

Exploring bereavement and public health: the role of family and friend caregivers in community well-being

Edited by

Toni P. Miles, Wendy G. Lichtenthal, Clare Killikelly,
Lauren Jennifer Breen and Don Lollar

Published in

Frontiers in Public Health



FRONTIERS EBOOK COPYRIGHT STATEMENT

The copyright in the text of individual articles in this ebook is the property of their respective authors or their respective institutions or funders. The copyright in graphics and images within each article may be subject to copyright of other parties. In both cases this is subject to a license granted to Frontiers.

The compilation of articles constituting this ebook is the property of Frontiers.

Each article within this ebook, and the ebook itself, are published under the most recent version of the Creative Commons CC-BY licence. The version current at the date of publication of this ebook is CC-BY 4.0. If the CC-BY licence is updated, the licence granted by Frontiers is automatically updated to the new version.

When exercising any right under the CC-BY licence, Frontiers must be attributed as the original publisher of the article or ebook, as applicable.

Authors have the responsibility of ensuring that any graphics or other materials which are the property of others may be included in the CC-BY licence, but this should be checked before relying on the CC-BY licence to reproduce those materials. Any copyright notices relating to those materials must be complied with.

Copyright and source acknowledgement notices may not be removed and must be displayed in any copy, derivative work or partial copy which includes the elements in question.

All copyright, and all rights therein, are protected by national and international copyright laws. The above represents a summary only. For further information please read Frontiers' Conditions for Website Use and Copyright Statement, and the applicable CC-BY licence.

ISSN 1664-8714
ISBN 978-2-8325-7595-6
DOI 10.3389/978-2-8325-7595-6

Generative AI statement

Any alternative text (Alt text) provided alongside figures in the articles in this ebook has been generated by Frontiers with the support of artificial intelligence and reasonable efforts have been made to ensure accuracy, including review by the authors wherever possible. If you identify any issues, please contact us.

About Frontiers

Frontiers is more than just an open access publisher of scholarly articles: it is a pioneering approach to the world of academia, radically improving the way scholarly research is managed. The grand vision of Frontiers is a world where all people have an equal opportunity to seek, share and generate knowledge. Frontiers provides immediate and permanent online open access to all its publications, but this alone is not enough to realize our grand goals.

Frontiers journal series

The Frontiers journal series is a multi-tier and interdisciplinary set of open-access, online journals, promising a paradigm shift from the current review, selection and dissemination processes in academic publishing. All Frontiers journals are driven by researchers for researchers; therefore, they constitute a service to the scholarly community. At the same time, the *Frontiers journal series* operates on a revolutionary invention, the tiered publishing system, initially addressing specific communities of scholars, and gradually climbing up to broader public understanding, thus serving the interests of the lay society, too.

Dedication to quality

Each Frontiers article is a landmark of the highest quality, thanks to genuinely collaborative interactions between authors and review editors, who include some of the world's best academicians. Research must be certified by peers before entering a stream of knowledge that may eventually reach the public - and shape society; therefore, Frontiers only applies the most rigorous and unbiased reviews. Frontiers revolutionizes research publishing by freely delivering the most outstanding research, evaluated with no bias from both the academic and social point of view. By applying the most advanced information technologies, Frontiers is catapulting scholarly publishing into a new generation.

What are Frontiers Research Topics?

Frontiers Research Topics are very popular trademarks of the *Frontiers journals series*: they are collections of at least ten articles, all centered on a particular subject. With their unique mix of varied contributions from Original Research to Review Articles, Frontiers Research Topics unify the most influential researchers, the latest key findings and historical advances in a hot research area.

Find out more on how to host your own Frontiers Research Topic or contribute to one as an author by contacting the Frontiers editorial office: frontiersin.org/about/contact

Exploring bereavement and public health: the role of family and friend caregivers in community well-being

Topic editors

Toni P. Miles – Carter Center, United States

Wendy G. Lichtenthal – University of Miami, United States

Clare Killikelly – University of Zurich, Switzerland

Lauren Jennifer Breen – Curtin University, Australia

Don Lollar – Oregon Health and Science University, United States

Citation

Miles, T. P., Lichtenthal, W. G., Killikelly, C., Breen, L. J., Lollar, D., eds. (2026). *Exploring bereavement and public health: the role of family and friend caregivers in community well-being*. Lausanne: Frontiers Media SA. doi: 10.3389/978-2-8325-7595-6

Dr. Toni Miles declares the following conflicts of interest: (1) Rosalynn Carter Institute for Caregivers, Pope Eminent Scholar-In-Residence, (2) Member, Alliant Health Center of Excellence for Behavioral Health in Nursing Facilities Technical Expert Panel, (3) Altarum, Population Health, Consultant, (4) Member, Convergence Older Adults & Healthy Aging Working Group, (5) Frontiers in Public Health, One of several section editors.

Dr. Wendy Lichtenthal declares the following conflicts of interest: (1) Inventor of Meaning-Centered Grief Therapy, (2) Inventor of EMPOWER, (3) Owner of Light in the Valley LLC, (4) Partner in PsyOnc Partners LLC, (5) Previously involved with Blue Note Therapeutics. The other Topic Editors declare no other competing interests with relation to this topic theme.

Table of contents

- 04 **Editorial: Exploring bereavement and public health: the role of family and friend caregivers in community well-being**
Toni P. Miles, Wendy G. Lichtenthal, Clare Killikelly, Lauren J. Breen and Don Lollar
- 07 **Trajectory patterns and influencing factors of depression due to child bereavement among older adults in China: a 5-year longitudinal study**
Li Chen, Zhangyi Wang, Qiaoyan Wu and Xiaochun Tang
- 17 **Risk of mental health conditions in bereavement: a population-based analysis of lung cancer spouses**
Djin L. Tay, Kline Dubose, Jonathan Chipman, Lee Ellington, Malek Alnajjar, Eli Iacob, Caroline Stephens and Katherine A. Ornstein
- 27 **Men's experiences of suicide bereavement: a qualitative study of psychosocial impacts and coping**
Karl Andriessen, Nina Logan, Shelley-Anne Ball, Tim De Goey, Dianne Currier and Karolina Krysinska
- 38 **Experiences and needs of family members of perinatal infant deaths: a meta-synthesis**
Nana Cui, Shasha Wu, Xiaoyun Wang and Lei Sheng
- 48 **Grief trajectories and long-term health effects in bereaved relatives: a prospective, population-based cohort study with ten-year follow-up**
Mette Kjærgaard Nielsen, Kaj Sparle Christensen, Mette Asbjørn Neergaard, Pernille Envold Bidstrup and Mai-Britt Guldin
- 58 **Correction: Grief trajectories and long-term health effects in bereaved relatives: a prospective, population-based cohort study with ten-year follow-up**
Mette Kjærgaard Nielsen, Kaj Sparle Christensen, Mette Asbjørn Neergaard, Pernille Envold Bidstrup and Mai-Britt Guldin
- 60 **Understanding family caregiving and well-being in adult chronic illness: a call for a more comprehensive perspective**
Bettina Schwind, Rosa Visscher, Jörg Haslbeck, Thomas Falkenstein, Christina Riewoldt, Lennert Griese, Birgit Behrisch, Sabine Metzinger and Martin Nagl-Cupal
- 67 **Reciprocal regulation in social support interactions between bereaved parents and their potential supporters: a qualitative study**
Josephine Tognela, Lauren J. Breen and Daniel Rudaizky
- 80 **A public health model for bereavement care: learnings from COVID-19 bereavement experiences in Ireland**
Elizabeth Weathers, Fankun Cao, Helen Coughlan, Avril Easton and Orla Keegan



OPEN ACCESS

EDITED AND REVIEWED BY
Wulf Rössler,
Charité University Medicine
Berlin, Germany

*CORRESPONDENCE

Toni P. Miles
✉ tonimile@uga.edu

RECEIVED 25 January 2026
ACCEPTED 26 January 2026
PUBLISHED 18 February 2026

CITATION

Miles TP, Lichtenthal WG, Killikelly C,
Breen LJ and Lollar D (2026) Editorial:
Exploring bereavement and public
health: the role of family and friend
caregivers in community well-being.
Front. Public Health 14:1795849.
doi: 10.3389/fpubh.2026.1795849

COPYRIGHT

© 2026 Miles, Lichtenthal, Killikelly,
Breen and Lollar. This is an open-access
article distributed under the terms of the
[Creative Commons Attribution License
\(CC BY\)](#). The use, distribution or
reproduction in other forums is
permitted, provided the original author(s)
and the copyright owner(s) are credited
and that the original publication in this
journal is cited, in accordance with
accepted academic practice. No use,
distribution or reproduction is permitted
which does not comply with these terms.

Editorial: Exploring bereavement and public health: the role of family and friend caregivers in community well-being

Toni P. Miles^{1,2*}, Wendy G. Lichtenthal³, Clare Killikelly⁴,
Lauren J. Breen⁵ and Don Lollar⁶

¹Carter Center, Mental Health and Caregiver Program, Atlanta, GA, United States, ²University of Georgia, Athens, GA, United States, ³University of Miami Miller School of Medicine, Miami, FL, United States, ⁴Universität Zurich, Zurich, Switzerland, ⁵Curtin School of Population Health and Curtin enAble Institute, Curtin University, Perth, WA, Australia, ⁶Professor Emeritus, Department of Public Health, Oregon Health & Sciences University, Portland, OR, United States

KEYWORDS

bereavement—life change events—prevention, caregivers, culture and mental health, policy, population, prolonged grief disorder (PGD), public health

Editorial on the Research Topic

[Exploring bereavement and public health: the role of family and friend caregivers in community well-being](#)

The circle of bereavement after the deaths of family and friends broadly influences societal health (1, 2). As yet, no public health surveillance systems quantify bereavement at population or geographic scales. This is a huge gap in our understanding of population health factors. Consider the course of bereavement among family caregivers. They are a group who is largely unseen in their grief, both before and after the death of the care recipient. With an intentional research focus on bereavement, their needs as well as those of the broader society could be met with effective and timely care for the emotional distress and declines in physical health. Bereavement is a global issue shaped by cultural and local practices (3). The support of bereaved populations requires a broader frame for research questions, study designs that incorporate qualitative and quantitative methods, and a longitudinal perspective. This collection of papers is designed to encourage scaling by showing research designed to fill these gaps. With this Research Topic “Exploring bereavement and public health: the role of family and friend caregivers in community well-being”, we recruited studies that highlight the public health implications of bereavement beyond individual grief. As seen through the lens of caregiver bereavement, public health must develop strategies to overcome the challenges faced by caregivers and their communities and address their underrepresentation in the work of researchers, funding agencies, and policymakers (4). To achieve this goal, we sought to draw attention to the essential roles of caregivers and emphasize the impacts of caregiving and bereavement on caregivers’ mental, physical, and social well-being. In doing so, we hope to amplify the importance of efforts to enhance the overall well-being of caregivers and create stronger support networks for those experiencing the loss of the persons in their care.

In recognition of this reach, Frontiers in Aging & Public Health partnered with Frontiers in Public Mental Health to promote this series. Grief is universal, and thus an international matter. This recognition formed the basis for selection of the articles

selected for inclusion. The eight articles in this collection provide readers with a glimpse of this broader landscape. A second volume is currently under development. Forty-five authors from across the globe contributed their research. The larger community showed their interest in this topic with 29,876 article views and 3,794 downloads to date.

Weathers et al. showed that 54% of 2,259 adults in Ireland surveyed in 2021 and 2022 reported having experienced one or more losses during the COVID-19 pandemic. Of these, 14% met criteria for prolonged grief disorder and 26% indicated sub-threshold prolonged grief disorder, leading the authors to conclude that the findings provide support for public health models of bereavement care.

Nielsen and colleagues measured prolonged grief symptoms in a sample of 1,735 adults in Denmark who were bereaved by the death of a relative over a period of 10 years. Compared to a low grief trajectory group (45%), a high grief trajectory group (6%) showed persistent high grief symptom levels and had significantly more general practitioner appointments, mental health service use, prescription medication use, and excess mortality.

Tognela et al. interviewed 16 bereaved parents in Australia about their social support experiences—including when it goes well and when it doesn't—showing that social support is a dynamic, relational, and subjective process where attunement between the supporter and recipient matters. The findings align with concern about approaches that uncritically positioned bereavement care as a community responsibility without acknowledgment that community members are not always equipped to provide such support (1).

Schwind et al. provide a multidisciplinary, multi-national perspective of family caregiving and wellbeing in adult chronic illness. In drawing on their scholarly expertise in Australia, Germany, and Switzerland, the authors outline a compelling argument for reimagining research and practice so that the wellbeing of families, structural enablers and barriers, and broader family and social contexts, become central areas of focus.

In a systematic review, Cui et al. conducted a qualitative meta-synthesis of studies to explore the experiences and needs of family members following perinatal infant deaths. The researchers identified 10 studies from nine countries that together showed several unmet needs requiring comprehensive, tailored support strategies.

Andriessen et al. interviewed 34 men bereaved by suicide in Australia. The findings showed the profound, multifaceted impacts of suicide bereavement, including disruptions to close relationships and caregiving roles such as being a full and present parent.

Tay et al. conducted a retrospective cohort study of linked health facility records of 1,224 dyads comprising deceased lung cancer patients and their bereaved spouses in the United States over an 8-year period. After controlling relevant covariates, analysis showed that spouses with preexisting mental health conditions were over four times more likely to develop mental health conditions following bereavement compared to spouses with no preexisting mental health diagnoses.

Finally, Chen et al. used data from the China Health and Retirement Longitudinal Study to investigate the trajectories of depressive symptoms associated with child bereavement among older adults in China. Analysis showed the presence

of four trajectories of depressive symptoms associated with child bereavement: low depression that rapidly increases (12%), high depression that rapidly declines (12%), high depression that slowly increases (23%), and stable low depression (53%).

The International Alliance of Carer Organizations—representing 17 countries—reported an estimated 251.5 million persons are engaged in family caregiving (5). In addition to family caregivers, individuals employed in public safety, public health, and other professional fields are also exposed to high rates of deaths and dying. These are individuals who are particularly vulnerable to the health risks associated with bereavement. Building on this first volume, a second volume is planned, which will continue the focus on caregiving while broadening the umbrella of populations to include professional caregivers and increasing the scope of associated domains of investigation. To guide clinical care and policy support, it is essential to expand the research focus on bereavement.

Author contributions

TM: Conceptualization, Writing – original draft, Writing – review & editing. WL: Conceptualization, Writing – review & editing. CK: Writing – review & editing. LB: Writing – original draft, Writing – review & editing. DL: Conceptualization, Writing – review & editing.

Conflict of interest

The author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declared that generative AI was not used in the creation of this manuscript.

Any alternative text (alt text) provided alongside figures in this article has been generated by Frontiers with the support of artificial intelligence and reasonable efforts have been made to ensure accuracy, including review by the authors wherever possible. If you identify any issues, please contact us.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

References

1. Breen LJ, Kawashima D, Joy K, Cadell S, Roth D, Chow A, et al. Grief literacy: a call to action for compassionate communities. *Death Stud.* (2022) 46:425–33. doi: 10.1080/07481187.2020.1739780
2. Miles TP. *Why Bereavement Matters*. Scientia (2024). doi: 10.33548/SCIENTIA 1025
3. Killikelly C, Christen LM, Groen S, Ogrodniczuk JS, Maercker A, Smid GE, et al. Feasibility, acceptability and clinical utility of the bereavement and grief cultural formulation interview for prolonged grief disorder. *Cult Med Psychiatry.* (2025) 49:1150–67. doi: 10.1007/s11013-025-09927-2
4. Lichtenthal WG, Roberts KE, Donovan L, Breen LJ, Aoun SM, Connor SR, et al. Investing in bereavement care as a public health priority. *Lancet Public Health.* (2024). 9:e270–4. doi: 10.1016/S2468-2667(24)00030-6
5. *Global State of Caring.* (2021). Available online at: <https://internationalcarers.org/carer-facts/global-carer-stats/> (Accessed January 31, 2026).



OPEN ACCESS

EDITED BY

Don Lollar,
Oregon Health and Science University,
United States

REVIEWED BY

Xiaofang Liu,
Columbia University, United States
Lei Yuan,
Second Military Medical University, China

*CORRESPONDENCE

Zhangyi Wang
✉ 283537548@qq.com

RECEIVED 19 December 2024

ACCEPTED 23 April 2025

PUBLISHED 09 May 2025

CITATION

Chen L, Wang Z, Wu Q and Tang X (2025)
Trajectory patterns and influencing factors of
depression due to child bereavement among
older adults in China: a 5-year longitudinal
study.

Front. Public Health 13:1548256.
doi: 10.3389/fpubh.2025.1548256

COPYRIGHT

© 2025 Chen, Wang, Wu and Tang. This is an
open-access article distributed under the
terms of the [Creative Commons Attribution
License \(CC BY\)](https://creativecommons.org/licenses/by/4.0/). The use, distribution or
reproduction in other forums is permitted,
provided the original author(s) and the
copyright owner(s) are credited and that the
original publication in this journal is cited, in
accordance with accepted academic
practice. No use, distribution or reproduction
is permitted which does not comply with
these terms.

Trajectory patterns and influencing factors of depression due to child bereavement among older adults in China: a 5-year longitudinal study

Li Chen^{1,2}, Zhangyi Wang^{1*}, Qiaoyan Wu¹ and Xiaochun Tang¹

¹School of Nursing, Hunan Normal University & Affiliated Hengyang Central Hospital, Changsha, Hunan, China, ²School of Nursing, Kiang Wu Nursing College of Macao, Macao, Macao SAR, China

Objective: As a result of the aging of the world population, a high number of older adults lose their children during their lifetime. Depression due to child bereavement is a significant psychological problem. Therefore, it is necessary to investigate the trajectories of depressive symptoms associated with child bereavement among older adults in China and determine the influencing factors.

Methods: In this study, data from the China Health and Retirement Longitudinal Study were used as the longitudinal data, and 284 women and 117 men aged over 60 years were included. A latent growth mixture model was used to identify trajectory patterns in depression due to child bereavement over time. Multivariate logistic regression analysis was used to determine the influencing factors.

Results: Four trajectory patterns of depressive symptoms associated with child bereavement were identified: a low depression rapidly increasing group (12.0%), a high depression rapidly declining group (12.1%), a high depression slowly increasing group (23.1%), and a low depression stable group (52.8%). The findings of the multivariate logistic regression analysis showed that residence, sleep status, satisfaction with life, and self-report of health were related to the trajectory patterns of depressive symptoms among the participants.

Conclusion: This study revealed heterogeneity in changes in depressive symptoms among older adults with child bereavement in China. The government and medical institutions should consider these trajectory patterns of depression and adopt individualized support measures based on the characteristics of different groups.

KEYWORDS

child bereavement, depressive symptoms, developmental trajectory, latent growth mixture model, older adults

1 Introduction

Aging is a critical public health issue worldwide (1). In the 2020 China Census, the proportion of older adults aged 60 years and above was 18.70%, an increase of 5.44 percentage points compared with that in 2010 (2). In the context of global population aging, the concept of “healthy ageing,” as proposed by the World Health Organization (WHO), is especially important (3, 4). However, as the older adult population increases, a high number of older

adults may lose their children during their lifetime (5). Child bereavement can be the most distressing event for older parents, especially in China. In traditional Chinese culture, children play an important role in the family. They not only offer emotional and material support to their older adult parents but also fulfill their filial support obligations. Moreover, children are regarded as the most crucial spiritual sustenance for the Chinese older adult (5, 6). According to a report (7), it is estimated that 10 million families will experience child bereavement in China by 2035. Due to the physical frailty factors associated with the aging process, the mental health of older adults is more likely to be influenced by loss (8, 9), and the risk of developing depression may be high (10). Studies (7, 11) have shown that the loss of a child can be more persistent and intense in older parents than other types (such as loss of spouse) of bereavement-related depression, and it may also induce the persistence of abnormalities in the inferior parietal cortex. Therefore, losing children can result in a huge psychological shock for older adults. Thus, the early prediction of and interventions for influencing factors will be of great significance in reducing the prevalence of depression related to child bereavement.

