

Time to Reflect

Irish Hospice Foundation Survey About Dying, Death and Bereavement During the COVID-19 Pandemic



**Irish
Hospice
Foundation**

To die and grieve well wherever the place

December 2023





Table of Contents

Acknowledgements	4
1. Executive Summary	6
2. Methodology and Approach to the Survey	8
3. Results from the Time to Reflect Survey	13
4. Discussion	38
5. Recommendations	44
6. Appendices	47



Acknowledgements

We would like to express our thanks to current and former members of staff at Irish Hospice Foundation who have contributed to this report. The genesis for the work and the survey was led by the vision of Dr Helen Coughlan who contributed throughout the process.

We would like to thank Dr Carla Perotta and Ms Vicky Downey for their work on the cleaning, analysis, and write-up of the study findings. We would also like to thank Dr Elizabeth Weathers for writing the final report and contribution to the literature review, discussion and recommendations.

Finally, we would like to extend our gratitude and appreciation to the large numbers of people across Ireland who took the time and energy to participate in the survey and recount their experiences of dying, death and bereavement during COVID-19. This study would not have been possible without them.

Time to Reflect is their story.

Recommended Citation

Cited as: Irish Hospice Foundation (2023) *Time to Reflect: Irish Hospice Foundation Survey About Dying, Death and Bereavement During the COVID-19 Pandemic*. Dublin: Irish Hospice Foundation.



Project Team

Avril Easton, Orla Keegan, Paula O'Reilly, (Irish Hospice Foundation), Dr Helen Coughlan, Lynn Murtagh and Sharon Foley (formerly Irish Hospice Foundation), Dr Elizabeth Weathers (ECNE Research), Dr Carla Perrotta and Vicky Downey (UCD Centre for Safety and Health at Work, School of Public Health, Physiotherapy and Sports Science).

Irish Hospice Foundation,
Morrison Chambers,
32 Nassau Street,
Dublin 2,
D02 X627.

hospicefoundation.ie
info@hospicefoundation.ie

This report was commissioned by Irish Hospice Foundation, and completed in December 2023.

1. Executive Summary

The Time to Reflect survey was commissioned by Irish Hospice Foundation to explore the impact of COVID-19 on the experiences and perceptions of the Irish population in relation to dying, death, and bereavement during this time. A total of 2,259 participants completed the national survey from November 2021 to February 2022.

Participants were invited to share their (a) perspectives and (b) their personal experiences of dying, death and bereavement as well as (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 end-of-life care, grief, and bereavement during the pandemic.

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 the participants were not present when their loved one died.

These difficult experiences were impacted by the COVID-19 public health measures and the overwhelming strain placed on health and social care services. Limits on numbers attending funerals and mourning rituals were also cited as having an impact on the grief experience of bereaved individuals. Participants emphasised the importance of attending funerals and having an opportunity to say goodbye but also how they appreciated the ways in which their communities innovated and reimagined how they paid their respects and provided support.

Healthcare workers were particularly impacted by the distress of witnessing so many deaths and the challenging circumstances they faced. Although the research did not set out to target healthcare workers one in five of the cohort that responded were healthcare workers. They recalled the difficulty of loved ones not being permitted to visit the patients they were caring for. They described the moral struggle of not being able to provide patients with the standard of care they required. Both family members and healthcare workers referred to situations in which a patient died alone without family or staff present and the pervasive impact that had on them.

A short questionnaire – Brief Grief Questionnaire (BGQ) was incorporated into the survey and was used to screen bereaved survey participants for Prolonged Grief Disorder (PGD). PGD

is defined by profound and debilitating feelings of loss and can include intense feelings of grief that are long-lasting and can interfere with everyday life. It is noted that in general, only 10% of bereaved people would be expected to fall into the category of PGD.

Findings from the BGQ found that 14% of participants exhibited signs of PGD, which is less than findings from similar studies in other countries. The findings also demonstrated a resilience among healthcare workers as they showed lower score indicators for PGD (12%) compared to non-healthcare workers. This suggests a protective component from PGD for healthcare workers.

There is concern globally regarding the impact of the COVID-19 pandemic and future public health emergencies on the grieving process and the provision of bereavement support. Studies from the literature review indicated that there is likely to be long-standing consequences on dying, death, and bereavement. Other studies suggested that the impact may not be as extensive as originally anticipated. However, there is consensus regarding the need for continued research on the subject and close monitoring of people who have been bereaved to identify those most at risk of developing PGD or other complications and to intervene early.

Several recommendations are made in terms of how the findings can be used to inform the improved delivery of end-of-life care in the event of future public health emergencies. The recommendations highlight the need for the enhancement of bereavement supports. They also suggest that the data from the report could be used to inform future public health policy and practice. Finally the recommendations point to the potential for future research opportunities.

Specifically the recommendations include the need to prioritise visiting for those at end of life in healthcare settings, equipping health services with appropriate bereavement resources and support services for patients, families, and staff. Screening and early intervention for those experiencing PGD should be incorporated into health policy and practices. Further research should be undertaken to explore the experiences of those not captured in the study such as migrant healthcare staff.

The society-wide implementation of public health measures to prevent the spread of COVID-19 and death, particularly among our vulnerable populations, had a deep impact on the dying, death, and bereavement experience in Ireland. The measures saved lives and spared many people the difficult experience of a loved one dying during the pandemic. The pandemic demonstrated how communities can respond in innovative ways to support people who are grieving. This report highlights the resilience of our healthcare workers to cope in remarkably challenging circumstances. The very profound and challenging experiences that people went through are presented in this report and it is imperative that these voices inform and guide our future responses to public health emergencies.

2. Methodology and Approach to the Survey

The project was conducted in two phases. Phase one consisted of a scoping review of the literature on COVID-19 and its impact on dying, death, and bereavement. This review sought to understand the impact of public health measures, changes to health service procedures, guidance on funerals and gatherings and the number of deaths, on the overall experience of 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 (IHF) between November 2021 and February 2022. A survey was circulated via social media and among networks in IHF to self-selecting individuals over the age of 18 years. The survey aimed, to explore perspectives and experiences of dying, death, and bereavement in Ireland during the pandemic. A total of 2,259 responses were received.

