A Human Rights based approach for Palliative Care:
Towards Solutions for Public Health Palliative Care

3rd International Research Seminar
AIIHPC and EAPC Reference Group on
Public Health and Palliative Care

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The Financial Impact of Bereavement in Ireland

Irish Hospice Foundation
To die and grieve well wherever the place

Avril Easton, Irish Hospice Foundation, Dr Amanda Roberts, Irish Hospice Foundation, Orla Keegan, Irish Hospice Foundation and Dr Caroline Dalton, UCC

Background to the study

Bereavement is an experience that will affect most people in their lifetime.

The costs of bereavement are multidimensional, multifactorial and intertwined. For some the impacts are temporary, for others they are significant impacting on their ability and capacity to continue with daily life.

This is the first study in Ireland examining the financial impact of bereavement, from funeral costs to longer-term impacts on health, employment and a person's wellbeing.

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Quantitative Study

Undertaken by Europe Economics (May 2021)

- Literature review on the various impacts of bereavement
- Scoping review of relevant quantitative datasets
- Nationally representative survey sample of 1,000 adults

Qualitative Study

Undertaken by UCC (Feb 2022)

Research Advisory Group

Chair	Ita Mangan
Alone	Andrew Rooney
Citizen Information Service	Joan O'Connor
Department of Social Protection	Ciaran Diamond
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European Anti Poverty Network	Paul Ginnell
Irish Association of Social Workers	Dr Annemarie Jones
	Rachel Colvin
Irish Hospice Foundation	Sharon Foley
	Orla Keegan
	Angela Edghill
MABS	Annemarie O'Connor
	Nicola Fox
National University of Ireland, Galway	Prof Eamon O'Shea
Social Justice Ireland	Colette Bennett
St Vincent De Paul	Dr Tricia Keilthy

1000
Full sample

684
Bereaved

- Funeral costs
- Payment of funeral
- Difficulties paying
- Support accessed
- Direct financial impacts
- Employment impacts
- Health impacts

- Comfortable talking about death and dying
- Knowledge of the costs of a funeral
- Awareness of the different financial supports available
- Planning ahead
- Attitudinal questions

310
Non-bereaved

367
Bereaved/Organised a funeral

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Demographics of the qualitative study

1

Bereaved individuals:

Over the age of 18

Economically impacted by bereavement in the last three years

By a variety of costs

2

Professionals:

Work for a service providing support to bereaved individuals

Have supported a bereaved person, who has been economically impacted, within the past three years

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Financial Impact of Bereavement

- Impact of not planning ahead
- Funeral Costs
- Household Costs
- Impact on Employment
- Health Related Issues

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Impact of not planning ahead

- 40% (of 1000) of participants did not discuss with someone what they would like to happen after they die
- 27% have put in place financial plans for their own funeral
- 60% of bereaved people paid for the funeral estate through their loved ones estate or money earmarked for the funeral

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1000
Full sample

Understanding of funeral costs

- The national survey did not seek to quantify the actual costs of organising a funeral, rather it sought to explore the public's understanding and experiences of funeral costs

- Over half of respondents expected a funeral to cost at least €5,000, taking everything into account, €5,500 was the average estimated response

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The importance of “doing the right thing”

84% of those surveyed believed that **no-one should get into debt** to pay for a funeral

BUT nearly as (75%) felt there was a lot of pressure to provide a **‘decent’ funeral**

Almost 40% of all the survey participants believe that it is a **family’s responsibility** to be able to withstand any financial hardship resulting from the cost of a loved one’s funeral.

Over a quarter (28%) of the survey respondents said that they would **prefer to take out a private loan**, rather than seek assistance from Government or a charity

1000
Full sample

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Funeral culture

"It's got that real import[ance] to it that if you get yourself into debt well, at least ya got the send-off done ya know? I think that's quite important for a lot of people irrespective of background and culture" (FG)

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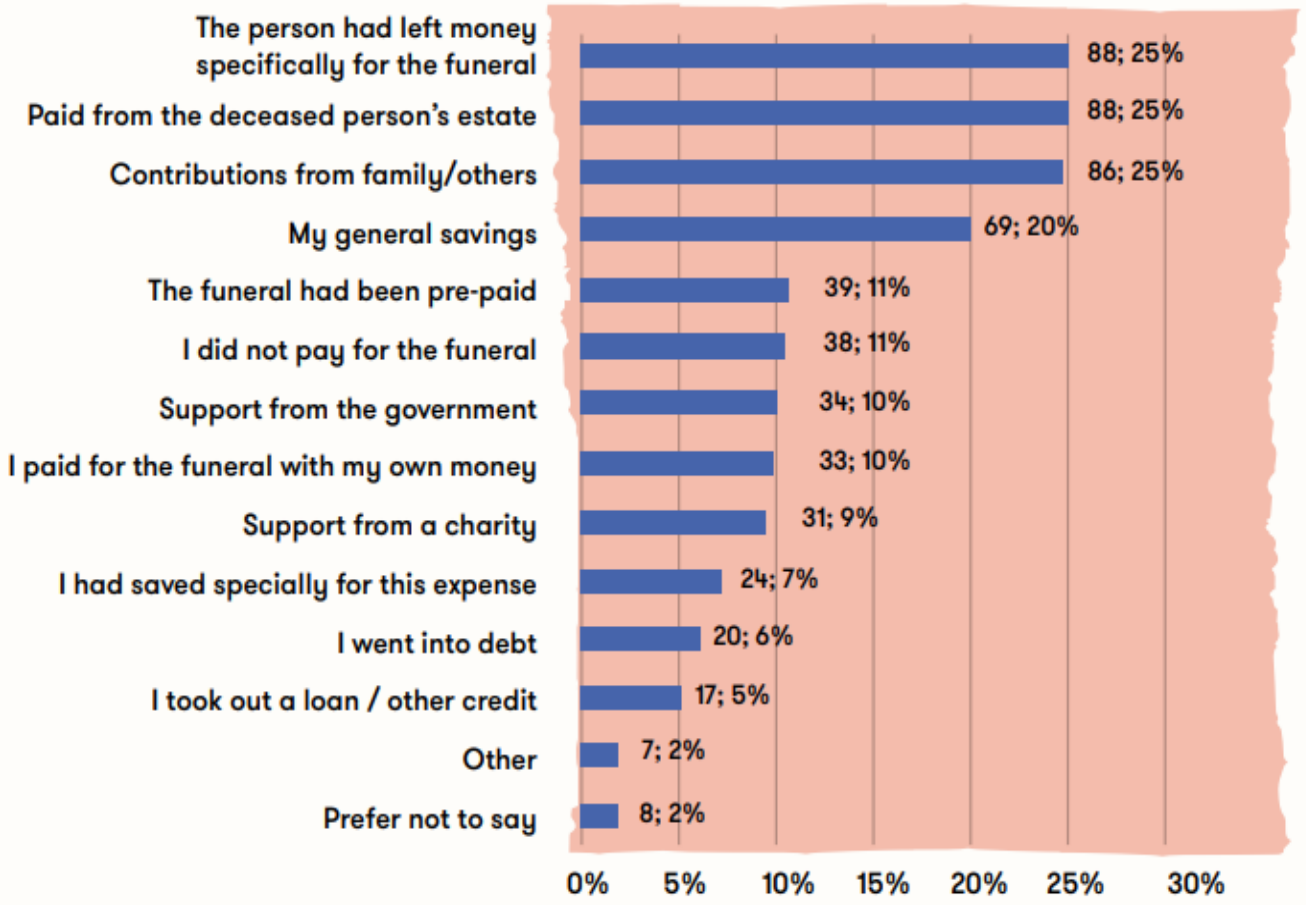
Where does the money come from?

