, but not unnatural bereavement. The expectedness of the death was found to explain this effect i.e., higher grief levels among people bereaved due to COVID-19 compared to natural loss. Eisma et al. (2021) concluded that pandemic-related increases in pathological grief will become a worldwide public health concern. Meanwhile, Eisma and Tamminga (2022) concluded that improving opportunities to say goodbye before and after death (e.g., by means of rituals) may provide an important means of preventing and reducing severe grief following COVID-19 deaths.

A more recent study in the Netherlands by Lenferink and Boelen (2023) used the Traumatic Grief Inventory-Self Report to compare PGD severity among people who experienced the death of a loved one during the pandemic from a natural cause (e.g., illness; N=1036), COVID-19 (N=76), or unnatural cause (e.g., accidents, suicides, homicides; N=271). Approximately two-thirds of participants scored above the cut-off for acute probable PGD, and higher acute PGD-severity was found in people after unnatural loss compared with COVID-19 (p=0.005) or natural loss (p<0.001), when controlling for differences in groups in terms of gender, age, and time since loss. However, these differences were small in terms of effect sizes. PGD levels did not differ between the three groups for people who lost their loved one ≥ 12 months earlier (N=380). The authors concluded that these findings are aligned with some prior studies (e.g., Edwards et al. 2022, Breen et al. 2022) but seem to contradict prior Dutch findings from Eisma et al. Lenfering and Boelen (2023) suggest that the differences relate to the recruitment period for the studies i.e., they recruited people somewhat later than the start of the pandemic during a time when the conditions that would make COVID-19 deaths difficult to cope with were less of an issue. Nonetheless, Lenferink and Boelen (2023) proposed that the present study suggests that the consequences of COVID-19 deaths may not be as alarming as initially predicted. However, they caution that further scrutiny is needed to truly understand the impact.

Risk Factors for Prolonged Grief Disorder / Complicated Grief

In China, Chen and Tang (2021) used latent profile analysis (LPA) to identify heterogeneous profiles of prolonged grief, post-traumatic stress, and post-traumatic growth among people bereaved due to COVID-19 (N=422). An online survey was conducted between September and October 2020 and participants were recruited through social network websites and mobile applications. Four latent profiles were identified: resilience (10.7%), growth (20.1%), moderate combined (42.2%) and high-combined (27.0%). The bereaved who shared a close relationship with the deceased and identified COVID-19 as the fundamental cause of death were more likely to be in the high-combined group. A conflictful bereaved-deceased relationship reduced the chance of being in the growth group. Moreover, the death of a younger person and loss of a partner attributed to maladaptive outcomes. The authors concluded that attention needs to be paid to the mental health issues of people bereaved due to COVID-19 because nearly 70% of this group would have a moderate combined or high-combined symptom profile. Special care should be given to those who lost someone younger, lost a partner or shared a close relationship with the deceased. The authors also proposed that grief therapies that work on the conflicts between the deceased and the bereaved and unfinished business should be applied to facilitate growth.

Using the same dataset, Tang and Xiang (2021) estimated the prevalence of PGD and investigated demographic and loss-related factors associated with PGD symptoms among Chinese individuals bereaved due to COVID-19 (N=422). The goal was to identify individuals at a higher risk of developing PGD and to provide early bereavement support. Participants who had lost their partner consisted of 32.9% of the sample, followed by those who lost a parent (23.0%), a grandparent (16.4%), and a friend (15.2%). Results showed that prevalence of PGD was 37.8% when screened by the International Prolonged Grief Disorder Scale (IPGDS) and 29.3% when screened by the Traumatic Grief Inventory Self Report (TGI-SR). More severe PGD symptoms were associated with losing a person due to COVID-19, losing a partner, child, or parent, feeling more traumatized about the loss, and being closer with the deceased. Also, losing a grandparent and having more conflicts with the deceased were related to higher levels of grief symptoms. The authors concluded that the prevalence of PGD is high among individuals bereaved due to COVID-19 and it is important to recognize that the pandemic has changed the perception of death and the grieving process for bereaved individuals. It is further recommended that practitioners monitor for signs of PGD and intervene early.