In older adults, depression after losing their children, which manifests as emotional and psychological responses such as helplessness, sadness, self-blame, and self-guilt, can change over time (12). Studies have shown that approximately 34% of mothers and 35% of fathers suffer from moderate-to-severe depression 3 to 5 years after they lose their child (10). In addition, depression related to child bereavement is a chronic stressor in older adults, exerting cumulative and detrimental effects on their psychological well-being (13). However, some studies have found heterogeneity in older adults in terms of the depression status (14, 15). Some older adults who have a brief but intense experience of depression show a gradual decline in depressive symptoms, whereas others show progressively increasing symptoms of depression (16). Research has found that the trends in depression caused by child bereavement are different at different periods. For example, some older adults experience less intense depression in the short term after the loss of a child, whereas others experience significant depression within 18 months after the loss (17). These results suggest that longitudinal trajectories in child-bereavement-related depression are heterogeneous (18).

The majority of the existing studies have focused only on the changes in depressive symptoms among young or middle-aged parents with child bereavement, but without taking into account the trajectory patterns in older adults with child bereavement (18, 19). In addition, since the trajectory patterns of child-bereavement-related depression change in individuals over time (20), changes in depressive symptoms can be regarded as a stage-sequential process (21). This observation points to the specific pattern of bereavement-related depression in older adults who have lost a child.

Currently available studies have limitations in understanding the evolution of bereavement-related depression. The majority of these studies rely on cross-sectional surveys or qualitative research. Cross-sectional studies (22–24) only capture a single-point depressive state and do not consider long-term changes. Qualitative research, though insightful, cannot systematically quantify these temporal shifts. Furthermore, traditional longitudinal data analysis methods (18) assume a homogeneous population and overlook individual differences, which leads to inaccurate conclusions. In contrast, the latent growth mixture model (LGMM) (25), which is designed for

longitudinal data, can reveal heterogeneity in growth trajectories. By estimating the parameters for different latent classes, it identifies distinct change patterns. The present study uses five-year follow-up data from a representative older adult Chinese sample. Using the LGMM, it aims to uncover trajectory patterns of depression in older adult parents who have lost their children and fill gaps in the current literature.

2 Methods

2.1 Data source

The data were acquired from the China Health and Retirement Longitudinal Study (CHARLS) database, which is a high-quality public database that includes information on middle-aged and older residents in China. Currently, the CHARLS database has been used in various research fields, such as economics, demography, public health, and nursing. The data used in this study were drawn from three waves of surveys of the CHARLS database conducted in 2013, 2015, and 2018. The inclusion criteria were as follows: (1) baseline age ≥ 60 years; (2) indicated child bereavement (loss of at least one child) in the baseline survey in 2013; and (3) participants who completed all three phases of the survey. The exclusion criteria were as follows: (1) missing depressive symptom scores in one phase or more and (2) missing data on other influencing factors. In 2013, the total number of older adult individuals with child bereavement was 1,007. When the survey was conducted in 2015, 1,054 individuals were successfully followed up, and 198 were lost to follow-up or had died. In 2018, 834 individuals were followed up again, and 220 were lost to follow-up or had died. The total number of samples lost to follow-up or dead was 418, which accounted for 33.3%. In total, 401 participants aged 60 to 93 years were included in this study, with 284 (70.80%) being female and 117 (29.20%) being male. The sample selection process is presented in detail in Figure 1. A comparison of baseline characteristics was carried out to verify the representativeness of the sample. Specifically, the demographic characteristics (age, gender, educational level, residence, and marital status) of the 401 participants were compared with those of the total number of older adult individuals who had experienced child bereavement in 2013. The findings of this comparison showed that there were no statistically significant differences between the two groups (all $p > 0.05$). Further details are presented in Table 1.

2.2 Dependent variable

Bereavement-related depressive symptoms in older adults were quantified using the 10-item version of the Centre for Epidemiologic Studies Depression Scale (CES-D-10) (26). CES-D-10 was derived from the 20-item Epidemiological Studies Depression Scale. The 10 items in CES-D-10 included three depression items, five physical symptom items, and two positive emotion items. Each item had four options: “Rarely or none of the time (<1 day),” “Some or a little of the time (1–2 days),” “Occasionally or a moderate amount of time (3–4 days),” and “Most or all of the time (5–7 days).” Each item was scored on a scale of 0 to 3, with the exception of items 3 and 5, which were reverse-scored. The total score ranged from 0 to 30, and participants who scored ≥ 10 points were considered having depressive symptoms. The

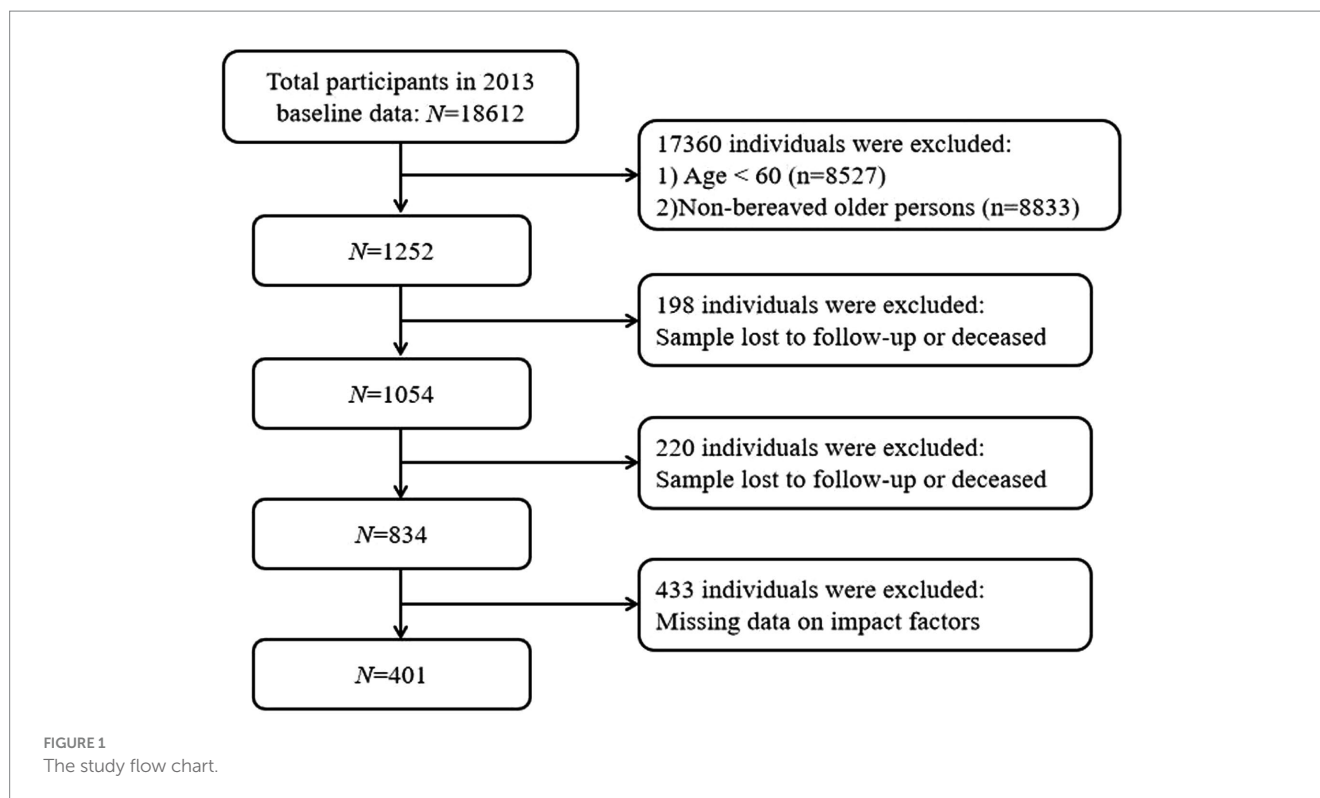


TABLE 1 Comparison of demographic characteristics.

Demographic characteristics	Initial Sample of the older adult with child Bereavement (n = 401)	Final included sample (n = 1,252)	Statistic	p-value
Age (years, $\bar{x} \pm s$)	70.87 \pm 8.31	71.92 \pm 10.28	$t = -1.871$	0.062
Gender (female, %)	70.80(284)	66.45(832)	$\chi^2 = 2.644$	0.104
Education level (illiteracy, %)	48.38(194)	49.84(624)	$\chi^2 = 0.259$	0.611
Residence (rural, %)	71.07(285)	69.41(869)	$\chi^2 = 0.399$	0.528
Marital status (married, %)	72.31(290)	75.96(951)	$\chi^2 = 2.150$	0.143

Chinese version of this scale achieved a Cronbach's alpha value of 0.813 when administered to the older adult population in China (27).

2.3 Independent variables

Data regarding influencing factors were collected in 2013. Fifteen factors were included: (1) age; (2) gender; (3) residence; (4) marital status; (5) educational level; (6) smoking; (7) drinking; (8) number of living children; (9) number of deceased children; (10) disability; (11) sleep restlessness; (12) life satisfaction; and (13) difficulty with any one of the instrumental activities of daily living (IADLs, namely doing household chores, cooking, shopping, managing money, and taking medications) (28); (14) chronic comorbidity; (15) self-report of health.

2.4 Statistical analysis

Statistical analysis of the data was carried out using SPSS 27.0 software. The LGMM analysis was conducted using Mplus 8.3

software. The best-fit model was selected by comparing fit indexes across multiple models, taking into account both practical significance and statistical indicators. This approach ensured that the selected model not only statistically fit the data well but also had meaningful implications for understanding the latent growth patterns. The fitting indices for this model verification were as follows: (1) Akaike information criterion (AIC), Bayesian information criterion (BIC), and sample-adjusted Bayesian information criterion (aBIC); (2) entropy; and (3) test statistics: Lo–Mendell–Rubin likelihood ratio test (LMRT) and bootstrapped likelihood ratio test (BLRT) (29). The lower the values of AIC, BIC, and aBIC, the better the fitting effect of the model. The closer the entropy value is to 1, the more accurate the classification of the model. Both LMRT and BLRT reached a significant level ($p < 0.05$), which indicated that the model with k categories showed a better fitting effect than the model with $k-1$ categories. To ensure clinical significance, each category should include at least 5% of the participants (30). Chi-square test was used to investigate the relationship between sociodemographic and clinical variables in different subgroups. Multivariate logistic regression, with potential categories of depression among older individuals who have

lost a child as the dependent variable, was used to identify the influencing factors for different potential categories of depression among this population. Statistical significance was set at $p < 0.05$, and all p values were two-sided.

2.5 Ethical approval

Approval for the CHARLS data was granted by the Ethics Review Committee of Peking University, with the reference number IRB00001052-11015.

3 Results

3.1 Identification of the trajectory patterns of depressive symptoms of child bereavement among older adults

This study analyzed the trajectory patterns of three-wave CES-D-10 scores in individuals with child bereavement. The participants' overall CES-D-10 scores were 9.88 ± 6.574 , 10.48 ± 7.182 , and 11.08 ± 7.325 at wave 1, wave 2, and wave 3, respectively. The fit indexes of the LGMM were used to identify three trajectory groups. Compared with other models, model 4 showed lower AIC and BIC values. As shown in Table 2, in model 4, both LMRT and the BLRT were statistically significant. Therefore, model 4 was identified as the best model.

Using model 4, a trajectory plot was constructed with CES-D-10 scores as the vertical axis and wave 1 to wave 3 as the horizontal axis. This plot categorized the trajectory patterns of depressive symptoms among older Chinese adults who have experienced the loss of a child into four distinct groups, as shown in Figure 2:

- 1 Low depression rapidly increasing group (C1): This group had a low initial score (7.05) ($I = 7.846$, $p < 0.05$), and depressive symptoms improved effectively over time ($S = 5.925$, $p < 0.05$). It consisted of 41 older adults, accounting for 12.0% of the older adults.
- 2 High depression rapidly declining group (C2): This group had a high initial score (17.28) ($I = 16.532$, $p < 0.05$), and depressive symptoms declined rapidly over time ($S = -4.600$, $p < 0.005$). It consisted of 46 older adults (12.1%).
- 3 High depression slowly increasing group (C3): The mean intercept and mean slope were 16.673 ($p < 0.05$) and 0.925 ($p > 0.05$), respectively, and the initial score (17.08) of this

group was high ($I = 16.673$, $p < 0.05$), with an overall increasing trend. In addition, depression symptoms did not significantly improve over time ($S = 0.925$, $p > 0.05$), and this group consisted of 96 older adults (23.1%).

- 4 Low depression stable group (C4): This group had the lowest initial score (5.67) ($I = 5.844$, $p < 0.05$), and depressive symptoms remained stable over time ($S = 0.0445$, $p < 0.05$). This group had 218 older adults (52.8%).

The significant level of variance in the intercepts between the four patient groups ($p < 0.05$) indicates that there are individual differences in the initial levels of depressive symptoms between older adult individuals who have experienced the loss of a child. In contrast, the lack of significant variance in the slopes between the four groups suggests that there are no individual differences in the rate of change of depressive symptoms among these older adult individuals.

3.2 Single-factor analysis of influencing factors for trajectory patterns of depressive symptoms in older adults with child bereavement

Using these latent classes as grouping variables, the baseline characteristics of older adults with child-bereavement-related depression belonging to different trajectory categories were compared. The results showed that there are statistically significant differences between the four groups ($p < 0.05$) in the distributional comparisons of gender ($\chi^2 = 11.823$, $p = 0.008$), residence ($\chi^2 = 16.904$, $p = 0.001$), sleep restlessness ($\chi^2 = 16.904$, $p < 0.001$), life satisfaction ($\chi^2 = 27.985$, $p < 0.001$), difficulty with IADLs ($\chi^2 = 50.953$, $p < 0.001$), number of chronic diseases suffered ($\chi^2 = 20.806$, $p = 0.014$), and self-report of health ($\chi^2 = 22.677$, $p < 0.001$). Further information is presented in Table 3.

3.3 Logistic regression analysis of influencing factors for trajectory patterns of depressive symptoms in older adults with child bereavement

Logistic regression was conducted using the results of the trajectory category analysis as the dependent variable and all significant variables from the single-factor analysis as independent variables. The results revealed that in the comparison of C1 with the reference group C3, city dwellers and those with sleep restlessness for

TABLE 2 Fitting of the LGMM of depressive symptoms of older adults with child bereavement in China.

GMM	LL	AIC	BIC	aBIC	Entropy	P (LMRT)	P (BLRT)	Probability (%)
1C	-3889.667	7795.335	7827.286	7801.902	-	-	-	1.000
2C	-3864.272	7750.544	7794.477	7759.573	0.749	<0.001	<0.001	32.9/67.1
3C	-3860.686	7749.372	7805.288	7760.865	0.755	0.4323	0.3333	03.5/31.2/65.3
4C	-3845.541	7725.081	7792.979	7739.036	0.763	0.0300	<0.001	10.2/11.5/23.9/54.4
5C	-3839.954	7719.909	7799.788	7736.326	0.801	0.4483	0.0300	2.5/50.1/25.2/14.0/8.2

aBIC, sample-size-adjusted Bayesian information criterion; AIC, Akaike information criterion; BIC, Bayesian information criterion; BLRT, bootstrapped likelihood ratio test; LL, log likelihood; LMRT, Lo-Mendell-Rubin adjusted likelihood ratio test.

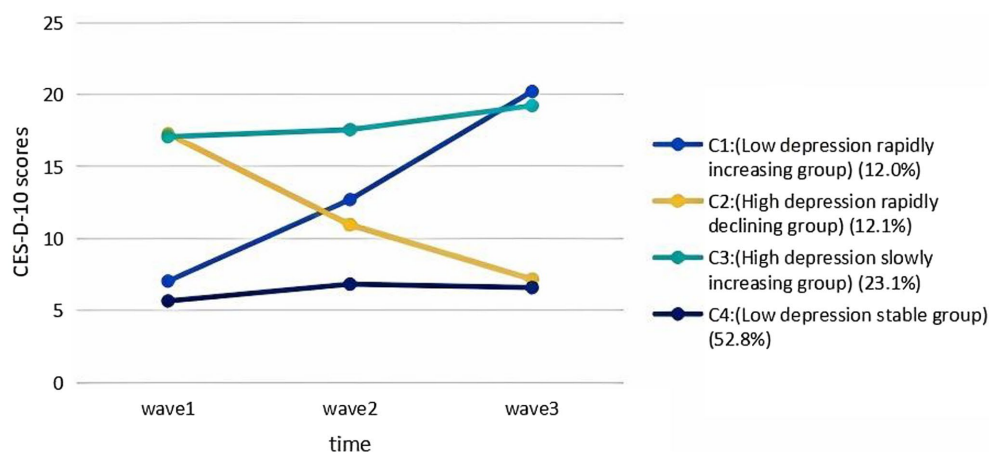


FIGURE 2
The trajectories of depressive symptoms among bereaved older adults in China.

<1 day, 1–2 days and 3–4 days were more likely to be categorized as C1. Similarly, when comparing C2 with the reference group C3, city dwellers were more likely to be categorized as C2. In addition, when comparing C4 with the reference group C3, city dwellers; those with sleep restlessness of <1 day, 1–2 days, and 3–4 days; and those with self-reported good health were more likely to be categorized as C4. Older adults who were not satisfied with life were more likely to be classified as C3 (all $p < 0.05$). Further details about logistic regression analysis are presented in [Table 4](#).

4 Discussion

4.1 Analysis of the trajectory of change in depressive symptoms in older adults with child bereavement

This study categorized the trajectory of depressive symptoms in older people with child bereavement into four categories: a low depression rapidly increasing group (12.0%), a high depression rapidly declining group (12.1%), a high depression slowly increasing group (23.1%), and a low depression stable group (52.8%), as determined by the LGMM. This suggests the heterogeneity of depressive symptoms in older adults with child bereavement. This finding serves as a guideline to future researchers, emphasizing the need for a nursing assessment system with group heterogeneity and individual heterogeneity.

The proportion of older adults in the C1 group was 12.0%, who had increasingly obvious symptoms of depression, which is consistent with the studies of Pohlkamp et al. (31) and D'Epinay et al. (32). In this study, older parents with bereavement experienced the loss of their most beloved children, and in the early stage of the loss, they may experience shock and even deny the truth. However, as reality continued to hit them, they gradually experienced an emotional breakdown and an increased sense of isolation. In traditional China, first, others may sympathize with the older parents with child bereavement, but over time, these parents may suffer from strange looks, be regarded undesirable, or even be bullied. In China, it is

considered an individual tragedy to have no surviving child because the Chinese believe that without a surviving child, there are no descendants and they cannot inherit the bloodline, which is considered an act of shame to the ancestors (33). Therefore, in older adults with child bereavement, depressive symptoms gradually worsen and have lasting effects, even affecting their physical health, consistent with the findings of a previous study (32). These older adults are in the most vulnerable situation as they are older (mean age = 68.46 years), live in rural areas (70.7%), and have a low level of education (61% illiterate and 39% with primary school education or lower). These data indicate that older adults with child bereavement are less likely to have high incomes and receive pensions. Therefore, providing effective social support and promoting the idea of a new era of parenting can contribute to mitigating some adverse effects of the loss among older individuals.

In contrast to the C1 group, the depression level in older adults in the C2 group decreased rapidly over time, and the proportion of those with a significant reduction in depression levels in the C2 group accounted for 12.1%. This trajectory model has long been confirmed in the studies (34, 35), and it even predicts that 7–9 years after bereavement, depression levels of these parents are similar to those of parents with no bereavement (34). Over time, the majority of them gradually recovered from their child-bereavement-related depression through having surviving children, receiving social support, and actively participating in social activities (36). Thus, their psychological condition reached a relatively stable stage with no prolonged grief disorder or post-traumatic stress disorder. This indicates that their depressive symptoms of losing a child had decreased (34). Nevertheless, it is important to emphasize that despite a decline in bereavement-related depressive symptoms, routine mental health assessments and social support should continue, and new stressors that these older adults may encounter should be investigated. Encouraging support and involvement from community, friends, and family is advised, and social volunteering also helps (21). This service is grief-recovery-oriented, which enriches their social networks, improves life satisfaction, and enables them to regain control of their lives. In addition, it is crucial to provide professional and high-quality counselling to these older adults to prevent grief rumination (37).

TABLE 3 Comparison of general data of different depression trajectory groups (N = 401).