Over 60% of bereaved people paid for the funeral from the **deceased person's estate**

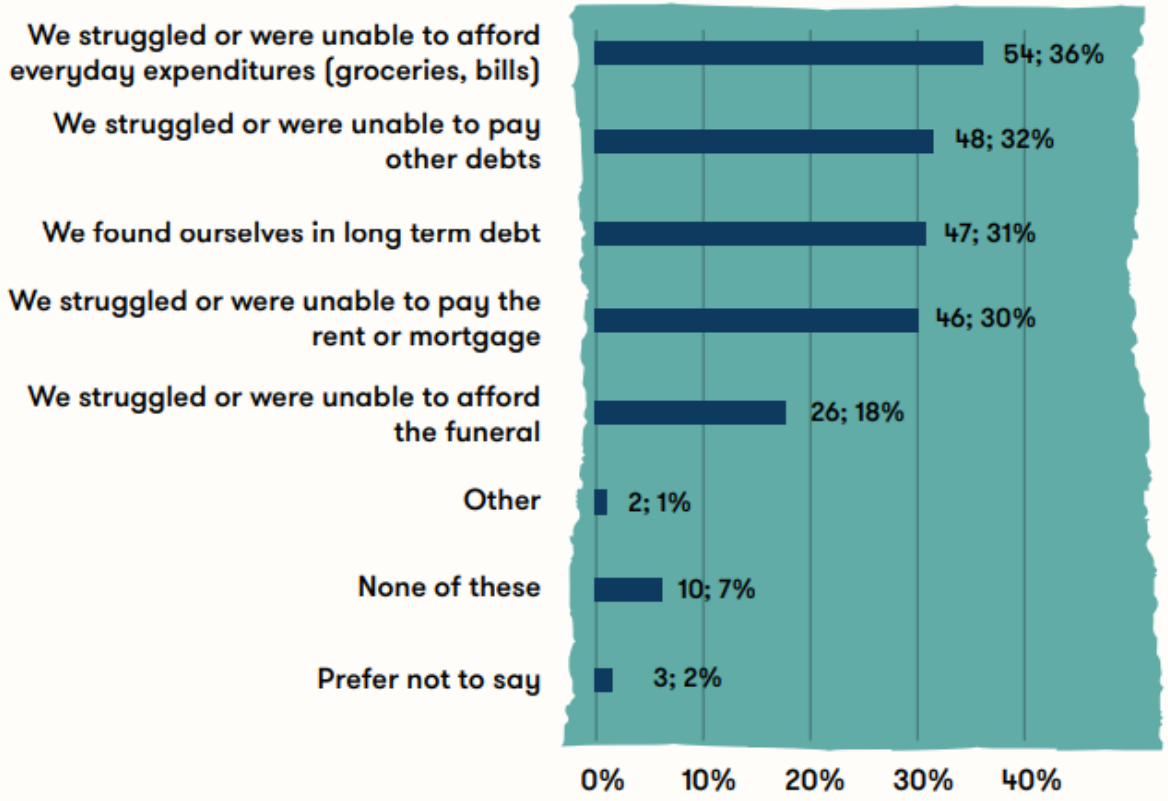


684
Bereaved

Base: All respondents who have experienced a bereavement in the last three years (684). **Note:** Respondents could select multiple responses. **Source:** *"The Economic Impacts of Bereavement in Ireland"*, page 47 of Europe Economics, May 2021.

Impact of bereavement on household costs

One in five participants (22%) who had experienced a bereavement (n = 151 / 684), faced **financial challenges** as a result



Base: All respondents who have experienced other types of financial impact (151). **Note:** Respondents could select multiple responses. **Source:** *"The Economic Impacts of Bereavement in Ireland"*, page 55 of Europe Economics, May 2021.

Impact of bereavement on household costs

"Unfortunately, with a lot of these things if you're unaware of it you could end up never getting it, there's no one to tell ya about it" (FG)

People are unaware of the social protection supports available

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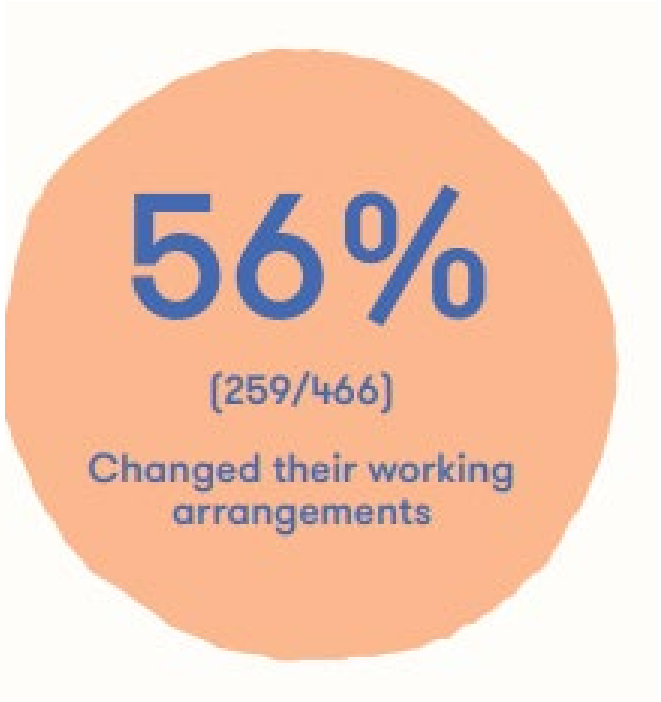
Impact of bereavement on employment