2.1 Phase 1: Scoping Review of the Literature

The aim was to conduct a scoping review of the academic and grey literature to gather up-to-date information on the impact of the public health measures and other public health measures on grief and bereavement during the pandemic. Read about the methods used to conduct the review of the literature - <https://hospicefoundation.ie/our-supports-services/advocacy-research/research/time-to-reflect/>

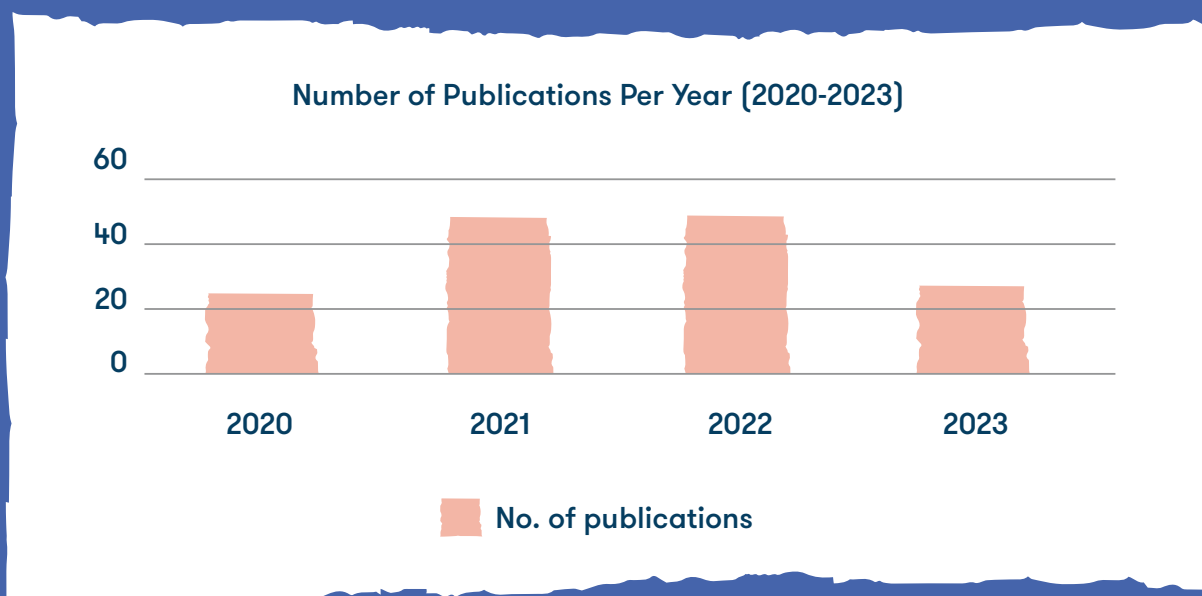
Two key themes emerged from the literature review as follows:

1. Increase in global interest in the impact of COVID-19 on grief and bereavement
2. Findings of survey research exploring impact of COVID-19 on dying, death, and bereavement.

2.1.1 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)



A range of populations were included in the previous 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). A variety of research designs were used but most studies were quantitative or review/discussion papers.

It can be concluded from this summary analysis that there is concern on a global level regarding the detrimental impacts of the pandemic experience on the grieving process and the provision of bereavement support.

2.1.2 Findings of survey research exploring impact of COVID-19 on dying, death, and bereavement

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 (PGD) 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 prolonged grief. Many authors called for extensive screening to identify those at risk and intervene early.

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.

Several authors highlighted that there is likely to be long-standing consequences due to the 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 PGD, and to intervene early.

A recurring theme was the need for more investment and funding for bereavement support services and psychotherapy interventions to address the grief outcomes. 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.

Several recommendations were made to address and improve the experience of healthcare workers. Authors proposed that governments and health authorities should support healthcare workers to reduce the adverse impact on their health and well-being. The need for supportive interventions at the organisational 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 organisations should promote 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 investment in grief support resources for staff; development of interventions to help healthcare workers prepare for loss and support them in their grief; and ensuring the continuity of spiritual and religious activities as well as social support for patients and their families.

2.2 Phase 2: Time to Reflect Survey

The second phase of this study presented the findings of a national survey administered by Irish Hospice Foundation (IHF) to self-selecting adults (when individuals choose or opt in to participate in a research study) in 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.

2.2.1 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.

2.2.2 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 one year after the COVID-19 vaccination was made available for vulnerable patients. Many public health measures remained in place, including the wearing of face masks and visiting restrictions, making this an appropriate time to reflect on the past collective experience.

The survey was completed by 2,259 respondents. It was available in both digital forms (via Survey Monkey) and paper forms. Individuals who participated in the survey self-selected, were aged over 18 years old and living in Ireland.

The survey was disseminated by IHF through different platforms including IHF events, social media, network connections, and relevant programmes. Promotion of the survey was also done within hospitals via the End-of-Life Care Coordinators Networks and posterage. Paper versions of the survey were distributed to individuals in nursing homes.

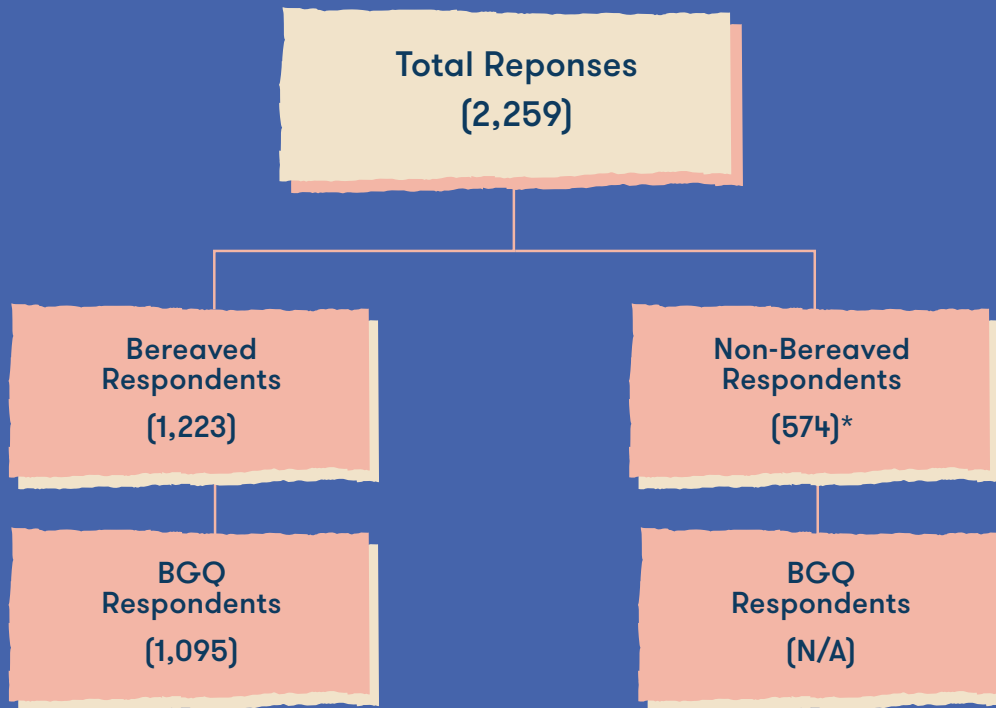
2.2.3 Survey Instrument

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 the 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.