In a related study by Tang et al. (2021), results showed that almost half of participants (49%) scored above the clinical cut-off for PGD symptoms and about one-fifth of participants had clinically relevant posttraumatic stress disorder (PTSD) symptoms. Approximately 70% of the participants reported clinically relevant symptoms of anxiety and 65%

of participants reported clinically relevant symptoms of depression. Factors such as gender, time since loss, relationship with the deceased, feeling traumatized by the loss, closeness with the deceased, and conflict with the deceased, impacted mental health outcomes. Shorter time since loss was related to higher anxiety and depressive symptoms. The authors concluded that many Chinese adults who have been bereaved due to COVID-19 experience severe mental health problems, including prolonged grief, posttraumatic stress, anxiety, and depressive symptoms. These individuals may require psychological treatment, which should be provided as early as possible. The authors also highlighted the benefits of remotely delivered grief interventions for individuals experiencing severe loss-related mental health problems.

In Italy, Bovero et al. (2021) investigated factors associated with the development of complicated grief (CG) in a sample of caregivers who had lost a loved one at least six months beforehand due to COVID-19 (N=31). All deceased individuals in question had died whilst hospitalized in Molinette Hospital (City of Health and Science, Turin, Italy) during the first wave of COVID-19 (March to May 2020). Results showed that 48.4% of caregivers experienced CG after the death of their loved ones and the presence of CG was significantly associated with marital and cohabitant status during lockdown, perceived sense of guilt, and depression levels. Attendance at the funeral and social support were found to be significant protective factors against CG. Being single or widowed was associated with a significantly higher risk of developing CG compared to being married or cohabiting. Living during lockdown with one's partner or with one's child/children only was associated with a higher risk of experiencing CG compared to living with both partner and child/children. Perceived social support was a protective factor, with a risk reduction of 44% for each 1-point increase on the social support scale. The authors concluded that concern over the high transmissibility of the virus resulted in exceptional measures being imposed to limit infections, which may have increased the risk of bereaved people having trouble processing grief normally or developing CG. Furthermore, all patients in the sample died in hospitals, meaning that their family caregivers could not be present during their last moments or see their body in person following death. The lack of traditional rituals to say goodbye, honour the dead, and comfort mourners, such as holding funerals or attending end of life ceremonies, during the pandemic's first wave in Italy may have affected the grieving process. The authors further concluded that it is important for the global community to discover new ways of coping with loss and developing new possibilities for patients and caregivers to stay connected to support the grieving process during times of crises.

In the USA, Schneider et al. (2023) investigated the risk factors for pandemic grief and prolonged grief disorder (PGD) in bereaved young adults (N=196) who had a family member or close friend die during the pandemic. Data were collected with the Prolonged Grief Disorder-12 Questionnaire and the Pandemic Grief Risk Factors Questionnaire. Results showed that participants who spent more time with the deceased person before the loss, and who exhibited more of the pandemic grief risk factors, had a significantly higher risk of meeting the diagnostic criteria for PGD ($p<0.001$). Results also showed that non-White participants had significantly higher PGD scores than the White group ($p=0.02$). The authors concluded that the pandemic created unique risk factors that affected the grieving process for bereaved individuals, regardless of whether the death was related to COVID-19 infection. It was also concluded that there may be long-term detrimental psychological outcomes for bereaved individuals, regardless of the cause of death. Routine screening is recommended to help identify those who may benefit from early intervention. Furthermore, it is suggested that current interventions and preventions programs may need to be modified to directly address the unique pandemic grief risk factors.

Lobos-Rivera et al. (2023) examined the dysfunctional grief associated with COVID-19 death among Salvadoran adults who had lost a family member or loved one to COVID-19 (N=435). An exploratory cross-sectional design was used, and an online survey was used to collect data. Participants were mostly female (N=268, 61.5%) and had an average age of 29 years old (SD=8.75). Most participants had not been diagnosed with COVID-19 (N=210, 48.3%), resided in an urban area (N=338, 77.7%), and did not suffer from a chronic disease (N=377, 86.7%). Results from the Pandemic Grief Scale showed that:

- 33.1% stated that nothing seemed to matter to them because of the loss.
- 32.9% experienced confusion about their role in life or felt like their identity was diminished due to the loss.

- 29.4% found it difficult to have positive memories of the deceased person.
- 27.6% believed that without the deceased person, life was meaningless or could not continue.
- 18.4% of participants expressed a desire to die in order to be with the deceased person.