67% of **all survey respondents** said they were aware of people who have struggled to perform or be productive in work following the death of a loved one

Reasons given for **changing work arrangements** included (n=259):

- Needing time to grieve (43%)
- To care for their emotional/mental health (36%)

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Impact of bereavement on health

- 37% (256/684) of bereaved survey respondents said that it had affected their health

- Of those whose health was affected (n=256);
  - Mental health, 23%
  - Social isolation, 16%
  - Physical health, 10%
  - 1 in 3 required some form of treatment
  - 3 in 5 reported that these health issues had a financial impact on their life

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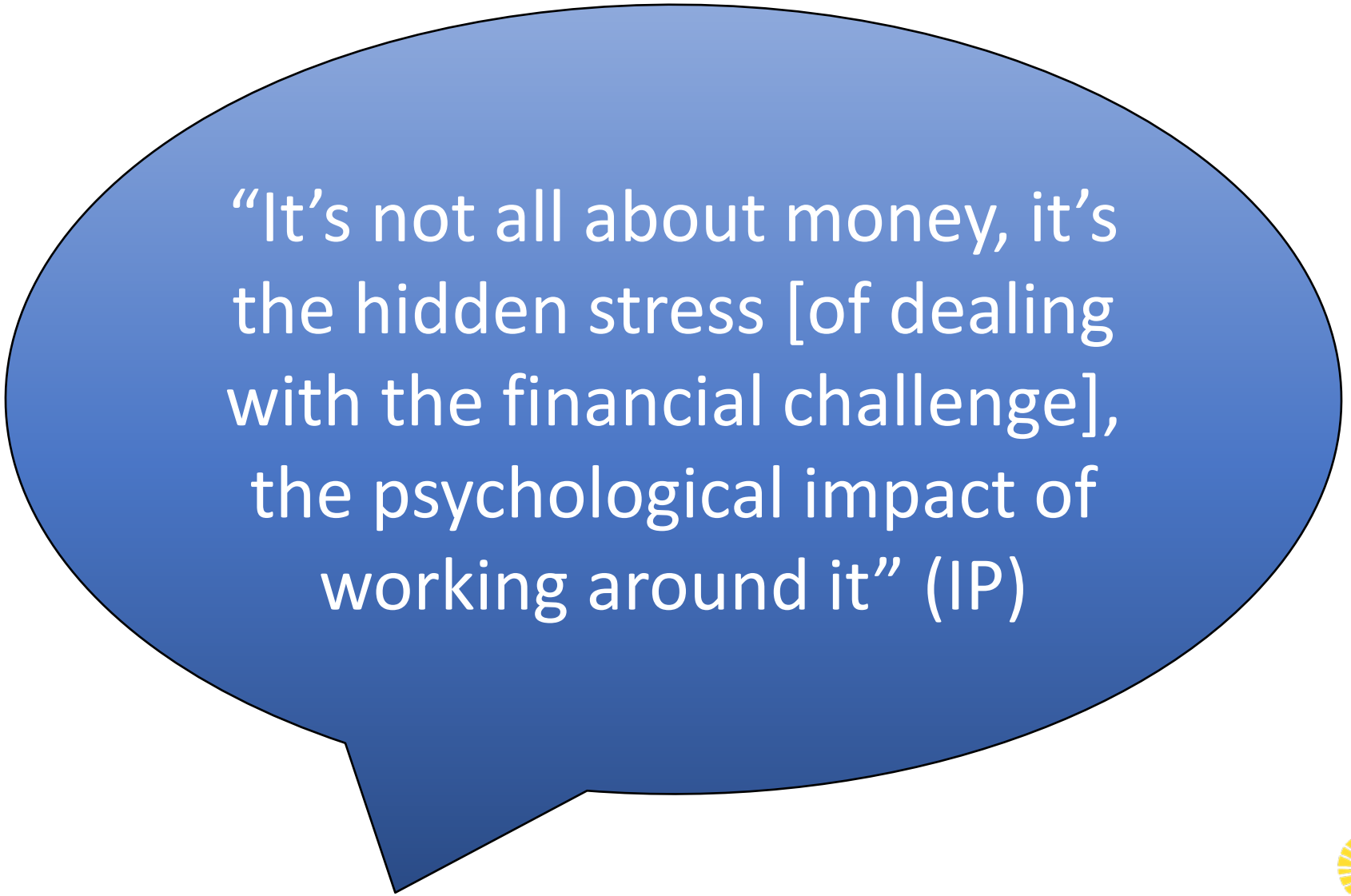
Impact of bereavement on health



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Context for Recommendations

Recommendations assimilate and consider the findings from:

- Quantitative and qualitative studies
- Literature reviews
- Scoping of datasets
- Irish Hospice Foundation's 30 years experience of working in bereavement care
- Knowledge and expertise of the Research Advisory Group

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Key recommendations - Policy

1. National policy on bereavement

- Lack of any sort of coherent national policy on bereavement in Ireland
- Report highlights the cross-cutting impact of bereavement
- Whole of Government approach is needed
- Adult Bereavement Care Pyramid could be used as a framework