Variables	Code	C1 (n = 41)	C2 (n = 46)	C3 (n = 96)	C4 (n = 218)	χ^2	p-value
Age at baseline, years						4.342	0.227
60–69	1	24 (58.5)	24 (52.2)	61 (63.5)	112 (51.4)		
≥70	2	17 (41.5)	22 (47.8)	35 (36.5)	106 (48.6)		
Gender						11.823	0.008
Male	0	8 (19.5)	11 (23.9)	19 (19.8)	79 (36.2)		
Female	1	33 (80.5)	35 (76.1)	77 (80.2)	139 (63.8)		
Residence						16.904	0.001
City	1	12 (29.3)	12 (26.1)	13 (13.5)	79 (36.2)		
Rural	2	29 (70.7)	34 (73.9)	83 (86.5)	139 (63.8)		
Marital status						1.434	0.698
Married	1	28 (68.3)	36 (78.3)	71 (74.0)	155 (71.1)		
Widowed/single	2	13 (31.7)	10 (21.7)	25 (26.0)	63 (28.9)		
Educational level						11.022	0.088
Illiterate	1	25 (61.0)	21 (45.7)	47 (49.0)	101 (46.3)		
Primary school or lower	2	16 (39.0)	22 (47.8)	40 (41.7)	92 (42.2)		
Junior high school and above	3	0 (0.0)	3 (6.5)	9 (9.3)	25 (11.5)		
Smoking						2.365	0.500
No	0	35 (85.4)	37 (80.4)	82 (85.4)	172 (78.9)		
Yes	1	6 (14.6)	9 (19.6)	14 (14.6)	46 (21.1)		
Drinking						4.964	0.174
No	0	32 (78.0)	39 (84.8)	70 (72.9)	152 (69.7)		
Yes	1	9 (22.0)	7 (15.2)	26 (27.1)	66 (30.3)		
Number of living children						4.550	0.603
0–2	1	17 (41.5)	11 (23.9)	30 (31.3)	81 (37.2)		
3–5	2	20 (48.8)	29 (63.0)	54 (56.3)	115 (52.8)		
≥6	3	4 (9.7)	6 (13.1)	12 (12.4)	22 (10.0)		
Number of deceased children						5.394	0.145
1	1	33 (80.5)	35 (76.1)	69 (71.9)	181 (83.0)		
≥2	2	8 (19.5)	11 (23.9)	27 (28.1)	37 (17.0)		
Disability						4.876	0.181
No	0	36 (87.8)	43 (93.5)	88 (91.7)	209 (95.9)		
Yes	1	5 (12.2)	3 (6.5)	8 (8.3)	9 (4.1)		
Sleep restlessness, days						102.870	<0.001
<1	1	21 (51.2)	7 (15.2)	15 (15.6)	130 (59.6)		
1–2	2	6 (14.6)	5 (10.9)	13 (13.5)	37 (17.0)		
3–4	3	10 (24.4)	13 (28.3)	21 (21.9)	28 (12.8)		
5–7	4	4 (9.8)	21 (45.6)	47 (49.0)	23 (10.6)		
Life satisfaction						27.985	<0.001
Not satisfied	0	5 (12.2)	13 (28.3)	24 (25.0)	14 (6.4)		
Satisfied	1	36 (87.8)	33 (71.7)	72 (75.0)	204 (93.6)		
Difficulty with IADLs						50.953	<0.001
No	0	18 (43.9)	22 (47.8)	39 (40.6)	135 (61.9)		
Yes	1	23 (56.1)	24 (52.2)	57 (59.4)	83 (38.1)		

(Continued)

TABLE 3 (Continued)

Variables	Code	C1 (n = 41)	C2 (n = 46)	C3 (n = 96)	C4 (n = 218)	χ^2	p-value
Number of chronic diseases suffered						20.806	0.014
0	1	10 (24.4)	2 (4.3)	14 (14.6)	47 (21.6)		
1	2	10 (24.4)	15 (32.6)	17 (17.7)	62 (28.4)		
2	3	8 (19.5)	16 (34.8)	23 (24.0)	52 (23.9)		
≥3	4	13 (31.7)	13 (28.3)	42 (43.7)	57 (26.1)		
Self-report of health						47.215	<0.001
Healthy	1	7 (17.1)	10 (21.7)	9 (9.4)	73 (33.5)		
General	2	24 (58.5)	17 (37.0)	41 (42.7)	109 (50.0)		
Fragile	3	10 (24.4)	19 (41.3)	46 (47.9)	36 (16.5)		

TABLE 4 Multivariate logistic regression analysis of the trajectory of depressive symptoms of older adults with child bereavement (N = 401).

Groups	Related factors	β	SE	Wald χ^2	p-value	OR	95% CI
C1 vs. C3	City	1.535	0.507	9.159	0.002	4.643	1.718–12.549
	Sleep restlessness (<1 day)	3.024	0.653	21.442	<0.001	20.582	5.722–74.037
	Sleep restlessness (1–2 days)	1.684	0.737	5.219	0.022	5.387	1.270–22.844
	Sleep restlessness (3–4 days)	2.063	0.677	9.300	0.002	7.871	2.090–29.639
C2 vs. C3	City	0.945	0.474	3.981	0.046	2.574	1.017–6.514
C4 vs. C3	City	1.859	0.403	21.321	<0.001	6.419	2.916–14.133
	Sleep restlessness (<1 day)	2.947	0.433	46.312	<0.001	19.054	8.153–44.527
	Sleep restlessness (1–2 days)	1.656	0.460	12.976	<0.001	5.236	2.127–12.890
	Sleep restlessness (3–4 days)	1.389	0.437	10.087	0.001	4.012	1.702–9.457
	Satisfied with life (not satisfied)	−1.321	0.442	8.934	0.003	0.267	0.112–0.635
	Self-report of health (healthy)	1.704	0.509	11.198	0.001	5.496	2.026–14.909

The reference group: residence, rural; sleep restlessness, 5–7 days; satisfied with life, satisfied; self-report of health, fragile; group, C3.

The proportion of older adults in the C3 group was 23.1%. These older adults had high CED-S-10 scores, indicating no improvement in depressive symptoms, which is in line with the study of Lykke et al. (10). These older adults experienced a multifaceted attack on physical, psychological, and life support after a child loss, such as increased incidence of chronic diseases, loss of their main source of caregiving, termination of family lineage, loneliness, and prolonged grief, resulting in depression. Therefore, they found it difficult to accept the loss of their children and had persistent bereavement-related depressive symptoms, which is consistent with previous studies (33, 38). The concept of “child-rearing for old age” is deeply rooted in Chinese culture, and when older people are confronted with having no child after the loss of their only child, their risk of depression is high and persistent (33, 39). Within 3 to 5 years of losing a child, if older adults show poor psychological resilience, they become more vulnerable to stressors, which in turn may contribute to long-term depression and even social withdrawal (10, 39). This is because communicating with older parents about the death of their child is difficult and can be hurtful and stigmatizing (39). Older adults necessitate continuous care and social support, including old-age security, psychological aid, and grief counselling. Primary care organizations should consistently track, evaluate, and intervene in the activities of older parents with child bereavement, encompassing

living needs, mental health, physiological disease, and even spiritual needs. In addition, states should increase benefits (pension and medical insurance) to these older adults and provide social services, especially mental health services.

The highest percentage of older adults with child bereavement was observed in the group with stabilized low depressive symptoms, which is consistent with a previous study (24). This trajectory group had a slow increase in depressive symptoms at first and then a gradual decrease. Depression peaked at one timepoint, and its overall volatility was low. This may be related to individual coping style and resilience. An individual’s adaptability, which is an important coping quality, plays a key role in recovery when they experience adversity. Previous studies (24, 40, 41) have shown that high resilience and positive coping are negative predictors of depressive symptoms and that when individuals face adversity or a major negative life event, it stimulates their protective mechanisms (e.g., resilience) to resist negative emotions, effectively alleviating maladaptation after the loss of a child. Therefore, we explored the characteristics of individuals in the group with low depressive symptoms to provide effective intervention measures to other groups. In addition, we should encourage individuals in this group to continue maintaining a good mental state and ensure that their living needs are met.

4.2 Analysis of factors influencing potential categories of depressive symptoms

4.2.1 Demographic factors

The trajectory of bereavement-related depressive symptoms has been found to be associated with residence, with urban older adults with child bereavement being less likely to be in the C3 group than rural older adults. Previous studies (42) have found that place of residence was a predictor of bereavement-related depressive symptoms, with urban older adults having significantly lower depressive symptoms than rural older adults, which is consistent with the results of this study. This observation is primarily attributable to the fact that urban areas are rich in high-quality healthcare resources, which makes it easier for the older adult to access professional psychological interventions (43). In urban areas, a well-developed social security system reduces the financial burden, and a variety of social activities provide adequate emotional support. Rural areas, however, are weaker in terms of medical care, security, and social support, which makes older adults in these areas more prone to high levels of depressive symptoms. The government should pay close attention to the social and psychological needs of the older people with child bereavement in rural areas. On the one hand, it should increase the investment in rural healthcare resources and should actively carry out mental health screening and free medical consultations in these areas; on the other hand, it should improve the social security system in rural areas, increase the standard of old-age pensions, and set up a special relief fund to alleviate their financial burdens. Furthermore, older adults with bereavement in rural regions should be given priority access to psychological services, and volunteers should be organized to care for them, encouraging them to express their life and psychological needs, so as to comprehensively improve the medical, economic, and social conditions of these individuals, to promote their psychological health, and to reduce the risk of depression.

4.2.2 Others factors

In this study, older adults with child bereavement who experienced restless sleep most or all of the time were more likely to be categorized into the C3 group than in the C1 and C4 groups. This indicates a strong association between poor sleep quality and a specific depressive symptom trajectory. Continuous restlessness in sleep may disrupt the normal psychological and physiological rhythms of these older adults, gradually leading to a more severe and complex pattern of depressive symptoms as represented by the C3 group. Sveen et al. (37) also reported that older adults with child bereavement who had severe insomnia showed significant depressive symptoms, which is consistent with our finding and suggests that sleep quality is an important predictor of the trajectory of depressive symptoms. The trajectory of bereavement-related depressive symptoms has also been found to be associated with satisfaction with life, and older adults who are dissatisfied with their life are more likely to be categorized into the C3 group than those in the C4 group. Dissatisfaction with life can create a negative psychological environment, which may exacerbate the depressive symptoms of these older adults over time. A study has shown (21) that older parents who have lost their children reported more depressive

symptoms and lower life satisfaction than older parents who have not lost their children. The present study further emphasizes that life satisfaction is a significant factor influencing the trajectory of depressive symptoms. A lower level of life satisfaction at the initial stage may set the stage for a more challenging trajectory of depressive symptoms. In addition, the results of this study showed that older adults with child bereavement who self-reported good health were approximately 5.5 times more likely to be categorized into the C4 group than those with poor self-reported health. Self-reported health reflects an individual's subjective perception of their physical and mental state. A positive self-reported health status may be associated with better coping mechanisms and a more optimistic attitude, which in turn contributes to a more favorable trajectory of depressive symptoms. However, in Ye et al.'s (38) study, self-reported health status was not a factor for depression among older adults with bereavement. This discrepancy might be due to the limited sample source in Ye et al.'s (38) study, which was restricted to three cities in China and may not be well representative of the general population. The co-occurrence of these factors increases the complexity of bereavement-related depression, resulting in higher levels of depression in the C3 group. These findings reveal that the government should prioritize care for older adults with child bereavement who are residing in rural regions and who report poor health. By offering appropriate material needs and personalized health plans that can prevent the development of depression and improve their health conditions and by providing volunteer help to these individuals, the government can better address the situation.

5 Limitations

This study has some limitations. First, due to the long-term follow-up of the study cohort, some older adult individuals who had experienced child bereavement were lost to follow-up, resulting in a limited sample size for this study. Although a baseline characteristic comparison analysis was carried out to verify the representativeness of the sample, the validity of the model was, to a certain extent, still restricted. Second, because this study did not incorporate data from every longitudinal data point, the effects of specific alterations in individual health factors on the evolution of bereavement-related depressive symptoms could not be investigated. This limitation restricts our understanding of how these factors interact and contribute to the dynamic nature of bereavement-related depression. Third, key potential factors such as income and time since losing a child were not included. Income can affect access to resources and wellbeing, and the impact of the grieving period varies depending on depressive symptoms. Not including income and time since losing a child may limit our ability to fully capture all relevant influences on depressive symptoms. Finally, due to the long time span, it was difficult to measure the effects of environmental changes and other latent influencing factors. Therefore, in future studies that explore the trajectories of depressive symptoms among older adults who have experienced loss of a child, it is necessary to further reduce the dropout rate and increase the sample size. In addition, efforts should be made to enhance the ability to describe the relationship between depression resulting from the loss of a child and baseline factors and to expand the exploration of other key factors.

6 Conclusion

In conclusion, this study identified four different latent categories of depressive symptoms in Chinese older adults who lost a child, revealing the diverse trajectories of depression levels in older adults with child bereavement. The government and medical institutions should develop predictive social security policies and healthcare measures based on the changing characteristics of depression trajectories. In addition, it is recommended that medical institutions prioritize long-term dynamic evaluation for rural older adults with a high level of sleep restlessness, who usually are not satisfied with life and self-report that their health is fragile. Future studies should develop a dynamic evaluation system for different levels of depressive symptoms in older adults with child bereavement in China to better address the depressive symptoms of older adults at different times.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

LC: Writing – original draft, Writing – review & editing. ZW: Funding acquisition, Writing – review & editing, Writing – original draft. QW: Methodology, Resources, Writing – original draft, Writing – review & editing. XT: Funding acquisition, Writing – review & editing, Writing – original draft.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. This study was supported the Natural Science Foundation of Hunan Province in 2025 (CN)

References

- Khalatbari-Soltani S, Si Y, Dominguez M, Scott T, Blyth FM. Worldwide cohort studies to support healthy ageing research: data availabilities and gaps. *Ageing Res Rev.* (2024) 96:102277. doi: 10.1016/j.arr.2024.102277
- National Bureau of Statistics of China. Main Data of the Seventh National Population Census. National Bureau of Statistics of China (2021). Available at: http://www.stats.gov.cn/english/PressRelease/202105/t20210510_1817185.html (Accessed April 30, 2025).
- Rudnicka E, Napierała P, Podfigurna A, Męczekalski B, Smolarczyk R, Grymowicz M. The World Health Organization (WHO) approach to healthy ageing. *Maturitas.* (2020) 139:6–11. doi: 10.1016/j.maturitas.2020.05.018
- Cesari M, Sumi Y, Han ZA, Perracini M, Jang H, Briggs A, et al. Implementing care for healthy ageing. *BMJ Glob Health.* (2022) 7:e007778. doi: 10.1136/bmjgh-2021-007778
- Safa A, Adib-Hajbaghery M, Rezaei M, Araban M. The meaning of losing a child in older adults: a qualitative study. *BMC Geriatr.* (2021) 21:652. doi: 10.1186/s12877-021-02609-9
- Zhai S, Zhuang Q, Wang Z. Study on the relationship between social support and mental health of the elderly in China: a case study of Xi'an city, Shaanxi province. *J Ment Health.* (2019) 28:119–24. doi: 10.1080/09638237.2017.1340626
- Lan Q, Ge J, Dai H, Lu J, Wu L, Liu B, et al. Longitudinal changes in brain structure and their relationship with subclinical psychiatric symptoms in parents who lost their only child in China. *Eur J Psychotraumatol.* (2023) 14:2216624. doi: 10.1080/2008066.2023.2216624
- Dixon A. The United Nations decade of healthy ageing requires concerted global action. *Nat Aging.* (2021) 1:2. doi: 10.1038/s43587-020-00011-5
- Jiang R, Noble S, Rosenblatt M, Dai W, Ye J, Liu S, et al. The brain structure, inflammatory, and genetic mechanisms mediate the association between physical frailty and depression. *Nat Commun.* (2024) 15:4411. doi: 10.1038/s41467-024-48827-8
- Lykke C, Ekholm O, Schmiegelow K, Olsen M, Sjøgren P. Anxiety and depression in bereaved parents after losing a child due to life-limiting diagnoses: a Danish Nationwide questionnaire survey. *J Pain Symptom Manag.* (2019) 58:596–604. doi: 10.1016/j.jpainsymman.2019.06.025
- Gijzen S, L'Hoir MP, Boere-Boonekamp MM, Need A. How do parents experience support after the death of their child? *BMC Pediatr.* (2016) 16:204. doi: 10.1186/s12887-016-0749-9
- Chai Y, Sheline YI, Oathes DJ, Balderston NL, Rao H, Yu M. Functional connectomics in depression: insights into therapies. *Trends Cogn Sci.* (2023) 27:814–32. doi: 10.1016/j.tics.2023.05.006
- Liang Y, Xu H, Chen F, Liang H, Wu B. Which wound cuts deeper: loss of an only child or loss of a spouse? An examination of bereavement in older adults within a Chinese cultural context. *Aging Ment Health.* (2022) 26:1217–25. doi: 10.1080/13607863.2021.1913473
- Chen C, Chow A, Tang S. Trajectories of depression symptoms in Chinese elderly during widowhood: a secondary analysis. *Aging Ment Health.* (2020) 24:1254–62. doi: 10.1080/13607863.2019.1603285
- Xie Y, Ma M, Wang W. Trajectories of depressive symptoms and their predictors in Chinese older population: growth mixture model. *BMC Geriatr.* (2023) 23:372. doi: 10.1186/s12877-023-04048-0

[grant no: 2025JJ80594], the Scientific Research Project of Hunan Nursing Association (CN) [grant no: HNKYP202413], the Young Talent Project of Hunan Nursing Association (CN) [grant no: Q20241204020], the Health Research Project of Hunan Provincial Health Commission (CN) [grant no: W20243278], and the Hengyang Science and Technology Plan Project (CN) [grant no: 202323036686].