Results also revealed that 35.1% of Salvadorans who lost a family member or loved one to COVID-19 reported clinically elevated symptoms of dysfunctional grief and 25.1% of the sample exhibited clinically relevant symptoms of coronavirus-related anxiety, which is similar to what has been reported in the USA (31.2%; Lee et al., 2020) and Mexico (30.3%; Mora-Magana et al., 2022). The authors concluded that the findings confirm that many bereaved Salvadorans are suffering from the disabling effects of both dysfunctional grief and anxiety, and that mental health providers working with the bereaved may need to develop intervention plans that consider a wide range of psychological problems, such as coronavirus-related anxiety, in addition to pandemic grief.

Bereavement Support

Pearce et al. (2021) conducted a survey of bereavement care provision in the UK and Ireland[2] during COVID-19. A descriptive cross-sectional online survey design was used with a sample of people working in hospice, community, and hospital settings across the UK and Ireland (N=805). In terms of major changes to the provision of bereavement care, results showed that 90% of participants (N=904) had to use telephone, video, or other forms of remote support. Practitioners also reported changes in skills required to support people bereaved by non-COVID-19 conditions (N=586, 76%) and COVID-19 (N=500, 65%). Support for people bereaved before the pandemic also experienced significant change (N=468, 61%) as many bereavement services had been suspended and / or shifted to online or telephone formats. Participants frequently reported the impact of restrictions on funeral arrangements (N=446, 61%) and reduced opportunities for in-person interaction also produced difficulties when identifying bereaved people who might need support (N=437, 56%). Less changes in managing complex forms of grief (N=356, 48%) and access to specialist services (N=301, 41%) were reported; however, many were unsure of changes in these areas. Analysis of free-text responses revealed three themes: impact on services, impact on clinicians and relationships with patients, and impact on bereaved people. In terms of services, findings showed that waiting lists for bereavement support increased in some cases and this was due to the increase in deaths during the pandemic. Regarding the impact on clinicians and relationships with patients, emotional support was found to have been greatly disrupted. One palliative medicine doctor stated that:

> *"It has felt as though we are dealing with them at arm's length whereas we would be there to hold their hands, give them a hug as needed."*

In terms of the impact on bereaved people, many participants 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 on the grieving process. Family members were reported to feel guilty that they had not been able to be with the dying person and were denied the opportunity to say goodbye. They also reported feeling frustrated that they had been unable to ensure their loved one's wishes were respected at the end of life.

Restrictions around returning the deceased person's belongings and viewing the body, particularly for patients with COVID-19 and restricted funeral arrangements were reported to have caused significant distress and exacerbated feelings of unfairness. While those bereaved from COVID-19 and non-COVID-19 conditions were similarly affected by the restrictions, specific challenges related to COVID-19 were reported. Family members of people who died of COVID-19 felt like they had failed to protect their family member from COVID-19. The focus on COVID-19 deaths had adversely impacted on the bereavement experiences of those whose loved one had died of other conditions because they felt like their loss was not as important as those who lost someone to COVID-19. In some cases, funding was allocated only for those who had been bereaved by COVID-19, which was said to create inequality of service provision. The authors concluded that COVID-19 created major challenges to bereavement care provision and that the experience of bereavement is one of the long-term impacts of the pandemic, which if left unaddressed may lead

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[2] *Only 5 responses were received from practitioners in Ireland, which represents just 0.6% of the total sample.*

to significant physical and mental health morbidity and create a further burden on health and social care services. Therefore, it is imperative that bereavement support services become a high priority in the health policy agenda.

Bates et al. (2022) described the implementation and evaluation of a national bereavement helpline in response to COVID-19 in Ireland. The study sought to respond to a perceived gap in bereavement support that arose because of severe restrictions in social contact resulting from COVID-19 regulations. The rationale was that timely accessible support, by telephone, would lead to education about grief, normalization of responses, listening, and support to express grief, and signposting if necessary to other resources. A retrospective service evaluation of six months of the operation of the line was conducted using a volunteer survey, interviews, and line usage data. At the time of the survey, there were 17 volunteers; 86% were female, 14% male averaging 60 years old ranging from 41 to 73 years old. The survey response rate was 82% (15 responded, one participant completed only section one of the survey so valid responses were reported for 14). There were 691 calls recorded on Amazon Connect, and completed call data was available for 374 calls covering the period September 2020 to January 2021. There were 66 records of supervision sessions from June 2020 to January 2021. Each supervision session was documented and analyzed using a thematic analysis to extract themes. Results showed that the main themes of the calls were the impact of COVID-19, emotional pain, reduction in access to healthcare services, and enquiries from other professionals. COVID-19 restrictions on social contact and support prevented visits to hospitals and family presence at the time of death, resulting in increased emotional distress for callers. Callers were more emotionally distressed at the time of the call, possibly due to the limitations on funeral rites and the closure or reduction of mental health services. Approximately 10% of callers had urgent care needs and were advised to contact their general practitioner or mental health service. However, the authors cautioned that the data were collected early in the pandemic, and high rates of PGD may yet emerge. Volunteers reported being emotionally impacted by the calls they received, but overall, their role satisfaction was high, and most expressed an intention to continue volunteering. The authors concluded that the national bereavement support line provided a valuable service in addressing the needs of individuals experiencing grief and bereavement during COVID-19.