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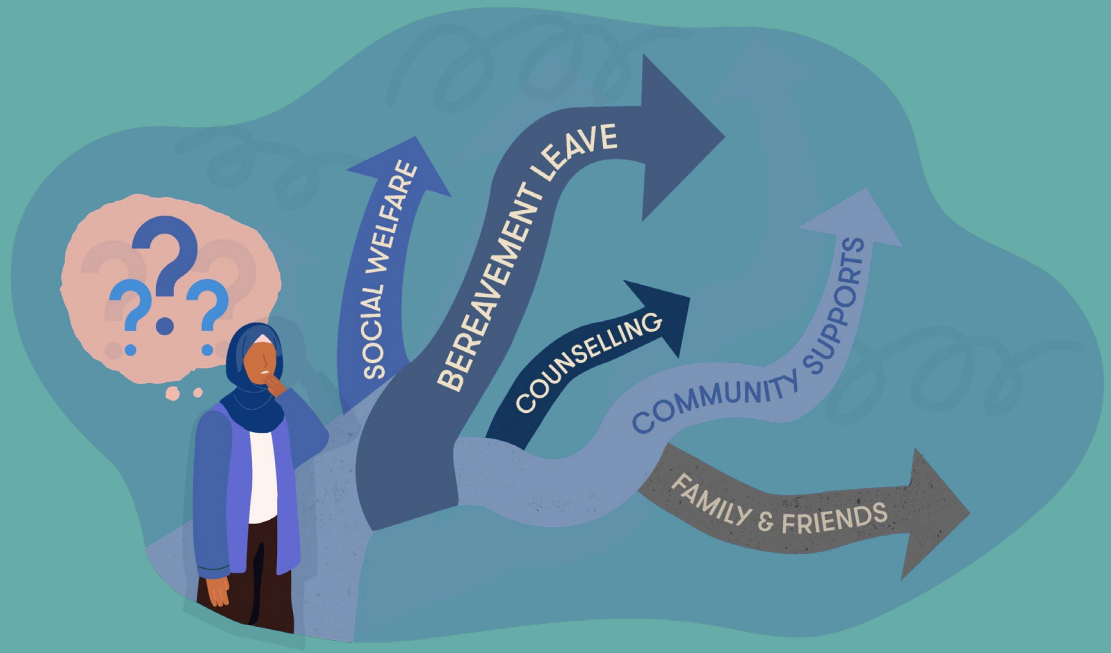
Key recommendations - Practice

2. Signposting people to bereavement supports available

3. Review of the knowledge & communication about Exceptional Needs Payment (ENP)

4. Transparency of funeral costs

5. Statutory bereavement leave



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Key recommendations - Research

6. **Impact of bereavement on specific population groups**
    - Family carers
    - Families - left without an income and those with young children
    - Pensioners
    - Migrant communities
7. **Research using existing databases**

8. **Adding questions to existing databases**

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Reflecting on Bereavement during Covid-19: using survey data from Ireland to examine public health implications

Orla Keegan, Avril Easton, Elizabeth Weathers, Helen Coughlan

3rd International Research Seminar, AIIHPC and EAPC Reference Group on Public Health Palliative Care, November 16th 2023

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What is a public health approach to bereavement care?

Level of public health interventions	Levels of risk or need	Type of support	Support provided by	Target population and level of support needed
Universal	1	Information about bereavement and relevant supports	Family and friends (information supplied by health and social care professionals)	All bereaved (normal grief) Low need
Selective or Targeted	2	Non-specialist support	Trained volunteers, mutual-help groups, community supports	Those at-risk of developing complex needs Moderate need
Indicated	3	Professional specialist interventions	Mental health services, bereavement services, or psychotherapy	Those with complex needs High need

(Aoun et al, 2012)

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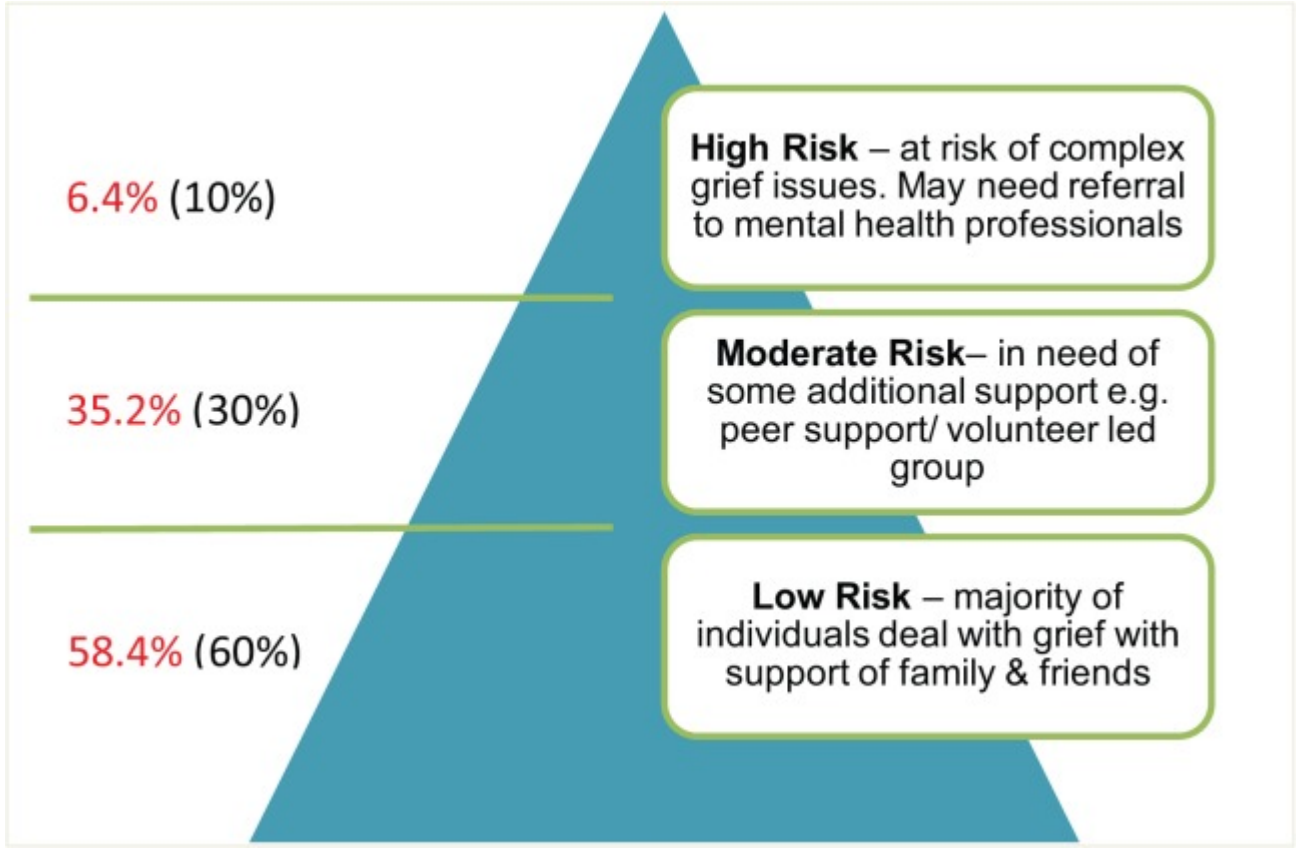
Public health model of bereavement , Aoun et al, 2015