Acknowledgments

All researchers would like to express their gratitude to all the participants for taking their precious time to participate in this study and also thank the hospital managers and nursing administrators for their strong support and help to this study.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

16. Jung JH, Lee HJ. Death of a child, religion, and mental health in later life. *Aging Ment Health.* (2022) 26:623–31. doi: 10.1080/13607863.2021.1889968
17. Chen D, Tong Y. Do social timing and gender matter to parental depression aroused by traumatic experience of child bereavement? Evidence from China. *Int J Environ Res Public Health.* (2021) 18:12058. doi: 10.3390/ijerph182212058
18. Park S, Kim J. The death of an adult child and trajectories of parental depressive symptoms: a gender-based longitudinal analysis. *Soc Sci Med.* (2024) 341:116544. doi: 10.1016/j.socscimed.2023.116544
19. Umberson D, Donnelly R, Xu M, Farina M, Garcia MA. Death of a child prior to midlife, dementia risk, and racial disparities. *J Gerontol B Psychol Sci Soc Sci.* (2020) 75:1983–95. doi: 10.1093/geronb/gbz154
20. Donnelly R, Umberson D, Hummer RA, Garcia MA. Race, death of a child, and mortality risk among aging parents in the United States. *Soc Sci Med.* (2020) 249:112853. doi: 10.1016/j.socscimed.2020.112853
21. Huo M, Kim K, Wang D. Long-term psychological consequences of parental bereavement prior to midlife: volunteering helps. *Aging Ment Health.* (2023) 27:992–1000. doi: 10.1080/13607863.2022.2087209
22. Safa A, Adib-Hajbaghery M, Rezaei M. A model for older adults' coping with the death of their child: a grounded theory study. *BMC Psychiatry.* (2024) 24:150. doi: 10.1186/s12888-024-05597-3
23. Zhao S, Ren L, Wang Q, Long M, Wu H, Wang Y. Predictors of prolonged grief disorder in Chinese elderly shidu parents: the role of perceived stigma and perceived stress. *Asia Pac Psychiatry.* (2022) 14:e12489. doi: 10.1111/appy.12489
24. Gerino E, Rollè L, Sechi C, Brustia P. Loneliness, resilience, mental health, and quality of life in old age: a structural equation model. *Front Psychol.* (2003) 8:8. doi: 10.3389/fpsyg.2017.02003
25. Muthén B, Shedden K. Finite mixture modeling with mixture outcomes using the EM algorithm. *Biometrics.* (1999) 55:463–9. doi: 10.1111/j.0006-341X.1999.00463.x
26. Andresen EM, Malmgren JA, Carter WB, Patrick DL. Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *Am J Prev Med.* (1994) 10:77–84. doi: 10.1016/S0749-3797(18)30622-6
27. Chen H, Mui AC. Factorial validity of the Center for Epidemiologic Studies Depression Scale short form in older population in China. *Int Psychogeriatr.* (2014) 26:49–57. doi: 10.1017/S1041610213001701
28. KATZ S, FORD AB, MOSKOWITZ RW, JACKSON BA, JAFFE MW. Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *JAMA.* (1963) 185:914–9. doi: 10.1001/jama.1963.03060120024016
29. Brusco MJ, Shireman E, Steinley D. A comparison of latent class, K-means, and K-median methods for clustering dichotomous data. *Psychol Methods.* (2017) 22:563–80. doi: 10.1037/met0000095
30. Amouzegar A, Honarvar M, Masoumi S, Khalili D, Azizi F, Mehran L. Trajectory patterns of metabolic syndrome severity score and risk of type 2 diabetes. *J Transl Med.* (2023) 21:750. doi: 10.1186/s12967-023-04639-w
31. Pohlkamp L, Kreicbergs U, Sveen J. Bereaved mothers' and fathers' prolonged grief and psychological health 1 to 5 years after loss—a nationwide study. *Psycho-Oncology.* (2019) 28:1530–6. doi: 10.1002/pon.5112
32. D'Epina CJ, Cavalli S, Guillet LA. Bereavement in very old age: impact on health and relationships of the loss of a spouse, a child, a sibling, or a close friend. *Omega.* (2009) 60:301–25. doi: 10.2190/OM.60.4.a
33. Feng Z. Childlessness and vulnerability of older people in China. *Age Ageing.* (2018) 47:275–81. doi: 10.1093/ageing/afx137
34. Kreicbergs U, Valdimarsdóttir U, Onelöv E, Henter JI, Steineck G. Anxiety and depression in parents 4–9 years after the loss of a child owing to a malignancy: a population-based follow-up. *Psychol Med.* (2004) 34:1431–41. doi: 10.1017/S0033291704002740
35. Nyberg T, Hed MI, Omerov P, Steineck G, Nyberg U. Depression among parents two to six years following the loss of a child by suicide: a novel prediction model. *PLoS One.* (2016) 11:e164091. doi: 10.1371/journal.pone.0164091
36. Barrera M, D'Agostino NM, Schneiderman G, Tallett S, Spencer L, Jovcevska V. Patterns of parental bereavement following the loss of a child and related factors. *Omega.* (2007) 55:145–67. doi: 10.2190/OM.55.2.d
37. Sveen J, Pohlkamp L, Kreicbergs U, Eisma MC. Rumination in bereaved parents: psychometric evaluation of the Swedish version of the Utrecht grief rumination scale (UGRS). *PLoS One.* (2019) 14:e213152. doi: 10.1371/journal.pone.0213152
38. Ye YP, Wang JN, Li QC, Xu CM, Rong C. Factors associated with the depression status of Chinese parents who have lost their only child. *Front Public Health.* (2022) 10:931945. doi: 10.3389/fpubh.2022.931945
39. Yin Q, Shang Z, Zhou N, Wu L, Liu G, Yu X, et al. An investigation of physical and mental health consequences among Chinese parents who lost their only child. *BMC Psychiatry.* (2018) 18:45. doi: 10.1186/s12888-018-1621-2
40. Zhao X, Wang A, Chen J, Zhang J, Li Z. Subtypes of Chinese Shidu parents' (parents who have lost their only child) depressive symptoms and their relationships with resilience and coping styles. *Psych J.* (2023) 12:100–7. doi: 10.1002/pchj.587
41. Cao X, Yang C, Wang D. The impact on mental health of losing an only child and the influence of social support and resilience. *Omega.* (2020) 80:666–84. doi: 10.1177/0030222818755284
42. Murrell SA, Himmelfarb S. Effects of attachment bereavement and pre-event conditions on subsequent depressive symptoms in older adults. *Psychol Aging.* (1989) 4:166–72. doi: 10.1037/0882-7974.4.2.166
43. Arredondo K, Touchett HN. Bridging the gap: addressing the rural-urban imbalance in health care through the NHSC. *JAMA Netw Open.* (2024) 7:e2446006. doi: 10.1001/jamanetworkopen.2024.46006



OPEN ACCESS

EDITED BY

Toni P. Miles,
Rosalynn Carter Institute for Caregivers,
United States

REVIEWED BY

Vahid Rashedi,
University of Social Welfare and Rehabilitation
Sciences, Iran
Molnar Rebeca Isabela,
Emergency County Hospital Targu Mures,
Romania
Don Lollar,
Oregon Health and Science University,
United States

*CORRESPONDENCE

Djin L. Tay
✉ djin.tay@nurs.utah.edu

RECEIVED 03 December 2024

ACCEPTED 14 April 2025

PUBLISHED 12 May 2025

CITATION

Tay DL, Dubose K, Chipman J, Ellington L,
Alnajar M, Iacob E, Stephens C and
Ornstein KA (2025) Risk of mental health
conditions in bereavement: a
population-based analysis of lung cancer
spouses.

Front. Public Health 13:1539180.
doi: 10.3389/fpubh.2025.1539180

COPYRIGHT

© 2025 Tay, Dubose, Chipman, Ellington,
Alnajar, Iacob, Stephens and Ornstein. This is
an open-access article distributed under the
terms of the [Creative Commons Attribution
License \(CC BY\)](https://creativecommons.org/licenses/by/4.0/). The use, distribution or
reproduction in other forums is permitted,
provided the original author(s) and the
copyright owner(s) are credited and that the
original publication in this journal is cited, in
accordance with accepted academic
practice. No use, distribution or reproduction
is permitted which does not comply with
these terms.

Risk of mental health conditions in bereavement: a population-based analysis of lung cancer spouses

Djin L. Tay^{1*}, Kline Dubose^{2,3}, Jonathan Chipman^{2,3},
Lee Ellington¹, Malek Alnajar¹, Eli Iacob¹, Caroline Stephens¹ and
Katherine A. Ornstein³

¹College of Nursing, University of Utah, Salt Lake City, UT, United States, ²Department of Population Health Sciences, School of Medicine, University of Utah, Salt Lake City, UT, United States, ³School of Nursing, Johns Hopkins University, Baltimore, MD, United States

Background: Caregiving to lung cancer patients is distressing, isolating, and associated with a high burden of anxiety and depression. However, few population-based studies in the U.S. have examined the risk of mental health conditions (MHCs) among spouses of lung cancer patients after the death of their partner. Guided by Anderson's Behavioral Health Utilization model, we examined the role of sex, pre-bereavement MHC, and decedents' healthcare utilization on the risk of having a diagnosed MHC after the death of a lung cancer patient.

Methods: This retrospective cohort study linked state-wide health facility records of 1,224 dyads—deceased lung cancer patients and their bereaved spouses (824 female, 400 male)—in Utah between 2013 and 2021. Bereavement-related mood/stress-related conditions were identified for spouses using diagnostic codes (starting from day 1 following the patients' deaths). The Kaplan–Meier curves and Cox proportional hazard models were used to estimate the risk for a composite outcome of MHC/death and the risk of MHC, after adjusting for censorship due to death and controlling for covariates.

Results: The majority of spouses were aged 65+ (female: 67%; male: 33%), white/non-Hispanic (female: 89%; male: 90%), and urban-dwelling (female: 69%; male: 71%). Spouses experienced 374 events (MHCs/death) across the follow-up period. Adjusting for census-tract level income, cancer stage, insurance, censoring due to death, and the interaction between sex and MHC, spouses with preexisting MHCs had 4.09 times higher risk of developing MHCs during bereavement (95% CI: 2.70, 6.19) compared to spouses without pre-existing MHCs. Spouses of decedents with some college education (aHR: 0.68, 95% CI = 0.48–0.97) and longer survival (aHR: 0.85, 95% CI = 0.74–0.99) had a lower risk of MHCs compared to those of decedents with high school education and shorter survival.

Discussion: This population-based study supports evidence for multi-level risk factors associated with having MHC after the death of a spouse with lung cancer. Findings suggest the need for targeted bereavement support for subgroups of spouses at greater risk of MHCs.

KEYWORDS

bereavement, neoplasms, caregiver stress, mental health, epidemiologic studies

Introduction

Cancer caregivers, particularly those supporting patients at the end of life, are a vulnerable population with increased mental health risks (1, 2). Research shows that partners of cancer patients experience anxiety and depression at levels higher than the general population and comparable to those of the cancer patients themselves (3–5). In addition to poorer self-reported mental health, cancer caregivers experience greater psychiatric morbidity before and after bereavement. Population-level studies from other countries have established that spouses of cancer patients have a 30% higher risk than spouses of non-cancer patients of developing new-onset substance abuse, depression, or stress-related conditions within the year following a cancer diagnosis. A 29% increased risk of these mental health diagnoses in bereavement persists, even after adjusting for confounders and other pre-existing mental health diagnoses (6). Similarly, in the United States (US), analyses of commercial insurance claims data found that, compared to non-cancer caregiver controls, almost 2 in 10 (19.6%) cancer caregivers had new mental health diagnoses in the year after losing their partner (7).

Lung cancer is characterized by a high rate of recurrence, low survival (8), and distressing symptoms that contribute to poor quality of life for patients and family caregivers (9–11). The intense symptom management and stigma associated with lung cancer may be particularly isolating for spouse caregivers (11, 12). Lung cancer patients have a higher prevalence of anti-cancer treatment utilization at the end of life (13), which has been associated with poorer mental health among cancer caregivers (14, 15). Analyses of cancer caregivers covered under the same health insurance policy found that caregivers of lung cancer patients were more likely to be diagnosed with a new mental health disorder following the patient's diagnosis compared to caregivers of non-lung cancer patients (18.9% vs. 10%) (7).

During cancer caregiving, wives have been observed to report poorer mental health than husbands (16). However, studies report mixed findings by gender in bereavement. While the loss of a spouse is among the most distressing life events across genders, husbands

experience greater overall physical health impacts compared with wives after losing their spouse (17–19). Yet, with regard to mental health, the findings are less clear. While wives have been reported to experience a prolonged trajectory of distressing symptoms compared with husbands in population studies in Denmark (20), the opposite finding has been observed in a Korean cohort (21). Additionally, symptoms may also differ by gender and time. In the acute bereavement phase, husbands exhibit greater initial shock, while wives exhibit greater long-term psychological resilience around the 1-year mark (22). However, these mixed findings regarding gender could be due to the greater participation of female individuals in caregiving research, as well as the influence of social norms that facilitate female caregivers' expression of distress and mental health care (23), highlighting the need to examine gender effects in bereavement using population-based approaches.

While the majority of population-based studies on bereavement have been conducted outside of the US (6, 24), findings from these studies may be less generalizable to the US healthcare system. Examining the risk factors associated with MHCs among lung cancer spouses, a population vulnerable to the mental health impact of caregiving is needed to provide scientific evidence for targeted bereavement interventions in this population. Given these gender-based differences in bereavement mental health, we sought to focus on the relationship between gender and mood- and stress-related mental health diagnoses after the loss of a partner to cancer. Guided by Anderson's Behavioral Health Model (25), we tested the hypothesis that predisposing characteristics (female sex) and need characteristics (spouses' pre-existing mental health conditions and decedents' healthcare utilization) would be associated with the risk of bereavement MHCs (Figure 1).

Methods

This secondary analysis used data from bereaved spouses and partners of decedents diagnosed with lung cancer between 2013

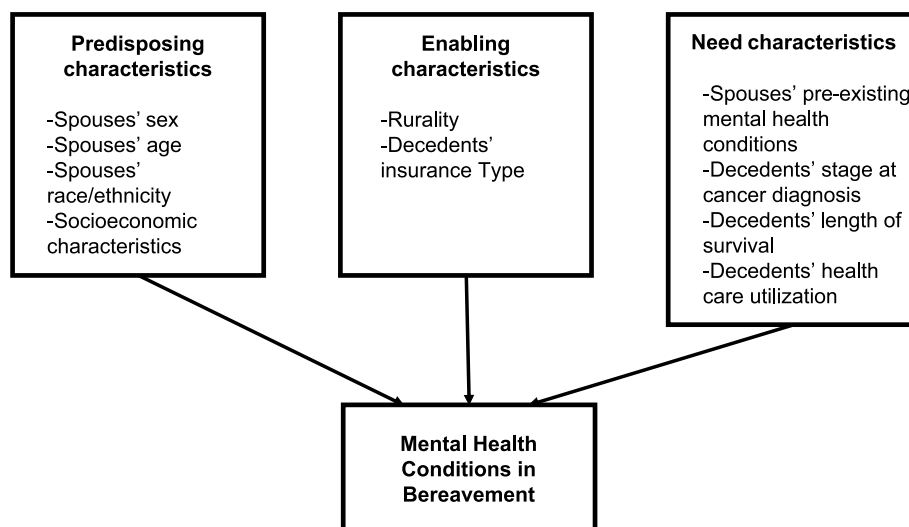


FIGURE 1

Adapted Anderson Behavioral Health Model for spouses' bereavement mental health utilization.

and 2018 in Utah identified with the Immunotherapy, Palliative, End of Life Treatment Utilization, and Spousal Outcomes (ImmPETUS) cohort (23). ImmPETUS was developed to facilitate the study of changes in cancer patients' end-of-life and primary caregiver health utilization during a period of rapid adoption of immunotherapies in advanced cancers. The ImmPETUS cohort is a linked dataset comprising demographic, clinical, end-of-life, and spousal caregiver data that combine several key population datasets in Utah: the Utah Population Database's (UPDB) statewide health facility data from the Utah Department of Health, the Utah All-Payer Claims Database (APCD), and the Utah Cancer Registry (UCR).

Data sources

UPDB

The UPDB is a statewide database that enables the linkage of health and family records from statewide health registries, sociodemographic data, vital records, and genealogical data for all Utah residents at the individual level. The UPDB health facility data are complete as they contain all inpatient, ambulatory surgery, and emergency department administrative data for every encounter in the state, regardless of insurance coverage, including encounters among the uninsured population. However, the UPDB's health facility data does not capture administrative data from care settings outside of inpatient, ambulatory surgery, and emergency department settings, such as physician visits.

APCD

The Utah APCD contains all administrative data, including pharmacy records for the insured population, Medicaid, and commercial Medicare Supplemental and Advantage plans for older adults aged 65 years and above. The APCD does not collect data from non-commercial Medicare plans, health plans covering fewer than 2,500 individuals (26), the Veterans Health Administration or TRICARE system (serving active service members and veterans), Indian Health Services (tribal and urban Indian health programs), and individuals who self-pay are underrepresented (27). As such, the data collected by the APCD represent approximately 60%–70% of Utah's non-Medicare population (28).

UCR

The UCR collects, stores, and manages cancer surveillance data in Utah for the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute. The UCR captures data on cancer staging, diagnosis, and sociodemographic data current at the time of the index cancer diagnosis. According to the SEER program, cancer data from the UCR are complete and valid (29).

To maximize coverage of the population and data completeness, we linked the UPDB health facility, Utah APCD, and UCR data for the sample. Eligible cancer patients (1) had a record in the UCR; (2) had a diagnosis of lung or bronchus cancer between 2013 and 2018; and (3) were at least 18 years of age or older at the time of cancer diagnosis. Spouses and partners aged 18 and above were identified with UPDB's family groups, which are derived using a combination of marital records and children's birth records. Cancer patients with a non-natural cause of death (e.g., an accident) were excluded.

Measures

The variables were selected *a priori* and informed by Anderson's Behavioral Health Utilization Model (25). We examined the associations between *predisposing* (spouses' sex, age, ethnicity, and socioeconomic characteristics), *enabling* (rurality and insurance type), and *need* characteristics (spouses' pre-existing MHCs, decedents' stage at cancer diagnosis, survival, and cancer decedents' healthcare utilization) and the outcome of MHCs.

MHCs

The outcome of interest was a documented diagnosis of mood- or stress-related disorder documented in administrative data any day after day 1 of the death of the partner. Anxiety, depression, and stress-related disorders were identified with International Classification of Disease (ICD) 9 and 10 codes identified by other large, published studies using administrative records that were developed by or verified with physician input (6, 30) (codes are listed in [Supplementary Table 1](#)).

Predisposing characteristics

Our primary independent variable was binary sex derived from birth records. We also adjusted the models for age (years), spouses' ethnicity (non-Hispanic White, Hispanic, and non-Hispanic other ethnicity), census-tract level median annual income quartiles (\$16,900–\$46,604; \$46,605–\$60,057, \$64,058–\$74,624, \$74,625–\$193,958) obtained from the UPDB's American Community Survey data, and the maximum education level of decedent as recorded on death certificates (less than high school, high school graduate, some college, college graduate, and postgraduate).

Enabling characteristics

Rurality was based on the Utah Department of Health definitions of Urban (counties with a population of 100 persons or more per square mile), Rural (7–99 persons per square mile), and Frontier (<7 persons per square mile) (25). Decedents' primary insurance type (Medicaid, Medicare, Private, and Other) was also assessed.

Need characteristics

We assessed spouses' pre-existing MHCs and decedents' stage at cancer diagnosis (localized, regional, and distant) and survival (time from diagnosis to death, in years). Inpatient and emergency department visits after cancer patients' diagnosis were included as a covariate to assess healthcare utilization.

Analyses

Descriptive statistics were calculated for the sample, and standardized mean differences were used to compare effect sizes between male and female individuals in the sample. The Kaplan–Meier curves and survival analyses assessing the composite outcome of death and MHCs were conducted, followed by cause-specific analyses, accounting for censoring at death. To avoid overfitting, we included spouses' sex, age, and history of MHCs, and patients' cancer stage, survival, education, census-tract level income quartile, inpatient stays, and emergency department visits in the models. To account for the higher use of mental healthcare among female individuals, in general, we included the interaction of sex with mental

health condition in the models. After applying the inclusion and exclusion criteria, missing data for each variable were assessed. The proportion of missing information for all variables did not exceed 8%. We assumed missing data to be missing at random and used multiple imputation models to address the missing data (31). After identifying variables with missing data, we used the *Hmisc* and *rms* packages in R to impute the data using the AREG method to impute the data and aggregate the information across 23 iterations of the imputed data (32–34). All analyses were conducted in R with significance at a *p*-value of <0.05.

Results

Characteristics of the sample

A total of $N = 1,224$ spouse-patient dyads (female spouses $n = 824$; male spouses $n = 400$) were identified after excluding lung cancer patients without spousal links ($n = 31,379$) and patients who were living ($n = 14,824$; $n = 3$; Figure 2). Female spouses had a median age of 68 years (interquartile range (IQR) = 61–76), and male spouses had a median age of 70 years (IQR = 64–77; Table 1). The majority of spouses were non-Hispanic White (female $n = 723$, 89%; male $n = 354$, 90%) and lived in urban areas (female 566, $n = 69\%$, male = 285, 71%). Almost one in five female and male spouses lived in census tracts with the lowest quartile of annual household income. Greater proportions of male spouses had lost a partner with less than a high school education (19% vs. 17%) and a high school education (37% vs. 33%), while greater proportions of female spouses lost a partner with a post-college education (9.5% vs. 5.5%).

Pre-existing MHCs prior to decedents' deaths were observed in 6.6% of female ($n = 64$) and 5.3% ($n = 21$) of male spouses, respectively. A greater proportion of cancers diagnosed at distant stages was observed for deceased partners of both female and male spouses (67% and 73%, respectively), and the majority of decedents were insured through Medicare (partners of female spouses $n = 580$, 73%; partners of male spouses $n = 268$, 68%). Deceased

partners of female and male partners had a median of 3 inpatient visits and 1–2 emergency department visits after their cancer diagnosis, with a majority of decedents dying at home (62%–64%). Female spouses were significantly younger (standardized mean difference, $SMD = -0.16$, 95% $CI = -0.28$ – 0.04), differed in deceased partners' maximum education level ($SMD = 0.17$, 95% $CI = 0.05$ – 0.29), and cancer stages ($SMD = 0.22$, 95% $CI = 0.10$ – 0.34), which supported the fact that these differences were not large in magnitude.