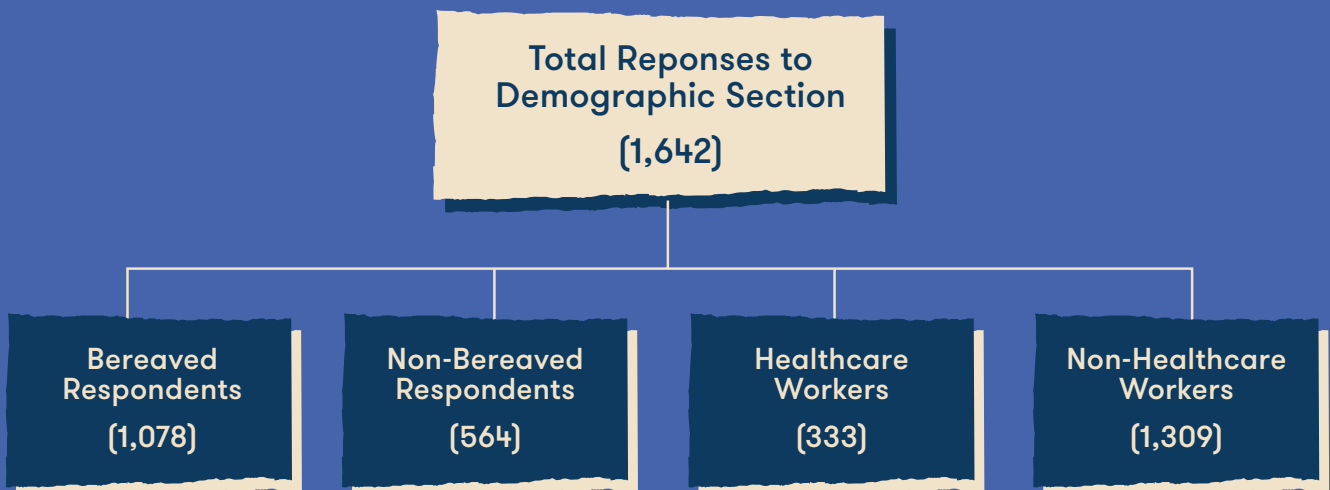
Bereaved participants were also invited to complete the Brief Grief Questionnaire (BGQ). The BGQ is a validated questionnaire for screening for Prolonged Grief Disorder (PGD) and comprises five statements. The five item screening measure scored on a three-point Likert scale (0 = not at all, 1 = somewhat, 2 = a lot) asks respondents to report on the extent of complicated grief symptoms they are currently experiencing. An example item is, 'How much are you having trouble accepting the death of _____?'¹

1. Patel, SR., Cole, A., Little, V., Skritskaya, NA., Lever, E., Dixon, LB., Shear, K., (2019). Acceptability, feasibility and outcome of a screening programme for complicated grief in integrated primary and behavioural health care clinics, *Family Practice*, Volume 36, Issue 2, Pages 125-131, <https://doi.org/10.1093/fampra/cmz050>

Figure 2: Survey Flow And Response Rates



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



3. Results from the Time to Reflect Survey

The quantitative and qualitative results from the survey are presented in the following order:

1. Demographic Information
2. Health and Wellbeing of Participants
3. Perceptions of Dying, Death, and Bereavement
4. End-of-Life Care during COVID-19
5. Healthcare Workers' Experience of End-of-Life Care during COVID-19
6. Bereaved Participants' Experience of Dying and Death
7. Funerals and Mourning Rituals
8. Experience of Bereavement and Grief
9. Likelihood of Prolonged Grief as Measured by the Brief Grief Questionnaire
10. Future Priorities for End-of-Life Care in Ireland.

3.1 Demographic Information

3.1.1 Survey Participants

It should be noted that 617 of the overall 2,259 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 2 in Appendices). The majority of participants were white Irish ethnicity (N=1521, 92.6%). Most 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%).

3.1.2 Bereaved Participants

A total of 1,078 (88.1%) of 1,223 bereaved participants completed the demographic section of the survey. The profile of bereaved participants was very similar to the overall survey participants, in that most bereaved respondents were female, aged between 45 and 54 years old, white Irish, and living in rural areas with their family. Most bereaved participants (N=990, 80.9%) were not healthcare workers.

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. Most participants reported the death of a parent. A total of 37.9% of participants (N=448) reported that the death of their loved one was unexpected or sudden.