Children and Young People

Wiener et al. (2021) used a survey-based study to define the ways that the pandemic has impacted end-of-life care and the approach to bereavement care in paediatric palliative care (PPC) in the United States. Healthcare professionals providing PPC (N=207) from medical settings across 80 cities in the United States were asked to complete the study survey. Participants included physicians, nurses, child life specialists, social workers, chaplains, and psychologists. Results highlighted the impact on funeral services since the pandemic began with most families delaying life memorials until people can gather again, while some held teleconference funerals soon after a death. Bereavement support groups were also affected by the pandemic with over a third of participants never provided bereavement support groups. Of those who did, some were canceled, while others were provided online or by phone. Participants reported experiencing moral distress associated with the care provided during the pandemic. This distress was often related to an inability to provide a desired level of care to a loved one due to existing rules and policies, as well as bearing witness to patient and family suffering enhanced by the pandemic. Some participants also described moral uncertainty when struggling to determine the correct decisions for patient care. The authors concluded that the pandemic has had a profound impact on the provision of end-of-life care and bereavement for children, family caregivers, and paediatric palliative care providers. The authors further concluded that it is imperative that we find solutions for future global challenges, to ensure families do not suffer the added pain of a stunted grieving process.

Harrop et al. (2022) investigated the experiences and support needs of bereaved children and young people in the United Kingdom during COVID-19 from the perspective of their parents and guardians (N=104) using a cross-sectional qualitative design analysis of free-text results from the second round of a longitudinal survey. The goal was to identify the challenges and struggles faced by children and young people, as well as the support they received from family, schools, and services. Findings revealed three main themes: the pandemic-related challenges and struggles experienced by children and young people; family support and coping; and support from schools and services. Pandemic-related challenges included the impacts of being separated from the relative prior to their death, isolation from peers and other family members, and disruption to daily routines and wider support networks. Examples were given of effective family coping and communication, but also of difficulties relating to parental grief and children's existing mental health problems. Schools and bereavement organizations' provision of specialist support was valued, but there was evidence of unmet need, with some participants reporting a lack of access to specialist grief or mental health support. The authors concluded that children and young people have faced additional strains and challenges associated with pandemic bereavement. The authors also recommended resources and initiatives that facilitate supportive communication within family and school settings, adequate resourcing of school and community-based specialist bereavement/mental health services, and increased information and signposting to the support that is available.

Older Adults

Wang et al. (2022) examined the association between COVID-19 bereavement and reports of depression among older adults in Europe. Variations in this association by gender and country context were evaluated by analyzing data from the Survey of Health, Ageing and Retirement in Europe COVID-19 collected between June and August 2020 from 51,383 older adults living in 27 countries. Multilevel logit regression models were used to examine the association between COVID-19 bereavement and self-reported depression, and to test whether national COVID-19 mortality rates moderated this association. A cross-sectional descriptive, correlational design was used. COVID-19 bereavement was associated with significantly higher probabilities of both reporting depression and reporting worsened depression among older adults. Living in a country with the highest COVID-19 mortality rate was associated with worse depression in women but not in men. The authors concluded that bereaved older adults are in particular need of mental health support, as COVID-19 deaths have lingering mental health implications for them. Gender-specific mental health support may be necessary, as women living in countries with the highest COVID-19 mortality rates are more likely to report current depression. Policies and interventions should focus on providing mental health support to older adults who have experienced COVID-19 bereavement.