Events (composite outcome of MHCs and death)

To account for the possibility of death as a competing event to MHCs, i.e., spouses may die prior to presenting to a health facility where MHCs would be documented, we developed a composite outcome of MHC and deaths. A total of 374 events contributed by $N = 1,224$ spouses were documented across the study period. Figure 3 features the Kaplan–Meier curves by sex that describe the estimated overall probability of mood disorder or composite outcome (mood disorder or death) over time (years). The curves suggest that female spouses had a greater probability of mood disorder (Figure 3A), male spouses had a greater probability of death (Figure 3B), and that male and female spouses had a similar probability of any event (mood disorder + death; Figure 3C).

Cox proportional hazards models

Separate Cox proportional hazards models evaluated differences in time to the composite outcome and mood disorder accounting for censorship due to death (cause-specific model). After adjusting for the interaction between sex and MHCs, neither model showed a difference in the risk of MHCs in bereavement based on sex or decedents' healthcare utilization.

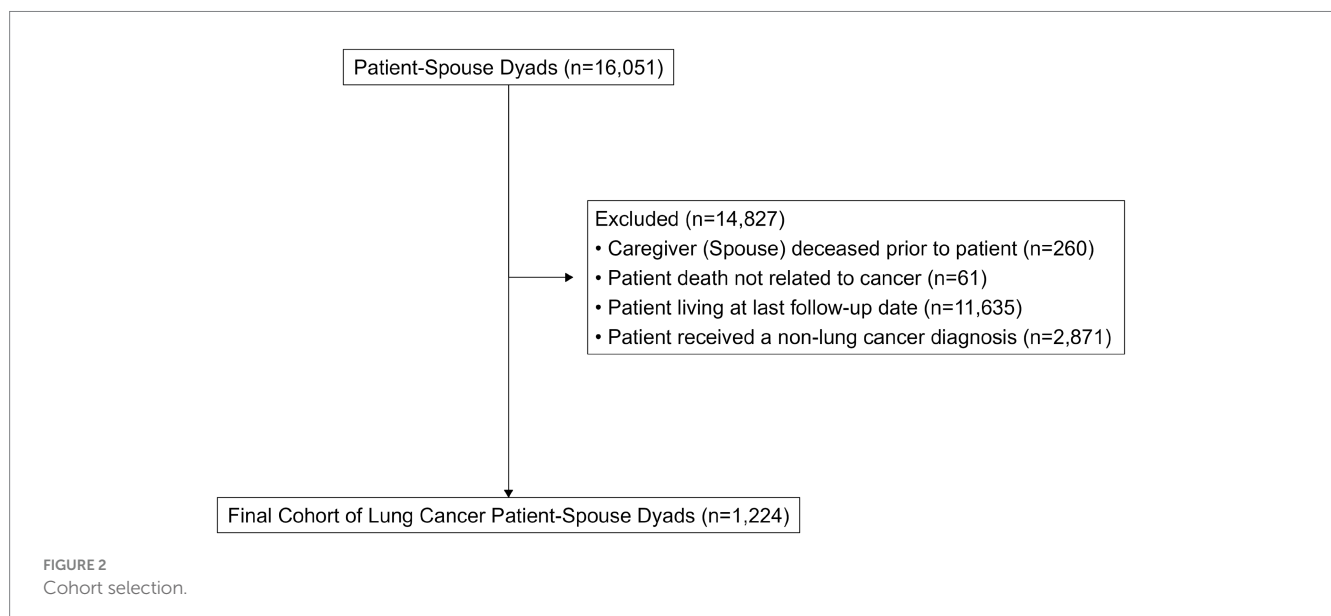


TABLE 1 Differences in characteristics between male and female spouses (N = 1,224).

Group	Characteristic	Spouse sex		SMD ²	95% CI ^{2,3}
		Female	Male		
		n = 824 ¹	n = 400 ¹		
Spouse	Age at Diagnosis (Median, IQR; years)	68 (61, 76)	70 (64, 77)	-0.16	-0.28, -0.04
	Ethnicity ^{4,5}			0.04	-0.08, 0.16
	Non-Hispanic White	723 (89%)	354 (90%)		
	Hispanic	59 (7.3%)	25 (6.3%)		
	Non-Hispanic Other	31 (3.8%)	15 (3.8%)		
	Spouse's pre-existing mood disorder	54 (6.6%)	21 (5.3%)	0.06	-0.06, 0.17
Patient	Rurality ⁴			0.06	-0.06, 0.18
	Urban	566 (69%)	285 (71%)		
	Rural	207 (25%)	95 (24%)		
	Frontier	50 (6.1%)	20 (5.0%)		
	Education ^{4,6}			0.17	0.05, 0.29
	Less than high school	136 (17%)	75 (19%)		
	High School Graduate	274 (33%)	146 (37%)		
	Some College	248 (30%)	114 (29%)		
	College Graduate	84 (10%)	41 (10%)		
	Postgraduate	78 (9.5%)	22 (5.5%)		
	Census-tract level median income (Dollars)			0.09	-0.03, 0.21
	16,900–46,604	154 (19%)	82 (21%)		
	46,605–60,057	270 (33%)	115 (29%)		
	64,058–74,624	231 (28%)	115 (29%)		
	74,625–193,958	169 (21%)	88 (22%)		
Stage ^{4,7}			0.22	0.10, 0.34	
Distant	532 (67%)	286 (73%)			
Localized	136 (17%)	38 (9.7%)			
Regional	128 (16%)	66 (17%)			
Insurance type ⁴			0.11	-0.01, 0.23	
Medicaid	25 (3.1%)	16 (4.1%)			
Medicare	580 (73%)	268 (68%)			
Other	13 (1.6%)	8 (2.0%)			
Private	179 (22%)	103 (26%)			
Inpatient visits post-diagnosis ⁴	3.0 (1.0, 6.0)	3.0 (1.0, 6.0)	0.05	-0.08, 0.17	
Emergency room visits ⁴	1.0 (0.0, 3.8)	2.0 (0.0, 4.5)	-0.08	-0.20, 0.04	

¹Median (IQR); n (%). ²SMD, standardized mean difference; bolded values are significant. A difference of 0.2 indicates a small, 0.5 a medium, and 0.8 a large effect size (34). ³CI, confidence interval. ⁴Indicates unknown/missing data, numbers suppressed due to small cell sizes to protect confidentiality. ⁵Due to small cell sizes, ethnicity was combined into three categories. Non-Hispanic and Others included individuals classified as American Indian/Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, or Multiple Ethnicities and Non-Hispanic. ⁶Decedents' lifetime maximum level of education was assessed using death certificate data. ⁷Reflects the stage of cancer diagnosis as indicated in Utah Cancer Registry records.

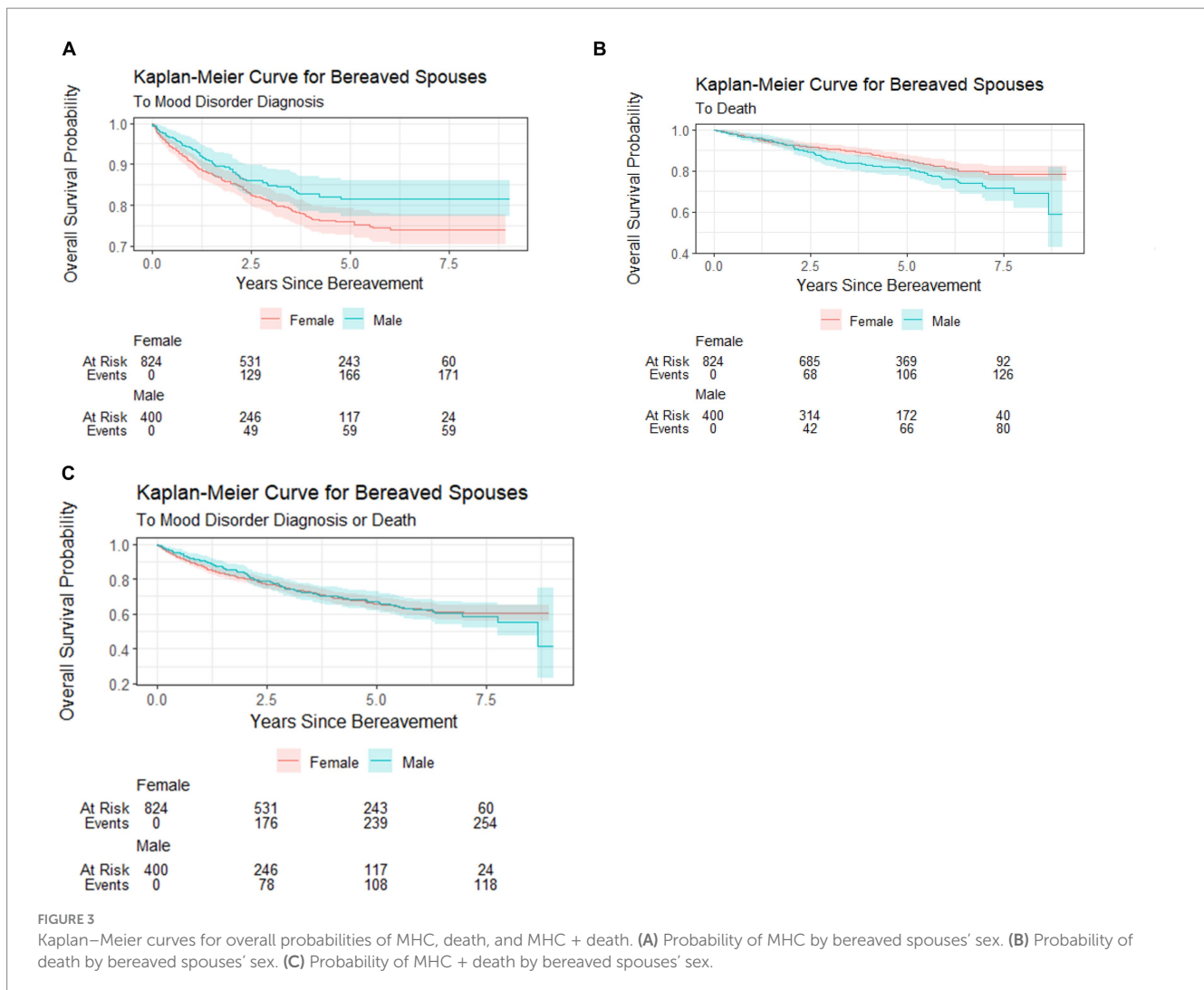
Model for the composite outcome

After adjusting for covariates, the risk of MHC/death was increased for each 10-year interval for surviving spouses. Specifically, at a given point in time, a 10-year increase in spouses' age at diagnosis was associated with a hazard ratio of 1.37 (95% CI: 1.19, 1.55). Having a diagnosed MHC prior to the cancer decedents' death was associated with a three times higher risk (aHR: 3.16, 95% CI: 2.21, 4.53) of MHC/death. Compared with decedents whose maximum lifetime education was at the high school level, spouses of decedents with some

college-level education (aHR: 0.69, 95% CI = 0.52–0.90) and who were college graduates (aHR: 0.64, 95% CI = 0.41–0.99) had a lower risk of MHCs in bereavement (Table 2).

Cause-specific model

In the cause-specific analysis, spouses' age was no longer a significant predictor of the risk of an outcome; however, the decedents' length of survival was associated with spouses' risk of MHCs. An additional year of survival was associated with a 15% decrease in the



risk of spouses experiencing an MHC in bereavement. As in the previous analysis, having a previously diagnosed MHC was associated with a significantly adjusted hazard ratio of 4.09 (95% CI: 2.70, 6.19). Spouses of decedents with some college-level education had a lower risk of bereavement MHCs (aHR: 0.68, 95% CI = 0.48–0.97) compared with decedents with a high school-level education, after accounting for censorship due to death (Table 3).

Discussion

Examining the impact of bereavement MHC over time is important for cancer spouses—a population at greater risk of developing psychiatric disorders after the death of their spouse. This was one of the few population-based studies in the US that examined diagnoses of MHCs among lung cancer spouses after the death of a partner.

Bereaved lung cancer spouses have been observed to be particularly at risk compared to non-cancer caregivers and even caregivers of decedents with other cancer types, and lung cancer caregivers' distress can exceed even that of patients themselves (3). Hu et al.'s analyses of two national registries in Sweden and Denmark

observed that spouses of lung cancer had a 45% higher risk of new MHCs compared to spouses of patients with less aggressive cancers (e.g., prostate cancer spouses HR = 1.05, any cancer HR = 1.14) after the diagnosis of cancer in their partners (6). However, there is limited epidemiologic research comparing differences in bereavement MHCs by cancer types in the US, except for a few. A 2021 study by Hess et al. using IBM MarketScan Administrative Data in the US observed that lung cancer caregivers had the highest proportions of new MHC-related diagnoses (18.9%) in the first year after a cancer patient's diagnosis compared with gastric (17.8%), colorectal (14.7%), sarcoma (14.3%), and breast cancer (10.1%) caregivers (7). Taken together, these findings support that lung cancer spouses may be a particularly at-risk caregiving population; however, future research comparing across cancer types is needed to verify these outcomes among spouses of other cancer patients in the US population.

While we anticipated that the female sex of the surviving spouse would be associated with greater MHCs, our cause-specific analysis did not find a statistically significant difference after accounting for earlier mortality in male spouses. This finding may be due to the lower reporting and help-seeking behaviors of male individuals for MHCs in general (35). Our previous studies examining prescriptions of antidepressants and anxiolytics in families of decedents in the last year

TABLE 2 Adjusted Cox proportional hazards for the composite outcome (time to MHC or death).

Variables	aHR ^{1,2}	S.E.	Lower 0.95	Upper 0.95
Male sex (spouse)	0.96	0.11	0.76	1.20
Spousal age at patients' diagnosis, per 10-year difference	1.36	0.07	1.19	1.55
Spouse's pre-existing MHC	3.16	0.18	2.21	4.53
Time from Diagnosis to Death	0.95	0.05	0.85	1.05
Decedents' maximum education, ref. High school graduate				
College Graduate	0.64	0.23	0.41	0.99
Less than high school	1.09	0.14	0.83	1.43
Postgraduate	0.81	0.23	0.52	1.27
Some College	0.69	0.14	0.52	0.90
Decedents' inpatient visits after cancer diagnosis	0.99	0.02	0.96	1.02
Decedents' emergency department visits after cancer diagnosis	1.01	0.01	0.98	1.03

¹Models have been adjusted for decedents' census-tract level income, cancer stage at diagnosis, maximum lifetime education, insurance, and the interaction of sex*MHC (all not significant).

²Bolded coefficients indicate statistical significance.

TABLE 3 Adjusted Cox proportional hazards for the cause-specific model (time to MHC adjusted for censorship due to death).

Variables	aHR ^{1,2}	S.E.	Lower 0.95	Upper 0.95
Male sex (spouse)	0.75	0.15	0.56	1.02
Spousal age at patients' diagnosis, per 10-year difference	0.94	0.08	0.80	1.10
Spouse's pre-existing MHC	4.09	0.21	2.70	6.19
Time from Diagnosis to Death	0.85	0.07	0.74	0.99
Decedents' maximum education, High school graduate				
College Graduate	0.76	0.26	0.46	1.27
Less than high school	1.18	0.18	0.83	1.67
Postgraduate	0.88	0.28	0.51	1.50
Some College	0.68	0.18	0.48	0.97
Decedents' inpatient visits after cancer diagnosis	1.00	0.02	0.97	1.04
Decedents' emergency department visits after cancer diagnosis	1.01	0.017	0.98	1.05

¹Models have been adjusted for decedents' census-tract level income, cancer stage diagnosis, insurance, and the interaction of sex*MHC (all not significant). ²Bolded coefficients indicate statistical significance.

of life observed higher proportions of antidepressant prescriptions among wives compared with husbands (36), supporting the possibility that female individuals seek more care for MHCs. However, gender differences in the timing of symptoms may influence these findings. Other registry-based studies have found that male individuals exhibit prolonged grief symptoms more acutely, while female individuals have a more protracted trajectory of symptoms (20). Given our observation of earlier mortality in male individuals, there is a possibility that more acute and severe mental health symptoms associated with earlier mortality in male individuals may have affected these findings. While outside the scope of our study, future studies comparing outcomes with a non-bereaved matched cohort are recommended to better distinguish the gender effect of bereavement on mental health and mortality.

Losing a spouse is among the most difficult life events for adults, and 10–20% of bereaved spouses will develop severe or prolonged grief responses (37). Our findings support the finding that having a previously diagnosed mood or stress-related disorder was associated with over four times higher risk of having an MHC, which is in line with findings from other survey-based epidemiologic studies of complicated grief (38). Future studies should also examine serious mental health diagnoses such as schizophrenia, bipolar, major depressive disorders (39), or co-occurring substance or alcohol use disorders (6, 40, 41) to better identify the most at-risk individuals who may benefit from targeted support in bereavement.

We focused on MHCs that were documented in administrative data, which may reflect a sample with more severe MHC who were diagnosed or treated in healthcare settings (42). It is important to note

that these data may neither capture mental health outcomes for individuals with subclinical but meaningful levels of symptoms nor cases if individuals do not seek health care for their MHCs. A study of 168 bereaved cancer caregivers of lung and gastrointestinal cancer patients found that 30.4% of caregivers self-reported clinical levels of depressive symptoms, while 43.4% reported clinically significant levels of anxiety after the death of their loved one (43). Thus, it is possible that the prevalence of MHCs may be higher in the bereaved lung cancer spouse population than these findings observed.

The greater risk of MHC in this caregiver population may be due to the unique stresses of lung cancer caregiving (4, 10, 11). While we hypothesized that greater overall healthcare utilization in deceased patients would be associated with greater bereavement MHC, this association was not supported in our findings. A possibility may be that we assessed the number of inpatient and emergency department visits beginning after patients' cancer diagnoses, which may fail to capture the more stressful contexts of high-intensity care that cluster toward the end of life (44). In addition, dyadic effects may also exist, as poorer bereavement mental health in caregivers has been associated with perceived distress in their loved one prior to death (43). These factors associated with the end-of-life care context would be important to examine in future analyses.

Population studies observed that bereaved cancer spouses have an increased risk of psychiatric disorders if their partners had advanced cancers and cancers with poorer prognoses (6). Our findings add that longer survival among cancer decedents was associated with a lower risk of MHCs in bereavement. A possibility is that longer survival may facilitate greater emotional adjustment in spouses of cancer patients, particularly when death is expected (45). This finding is in contrast with our previous analysis of the hospice patient population that observed that longer hospice duration was positively associated with mortality risk for bereaved husbands but not wives in the general population (46). These findings collectively suggest that gender and trajectories of decline may play a modifying role in the end-of-life cancer caregiving stress experience.

Although we adjusted for multiple factors, our findings were unable to account for psychosocial factors or cultural influences on bereavement that can serve a protective or risk role. For example, perceived interpersonal support is protective for psychological wellbeing and health-related quality of life among cancer caregivers (47, 48). Additionally, caregiving and subsequent bereavement may be perceived as normative and a fulfillment of a spousal responsibility, influenced by certain cultural or ethnic backgrounds (49). Conversely, some cultures and communities may hold beliefs that discourage seeking bereavement support (50) or mental health services more broadly (51). Future research integrating self-reported or qualitative methods and exploring bereavement mental health outcomes in more racially and ethnically diverse samples may be helpful in distinguishing the contribution of psychosocial and cultural influences.

Finally, while our study did not have access to individual-level household income, our findings supported that socioeconomic status may be protective of spousal bereavement MHC. While indirect, this finding supports the implications that dyadic factors may continue to influence surviving members of dyads after the death of a partner. The higher level of educational attainment may be associated with greater income or wealth for the surviving partner, which should be examined

in future studies using individual-level measures of socioeconomic status. Examining the socioeconomic influences associated with bereavement is important as financial hardship in surviving spouses has been associated with an increased risk of suicidal ideation (38).

Limitations

While the strengths of this study were a population sample and the use of objective data, limitations include the retrospective nature of the study and the potential for detection bias. Individuals who do not have healthcare encounters in inpatient, ambulatory surgery, or emergency department settings or do not seek care for MHCs are not represented in these data. Studies using self-reported data may observe different findings. Future studies should evaluate MHCs using other measures, including self-reported measures. Due to the smaller sample and rarer occurrences of MHC, we limited the examination of additional predictors to prevent overfitting of the data. Thus, there is a possibility of potentially unmeasured confounders, such as access to social support, cultural factors, and the end-of-life caregiving context. Additionally, data from this study were specific to a single state, which poses implications for generalizability. Nevertheless, population data allow us to minimize selection bias compared with smaller, prospective samples, which is a strength of this study.