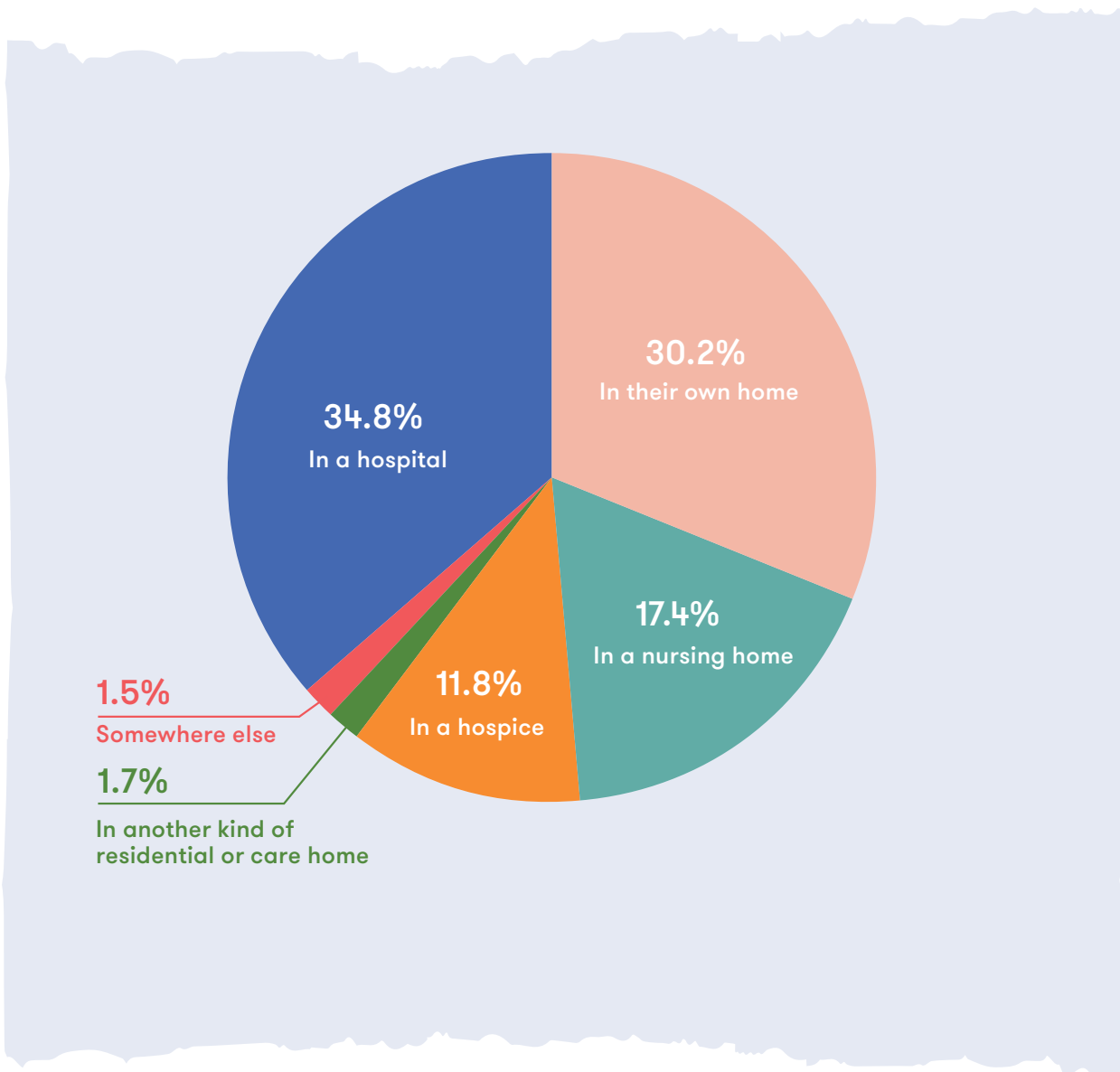
3.1.3 Healthcare Worker Participants

Of the 1,642 participants who responded to these demographic questions, 333 of them or one in five identified themselves as healthcare workers (N=333, 20.3%). There were significant similarities between the demographics of the healthcare workers group and the other survey participants. Most were aged between 45 and 54 years old and over 82% of healthcare workers were female. Most of the healthcare worker participants (N=311, 93.4%) were white Irish ethnicity and either married or in a civil partnership living in a rural location. Most healthcare workers had experienced bereavement (N=233, 70%) of healthcare workers.

3.1.4 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%). See Figure 3 below - Place of Death Reported by Participants.

Figure 3: Place of Death Reported by Participants



3.1.5 Cause of Death

Confirmed COVID-19 infection and suspected COVID-19 infections were reported by the respondents to the survey to be the primary cause of death in 14.1% and 1.4% of 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, dementia, and respiratory diseases (see Table 3 in Appendices).

3.2 Health and Wellbeing of Participants

All survey participants were invited to rate their overall health and wellbeing status. Findings showed that of the 1,635 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.

3.2.1 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 4 in Appendices). Participants who had not experienced bereavement during COVID-19 were found to have a slightly higher mean general health status, mental health status, and financial well-being score than those who were bereaved during the pandemic.

3.2.2 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 5 in Appendices). Healthcare workers were found to have a higher mean general health status, mental health status, and financial well-being score than other survey participants.

3.3 Perceptions of Dying, Death, and Bereavement

In this section all participants (N=2259), regardless of their bereavement status, were asked about their views on dying, death, and bereavement since the pandemic began (see Table 6 in Appendices).

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.

3.3.1 Bereaved vs Non-Bereaved Participants

Perceptions of dying, death, and bereavement were compared for bereaved participants and non-bereaved participants. 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).

3.4 Survey Participant Reflections

In the survey, participants were provided with an opportunity to respond to free-text questions where they could indicate their reflections and thoughts on their experiences and views of dying, death, and bereavement during the pandemic. Throughout the report a selection of these comments have been selected to represent what was shared.

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

3.4.1 Greater Cognisance of Life and Death

Some participants highlighted how the pandemic reminded them of the fragile nature 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?”

3.4.2 Self-Reflection on End-of-Life Wishes

A 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.”



3.4.3 Reflecting on the Dying Experience

COVID-19 did stimulate reflection on the current healthcare system, structures, and changes required in the future. Some participants stressed the need for more choice and autonomy around the dying experience:

“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.”

3.5 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%).

3.6 Survey Participant Reflections

The following themes emerged in relation to end-of-life care during COVID-19:

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

3.6.1 Lack of Appropriate 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 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-19. 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 two weeks and the lack of care she was given by healthcare staff:

“My mother was left alone in a single room for over two 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 traumatised by the way we were excluded from spending time with her, and her transfer to hospice care was delayed by COVID.”



3.6.2 Frustration with COVID-19 Public Health Measures

Participants emphasised their frustration with COVID-19 public health measures with many participants regarding them as inhumane. For example, one participant reported the harshness 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.”

3.6.3 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 emphasised 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.”

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.”



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

Healthcare workers described their specific experiences of providing end-of-life care and two key themes emerged:

- Emotional Impact on Healthcare Workers
- Unprecedented Working Conditions

3.7.1 Emotional Impact on Healthcare Workers

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 patients loved ones who were not permitted to enter due to visiting restrictions:

“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 worker described the sadness of watching a patient's family witnessing their father die 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.”



3.7.2 Unprecedented Working Conditions

Healthcare workers described the emotional difficulty they experienced, which was particularly due to the increased number in deaths, public health measures, and overall strain on healthcare settings:

“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.”



3.8 Bereaved Participants' Experience of Dying and Death

The next section presents findings of the bereaved participants' experience of dying and death of a loved one. 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 8 in Appendices).

3.9 Survey Participant Reflections

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

- Loneliness and Powerlessness
- Opportunity to Say Goodbye



3.9.1 Loneliness and Powerlessness

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

“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 to.”

“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.”



3.9.2. 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.”

3.10 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 guidance. 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, over half of the participants (N=608, 54.6%) felt that a funeral remained a source of comfort for them in their grieving. 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 importantly a similar number (N=608, 54.6%) stated that even with public health measures, some aspects of the funeral were a comfort to them (see Table 9 in Appendices).

3.11 Survey Participant Reflections

The above quantitative results were supported and reiterated in the qualitative responses. The following three themes emerged in relation to funerals and mourning rituals:

- Altered Funeral Structures and Guidance
- Lost Opportunities to Grieve
- Difficulty Supporting Others

3.11.1 Altered Funeral Structures and Guidance

Many participants mentioned difficult experiences due to the guidance 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...”

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

“...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.”



3.11.2 Lost Opportunities to Grieve

Participants emphasised the need to grieve properly, 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. One 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.”

3.11.3 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 public health measures in place. For example, one participant recalled the experience opposite:



“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.”



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.”

3.12 Experience of Bereavement and Grief

Over 60% of participants (N=691) stated that the pandemic made their grieving process more difficult, but over half of respondents (N=580, 53.6%) highlighted 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.

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.

3.13 Survey Participant Reflections

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

- Limited Bereavement Support
- Importance of Community Support

3.13.1 Limited Bereavement Support

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 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 - see opposite:

“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.”



3.13.2 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 emphasised 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.”

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

“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.”

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

3.14.1 Prolonged Grief Disorder and the Brief Grief Questionnaire

Prolonged Grief Disorder (PGD) is defined by profound and debilitating feelings of loss. The condition has also been referred to as complicated, traumatic, chronic, or pathological grief. While grief is a natural and normal response to painful or traumatic losses, PGD makes it challenging for a person to accept the reality of a loss and begin to move forward. PGD can include intense feelings of grief that are long-lasting and can interfere with everyday life.