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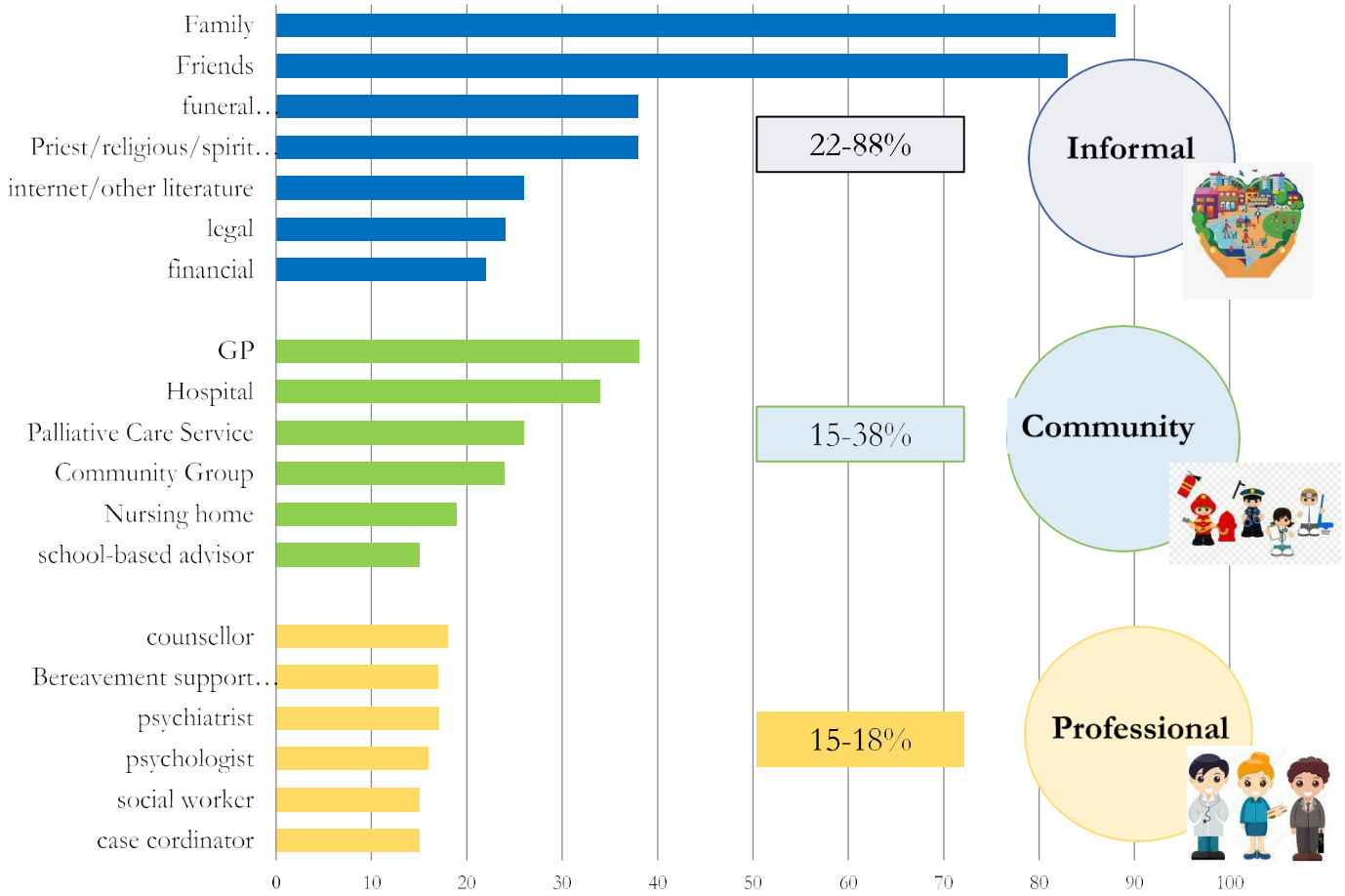
Support accessed after the death (n=767, full sample)