Conclusion

Bereavement is a major life stressor that can contribute to mental health morbidity and is one of the major stressors associated with serious illness caregiving. Building population-level evidence for the pervasive impacts of cancer caregiving is important to guide care delivery across the cancer continuum and beyond. Future research should investigate these outcomes in a more nationally representative sample and investigate other mental health outcomes that may be relevant to difficult loss. Nevertheless, our findings hold implications of greater mental health assessment and support for bereaved partners that may be at risk for greater mental health challenges after the loss of a spouse to lung cancer, such as lung cancer spouses that have pre-existing MHCs.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: use of the data held by the Utah Population Database (UPDB) and its data contributors are regulated. Under an Executive Order, the Utah Resource for Genetic and Epidemiologic Research (RGE) is responsible for regulatory oversight of all projects using data from the UPDB. Access to datasets from the UPDB (including those constructed for this application) is governed and approved by the RGE committee, which includes representatives of the data providers whose data are included in UPDB. An RGE protocol is ancillary to an Institutional Review Board (IRB) protocol, which may be held external to the University of Utah. Data may only be transferred from the University of Utah to an external institution with RGE approval and a fully executed data transfer agreement. Requests to access these

datasets should be directed to Nicola Camp, Nicola.camp@hci.utah.edu.

Ethics statement

The study involving humans were approved by the University of Utah Institutional Review Board. The study was conducted in accordance with the local legislation and institutional requirements. A waiver of informed consent was obtained for the limited dataset and secondary data analysis in accordance with the national legislation and institutional requirements.

Author contributions

DT: Conceptualization, Funding acquisition, Investigation, Project administration, Supervision, Writing – original draft, Writing – review & editing. KD: Data curation, Formal analysis, Investigation, Methodology, Validation, Visualization, Writing – review & editing. JC: Conceptualization, Investigation, Methodology, Supervision, Writing – review & editing. LE: Investigation, Resources, Writing – review & editing. MA: Investigation, Writing – review & editing. EI: Investigation, Writing – review & editing. CS: Investigation, Writing – review & editing. KO: Conceptualization, Investigation, Supervision, Writing – review & editing.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. This study was funded by the University of Utah's Vice President for Research Incentive Seed Grant (PI: DT). LE was supported by an NIA award (K07AG068185). We also acknowledge funding from the College of Nursing Emma Eccles Jones Nursing Research Center for publication fees. This study was also partially supported by the Huntsman Cancer Institute Comprehensive Cancer Center at the University of Utah P30CA042014, utilizing Cancer Biostatistics and Cancer Bioinformatics Shared Resources. We acknowledge the Pedigree and Population Resource of Huntsman Cancer Institute (Huntsman Cancer Foundation), the Utah Population Database (National Cancer Institute P30 CA2014, University of Utah, University of Utah's Clinical and Translational Science Institute), the Utah Department of Health Data (NCR R01 RR021746, PI: G. Mineau; Utah Department of Health, University of Utah), and the Utah Cancer Registry (National Cancer Institute's SEER Program, Contract No. HHSN261201800016I, US Centers for Disease Control and Prevention's National Program of

References

- Hasdenteufel M, Quintard B. Psychosocial factors affecting the bereavement experience of relatives of palliative-stage cancer patients: a systematic review. *BMC Palliat Care*. (2022) 21:212. doi: 10.1186/s12904-022-01096-y
- Kim Y, Shaffer KM, Carver CS, Cannady RS. Quality of life of family caregivers 8 years after a relative's cancer diagnosis: follow-up of the National Quality of life survey for caregivers. *Psychooncology*. (2016) 25:266–74. doi: 10.1002/pon.3843
- Li J, Li C, Zou J, Cheng F-Q, Peng L, Deng L-H, et al. Prevalence and influencing factors of the dyadic psychological stress among patients with lung cancer and their

Cancer Registries, Cooperative Agreement No. NU58DP006320, University of Utah, and the Huntsman Cancer Foundation). The support and resources of the Center for High Performance Computing at the University of Utah are gratefully acknowledged. The computational resources used were partially funded by the NIH Shared Instrumentation Grant 1S10OD021644-01A1.

Acknowledgments

We acknowledge Dr. Mia Hashibe for her guidance on the initial cohort design. We acknowledge the support of the University of Utah's Family Caregiving Collaborative (K07AG068185; PI: LE).

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

Author disclaimer

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2025.1539180/full#supplementary-material>

family caregivers: a cross-sectional study. *BMC Nurs*. (2025) 24:13. doi: 10.1186/s12912-024-02635-z

4. Geng HM, Chuang DM, Yang F, Yang Y, Liu WM, Liu LH, et al. Prevalence and determinants of depression in caregivers of cancer patients: a systematic review and meta-analysis. *Medicine*. (2018) 97:e11863. doi: 10.1097/md.00000000000011863

5. Bedaso A, Dejenu G, Duko B. Depression among caregivers of cancer patients: updated systematic review and meta-analysis. *Psycho-Oncology*. (2022) 31:1809–20. doi: 10.1002/pon.6045

6. Hu K, Liu Q, László KD, Wei D, Yang F, Fall K, et al. Risk of psychiatric disorders among spouses of patients with cancer in Denmark and Sweden. *JAMA Netw Open*. (2023) 6:560. doi: 10.1001/jamanetworkopen.2022.49560
7. Hess LM, Wong-Jacobson SH, Peterson PM. Health and resource burden of a cancer diagnosis on the caregiver: an analysis of administrative claims data. *BMC Health Serv Res*. (2021) 21:894. doi: 10.1186/s12913-021-06938-8
8. American Cancer Society. Lung Cancer Survival Rates: American Cancer Society; (2024). Available online at: <https://www.cancer.org/cancer/types/lung-cancer/detection-diagnosis-staging/survival-rates.html> (Accessed December 3, 2024).
9. Hendriksen E, Rivera A, Williams E, Lee E, Sporn N, Cases MG, et al. Manifestations of anxiety and coping strategies in patients with metastatic lung cancer and their family caregivers: a qualitative study. *Psychol Health*. (2019) 34:886–99. doi: 10.1080/08870446.2019.1579909
10. Hendriksen E, Williams E, Sporn N, Greer J, DeGrange A, Koopman C. Worried together: a qualitative study of shared anxiety in patients with metastatic non-small cell lung cancer and their family caregivers. *Support Care Cancer*. (2015) 23:1035–41. doi: 10.1007/s00520-014-2431-9
11. Lippitt KA, Richardson A, Myall M, Cummings A, May CR. Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research. *BMJ Open*. (2019) 9:e020515. doi: 10.1136/bmjopen-2017-020515
12. Carmack Taylor CL, Badr H, Lee JH, Fossella F, Pisters K, Gritz ER, et al. Lung cancer patients and their spouses: psychological and relationship functioning within 1 month of treatment initiation. *Annals Behav Med*. (2008) 36:129–40. doi: 10.1007/s12160-008-9062-7
13. Smith CEP, Kamal AH, Kluger M, Coke P, Kelley MJ. National Trends in end-of-life Care for Veterans with Advanced Cancer in the veterans health administration: 2009 to 2016. *J Oncol Pract*. (2019) 15:e568–75. doi: 10.1200/jop.18.00559
14. Nipp RD, El-Jawahri A, Fishbein JN, Gallagher ER, Stagl JM, Park ER, et al. Factors associated with depression and anxiety symptoms in family caregivers of patients with incurable cancer. *Annals Oncol*. (2016) 27:1607–12. doi: 10.1093/annonc/mdw205
15. Takao A, Arao H, Yamamoto S, Aoki M, Kouda K, Morita T, et al. Nationwide survey on caregiver burden when supporting terminal Cancer patients with dementia: bereaved family Members' perspective. *J Palliat Care*. (2023) 38:326–35. doi: 10.1177/08258597231169625
16. Ng JH, Luk BH, Lee NP. Gender differences in cancer spousal caregiving: a systematic review. *Palliat Support Care*. (2023) 21:880–9. doi: 10.1017/S1478951523000731
17. Stahl ST, Arnold AM, Chen JY, Anderson S, Schulz R. Mortality after bereavement: the role of cardiovascular disease and depression. *Psychosom Med*. (2016) 78:697–703. doi: 10.1097/psy.0000000000000317.P
18. Liu H, Umberson D, Xu M. Widowhood and mortality: gender, race/ethnicity, and the role of economic resources. *Ann Epidemiol*. (2020) 45:69–75.e1. doi: 10.1016/j.annepidem.2020.02.006
19. Sullivan AR, Fenelon A. Patterns of widowhood mortality. *J Gerontol B Psychol Sci Soc Sci*. (2014) 69B:53–62. doi: 10.1093/geronb/gbt079
20. Lunderoff M, Bonanno GA, Johannsen M, O'Connor M. Are there gender differences in prolonged grief trajectories? A registry-sampled cohort study. *J Psychiatr Res*. (2020) 129:168–75. doi: 10.1016/j.jpsychires.2020.06.030
21. Yoon H, Park GR, Kim J. Psychosocial trajectories before and after spousal loss: does gender matter? *Soc Sci Med*. (2022) 294:114701. doi: 10.1016/j.socscimed.2022.114701
22. Maccallum F, Lunderoff M, Johannsen M, Farver-Vestergaard I, O'Connor M. An exploration of gender and prolonged grief symptoms using network analysis. *Psychol Med*. (2023) 53:1770–7. doi: 10.1017/S0033291721003391
23. McLean S, Gomes B, Higginson IJ. The intensity of caregiving is a more important predictor of adverse bereavement outcomes for adult-child than spousal caregivers of patients who die of cancer. *Psychooncology*. (2017) 26:316–22. doi: 10.1002/pon.4132
24. Maura G, Blotière PO, Wastesson JW, Johnell K. Spousal bereavement and four-year trajectories of medication use: a nationwide register-based study in Swedish older adults. *J Am Geriatr Soc*. (2024) 72:2048–59. doi: 10.1111/jgs.18950
25. Aday LA, Andersen R. A framework for the study of access to medical care. *Health Serv Res*. (1974) 9:208–20.
26. Utah Office of Administrative Rules. Insurance administration rule 262: health data authority health insurance claims reporting. Utah: Utah Office of Administrative Rules (2024).
27. Garvin JH, Herget KA, Hashibe M, Kirchoff AC, Hawley CW, Bolton D, et al. Linkage between Utah all payers claims database and central Cancer registry. *Health Serv Res*. (2019) 54:707–13. doi: 10.1111/1475-6773.13114
28. Utah Department of Health & Human Services. About the Utah all payer claims database Salt Lake City, UT: Utah Department of Health & Human Services; (2025). Available online at: <https://healthcarestats.utah.gov/about-the-data/#:~:text=About%20the%20Utah%20All%20Payer%20Claims%20Database&text=As%20of%20December%202021%2C%20the%20most%20people%20in%20the%20state> (Accessed April 2, 2025).
29. Codden RR, Sweeney C, Ofori-Atta BS, Herget KA, Wigren K, Edwards S, et al. Accuracy of patient race and ethnicity data in a central cancer registry. *Cancer Causes Control*. (2024) 35:685–94. doi: 10.1007/s10552-023-01827-3
30. Frayne SM, Miller DR, Sharkansky EJ, Jackson VW, Wang F, Halanych JH, et al. Using administrative data to identify mental illness: what approach is best? *Am J Med Qual*. (2010) 25:42–50. doi: 10.1177/1062860609346347
31. Rubin DB, Schenker N. Multiple imputation in healthcare databases: an overview and some applications. *Stat Med*. (1991) 10:585–98. doi: 10.1002/sim.4780100410
32. Harrell EF. Hmisc: Harrell Miscellaneous. (2025). R package version 5.2-4. Available at: <https://github.com/harrelfe/hmisc>
33. Harrell F. Jr. Package 'rms'. R package version 8.0-0. (2025). Available at: <https://cran.r-project.org/web/packages/rms/rms.pdf>
34. Van Buuren S, Groothuis-Oudshoorn K. Mice: multivariate imputation by chained equations in R. *J Stat Softw*. (2011) 45:1–67. doi: 10.18637/jss.v045.i03
35. Roxo L, Silva M, Perelman J. Gender gap in health service utilisation and outcomes of depression: a cross-country longitudinal analysis of European middle-aged and older adults. *Prev Med*. (2021) 153:106847. doi: 10.1016/j.ypmed.2021.106847
36. Jacob E, Hollingshaus M, Utz R, Tay D, Ornstein KA, Alexander R, et al. Caregiving at end-of-life: How do family structure and dementia status impact antidepressant and anxiolytic prescriptions among families? *Alzheimer's Dement*. (2025). doi: 10.1002/alz.14590
37. Seiler A, von Känel R, Slavich GM. The psychobiology of bereavement and health: a conceptual review from the perspective of social signal transduction theory of depression. *Front Psych*. (2020) 11:565239. doi: 10.3389/fpsy.2020.565239
38. Viola M, Gang J, Maciejewski PK, Prigerson HG. Associations of financial hardship with suicidal ideation among bereaved cancer caregivers. *J Psychosoc Oncol*. (2023) 41:226–34. doi: 10.1080/07347332.2022.2067803
39. Tay DL, Thygesen LC, Kozlov E, Ornstein KA. Serious mental illness exacerbation post-bereavement: a population-based study of partners and adult children. *Clin Epidemiol*. (2022) 14:1065–77. doi: 10.2147/lep.S372936
40. Stewart SA, Copeland AL, Cherry KE. Risk factors for substance use across the lifespan. *J Genet Psychol*. (2023) 184:145–62. doi: 10.1080/00221325.2022.2130025
41. Bottomley JS, Williams JL, Pavlacic JM, Gex KS, Rheingold AA. Bereavement and problematic alcohol use: prevalence and predictors among a national sample of bereaved adults. *Alcohol Clin Exp Res*. (2025) 49:175–84. doi: 10.1111/acer.15496
42. Davis KA, Sudlow CL, Hotopf M. Can mental health diagnoses in administrative data be used for research? A systematic review of the accuracy of routinely collected diagnoses. *BMC Psychiatry*. (2016) 16:1–11. doi: 10.1186/s12888-016-0963-x
43. El-Jawahri A, Greer JA, Park ER, Jackson VA, Kamdar M, Rinaldi SP, et al. Psychological distress in bereaved caregivers of patients with advanced Cancer. *J Pain Symptom Manag*. (2021) 61:488–94. doi: 10.1016/j.jpainsymman.2020.08.028
44. Matsuzaka S, Ohba A, Masukawa K, Aoyama M, Morita T, Kizawa Y, et al. Factors associated with the preparedness for bereavement in families of patients with cancer: a secondary analysis of a nationwide bereaved family survey. *Psychooncology*. (2024) 33:e6276. doi: 10.1002/pon.6276
45. Tang ST, Hsieh C-H, Chou W-C, Chang W-C, Chen J-S, Wen F-H. Course of changes in emotional preparedness for death and its associations with caregiving outcomes for family caregivers of terminally ill cancer patients over their last year of life. *J Pain Symptom Manag*. (2021) 61:974–82. doi: 10.1016/j.jpainsymman.2020.09.033
46. Hollingshaus M, Smith KR, Meeks H, Ornstein K, Jacob E, Tay D, et al. Mortality risk following end-of-life caregiving: a population-based analysis of hospice users and their families. *Soc Sci Med*. (2024) 348:116781. doi: 10.1016/j.socscimed.2024.116781
47. Yoo H, Shin DW, Jeong A, Kim SY, Yang H-k, Kim JS, et al. Perceived social support and its impact on depression and health-related quality of life: a comparison between cancer patients and general population. *Jpn J Clin Oncol*. (2017) 47:728–34. doi: 10.1093/jjco/hyx064
48. García-Torres F, Jacek Jabłoński M, Gómez Solís Á, Moriana JA, Jaén-Moreno MJ, Moreno-Díaz MJ, et al. Social support as predictor of anxiety and depression in cancer caregivers six months after cancer diagnosis: a longitudinal study. *J Clin Nurs*. (2020) 29:996–1002. doi: 10.1111/jocn.15123
49. Große J, Tremel J, Kersting A. Impact of caregiver burden on mental health in bereaved caregivers of cancer patients: a systematic review. *Psychooncology*. (2018) 27:757–67. doi: 10.1002/pon.4529
50. Aaron SP, Supiano K, Elk R, Wallace B. Towards a framework for a culturally centered evidence based prolonged grief group therapy intervention. *Int J Palliat Nurs*. (2025) 31:109–18. doi: 10.12968/ijpn.2024.0027
51. Miller E, Bosun-Arjie SF, Ekpenyong MS. Black and ethnic minority carers perceptions on mental health services and support in the United Kingdom: a systematic review. *J Public Ment Health*. (2021) 20:298–311. doi: 10.1108/JPMH-12-2020-0152



OPEN ACCESS

EDITED BY

Clare Killikelly,
University of Zurich, Switzerland

REVIEWED BY

César Augusto Trinta Weber,
Lutheran University of Brazil, Brazil
Molnar Rebeca Isabela,
Emergency County Hospital Targu Mures,
Romania

*CORRESPONDENCE

Karl Andriessen
✉ karl.andriessen@unimelb.edu.au

RECEIVED 18 April 2025

ACCEPTED 12 May 2025

PUBLISHED 30 May 2025

CITATION

Andriessen K, Logan N, Ball S-A, De Goey T,
Currier D and Krysinska K (2025) Men's
experiences of suicide bereavement: a
qualitative study of psychosocial impacts and
coping.

Front. Public Health 13:1613951.

doi: 10.3389/fpubh.2025.1613951

COPYRIGHT

© 2025 Andriessen, Logan, Ball, De Goey,
Currier and Krysinska. This is an open-access
article distributed under the terms of the
[Creative Commons Attribution License
\(CC BY\)](#). The use, distribution or reproduction
in other forums is permitted, provided the
original author(s) and the copyright owner(s)
are credited and that the original publication
in this journal is cited, in accordance with
accepted academic practice. No use,
distribution or reproduction is permitted
which does not comply with these terms.

Men's experiences of suicide bereavement: a qualitative study of psychosocial impacts and coping

Karl Andriessen^{1*}, Nina Logan¹, Shelley-Anne Ball²,
Tim De Goey², Dianne Currier¹ and Karolina Krysinska¹

¹Centre for Mental Health and Community Wellbeing, Melbourne School of Population and Global Health, The University of Melbourne, Melbourne, VIC, Australia, ²StandBy Support After Suicide, Maroochydore, QLD, Australia

Introduction: Men bereaved by suicide have an increased risk of adverse psychosocial outcomes, including mental health problems and suicidal behaviour. Despite the potentially strong impact of suicide on their life, little is known of how men experience and cope with grief after suicide. The study aimed to investigate men's experiences of the psychosocial impacts of and coping with suicide bereavement.

Methods: Adhering to the Consolidated Criteria for Reporting Qualitative Research, we designed a study involving semi-structured interviews with a purposive sample ($N = 34$, $Mage = 49.44$ years) from across Australia. The transcripts of the interviews were subjected to a codebook thematic analysis.

Findings: The analysis identified three themes: (1) immediate reactions, (2) psychosocial impacts, and (3) psychosocial coping. The findings are underscored by the profound, multifaceted impacts of suicide bereavement, from immediate emotional reactions to long-term mental health effects and trauma. Suicide bereavement frequently disrupted participants' close relationships and their role as a carer. Participants' diverse coping strategies included maintaining a bond with the deceased, seeking distraction, or channelling grief into action-oriented approaches. While some potentially maladaptive strategies, such as overworking or substance use, provided temporary relief, other strategies led to personal growth, with some men using their experience to support others or raise awareness about suicide prevention and postvention.

Conclusion: The findings indicate that support must focus specifically on men's experiences of grief after suicide, and appeal to their coping strategies and feelings of responsibility and role as a carer. Further research is urgently needed to establish best practice to support this population, vulnerable to mental health problems and suicidal behaviour.