The Brief Grief Questionnaire (BGQ) is a short screening tool that is used to screen bereaved survey participants for PGD. Scores between 0 and 4 indicate no PGD. Scores above 8 have been validated as signifying the existence of prolonged or complicated grief and scores between 5 - 7 identify people who, while ‘sub-threshold’ for the disorder, still require support and monitoring.² A sub-threshold of PGD indicates that this cohort meet some but not all of the PGD criteria and suggests a higher risk of developing complicated grief without skilled therapeutic intervention. A US screening validation study in primary care settings used a BGQ score of 5 and above to identify those in need of therapeutic support (Patel et al, 2019).³

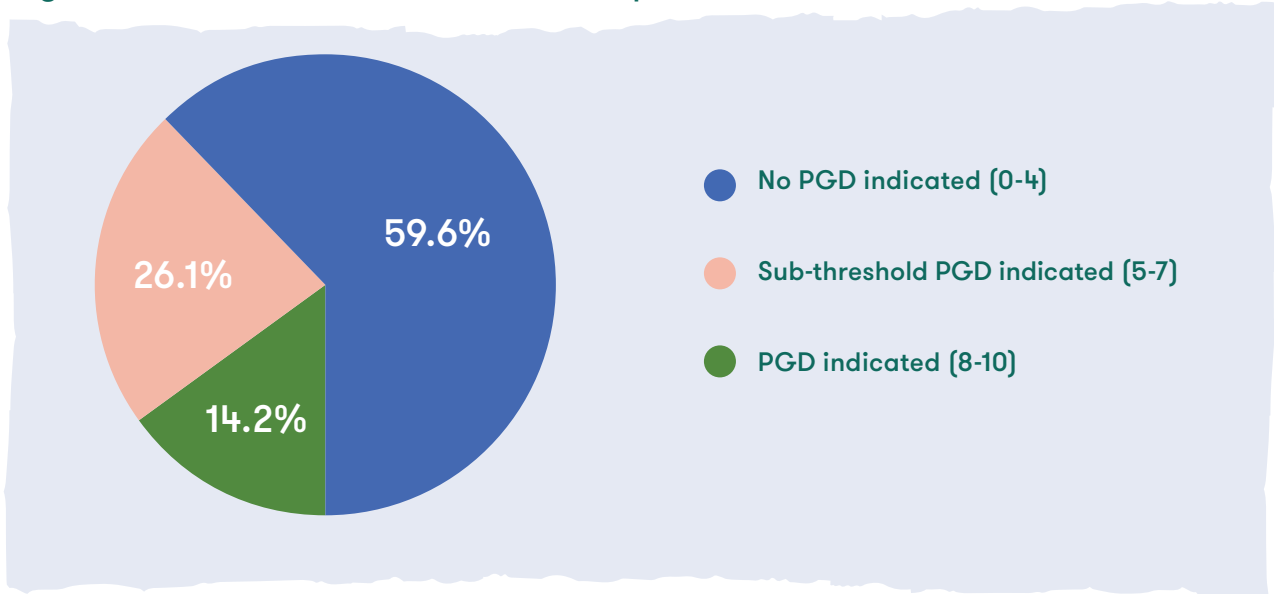
2. Szuhany, KL., Malgaroli, M., Miron, CD., Simon, NM. [2021]. Prolonged Grief Disorder: Course, Diagnosis, Assessment, and Treatment. *Focus (Am Psychiatry Publ)*. <https://doi.org/10.1176/appi.focus.20200052>

3. Patel, SR., Cole, A., Little, V., Skritskaya, NA., Lever, E., Dixon, LB., Shear, K., [2019]. Acceptability, feasibility and outcome of a screening programme for complicated grief in integrated primary and behavioural health care clinics, *Family Practice*, Volume 36, Issue 2, Pages 125-131, <https://doi.org/10.1093/fampra/cmz050>

3.14.2 Overall Brief Grief Questionnaire (BGQ) Scores

Overall results from the BGQ (N=1095) found that most participants (N=653, 59.6%) 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 Figure 4).

Figure 4: BGQ Scores for Bereaved Participants



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

3.14.3 BGQ Scores and Other Associations

When BGQ scores were compared for bereaved participants based on their location, their loved ones' cause of death and the place of death, there was no significant statistical association found between them.

However, a statistically significant association was found between BGQ scores and **participants' relationship to the deceased** (see Table 11 in Appendices). 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 such as a grandparent or a sibling.

BGQ scores were also compared to determine if associations were found between respondents being able to spend time with their loved one before they died. The results showed no differences between being able to spend time and BGQ scores.

However, there was a significant statistical association based on **whether the respondent was with the person when they died**. Specifically, there were higher rates of PGD indicated for those that were with the person at the time they died (25.8%) relative to those that were not with the person (10.4%).

A statistically significant association was found between BGQ scores and **participants' access to support during the pandemic**. 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 (see Table 1).

Table 1: BGQ Scores and Access to Support during COVID-19 Pandemic

Response to: "I didn't get the support I needed because of COVID-19 restrictions"	BGQ Category						
	No PGD Indicated (0-4)		Sub-threshold PGD (5-7)		PGD Indicated (5-7)		
	N	%	N	%	N	%	P
	Strongly Agree (N=128)	34	26.6%	41	32.0%	53	41.4%
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.

There were also statistically significant associations 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.

There were no statistical differences found between those who did have the funeral or ritual their loved one would have wanted and those who did not and their BGQ category.

BGQ scores were compared for bereaved participants who were also healthcare workers found that a lower percentage 12.2% (N=28) had scores indicating PGD than the non-healthcare workers. The scores for those who had no indications of PGD was also higher for healthcare workers 63.6% (N=147) and 58.6% (N=506) of non-healthcare workers. However, these scores were not found to be statistically significant when compared with other survey participants.

3.15 Future Priorities for End-of-Life Care in Ireland

All survey participants (N=2259) were asked to select their 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 what ever their age (N=1042, 46.1%).

Figure 5: Future Priorities for End-of-Life Care in Ireland



4. Discussion

The purpose of this study was to understand the impact of COVID-19 on experiences of dying, death, and bereavement among the population in Ireland. The results of this 'Time to Reflect' study 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 circumstances healthcare staff had to work in.

The findings also highlight the significant impact of public health measures on funerals and mourning rituals, and experiences of grief, loss, and bereavement. Time to Reflect was a significant opportunity to hear the voices and understand more about the experiences of the Irish public during what was one of the most significant events in our lifetime.