Aoun et al, 2020

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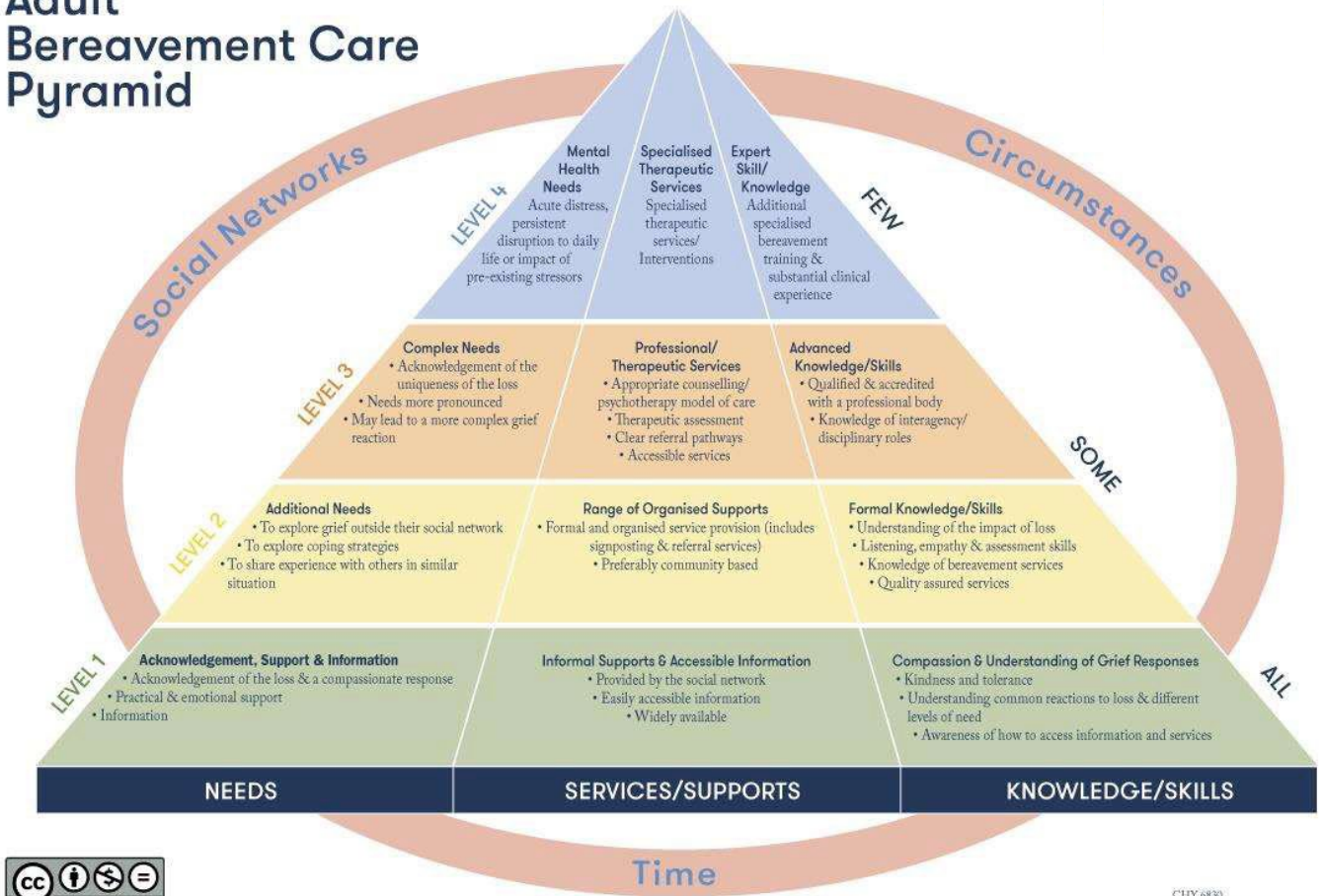
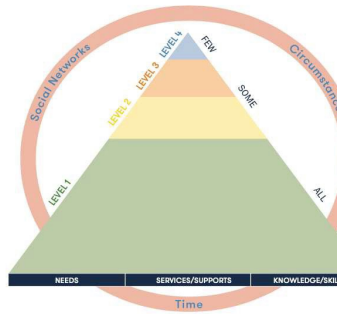
Adult Bereavement Care Pyramid





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Background

- Reference to a ‘tsunami of grief’ has not necessarily helped in understanding the diversity and nuance of bereavement.
- Some surveys[1,2] describe elevated needs, others show adaptation in grief[3] .
- A public health model emphasises risk factors, strengths & levels of support[4].

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Objectives

- Describe the impact of bereavement during two years of Covid-19 restrictions.

- Review bereavement experiences during Covid-19 with respect to a public health model

Methods

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Time to Reflect:
a survey about life, death and bereavement during a pandemic

Every story counts. Share yours.

- Survey; online and paper
- Nov 2021 to Feb 2022
- Categorical and scaled questions, open-ended questions - Experiences and personal attitudes to death, dying and bereavement during Covid
- Validated screening scale Brief Grief Questionnaire

- Analysis:
- Frequencies
- Non parametric statics for association
- Thematic analysis

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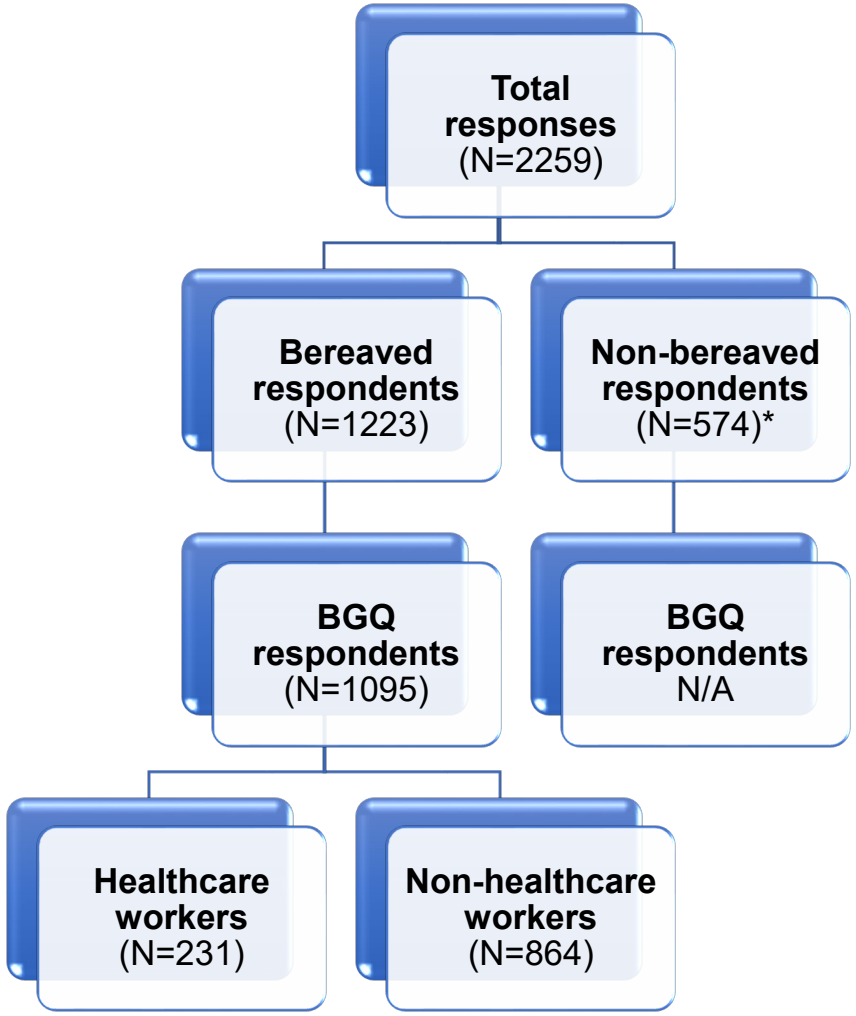
Sample



Bereaved individuals responding to the survey were slightly older than non-bereaved individuals (49 years old, SD + 14.9, p<0.03) More women (69%) than men (29.5%). Chi sq 8.95, p 0.03