KEYWORDS

bereavement, grief, males, men, mental health, postvention, suicide, trauma

1 Introduction

Suicide bereavement can present profound and unique challenges for men, including heightened risk across mental, physical, and social domains. Men bereaved by suicide experience a significantly higher risk of suicide compared to non-bereaved men, with some evidence suggesting this risk exceeds that experienced by individuals bereaved by other causes (1, 2). Men bereaved by a partner's suicide are at increased risk of suicide, mental health issues, substance use disorders, and hospitalisation for a range of health issues (3–5). Mental health outcomes such as posttraumatic stress disorder (PTSD), mood and anxiety disorders, and self-harm are considerably more prevalent in men bereaved by suicide than in non-bereaved men. These men are also more likely to seek psychological therapy and be hospitalised for psychiatric conditions (4).

Men bereaved by suicide also navigate a complex emotional landscape. Guilt, self-blame, and isolation are central to their experience, as they often wrestle with a sense of responsibility for the death and endure an intensely personal and frequently solitary grieving process (6, 7). Traditional masculine norms can exacerbate these difficulties, as expectations of stoicism and self-reliance may lead many men to suppress or distance themselves from their grief. This emotional repression can intensify distress and create barriers to accessing critical social and professional support networks (6, 7).

Men's coping mechanisms may further reflect the interplay between their grief experiences and personal and societal expectations of masculinity. The literature suggests that avoidance-based strategies, such as overworking or engaging in high-risk behaviours, are common and may serve as a means of emotional regulation consistent with ideals of control and resilience (8, 9). While some men eventually seek support through community networks, others may remain isolated, missing opportunities for connection and shared understanding with those who have had similar experiences (8, 9).

The impacts of suicide bereavement can also extend to men's relationships and physical health. Men bereaved by a partner's suicide may experience increased rates of disability, somatic health issues, and difficulties in maintaining family relationships (4). Some adopt the role of protector within their families as a coping strategy, which can offer a sense of purpose but also contribute to distress by diverting attention from their own grief and emotional needs (8, 9).

Despite these far-reaching effects, men bereaved by suicide are less likely to access formal support services or resources than women in similar circumstances, highlighting a significant unmet need (10). Research focusing specifically on suicide bereavement in men is urgently required to better understand their experiences of suicide bereavement, coping mechanisms and help-seeking behaviours, which may guide the development of tailored support services. This study aimed to address this gap by investigating the experienced psychosocial impact of and coping with suicide bereavement in men. In this study, grief refers to the psychosocial impact of bereavement, and coping refers to the strategies used to manage grief (11). Findings regarding experiences with help-seeking will be reported elsewhere.

2 Methods

2.1 Study design and sampling

We conducted the study according to the Consolidated Criteria for Reporting Qualitative Research (12). We recruited a purposive sample of men bereaved by suicide throughout Australia, between June and July 2024. StandBy Support After Suicide (StandBy), a national suicide postvention service, disseminated the study announcement through their local service delivery sites and collaborating centres. The researchers disseminated the announcement to various (suicide) bereavement services, and professional organisations of clinicians and counsellors. The announcement was also shared with non-government organisations and community-based men's organisations, and through social media to reach non-help-seeking men. Snowball recruitment was used by inviting participants to share the announcement with other potential participants. All potential participants were required to contact the researchers. The sample was stratified to include help-seeking and non-help-seeking participants from various locations. Participants were offered a \$30.00 AUD gift voucher as reimbursement.

Participants could choose between taking part in a semi-structured individual telephone/online interview, or an online or in-person group interview. Group interviews would be organised if more than one participant expressed interest and would be held at various locations in Australia at the premises of StandBy and co-facilitated by a StandBy lived experience facilitator. Research has shown that individual and group interviews complement each other regarding the breadth and depth of data collected on sensitive topics (13). Offering multiple methods also aimed to allow more potential participants to take part in the research (14), an approach successfully used in previous studies (15, 16). At the end of the interview, participants were invited to take part in an evaluation of their research participation by filling out a short anonymous questionnaire over the subsequent 2 weeks. The findings of this evaluation will be reported elsewhere.

2.2 Inclusion criteria

Eligible participants had to: (i) identify as man/male, (ii) be aged 18 years and over, and (iii) be bereaved by the suicide of a close person (such as a family member or friend) at least 6 months before participation. The 'six months' criterium was included to avoid recruiting participants who might still be in crisis after the bereavement, and we have used it successfully in previous qualitative suicide bereavement studies [e.g., (15, 16)].

2.3 Sample

Based on the literature on information power (17), and our experience with qualitative suicide bereavement research [e.g., (15, 16)], we estimated the required sample size at approximately 15 participants. Nonetheless, given the shortage of research with this population, it was *a priori* decided to provide an opportunity to all eligible participants to participate within the available time window (June–July 2024). As the analysis of the final interviews did not yield new codes, we determined that the sample size was adequate.

A total of 48 potential participants contacted us and 34 from across Australia participated in the study. Reasons for not participating were being unavailable ($n = 7$), being ineligible (i.e., being bereaved less than 6 months: $n = 3$; not identifying as man/male: $n = 1$), and participant withdrawal ($n = 3$).

The mean age of participants ($N = 34$) was $M = 49.44$ ($SD = 13.76$, range 23–71 years). The average time since the bereavement was $M = 8.62$ ($SD = 10.12$, range 0.5–43 years). There was no significant correlation between age of participants and time since bereavement.

About one in three participants (38.2%) had lost a child to suicide (son $n = 9$, daughter $n = 4$), one in six (17.6%) had lost a sibling (brother $n = 5$, sister $n = 1$), and one in six (17.6%) had lost a parent (father $n = 4$, mother $n = 2$). Four participants had lost a spouse or partner (11.8%), and five participants (14.7%) had lost another family member ($n = 1$) or friend ($n = 4$).

If participants had lost more than one person to suicide, the bereavement they felt most important was recorded. Six participants spoke about more than one person who had died by suicide. These included the participants' mother, mother-in-law, grandfather, friends, and colleagues. A total of 26 participants (76.5%) had used formal support (i.e., from services or counsellors) after the bereavement. The others had contacted a service only once or had not sought formal support.

2.4 Data collection

We developed a semi-structured interview guide, adaptable for individual and group interviews, with open-ended questions allowing for probing and follow-up questions (18). The lead questions inquired about what helped or hindered coping with suicide bereavement, the needs for support and how to meet such needs, experiences and help-seeking, and what participants perceived as effective in help-seeking. The interview guide was based on a strengths-based approach to validate the lived experience and agency of the participants, to explore protective factors and what is helpful and supportive from their perspective in terms of coping and help-seeking after the bereavement.

Due to limited participant interest in group interviews, only individual interviews were conducted. Researcher K.A. conducted all interviews and recorded field notes after the interviews. Interviews lasted on average $M = 50.69$ min ($SD = 10.53$, range: 27–68.5). Nineteen interviews were conducted via Zoom (55.9%), and 15 via telephone (44.1%). The mean duration of telephone interviews was shorter than Zoom interviews (44.17 min vs. 55.84 min, $p < 0.001$). Telephone interviews were often scheduled during the lunch break when participants were at work, which may, at least partly, explain the difference in duration. The interview duration was not associated with age of participants or time since bereavement. All interviews were audio-recorded and professionally transcribed with transcriptions checked for accuracy.

2.5 Research team and reflexivity

The study was based at the Centre for Mental Health and Community Wellbeing at The University of Melbourne, a national and international leader in suicide and mental health research. The lead researcher, K.A., is a social worker with ample experience in

qualitative (suicide) bereavement research. N.L. is an early career researcher focusing on gender and mental health promotion. S.B. is a clinical psychologist and Clinical Director at StandBy Support After Suicide. T.D.G. is a Partnership Coordinator and lead for Men Priority Population Group at StandBy Support After Suicide. D.C. is an Associate Professor specialised in evaluating suicide prevention service delivery, and men's mental health research. K.K. is an experienced suicide-related research psychologist and psychotherapist. Several team members have lived experience of suicide. The research team met regularly to ensure consistency throughout the study.

2.6 Data analysis

We uploaded the deidentified interview transcripts in NVivo14 (19) and conducted a thematic analysis (20). Two researchers (N.L. and K.A.) created a codebook based on independent analysis of three transcripts (21). Next, one researcher (N.L.) coded the remaining transcripts while holding regular discussions with the lead researcher. The same two researchers further analysed the data through an iterative process based on the six steps described by Braun and Clarke (22), adopting an inductive approach to capture the meaning of the data rather than its explicit content. Mind maps (i.e., diagrams) were used as a visual aid to conceptualise potential themes, which were checked against the data before deciding the themes.

3 Findings

The findings describe the impacts and experiences of suicide bereavement, including immediate reactions (theme 1), psychosocial impacts (theme 2), and psychosocial coping (theme 3). Table 1 summarises the themes and subthemes.

3.1 Theme 1: Immediate reactions

Participants described the profound and wide-reaching immediate effects of the bereavement, impacting every aspect of their lives. They reported an intense sense of disorientation and identity loss, as their understanding of themselves and their future was fundamentally altered. One participant shared: *"Everything I thought I knew or everything I thought about my future and what that looked like, that just completely shattered My understanding of who I was and my place in the world and all of that just completely fell apart."* (P65). In some cases, this severity of impact was linked to the unexpected nature of the death by suicide; *"the immediate feeling that I had was shock. It felt like I did not actually get to go through the proper grieving process for quite a long time. I was in that shock for a long time."* (P51).

However, when the suicide was less unexpected, the impacts could still be substantial: *"I knew it was going to happen. That does not make the loss any easier and it does not make it any less shocking than when it happened."* (P15).

A few participants described an immediate acceptance, particularly where they perceived the person who died by suicide had been suffering prior to their suicide; *"I do not think I was ever really ... that sad because ... he found life agonising I think and so very quickly I realised that ..."*

TABLE 1 Summary of themes and subthemes.

Theme	Subtheme	Example quote
Theme 1: Immediate reactions		“Everything I thought I knew or everything I thought about my future and what that looked like, that just completely shattered and came apart. My understanding of who I was and my place in the world and all of that just completely fell apart.” (P65).
Theme 2: Psychosocial impacts	1: Grief	“I was zeroed in white hot rage with a sniper rifle accuracy of exactly who I blamed for the action [son’s name] took on that Monday morning.” (P49).
	2: Mental health, trauma and suicidality	“Six weeks later, I ended up in the [name] Hospital, the psychiatric ward, because I did not want to be here, and I felt really strange, so I knew that that was the safest place to go.” (P40).
	3: Relationships with family and romantic partners	“... parents who lose a child, 80% of us get divorced ... Marriages fail three or four years down the track, including mine ... So, it’s like great pain on top of pain that we have got to deal with.” (P02).
	4: Social isolation	“... It was something that was in the air, this feeling that everyone knew how dad passed, but it was never really openly talked about. For me, having someone to be able to start that conversation without the burden having to be on me to actually bring it up would have been nice.” (P51)
Theme 3: Psychosocial coping	1: Continuing bonds and connection	“I was quite enjoying coming here because this is where his ashes were ... I said to [my partner] I need to make a road trip. I drove back up here again.” (P11).
	2: Reflection and restoration	“I’ve discovered art since and that helps me a huge amount ... you get out there and it’s like, bang, yeah, okay, I feel better.” (P02).
	3: Avoidance and distraction	“...you are just going about your day and not really taking in everything or feeling a lot ... It’s just feeling blank, feeling not very present, putting on a façade, like putting on a bit of a mask and being like, yeah, it’s all good. But then, deep down...” (P51).
	4: Active and practical	“I feel like I’m making a difference ... I’ve got to focus that anger and energy into a direction, otherwise it’s probably going to consume me.” (P02).

he made a decision that gave him peace. I saw him the day before and he was the calmest and happiest I’d seen him in over a decade.” (P20).

3.2 Theme 2: Psychosocial impacts

This theme describes the profound personal effects of suicide bereavement on participants by exploring the emotional, psychological, and relational challenges they experienced. The impact of grief, mental health struggles and trauma, as well as the impacts on relationships are central to understanding how men navigate life after losing someone to suicide.

3.2.1 Subtheme 1: Grief

For many participants, emotional experiences of grief were dominated by feelings of anger, guilt and confusion at the intentionality of the death by suicide. This anger could be directed at the person who died by suicide, other people who they felt were responsible for their death, or systems that failed them; “I was zeroed in white hot rage with a sniper rifle accuracy of exactly who I blamed for the action [son’s name] took on that ... morning.” (P49). Reflections on feelings of guilt frequently stemmed from participants attributing some degree of responsibility for the suicide to their own actions, such as ending a romantic relationship with their partner shortly before their death. Others experienced guilt relating to their own perceived inaction; they thought they had not done enough to provide support or prevent the suicide: “I felt like a fair bit of guilt about the fact that I had not realised he was

struggling so much, felt like I should have been able to help him, and I should have known ... if I had known, then he would not have done it.” (P03).

Many participants described oscillating through different strong emotions, particularly immediately following their bereavement by suicide, that felt completely outside of their control: “... you could’ve come and knocked on my door and there would’ve been one of four different [versions of myself] there at the door ... I could be in a good mood, I could be okay with life, but I do not want to talk about [son’s name]. I could be okay, but I need to talk about [son’s name]. Or I could be not in a good place, and I still need to talk about [son’s name], or I’m in a really bad place and I cannot go there at all. It’s not like I could ever pick that’s who I was that day. It’s just that’s who I happened to be that day.” (P66).

3.2.2 Subtheme 2: Mental health, trauma and suicidality

For many men, suicide bereavement precipitated significant declines in their mental health and wellbeing. In some cases, the impacts were immediate and severe, as illustrated by a participant who entered voluntary psychiatric hospitalisation shortly before his partner’s memorial: “... six weeks later, I ended up in the [Hospital], the psychiatric ward, because I did not want to be here, and I felt really strange, so I knew that that was the safest place to go.” (P40). Others experienced mental health problems for the first time, including diagnoses of depression, anxiety, PTSD, and prolonged grief disorder (complicated grief): “I was feeling just completely overwhelmed. I had never experienced mental ill health

before in terms of depression and anxiety, and I learned ways to cope with those.” (P12).

Experiences of PTSD were common among participants, particularly those who found the body of the deceased. Trauma could be triggered in many ways, even by searches for suicide bereavement support services: “... it’s quite traumatic. So, even to look up suicide bereavement services, or read any research on it and stuff like that, there’s still that slight trigger there.” (P51). While some men experienced recovery from these mental health problems, they often felt that “the wounds will always be there, and they always have ripple effects” (P18).

While participants were not directly asked to disclose their own suicidality, eight participants mentioned experiences of suicide ideation following their bereavement by suicide. Half of these individuals knew more than one person who had died by suicide, and all but one had lost a first-degree relative to suicide. A man whose child had died by suicide related that experiencing suicidality following bereavement was common among others in his support group for suicide-bereaved parents: “... the amount of times I’d speak to other bereaved parents and they would say that they are suicidal after the death of a child. For me, it’s a normal response. It’s such an impossible loss; to be thinking about the same thing, it just seems like a natural response ... the amount of parents who attempt or complete suicide after the death of a child ... I would suspect it would be very high ...” (P02).

Some men experienced passive suicide ideation, sometimes linked to changed ways of thinking about mortality following their experience of suicide bereavement: “I think that that sense of fear of death ... has abated but I still spend plenty of time thinking when will it be my turn to die, when will I get that opportunity to die?” (P17). Others attempted suicide, in some cases repeatedly: “Tried to take my own life ... [I was] in a black hole, yeah, really deep. Took me a long time to get out of it.” (P43).

The degree to which participants attributed experiences of mental health problems and suicidality to their experience of suicide bereavement varied and was often mediated by their relationship to the deceased and other impactful or traumatic events in their lives: “It’s all bundled up to be honest. I think it’s all my traumas from throughout my life. So yes, definitely [my brother dying by suicide] plays a part in it but it’s also my brain surgeries and my disability and stuff like that. It all plays a part” (P20).

3.2.3 Subtheme 3: Relationships with family and romantic partners

Many participants experienced a substantial impact on their relationships. For those whose bereavement by suicide occurred further in the past, there was often a reflection that the mental health and trauma-related effects of the bereavement were inseparable from its impacts on their relationships with those close to them, with both aspects compounding their distress. “I think where I’m not recovered is the impact on my whole family ... You can work on stuff yourself, but when it’s a relationship that’s harmed and there’s multiple different actors and dimensions to it, I think that’s the ongoing effect from a traumatic event ... that one person’s journey [will lead them to] look at [the experience of suicide bereavement] in one particular way [that] is different to somebody else’s. You wind up with quite different world views about things.” (P26).

Many fathers bereaved by the suicide of a child reported the breakdown of their relationship with their romantic partner (mainly the mother of the deceased child). They described this breakdown as compounding the grief from their child’s death: “... parents who lose a child, 80 % of us get divorced ... Marriages fail three or four years down the track, including mine ... it’s like great pain on top of pain that we have got to deal with.” (P02). Participants attributed these relational difficulties to various factors, including their own grief response: “[My child’s suicide] had a really big impact on my marriage ... I guess I was probably a pretty challenging person to be around going through that grief and bereavement.” (P65), use of alcohol to cope: “... my wife and my other kids, they were going to leave me. They said if I do not stop drinking and that, they are going to go.” (P43), or insufficient provision of social support: “I did not talk it through much with my partner, and probably was a factor in a year or so later us separating.” (P54).

Participants bereaved by suicide as children often experienced a profound loss of emotional support, particularly when the deceased parent had been the primary caregiver, and the surviving parent was unable to meet their needs. “... my dad was the type of guy that did not really talk about his emotions much and did not really open up. I wasn’t able to talk with him about it ... I’m an only child. My mum was the parent that did most of the stuff for me, most of the taking me to school, sporting events, music lessons, whatever ... To lose that mother, caregiver role, all I had was this pragmatic dad that I did not really need” (P65).

Regardless of the parenting role of the person who died by suicide, men bereaved as children often reflected on how their surviving adult family members were less able to provide care and support due to the impacts of their own grief: “my mum was very badly affected by my dad’s death ... she really wasn’t able to really be a supportive parent herself. So it’s like both parent figures just were gone in a day, that whole structure changed. I was on my own and had to come to grips with that. So I think that compounded things.” (P26). Some participants felt that the absence of formal and emotional support for both themselves and their grieving family members highlighted a missed opportunity for intervention: “I could have probably done with a bit of counselling and a bit of guidance. I think the people around me in my family could have done with a lot of support, and that would have supported me as a child, but it did not happen.” (P02).

3.2.4 Subtheme 4: Social isolation

Many participants reported often feeling socially isolated. This was more common, or intensified, for men who typically did not share personal feelings or issues with those close to them: “I do not have any close friends where I feel comfortable [talking about my bereavement] ... We focus on things that are good. We do not talk about how stressful and hard work was or our relationship problems ... We deal with our stuff outside of the social circle ...” (P13). This self-isolation was often justified by the conviction that they were alone in their experiences and that others could not understand their emotions or thoughts: “I’ve got to figure out my own solution ... I know lots of people experience it, but at the time, it just felt like no one’s going to understand ...” (P51).

Some men who did seek social support found it to be limited, particularly when trying to connect with family and friends who were also grieving. Some described how collective grief made meaningful conversations difficult: “[My wife] and I spoke all the time but we were

too immersed in our own grief and the three remaining siblings and the two daughters-in-law, they were all just coping and dealing [by] themselves. ... It was trying to take apart the details leading up to the event and trying to understand the why collectively. But I did not get a sense that they were ever going to give me what I needed ..." (P49). Over time, this participant withdrew from these conversations, fearing he would become a burden.

Beyond family, men also described a sense of social isolation in the broader community, where their grief felt known but unspoken. The perceived stigma surrounding suicide contributed to this silence: "... the stigma around suicide, it just made it really difficult to actually have those open conversations. It was something that was in the air, this feeling that everyone knew how dad passed, but it was never really openly talked about. For me, having someone to be able to start that conversation without the burden having to be on me to actually bring it up would have been nice." (P51) Some who attempted to initiate discussions found that others withdrew, particularly following the immediate aftermath of the death: "a lot of people do not necessarily want to talk much about it. Once there's the funeral ..., it just quickly goes away. You can see some people shy away if you try to engage. Which is what I found. I did not think my friends would do that. But they did not want to engage much." (P11).