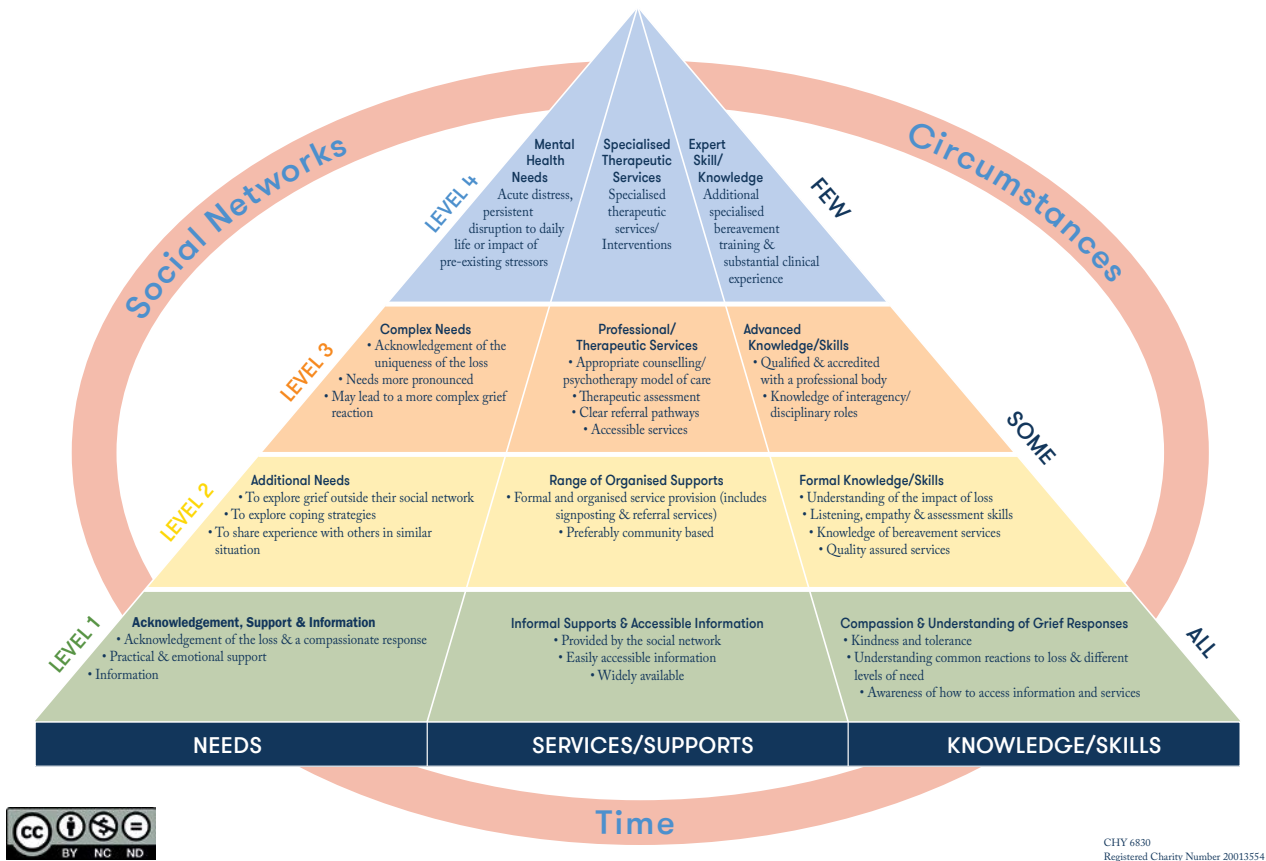
The study was conducted from the perspective of a public health model approach to bereavement. Irish Hospice Foundation has long advocated for a strategic and coordinated approach to bereavement care. Bereavement happens to people at any age, in different circumstances and with a wide range of consequences – psychological, physical, social and economic. A public health approach identifies bereavement needs and maps out the appropriate informal, community, organised and professional responses which are needed.

In this survey, it was recognised that all bereaved people have needs; for compassion, for information and for the support of those around them. However, being cognisant of the difficult factors affecting people who were bereaved during COVID-19, it was important to delve deeper and try to identify what was the possible scale of additional need for support.

This approach was based on the Adult Bereavement Care Pyramid which provides a national framework for adult bereavement care in Ireland.⁴ The pyramid suggests that every person who experiences a bereavement will have some level of need. Support at all levels of the continuum of grief must be available so that people can access the support when and where they need it. Others will require more intensive support, such as counselling and a few will require support from a specialist therapeutic service.

4. Adult Bereavement Care Pyramid - Irish Hospice Foundation. <https://hospicefoundation.ie/our-supports-services/bereavement-loss-hub/i-work-in-bereavement/adult-bereavement-care-pyramid/>

Figure 6: Adult Bereavement Care Pyramid, Irish Hospice Foundation; 2020



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

Findings highlighted that COVID-19 impacted general attitudes and perceptions of dying, death, and bereavement. Most participants reported that their views 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 were bereaved during this time and for healthcare workers.

These findings can be explained by the increased focus on dying and death by the public during COVID-19. For example, some studies highlighted the salience of sudden deaths reported by the media and the dehumanising effects of death statistics.⁵

4.2 Impact of COVID-19 on Grieving

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 public health measures 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 their loved one, they felt they had lost an opportunity to grieve without the chance to have the traditional aspects of a funeral.

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) that people face. For a small but significant proportion of the population, nearly 10%,⁶ their grief is described as Prolonged Grief Disorder (PGD). It is characterised as grief that is extremely debilitating over a longer period and will require more specialised support. Findings of the Time to Reflect survey indicated that PGD was present amongst 14% of participants, which is higher than the numbers outside of pandemic situations but aligns with or is less than prior studies conducted on this topic 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.⁷ In this Irish data, while indications of PGD at 14% are lower than proportions reported elsewhere, the relatively large levels of sub-threshold PGD at 26.1% demonstrate that one in four bereaved people may need closer monitoring. A sub-threshold of PGD indicates that this group of people meet some but not all the PGD criteria and would suggest that they are at a higher risk of developing complicated grief without skilled therapeutic intervention.

5. Torrens-Burton, A., Goss, S., Sutton, E., Barawi, K., Longo, M., Seddon, K., Carduff, E., Farnell, D. J. J., Nelson, A., Byrne, A., Phillips, R., Selman, L. E., & Harrop, E. (2022). "It was brutal. It still is": A qualitative analysis of the challenges of bereavement during the COVID-19 pandemic reported in two national surveys. *Palliative Care and Social Practice*, 16, 26323524221092456. <https://doi.org/10.1177/26323524221092456>

6. Lundorff, M., Holmgren, H., Zachariae, R., Farver-Vestergaard, I., O'Connor, M., (2017). Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis, *Journal of Affective Disorders*, Volume 212, <https://doi.org/10.1016/j.jad.2017.01.030>.

7. Harrop, E., Medeiros Mirra, R., Goss, S., Longo, M., Byrne, A., Farnell, D. J. J., Seddon, K., Penny, A., Machin, L., Sivell, S., & Selman, L. E. (2023). Prolonged grief during and beyond the pandemic: factors associated with levels of grief in a four time-point longitudinal survey of people bereaved in the first year of the COVID-19 pandemic. *Frontiers in public health*, 11, 1215881. <https://doi.org/10.3389/fpubh.2023.1215881>

The findings supported an association between the closeness of a relationship to the deceased and the bereaved persons PGD score. 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.