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Place and cause of death

Table 1. 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%**

Table 1. 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%

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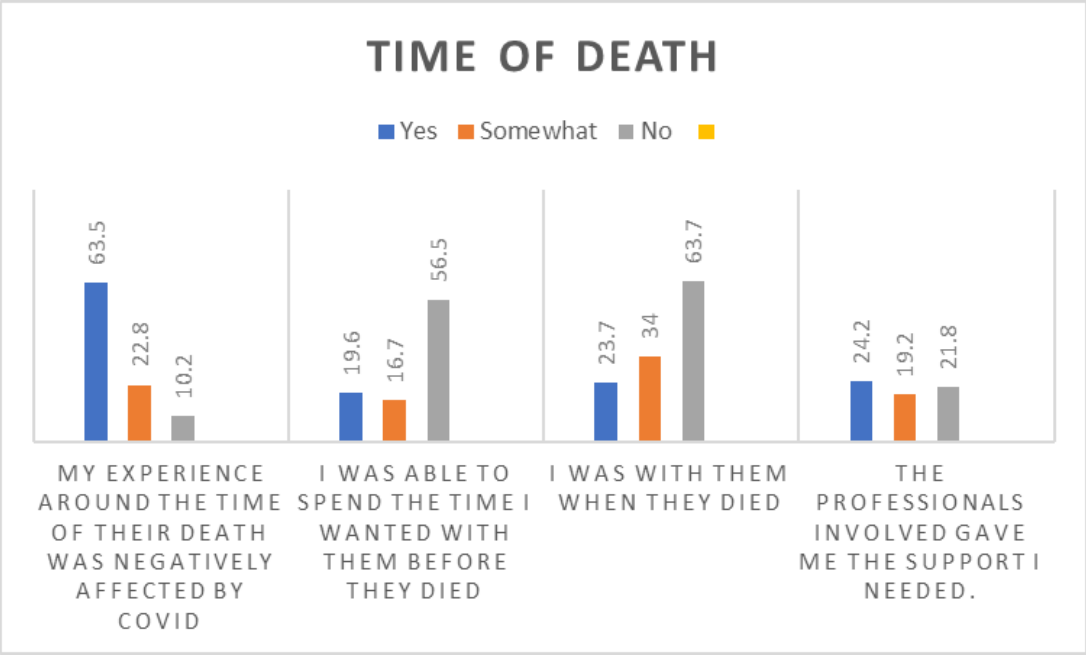
Results 1: Time of death



- Most people say their experience was negatively affected by Covid-19
- Less than one in five were able to spend the time they wanted before the death
- Less than one in four were with the person when they died
- One in five bereaved people said they did not get the support they needed from professionals

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- *“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.”*

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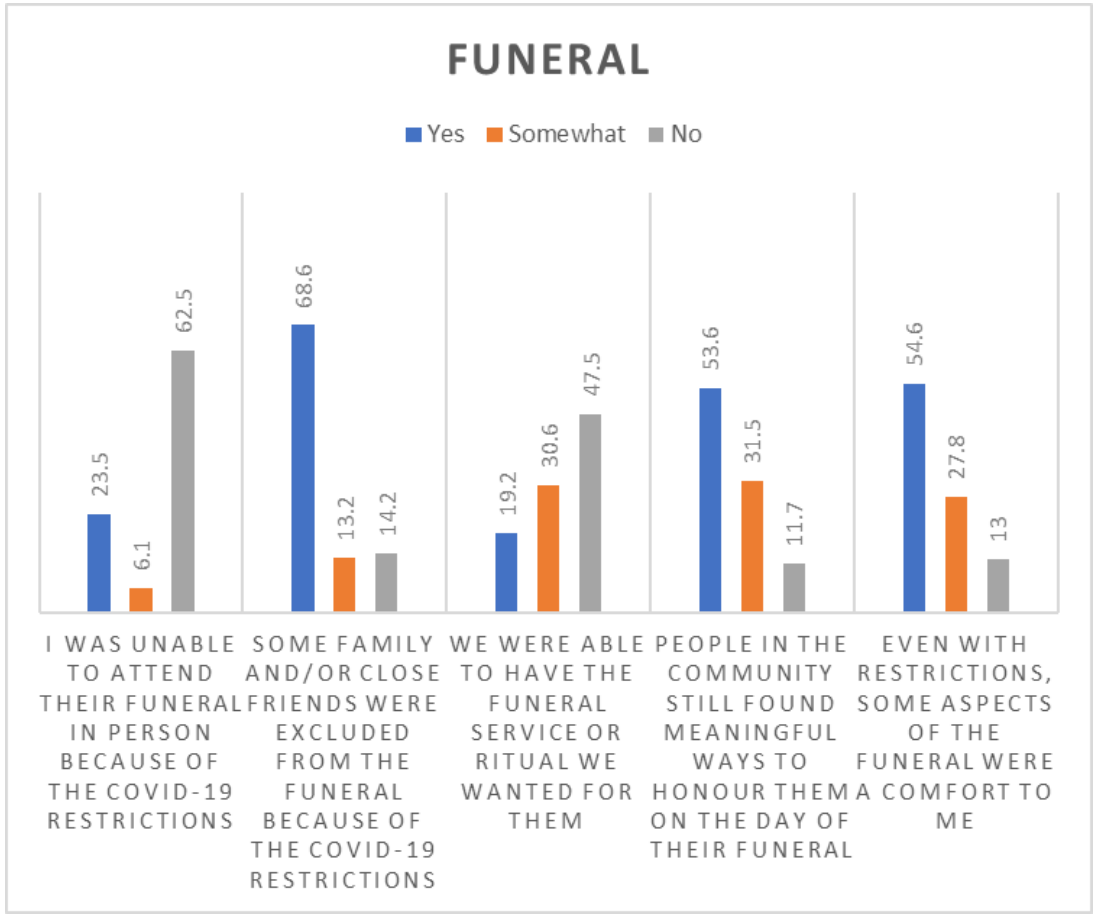
Results 2: Funeral/ritual



- Almost two thirds of respondents were able to attend the funeral
- Over two thirds said family and close friends were excluded

- While under half said they did not have the funeral ritual they wanted….
- …most noted that people in the community found ways to honour the person who died on the funeral day and said some aspects of the funeral were a comfort