Summary

COVID-19 impacted the bereavement experience and evidence indicates similar impacts were noted globally. For example, the pandemic caused bereaved individuals to feel more isolated due to an inability to connect with family or attend in-person support groups. Strategies identified to improve the bereavement experience included improving communication with families, safe facilitation of family visiting in healthcare settings, and strengthening the bereavement support sector through the provision of greater resourcing and expansion of support services. Specific recommendations were made in terms of the need to develop best practices for funeral practices and other similar rituals, that provide opportunities for remembrances, and enhanced social support for those who are grieving. Several authors indicated that there is likely to be long-standing consequences on dying, death, and bereavement due to the profound loss of human life during COVID-19. Other authors suggested that the impact may not be as extensive as originally anticipated. All authors agreed that there is a need for continued research on the topic and close monitoring of people who have been bereaved to identify those most at-risk of developing prolonged grief disorders or other complications, and to intervene early. Risk factors for developing prolonged grief disorder or complicated grief included those who lost a partner, child, or parent; shared a close relationship with the deceased; lost a person due to COVID-19; or were very close with the deceased. One study found that non-White participants had significantly higher PGD scores than White participants. Studies also showed that children and young people faced additional strains and challenges associated with pandemic bereavement, and resources and initiatives that facilitate supportive communication within family and school settings, adequate resourcing of school and community-based specialist bereavement/mental health services, and increased information and signposting to available support are important. Similarly, evidence suggests that bereaved older adults need additional mental health support, as COVID-19 deaths have lingering mental health implications for them. In terms of the provision of bereavement care and support services, it was reported that the pandemic created major challenges, which if left unaddressed may lead to significant physical and mental health morbidity and create a further burden on health and social care services. Therefore, it is imperative that bereavement support services become a high priority in the health policy agenda.

Impact on Healthcare Workers and Patient Care

Grief Experience and Response

In the USA, Williams et al. (2022) used a mixed methods design to explore the grief experience of registered nurses working on the frontlines during the pandemic (N=24), including their frustrations, stress, and coping strategies. The qualitative phase used grounded theory and a quantitative 30-question survey was also used. The registered nurse participants worked on the frontlines in acute care with patients diagnosed with COVID-19 between March and September 2020. Most participants (87.5%) were female, 75% were 40 years of age or younger, and 79.2% were Caucasian. Results showed that nurses working on the frontlines during COVID-19 experienced a significant number of patient deaths and they faced diverse unknowns related to the treatment of patients with COVID-19. They initially did not know how to treat the disease correctly and felt overwhelmed and confused by the constantly changing protocols and procedures. Findings of the qualitative phase identified four major core concepts related to grief and bereavement: 'facing a new reality', 'frustrations', 'stress', and 'coping'. 'Facing a new reality' was defined as becoming aware, confronting, and adjusting to the new reality of the work environment during the pandemic, including increased patient deaths, unknowns regarding effective nursing care, changing policies, lack of administrative support, and fear of infection. 'Frustrations' included factors such as frequent changes in policies, lack of staff, long work shifts, shortage of supplies, lack of respect, and feeling uncertain about the effectiveness of patient care. 'Stress' was defined as the physical, emotional, spiritual, and social turmoil experienced due to frustrations related to the new reality. Physical and emotional stress were the largest categories, with examples including lack of time for breaks, fertility issues, and feeling overwhelmed. 'Coping' strategies used by nurses to alleviate stress included adaptive strategies such as meditation, hiking, music, exercise, adopting a pet, returning to school, seeking support, and providing support to colleagues, family, and friends. Maladaptive coping strategies included drinking alcohol, overeating, sleeping excessively, and online shopping. The authors concluded that:

- Nursing educators should provide education related to self-care, resilience, and grief management strategies.
- Healthcare systems should develop interventions to help nurses prepare for loss and support them in their grief over the deaths of patients and co-workers from COVID-19.
- Healthcare systems should provide opportunities for nurses on the frontlines to take a brief and simple pause after hearing about or witnessing a patient's death to mourn the loss and invest in grief support resources for staff.
- Regular debriefing sessions should be provided for nurses to enable them to reflect on their experiences caring for individuals diagnosed with COVID-19, which may assist in processing their grief.
- Healthcare systems should implement occupational safety precautions which are critical in preventing long-term disability of workers affected by COVID-19.
- Public health officials should ensure the continuity of spiritual and religious activities as well as social support for patients and their families during the pandemic and provide training for nurses on this topic.