4.3 Impact of COVID-19 on the Delivery of Healthcare


The measures that were put in place during COVID-19 ensured that the spread of a highly transmissible disease was curtailed. In turn, this meant that many lives were saved, and significant mortality among the vulnerable was prevented, as well as helping to reduce the burden on the healthcare system. However, the visiting measures in place across the country caused a major disruption to the normal functioning of healthcare settings and nursing homes during the pandemic. Findings from the study emphasise the struggle of bereaved participants, many of whom did not have the opportunity to be present at their loved one's bedside as they approached end-of-life.

Results showed that participants who felt the pandemic experience prevented their loved one from having the death they would have wished for had significantly higher rates of sub-threshold PGD (32.3%) than those who did not. These findings highlight the impact that the end-of-life care experience can have on the bereaved and their likelihood of experiencing PGD.

Findings highlighted the impact of the emotional burden faced by healthcare workers, particularly when they were the only communication channel between the dying patient and their family. Participants discussed how these experiences gave rise to feelings of guilt, remorse, and moral suffering, which was also captured in the literature review.

Both 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 they would have wanted. This was reiterated by healthcare workers who highlighted the distress of situations where patients died alone.

However, the 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 (10.8%) compared with those who were with their loved ones (25.8%). This is an interesting finding given the literature points to the importance in the grieving process of being with a loved one as they die. These participants would have had the opportunity to be at their loved one's side when they died and yet, they had a higher indication of PGD.



One explanation is that they may have had a particularly close relationship to the deceased. Another could be the difficult circumstances in which their loved one died. If the person was in a healthcare setting or nursing home, 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.

The public health measures ensured that many lives were saved, and that the healthcare system could continue to function. The end-of-life and bereavement experiences reported by the respondents in this report should prompt policy makers and public health officials preparing for future emergencies to include alternative arrangements and provide resources to sustain and support the delivery of end-of-life care and family visiting arrangements.

4.4 Impact of COVID-19 on Bereavement Support

One in three bereaved people felt they did not get the support they needed at the time of the death and following the death due to the 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 by the bereaved.

The survey highlighted that Irish people 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 support from those around them 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. A recently published Irish survey of the impact of COVID-19 on bereavement care services in Ireland highlighted that almost half of them reported an increase in demand and many reported more complex needs among service users.⁸

4.5 Impact of COVID-19 on Healthcare Workers

Consistent with the literature, this study showed that healthcare workers were greatly impacted by their experiences during the pandemic, evidently suggesting that support should be in place for them, as they cope in the aftermath.

Yet, 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 score indicators for PGD compared to non-healthcare workers. This suggests a resilience and protective component to PGD for healthcare workers.

8. Roberts, A., Keegan, O., Holme, I., & Keeting, M. (2023). The impact of COVID-19 on bereavement care in Ireland: A national survey of bereavement care providers. *Bereavement*, 2. <https://doi.org/10.54210/bj.2023.1112>

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 who are facing increasing demands in the current healthcare climate. This is emphasised in the literature⁹ and recommendations to address the grief experience of healthcare workers included:

- Healthcare staff should be provided with education related to self-care, resilience, and grief management strategies.
- Healthcare systems should develop interventions to enable staff to prepare for loss and support them in their grief.
- Healthcare staff should have the opportunity to take a brief and simple pause after hearing about or witnessing a patient's death to acknowledge the loss.
- Regular debriefing sessions should be provided for staff to enable them to reflect on their caring experiences, which may assist in processing their grief.

4.6 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. Therefore, Future research with diverse populations is warranted.

Another limitation of the study was the sensitive approach of the survey questions relating to dying, death, and bereavement. This may have impacted the missing data throughout the survey responses.

9. Williams, L. A., Accardo, D., Dolgoff, J., Farrell, A., McClinton, T., Murray, E., & Jacob, S. R. (2022). A mixed methods study: The grief experience of registered nurses working on the frontlines during the COVID-19 pandemic. *Journal of Clinical Nursing*. <https://doi.org/10.1111/jocn.16579>

5. Recommendations

Context

The recommendations presented here consider the implications of the findings that are outlined in this report. They also incorporate the findings from the literature review, Irish Hospice Foundation's 30 years of experience working in the areas of dying, death and bereavement and the insights that were brought by the report contributors and authors.

A more detailed exploration of the literature review and the findings which informed these recommendations is available here - <https://hospicefoundation.ie/our-supports-services/advocacy-research/research/time-to-reflect/>

These are broad recommendations which will have implications for a wide set of stakeholders including the HSE, bereavement support organisations, Government departments and research agencies, to name but a few. Additionally, there are findings in the full report and the literature review which can further inform and provide for a more detailed discussion and distilling of the individual recommendations presented.

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

1. Importance of End-of-Life Care during Public Health Crises and Emergencies
2. Enhance Bereavement Support
3. Inform Health Policy and Practice
4. Invest in Future Research

Recommendations

5.1 Importance of End-of-Life Care during Public Health Crises and Emergencies

The report highlights that large numbers of participants reported their views on dying, death and bereavement had changed due to COVID-19. There was a recognition of the importance of planning ahead, particularly among the bereaved participants.

The findings demonstrate that the impact of the pandemic and the public health measures was very challenging for the delivery of quality end-of-life care. The following recommendations are focused on promoting compassionate end-of-life care in the event of future public health crises or emergencies.

In terms of future proofing for quality end of life experiences, more targeted education is needed to equip healthcare professionals to discuss the experience of death and dying.

- **Recommendation 1**

Investment is needed to raise awareness and actively promote the importance of people planning ahead for their wishes at end of life. **Think Ahead** (an IHF resource) is a key tool to support and enable people to plan ahead and it should be available and promoted through agencies supporting people at end of life across all care settings and in the community.

- **Recommendation 2**

In future planning, an emphasis must be placed on the importance of maintaining compassionate end-of-life care which is patient focused with family involvement.

- **Recommendation 3**

All healthcare staff (e.g. reception, porters, cleaners, maintenance, admin, community volunteers), across all care settings, should receive targeted education and continuous training to equip them to deliver quality end-of life and bereavement care.

5.2 Enhance Bereavement Support

This report has highlighted that bereavement supports were not adequate to meet the needs of people during the pandemic but also before the onset of COVID-19. The concerns about the impact of COVID-19 on the grieving process and notably the outcomes for people who were at the sub threshold for Prolonged Grief Disorder (PGD) need closer monitoring.

The impact of COVID-19 on healthcare workers needs to be recognised. There is a need for healthcare staff to have access to specialised bereavement support that acknowledges that they will have ongoing personal and professional grief, not just through public health emergencies.