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- *““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.”*

- *.“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.”*

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Grief

- Over 60% of participants (N=691) stated that the pandemic made their grieving process more difficult
- 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

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- *"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."*

- *"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."*

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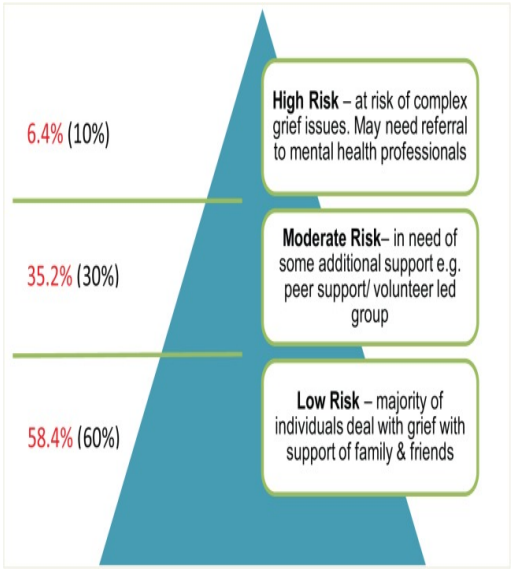
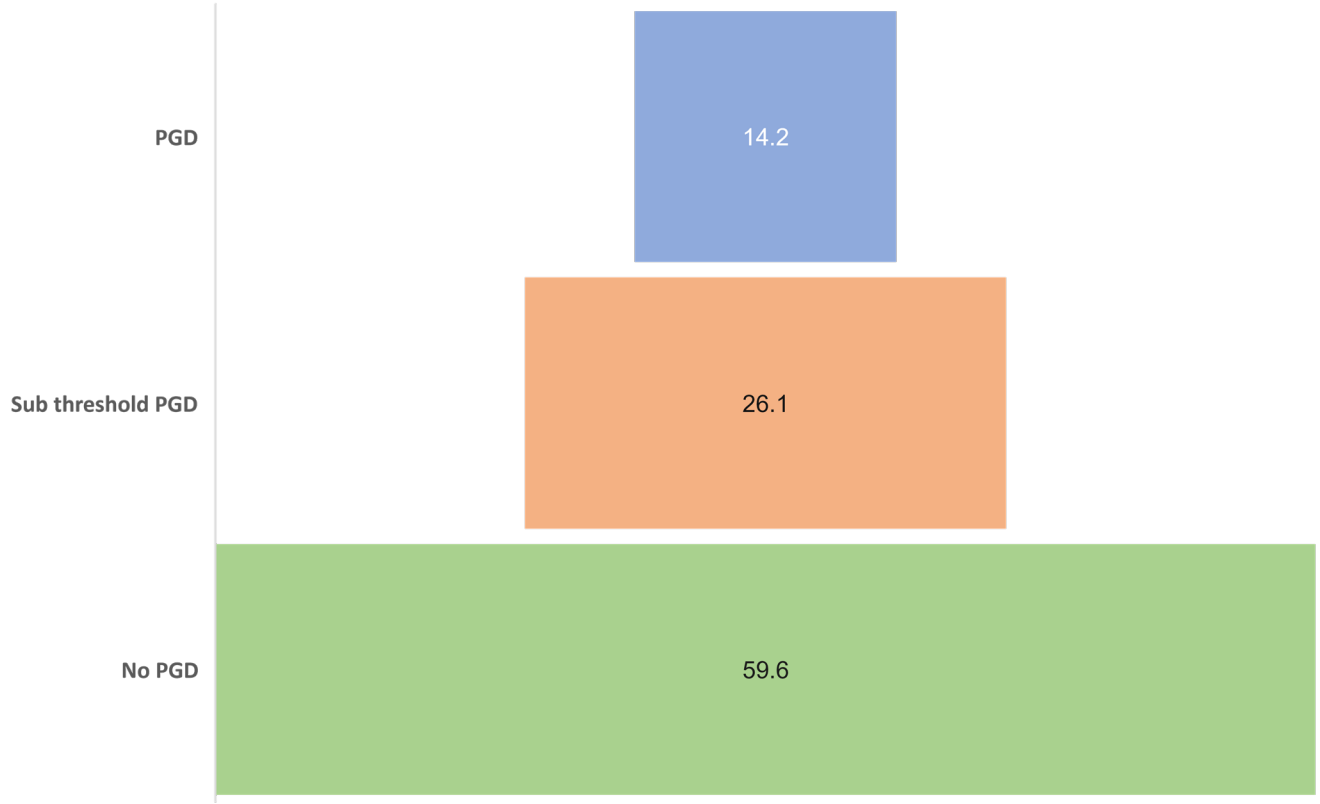


Prolonged Grief Disorder risk using Brief Grief Questionnaire (%)



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Associations with BGQ categories

- Cause of death — X^2 91.78 p0.79
- Location of death — X^2 18.88 p .275
- **Relationship to deceased** — **X^2 137.50 p <.001****

- **Present at the time of death** — **X^2 47.8 p<.001*****
- **Covid prevented the death they would have wanted** — **X^2 32.67 p<.001*****

- Able to have the funeral we wanted — X^2 3.41 p.491

- **Didn't get the support I needed due to Covid-19 restrictions** — **p.05***

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Conclusions

- Lower PGD levels than indicated in some studies
- Inclusion of sub-threshold levels for risk identification
- Presence at the death – reasons for association with PGD
- Those who say they have not had the support they need are those most at risk – self assessment/ referral

- Evidence of resilience and impactful social support at time of funeral and in grief

- Both the dynamics and proportions of the Public Health Model for bereavement evident in this data

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- 2 Selman, L. E., Farnell, D. J. J., Longo, M., Goss, S., Torrens-Burton, A., Seddon, K., Mayland, C. R., Machin, L., Byrne, A., & Harrop, E. J. (2022). Factors Associated With Higher Levels of Grief and Support Needs Among People Bereaved During the Pandemic: Results from a National Online Survey. Omega, 302228221144925. https://doi.org/10.1177/00302228221144925
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- 5 Shear, K. M., Jackson, C. T., Essock, S. M., Donahue, S. A., & Felton, C. J. (2006). *Brief Grief Questionnaire* [Database record]. APA PsycTests. https://doi.org/10.1037/t62516-000
- 6 Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

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