In terms of future research, the authors recommended that future studies should compare the grief experience of healthcare workers in different countries to enhance understanding of the professional grief experience.

Similarly, in Iran, Rahmani et al. (2023) investigated complicated grief and its related factors among nursing staff (N=375) working full-time at three centres designated for COVID-19 patients. The goal was to provide evidence for supportive interventions to maintain the health and well-being of nurses during the pandemic and future pandemics. Participants completed a survey containing demographic and clinical questions, the Inventory of Complicated Grief, and the Multidimensional Scale of Perceived Social Support. Almost 60% of participants (N=216, 57.6%) were found to be suffering from complicated grief. Participants with lower social support were found to have significantly higher levels of grief (p<0.001) and grief scores were also significantly higher among females (p<0.001). Participants who were single and floor nurses had significantly higher grief scores (p<0.001). Nurses who were working in a COVID-19 intensive care unit, had nursing work experience >10 years, and had worked in COVID-19 wards for more than two years, were more likely to experience pathologic / complicated grief (p<0.001). Complicated grief can result in significant health problems and burnout among nurses. Governments, health authorities, and managers should support nurses working in COVID-19 settings to reduce the adverse impact of the pandemic on their health and well-being. In summary, the study highlights the high prevalence of complicated grief among nursing staff during the pandemic and emphasizes the need for support and interventions to mitigate the negative impact on nurses' mental health.

Another similar study in South Korea explored whether nursing professionals' psychological states affected their grief response to a patient's death in the COVID-19 inpatients' ward in South Korea (Hong et al. 2023). The study sought to investigate the relationship between depression, viral anxiety, loneliness, insomnia, and grief response among nursing professionals working in COVID-19 inpatients wards. The study hypothesized that psychological state would at least partially mediate the relationships between depression and grief response. A sample of frontline nursing professionals working in COVID-19 inpatient wards at three tertiary-level affiliated hospitals were recruited (N=251). Participants were categorized into two groups based on their self-administered Patient Health Questionnaire-9 (PHQ-9) scores: depressed group and non-depressed group, and comparisons were conducted between the two groups using t-tests and chi-square tests. The correlation and influence of various variables on depression were explored using partial Spearman's rank correlation and linear regression analysis. Results showed that nursing professionals' depression directly influenced their grief reaction, and their work-related stress, viral anxiety, insomnia severity and loneliness partially mediated the relationship between depression and pandemic grief. The authors recommended the establishment of psychological and social support systems to positively affect the mental health of nurses working in COVID-19 inpatient wards.

In the Philippines, Sera Jose et al. (2023) examined the vicarious experiences of grief among 60 helping professionals aged 22 –64 (M= 37.28, SD= 12.64) who worked with the bereaved due to COVID-19 deaths. An explanatory sequential mixed methods design with two phases was used. In the first phase, a survey was administered to measure vicarious grief levels and in the second phase, in-depth interviews were conducted to explore themes related to the experiences of grief among these professionals. Participants belonged to one of the following sectors: healthcare workers (HCWs), faith-based workers (FBWs), and mental health workers (MHWs). HCWs reported the highest levels of vicarious grief (VG) compared to other helping professionals. HCWs had significantly higher VG scores than FBWs, particularly in relation to their exposure to clients distressed due to COVID-19 deaths, feeling overwhelmed by their workload, and ability to remain optimistic amidst COVID-19-death-related grief. MHWs did not significantly differ from HCWs and FBWs in terms of VG scores. Qualitative analysis revealed five themes: acknowledging contexts of grief, navigating relations with the bereaved, sharing others' grief, internalizing encounters, and negotiating challenges. The authors concluded that the study emphasized the need for supportive interventions at the organizational level to address VG experienced by HCWs, MCWs, and FBWs. Organizations should provide support and resources to help staff cope with the emotional toll of working with the bereaved during COVID-19. Training programmes should be implemented to enhance the coping skills and staff, and organizations should promote self-care and provide opportunities for staff to debrief and process their emotions related to their work with the bereaved.

Challenges to Providing Care

Gao et al. (2021) examined frontline healthcare workers' (N=724) delivering grief counselling for bereaved families of COVID-19 victims in Wuhan, China. Results showed that the average Skills of Grief Counseling (SGCS) score among health-care workers was 18.96 ± 4.66. This indicated that healthcare workers' grief counselling skills needed improvement. Furthermore, the average Attitudes of Grief Counseling (AGCS) score was 33.36 ± 8.70. This indicated that attitudes towards grief counselling among healthcare workers were not very positive. The authors concluded that many Chinese healthcare workers had not received systematic grief counselling training, and grief counselling was still in its preliminary stage in China. Furthermore, job burnout among healthcare workers may have impacted their attitudes toward grief counselling.