- **Recommendation 4**

Greater resourcing and investment into the expansion of bereavement support services is required in both primary care and acute care settings.

- **Recommendation 5**

Screening and early intervention should be incorporated into health policy and practices for those who are experiencing PGD or who may be more at risk.

- **Recommendation 6**

Equip health services with appropriate bereavement support services that can be made available to patients and families before, during and after their bereavement.

- **Recommendation 7**

Invest in supports to enable healthcare workers to deal with the impact of personal and professional grief and bereavement in their work.

5.3 Inform Health Policy and Practice

The findings are beneficial for public health officials, healthcare professionals, policymakers, and the public as they highlight gaps in the healthcare system that need more attention.

The report offers important insights into the lived experiences of dying, death, and bereavement during COVID-19, and should be used to inform and facilitate further discussion and planning for future public health crises or emergencies. The findings should be used to inform any future review into the COVID-19 pandemic response in Ireland.

Implementing services such as the **Bereavement Support Line** (an IHF service run in partnership with the HSE) and the **IHF COVID-19 Care & Inform Hub** played an important role early in the pandemic in supporting people through their grief and to navigate challenging end-of-life care experiences. Consideration should be given to how these types of resources and services can be upscaled quickly during future public health emergencies.

● Recommendation 8

The findings from this report must be used to inform future public health responses to similar situations as well as the proposed inquiry into the handling of the COVID-19 pandemic.

● Recommendation 9

In the event of any future public health emergency or pandemic, IHF would welcome early and continuous engagement with public health officials regarding the dying, death and bereavement experience.

5.4 Invest in Future Research

There is consensus in the literature that further research is warranted to explore the longer-term impacts of people's experiences during the pandemic. This should include large population-based samples, as well as studies that focus on more specialised groups (e.g., migrant healthcare staff, marginalised communities, older adults, children, people who were bereaved during COVID-19). The limitations noted in this report (see Discussion Section 4.6) should be seen as opportunities to build on this work.

● Recommendation 10

More studies to explore the impact on healthcare workers, and in particular subgroups like migrant staff, to help identify coping strategies and necessary supports required in the event of future global health crises.

● Recommendation 11

Explore the different bereavement experiences, in particular people who were at the sub-threshold of PGD to further inform public health responses and practices.

6. Appendices

Table 2	Demographic Characteristics of Total Study Sample
Table 3	Primary Cause of Death Reported by Participants
Table 4	Health and Wellbeing of Bereaved vs Non-Bereaved Participants
Table 5	Health and Wellbeing of Healthcare Workers vs Other Survey Participants
Table 6	Perceptions of Dying, Death, and Bereavement since the COVID-19 Pandemic
Table 7	End-of-Life Care During the COVID-19 Pandemic
Table 8	Experiences Before the Death of a Loved One
Table 9	Impact of COVID-19 on Funerals and Mourning Rituals
Table 10	Experiences After the Death of a Loved One
Table 11	Brief Grief Questionnaire Scores and Relationship to Deceased

Table 2: Demographic Characteristics of Total Study Sample

Variable	(All Participants)	
	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%

Table 2: Demographic Characteristics of Total Study Sample (continued)

Variable	(All Participants)	
	N	%
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%

Table 3: Primary Cause of Death Reported by Participants

Variable	(All Participants)	
	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%

Table 4: Health and Wellbeing of Bereaved vs Non-Bereaved Participants

Variable	Bereaved During Pandemic							T	P
	Yes			No					
	N	M	SD	N	M	SD			
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.

Table 5: Health and Wellbeing of Healthcare Workers vs Other Survey Participants

Variable	Healthcare Worker							T	P
	Yes			No					
	N	M	SD	N	M	SD			
Health Status	333	4.29	.75	1304	c	.88	-5.70	c	
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.

Table 6: 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 greater awareness of grief and loss	2247	96 (4.3%)	154 (6.9%)	485 (21.6%)	902 (40.1%)	610 (27.1%)
Because of the pandemic I have given more thought to my own end-of-life wishes	2243	138 (6.2%)	344 (15.3%)	712 (31.7%)	753 (33.6%)	296 (13.2%)

Table 7: 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%)

Table 8: 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 was negatively affected by COVID-19	1130	718 (63.5%)	258 (22.8%)	115 (10.2%)	14 (1.2%)	25 (2.2%)
I was able to spend the time I wanted with them <u>before</u> 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%)

Table 9: 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%)

Table 10: Experiences After the Death of a Loved One

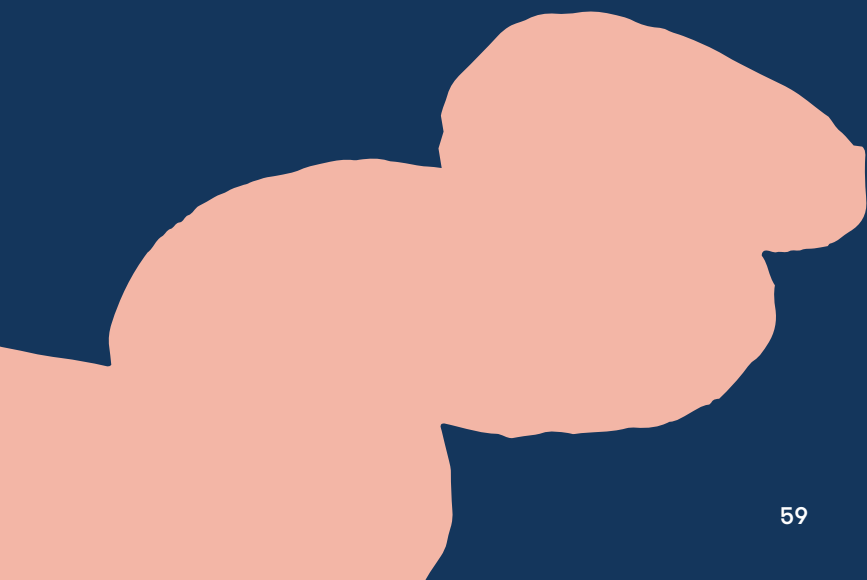
	Responses N (%)					
	N	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The Impact of COVID-19 made my grief more difficult	1086	280 (25.8%)	411 (37.8%)	253 (23.3%)	83 (7.6%)	59 (5.4%)
Even with restrictions, my family and friends have found meaningful ways to support me in 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%)

Table 11: Brief Grief Questionnaire Scores and Relationship to Deceased

Relationship	BGQ Category						X ² (22)	P
	Sub-threshold PGD							
	No PGD indicated N = 639		Sub-threshold PGD indicated N = 279		PGD indicated N = 152			
	N	%	N	%	N	%		
Parent/Step Parent (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.







Irish Hospice Foundation,
Morrison Chambers,
32 Nassau Street,
Dublin 2,
D02 X627.

hospicefoundation.ie
info@hospicefoundation.ie

Registered Charity Number 20013554.