Power et al. (2022) explored the experiences and perceptions of midwives in Ireland providing perinatal bereavement care during the pandemic (N=11) and identified the barriers and facilitators to providing compassionate bereavement care. A qualitative descriptive design was used, and data were collected via semi-structured interviews. Findings revealed that midwives expressed concern about the impact of COVID-19 on their ability to provide optimal care and support to bereaved parents. They found it challenging to provide compassionate care within the new and changing healthcare environment. The use of Personal Protective Equipment (PPE), such as facemasks, was described as a significant barrier to providing compassionate care. Midwives felt that the care they gave became impersonal, and it was harder to engage with the woman and her partner. The wearing of facemasks hindered non-verbal communication and made it challenging to build rapport with the woman. Visitor restrictions resulted in women not being able to access their usual support structures, and midwives were conscious of providing added support to compensate for this. Partners were often unable to stay with the woman, leaving her on her own during the grieving process. Concerns were also raised about the support structures available to bereaved parents on discharge. Due to public health restrictions, bereaved parents were not meeting many of their family and friends, and this lack of support may contribute to the overall stigma of bereavement experienced by women. Social isolation associated with COVID-19 restrictions was also seen as potentially leading to a more complex and prolonged grieving process.

Summary

Evidence shows that healthcare staff working on the frontlines during the COVID-19 pandemic experienced a significant number of patient deaths and they faced diverse unknowns related to the treatment of patients with COVID-19. They initially did not know how to treat the disease correctly and felt overwhelmed and confused by the constantly changing protocols and procedures. In one study conducted with nurses, almost 60% of participants were found to be suffering from complicated grief. Nurse participants who were floor nurses working in a COVID-19 intensive care unit, had more than 10 years clinical experience, and had worked in COVID-19 wards for more than two years, were more likely to experience complicated grief. Complicated grief can result in significant health problems and burnout among nurses. Similarly, one study conducted with midwives revealed that the COVID-19 pandemic impacted their ability to provide optimal care and support to bereaved parents. Furthermore, the use of Personal Protective Equipment (PPE), such as facemasks, was described as a significant barrier to providing compassionate care. Visitor restrictions and support on discharge were also highlighted as impacting on the provision of healthcare with clinicians being conscious of providing added support to compensate for restrictions and lack of support. Social isolation associated with COVID-19 restrictions was also highlighted by healthcare workers as potentially leading to a more complex and prolonged grieving process for patients.

Several recommendations were made by authors to address and improve the experience of healthcare workers. Authors proposed that governments, health authorities, and managers should support healthcare workers in pandemic settings to reduce the adverse impact on their health and well-being. The need for supportive interventions at the organizational level was highlighted including support and resources to help staff cope with the emotional toll of working with the bereaved during the COVID-19 pandemic. It was recommended that training programmes should be implemented to enhance the coping skills of staff, and organizations should promote self-care and provide opportunities for staff to debrief and process their emotions related to their work with the bereaved. Other self-care and grief management strategies identified included the provision of opportunities for healthcare workers on the frontlines to take a brief and simple pause after hearing about or witnessing a patient's death; investment in grief support resources for staff; development of interventions to help healthcare workers prepare for loss and support them in their grief over the deaths of patients and co-workers from COVID-19; and ensuring the continuity of spiritual and religious activities as well as social support for patients and their families.

Reliability and Validity Studies of Measures of Healthcare Related Grief

Grief Support in Healthcare Scale (GSHCS)

Ahn et al. (2023) examined the reliability and validity of the Grief Support in Healthcare Scale (GSHCS) among nursing professionals (N=229) in Korea working in COVID-19 inpatient wards at three tertiary-level affiliated hospitals. Results showed that the two-factor model of the GSHCS showed a good fit, indicating that it is a reliable and valid measure of psychological support for grief among nursing professionals who have witnessed the deaths of their patients. The GSHCS had good convergent validity with other rating scales that measure viral anxiety, depression, and general anxiety. The GSHCS subscale 1 (recognition of the relationship) was not significantly correlated with viral anxiety, depression, and general anxiety, while subscale 2 (acknowledgment of the loss) was significantly correlated with these variables. The authors recommended use of the 10-item Korean version of the GSHCS to assess and provide psychological support for frontline nursing professionals who have experienced grief while caring for COVID-19 patients.

Pandemic Grief Scale (PGS)

Lee et al. (2021) examined the incremental validity of the Pandemic Grief Scale (PGS) in identifying functional impairment from COVID-19 bereavement. A sample of people bereaved through COVID-19 (N=1065) in the United States was recruited. The study aimed to determine if the PGS can uniquely associate with multiple independent indicators of functioning, such as social/work impairments, difficulty making meaning of the loss, and substance use coping, above and beyond relevant participant characteristics, bereavement-related psychopathology, and separation distress symptoms. The study also aimed to assess the clinical utility of the PGS in identifying risk of deleterious outcomes across a range of functional and behavioral domains. The sample included individuals of various ages, genders, races, and COVID-19 diagnoses. Over half of participants (56.6%) scored above the cut score of ≥7 on the PGS for clinically dysfunctional pandemic grief and 69.7% coped with their loss using drugs or alcohol for at least several days in the past two weeks. PGS scores were not associated with time since loss. Hierarchical multiple regression models demonstrated that the PGS uniquely explained variance in functional impairment, meaning-making difficulties, and substance use coping, over relevant background factors, bereavement-related psychopathology, and separation distress. The authors concluded that the findings underscored the clinical utility of the measure in identifying risk of deleterious outcomes across a range of functional and behavioral domains.

Evren et al. (2021) validated a Turkish version of the PGS, which is a brief mental health screener to identify probable cases of dysfunctional grief associated with a COVID-19 death. Participants were recruited from the general Turkish population (N=758). Results showed that the PGS had good construct validity and demonstrated adequate convergent validity with positive correlations with the Patient Health Questionnaire-4 (PHQ-4) and the Work and Social Adjustment Scale (WSAS). The PGS was found to discriminate well between persons with and without dysfunctional grief using an optimized cut score. The PGS explained most of the variance (43%) in functional impairment due to a COVID-19 loss beyond measures of depression and generalized anxiety. The authors concluded that the study findings suggest that grief due to a COVID-19 death is more severe than that resulting from other forms of loss.

Similarly, Kim et al. (2023) explored the reliability and validity of the PGS for healthcare workers among the same sample of frontline nursing professionals (N=229) working in COVID-19 inpatient wards in three tertiary-level general hospitals in Korea. The survey included demographic characteristics and rating scales, such as the Korean version of the Pandemic Grief Scale for healthcare workers, the Fear of COVID-19 scale, the Generalized Anxiety Disorder-7 items, and the Patient Health Questionnaire-9 items. Results showed that the Korean version of the PGS for Healthcare Workers had good internal consistency (Cronbach's alpha = 0.866) and convergent validity with other anxiety and depression scales. Item analysis results showed that all items of the PGS had acceptable corrected item-total correlation, indicating their relevance to measuring grief reactions. The authors concluded that the PGS for healthcare workers is a valid and reliable tool for measuring grief reactions among nursing professionals from the COVID-19 pandemic.

Conclusion to Literature Review

In summary, a total of 32 survey studies examined the impact of COVID-19 on grief and bereavement. There was a consistent focus across all studies with most examining the impact on bereaved persons or healthcare workers, while other studies focused on establishing the reliability and validity of pandemic-specific measures. Many of the studies assessed for signs of prolonged grief disorder or complicated grief in various samples and almost all raised concerns about the severity of grief observed, which was reported to exceed pre-pandemic or expected levels of complicated and prolonged grief. Many authors called for extensive screening to identify those at risk and intervene early. A strong recurring theme in the literature was also the need for more investment and funding for bereavement support services and psychotherapy interventions to address the inevitable grief epidemic. Three of the survey studies were conducted in Ireland. One of the studies described the implementation and evaluation of a national bereavement helpline that was implemented by Irish Hospice Foundation in response to the pandemic; another explored the experiences and perceptions of midwives providing perinatal bereavement care during COVID-19; and the third study examined bereavement care provision in the UK and Ireland with a sample of people working in hospice, community, and hospital settings only. Therefore, a national Irish survey is warranted to elucidate the specific challenges and experiences of the Irish population in relation to grief and bereavement during the pandemic.

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