For some, this lack of engagement led to the breakdown of friendships, deepening their isolation. In response, some sought out support groups to find a sense of connection with others with similar experiences: "a lot of people I have not seen for years ... We did not have a lot of friends after [our son died by suicide]. I do not know if it was shame or they did not want to talk about it or whatever, but yeah, we sort of become a bit isolated ... It's hard because there's other people that are in that situation, that you could support each other, so that's why I started up the support group ... so that we could all support each other." (P43).

3.3 Theme 3: Psychosocial coping

This theme illustrates participants' diverse coping mechanisms following suicide bereavement, informed by both their personal preferences and complexity of their emotions. Some strategies aimed to maintain an ongoing connection with the deceased, while others focused on reflection, self-care, or active efforts to address their grief. Participants also addressed engaging in escapism and distraction, including substance use, overwork, and emotional detachment, as temporary means to manage overwhelming feelings. Additionally, practical and problem-focused coping often provided a sense of agency and control amidst the chaos of grief.

3.3.1 Subtheme 1: Continuing bonds and connection

Many participants engaged in acts of memorialisation to honour and maintain a connection with the deceased. This often involved visiting the place of interment, with one participant describing the comfort they found in returning to this location: "I was quite enjoying coming here because this is where his ashes were ... I said to [my partner] I need to make a road trip. I drove back up here again." (P11). Others found solace in talking about the deceased with friends and loved ones, acknowledging their positive qualities and shared memories: "It's also about acknowledging the

good parts of the mates that are lost ... being able to talk about them and with your loved ones, and being able to talk with your friends about that." (P46). In some cases, participants continued their bond with the deceased by engaging in conversations with them, using these interactions to preserve a sense of connection: "I have quite deliberate structured conversations with my dad ... about things that I think I would have conversations with him about if he was alive." (P26).

Many participants expressed that publicly acknowledging their loved one's mental health problems and death by suicide was integral to honouring their memory. For them, speaking openly was not only a means of processing their own grief but also a way of remaining true to the person they had lost: "we were not going to hide that [brother's name] had a mental illness. We were not going to hide that this is the decision that he made ... If we had done that, I feel like that that would have been a disservice to his memory. It would have been dishonest towards [him] and about the person that he was." (P16).

This openness often led to unexpected connections with others, fostering reciprocal sharing of grief and healing: "if in a conversation, an opportunity comes up to just mention the fact that I've lost my daughter, it's amazing how the conversation opens up and the number of people who then reveal their own experiences, whether it's a friend of theirs who took their life or their own struggles with mental health or a family member ... that's been also quite a cathartic experience, feeling that through our tragedy we have been able to help other people process or grapple with their own difficulties." (P42).

3.3.2 Subtheme 2: Reflection and restoration

Many participants described the positive impacts of engaging in self-care activities to help cope with their grief. The specific nature of these activities varied based on personal interests, but the benefits were often linked to staying busy, connecting with others, and finding mental relief. One participant highlighted the immediate sense of calm that came from their creative pursuits: "I've discovered art since and that helps me a huge amount ... you get out there and it's like, bang, yeah, okay, I feel better." (P02). Others engaged in self-care by taking time away from work or study.

In addition to leisure activities, self-compassion and dedicating time to care for themselves emotionally were crucial in managing the complex grief of suicide bereavement. This involved acknowledging difficult emotions and allowing space to process them: "The most helpful thing in my grief was recognising the days that I was having most trouble and just taking time for myself, being gentle with myself and honouring my emotions" (P16). Over time, this internal journey led some men to reach a sense of acceptance, as they gradually allowed themselves to experience happiness again: "I've spent a lot of time feeling like I wasn't entitled to feel any kind of joy ... so it's a matter of gradually learning to give yourself permission" (P17).

Participants described how self-care and self-compassion were coping strategies that often led to greater emotional regulation and improved relationships with others: "... if I feel sad or angry now, I just try to manage it and I do not let that linger for a day. I try not to let that affect my relationship with my partner ... Managing those emotions and feelings rather than feeling down for an extended period of time or pushing people away when I do not feel like talking

or communicating to them. Just a reminder to yourself that not everyone will understand what you are going through so you cannot blame them.” (P69).

3.3.3 Subtheme 3: Avoidance and distraction

Participants reflected on how some of their coping strategies were potentially maladaptive. Many described experiencing a sense of “numbness” for weeks or months following the bereavement. As this numbness began to fade, it was often replaced by a sense of emotional detachment: “... you are just going about your day and not really taking in everything or feeling a lot ... It’s just feeling blank, feeling not very present, putting on a façade, like putting on a bit of a mask and being like, yeah, it’s all good. But then, deep down ... more of that sadness came through.” (P51).

For some, this emotional restraint felt socially enforced, particularly by other men around them. One participant shared how masculine social norms restricted emotional expression, even among close friends: “It was a month [after] my wife passed away ... We’re drinking tequila at the kitchen table ... The biggest thing in my life was the loss of my wife. Do you know what subject we spent half an hour talking about? Whether golf was a game or a sport. I look back on it now and feel that moment was a betrayal ... I was screaming inside to deal with issues.” (P47).

Substance use was also a common strategy: “I drank a lot for probably two or three months after, every night I drank a lot of alcohol.” (P16). While offering temporary relief, participants felt that the use of alcohol or drugs to cope could also negatively impact their lives: “I drank a lot. I smoked a lot of pot ... overdid it a few times and just realised that it was really setting me on a bad track ...” (P26), or strain family relationships: “My wife was sort of looking after [our surviving children] ... whereas I was on the piss and taking drugs, that was my outlet.” (P43).

Overwork was frequently mentioned as a distraction from the emotional pain of suicide bereavement, often viewed similarly to substance use: “I think I coped with it by just working like a lunatic and drinking way too much alcohol.” (P02). Overworking could also provide a sense of control or escape or be a way to honour the memory of the deceased. For example, men who pursued mental health advocacy or awareness felt they were continuing the legacy of their loved one: “... my partner at the time said why are you doing that, why are you taking on more, you have just lost your daughter. Why are you taking on more and doing these things? I tried to explain that it was partly a reaction to losing my daughter, that she was someone who stepped up and did stuff, and I sort of felt like I needed to do that.” (P54).

3.3.4 Subtheme 4: Active and practical

Several participants adopted a problem-focused approach to coping with their grief, particularly those who identified with traits of “self-reliance and stoicism ... I’ve got to figure out my own solution to the problems, and no one else was really going to be able to understand or help” (P51). These participants often directed active coping efforts towards the source of their grief - suicide - with many engaging in suicide prevention efforts, including fundraising, or awareness raising activities: “I feel like I’m making a difference ... I’ve got to focus that anger and energy into a direction, otherwise it’s probably going to consume me.” (P02).

Some participants used their own lived experience of suicide bereavement to support others: “I am a lived experience advocate ... I do men’s mental health training and workshops.” (P47). Others entered mental health-related fields, driven by their personal loss: “I have learned so much since my dad passed away, about myself ... I have a purpose of helping other people with their mental health in general, but specifically people who have been bereaved by suicide ...” (P64).

While these active coping strategies often helped men feel “functional,” some participants acknowledged that deeper emotions remained unaddressed, particularly when these strategies were used in lieu of accessing formal support services. As one participant reflected: “I had basically coped for 10 years being crazy, but functional” (P47). Another further identified this need for agency as a distinctly masculine coping strategy, shaped by societal expectations of men’s roles: “It’s like I got control. I can fight. I can yell ... Men, in terms of control, influence, and power, have traditionally been afforded more control over outcomes in various areas of society ... I think that does play into how we approach agency in grief and bereavement” (P65).

4 Discussion

This study aimed to investigate how men have experienced the impact of the suicide of a close person, and their grief and psychosocial coping after the bereavement. The study fills a major gap in informing best practice in supporting this population. Thematic analysis identified themes in three key domains: bereaved men’s immediate reactions to the death by suicide; the impacts including grief experiences, their own mental health and suicidality, shifts in relationships with others; and the way they coped with suicide bereavement.

4.1 Immediate reactions and impacts of suicide

All participants in this study talked about how experiencing bereavement by suicide was a life-changing event with immediate and long-term impacts. Initial reactions included feelings of shock, disbelief and sadness, which are commonly reported in the suicide bereavement literature (23, 24). For many of the participants, suicide bereavement was a traumatic experience, shattering their dreams for their future. Consistent with the general suicide bereavement literature, many participants also reported feeling angry towards themselves or the deceased person; they struggled with trying to understand why the suicide had happened, and feelings of guilt for not being able to foresee and prevent the suicide (23, 24). Struggles with meaning-making have also been reported in studies with men bereaved by other traumatic causes [e.g., (25)].

Many study participants had experienced the onset or exacerbation of mental health problems after the bereavement, such as depression, anxiety and PTSD. For a few, this resulted in psychiatric hospitalisation. The literature indicates that suicide bereavement is a risk factor for mental health problems, especially

when there are pre-existing mental health or relationship problems (1, 26, 27), as was the case for some of our participants. Suicide-bereaved men compared to non-bereaved men have been found to have an 80% higher risk of mental health problems over 5 years after bereavement, and a double risk for psychiatric hospitalisation (4). Studies that compared suicide-bereaved men and women tend not to find significant differences in mental health problems; however, it has been noted that increases in scores of mental health problems in suicide-bereaved men could be masked due to higher baseline scores in women (11, 28).

Experiencing suicidal ideation or suicide attempts was a concern for several participants. Suicide bereavement, especially after suicide of a close family member, is an important risk factor for suicidal ideation, attempted suicide and death by suicide for men and women (27, 29, 30). However, there is evidence from the literature (1), including large population studies (31), that men bereaved by suicide are at increased risk of hospitalisation for suicide attempts and suicide mortality compared to non-bereaved men and those bereaved by other causes (1, 2). As attempted suicide is a major risk factor for suicide, suicide prevention efforts should be targeted at this high-risk group of suicide-bereaved men.

Participants reported a strong impact of suicide bereavement on their relationships and roles as a family carer, such as a father or spouse/partner. Some participants also felt a lasting impact of losing a parent by suicide during their childhood. While the importance of relationships was already noted in pioneering suicide bereavement literature (32), few studies have examined this issue (33). A recent study with suicide-bereaved adolescents and parents reported how bereavement disrupted the family equilibrium creating a limbo maintained by individual differences in grieving needs and grief reactions (34). It has also been noted that externalising problems in bereaved children are more associated with bereaved mothers' distress and their parenting and communication, than with those of fathers, highlighting their potential importance as a family carer (35).

Loneliness is associated with suicide attempts after sudden bereavement, including suicide bereavement (36). In suicide-bereaved men, feeling disconnected from others can compound the experiences of grief after suicide (7). This was described by many study participants who experienced relationship breakdowns and feelings of loneliness after the bereavement. While some felt disconnected from their social networks, for others it appeared to be a choice to self-isolate or be selective in sharing their grief. This finding expands our understanding of this aspect of suicide bereavement by describing how men may deliberately suppress their emotions to protect their families from the weight of their mourning (6). Suicide-bereaved men have attributed their emotional repression to masculine ideals of stoicism and the importance of self-control and being strong to support their loved ones (9).

In addition, men bereaved by a partner's suicide (4) or a child's suicide (37) have been found to have higher rates of unemployment and sick leave (4), or absences from work (37) than non-bereaved men, which may decrease opportunities for social interactions and support. As self-disclosure and social interaction may contribute to posttraumatic growth in people bereaved by suicide, interventions may focus on promoting social support (38), though studies specifically with men are needed.

4.2 Psychosocial coping

Expression of and coping with grief is deeply influenced by gender and sociocultural expectations. Doka and Martin (39) characterised masculine grief as instrumental or problem-solving, and feminine grief as intuitive or emotional, with one coping style being not necessarily less or more effective than the other. Although gender has a strong influence, it does not determine grief styles. Therefore, they proposed that grief styles represent a continuum between instrumental (action-oriented) and intuitive (affective-oriented) grieving (39). In Western societies it is more commonly expected and accepted that women express and share their grief, and for men to control and conceal it, as confirmed by some of our participants. The suicide bereavement literature indicates that men tend to grieve in secret, bottle up and mask their feelings, and feel uncomfortable publicly expressing their grief feelings (28, 40). Keeping strong to support a spouse or other bereaved family members may lead to delayed grief expression. This may lead to suicide-bereaved men feeling ignored and unacknowledged as a bereaved person, which has also been reported in studies with bereaved fathers (41), and adolescents bereaved by suicide (34, 42).

Participants in our study have used a range of coping strategies including strategies to engage with and/or to avoid their grief. Consistent with the grief dynamics described in the Dual Process Model of coping with bereavement (43), participants adapted and oscillated between loss-oriented and restoration-oriented stressors. Many participants shared experiences of how they actively maintained a bond with the deceased person, for example, by visiting the interment place. This is corroborated by the literature which found that maintaining a continuing bond is mainly a positive experience that may contribute to meaning-making (44). Men may express the continuing bond more privately than women, for example through conversing with the deceased (44).

While some participants took time for self-care and to acknowledge difficult emotions, many participants reflected on how they avoided engaging with their grief, for example by detaching emotionally, finding distractions, or engaging in substance use or work. Other studies have also noted engaging in substance use and work as a coping strategy in men bereaved by suicide (7, 8). Suicide-bereaved men often experience the same range and depth of emotions as women but struggle to identify and express them (9), or they express them differently (28, 40). As stated by our participants and the literature, engaging in work may contribute to regaining a sense of control and meaning, though some men lose motivation for work (45, 46).

Many participants adopted an active and problem-solving coping style, for example by engaging in fundraising, suicide prevention or bereavement support activities. The scarce literature on this topic reported that people (men and women) who had been bereaved by suicide for 5 years or more (i.e., long-term bereaved) had lower scores on mental health problems, higher scores on personal growth, and had taken up more caregiving roles at support group meetings (47). Our findings extend the scarce suicide bereavement literature on this topic (48, 49) as our study indicates that engaging in support and community activities may be particularly beneficial for suicide-bereaved men. It can alleviate feelings of loneliness and provide a way of honouring the deceased

person and an opportunity for finding purpose, meaning, and personal growth.

Adopting an active coping style can also be understood in the context of agency and self-empowerment, i.e., taking action to create a new future and find meaning (50). According to the general literature, individuals may engage in active coping strategies such as seeking knowledge by reading books or other resources on suicide and bereavement, helping others through altruistic actions like participating in suicide research, or becoming a peer supporter (50–52). These actions align with the active coping styles reported by our participants, enabling them to manage their bereavement while supporting others simultaneously.

Our findings indicate that the motivation to become a peer supporter is strongly associated with one's own suicide bereavement experience, the support they have received, and a wish to 'give back' by providing support and hope to others (47, 53). Our participants also wanted to 'make a difference', for example by tackling silence around suicide, creating public awareness, and contributing to preventing the suicide of others. Studies suggest that most peer supporters tend to experience their involvement positively, but they may also encounter important challenges related to being confronted with others' suicide grief and navigating group or individual support relationships (49). Nonetheless, the involvement of trained peer workers has been identified as contributing to the effectiveness of suicide bereavement support (54).

4.3 Implications

The study findings have important implications for developing support for men bereaved by suicide. Support offered to this population must focus specifically on experiences of grief after bereavement by suicide and appeal to men's coping strategies (55). Although study participants used various coping strategies, the most prevalent were feelings of responsibility and keeping strong to support others, including spouse/partner or children. Several participants were also aware of the importance of self-care. Therefore, the support offered may appeal to their role as a caregiver and accommodate both instrumental and action-oriented coping. Support services might actively engage with the lived experience of suicide-bereaved men to further develop and tailor support offered to this population (52, 55).

Given the scarcity of research in this field, further studies are urgently needed to examine support and services specifically offered to men bereaved by suicide and their potential to alleviate grief and mental health distress and decrease their risk of suicide (56, 57). Evaluation studies may contribute to establishing the evidence-base of various types of support (including peer and professional support), and to ensure that optimal support is offered to this population, vulnerable to mental health problems and suicidal behaviour.

4.4 Strengths and limitations

The study successfully used multiple recruitment channels to recruit a large purposive sample of men who had experienced bereavement due to suicide. Participants varied in age, time since

bereavement, type of relationship with the deceased, including non-family members, and location across Australia, which resulted in a rich data set. Nonetheless, a few limitations must be acknowledged. Recruitment of voluntary participants through suicide bereavement organisations may have attracted participants with a more active coping style. Those who were more verbally skilled and felt comfortable discussing their experiences may have been more likely to volunteer than others. Thus, the findings may not reflect the views of men who did not participate. The study relied on self-report of experiences up to more than 30 years previously, which is open to recall bias. The study did not collect data on ethnocultural or sexual diversity, or focus on social support or grief trajectories. Additionally, although participants had ample opportunity to talk about their experiences, it is possible that some important issues were not shared.

5 Conclusion

The study investigated the psychosocial impact of and coping with suicide bereavement in men. There is strong evidence of a substantial impact of suicide bereavement on men's feelings of grief, trauma, mental health, suicidality, and relationships, to the extent that it may affect their feelings of responsibility and care for others such as their spouse/romantic partner or children. The participating men used various coping strategies including maintaining a continuing bond with the deceased, self-awareness and self-care, finding adaptive and/or maladaptive distractions through substance use or work. Some also used active approaches such as becoming a peer supporter which contributes to reclaiming a sense of agency and control amidst the chaos of grief. Further research is urgently needed to establish best practice in line with men's coping strategies to support this population, vulnerable to mental health problems and suicidal behaviour.

Data availability statement

The datasets presented in this article are not readily available because the ethics approval does not allow sharing original data beyond the research team. Requests to access the datasets should be directed to Karl Andriessen, karl.andriessen@unimelb.edu.au.

Ethics statement

The studies involving humans were approved by Human Research Ethics Committee of The University of Melbourne (#29581, May 27, 2024). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

KA: Writing – original draft, Project administration, Validation, Funding acquisition, Methodology, Supervision, Investigation, Writing – review & editing, Conceptualization. NL: Data curation,

Formal analysis, Methodology, Writing – review & editing, Investigation, Writing – original draft. S-AB: Writing – review & editing, Validation, Resources, Funding acquisition. TG: Resources, Validation, Writing – review & editing, Funding acquisition. DC: Methodology, Supervision, Validation, Writing – review & editing. KK: Investigation, Methodology, Validation, Writing – review & editing, Supervision.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. The study was funded by StandBy Support After Suicide.

Acknowledgments

We are most grateful to all participants for sharing their experiences, and to all individuals and organisations that helped with the recruitment.

References

- Logan N, Krysinaka K, Andriessen K. Impacts of suicide bereavement on men: a systematic review. *Front Public Health*. (2024) 12:1372974. doi: 10.3389/fpubh.2024.1372974
- Pitman A, McDonald K, Logeswaran Y, Lewis G, Cerel J, Erlangsen A. Proportion of suicides in Denmark attributable to bereavement by the suicide of a first-degree relative or partner: nested case–control study. *Acta Psychiatr Scand*. (2022) 146:529–39. doi: 10.1111/acps.13493
- Agerbo E. Midlife suicide risk, partner's psychiatric illness, spouse and child bereavement by suicide or other modes of death: a gender specific study. *J Epidemiol Community Health*. (2005) 59:407–12. doi: 10.1136/jech.2004.024950
- Erlangsen A, Runeson B, Bolton JM, Wilcox HC, Forman JL, Krogh J, et al. Association between spousal suicide and mental, physical, and social health outcomes: a longitudinal and nationwide register-based study. *JAMA Psychiatry*. (2017) 74:456–64. doi: 10.1001/jamapsychiatry.2017.0226
- Rostila M, Saarela J, Kawachi I. “The psychological skeleton in the closet”: mortality after a sibling's suicide. *Soc Psychiatry Psychiatr Epidemiol*. (2014) 49:919–27. doi: 10.1007/s00127-013-0780-1
- Chan TS, Cheung M. The “men in grief” phenomenon among suicide bereaved Chinese men in Hong Kong. *Death Stud*. (2022) 46:1845–52. doi: 10.1080/07481187.2020.1855609
- Ferlatte O, Oliffe JL, Salway T, Knight R. Stigma in the bereavement experiences of gay men who have lost a partner to suicide. *Cult Health Sex*. (2019) 21:1273–89. doi: 10.1080/13691058.2018.1556344
- Entilli L, Ross V, De Leo D, Cippolletta S, Kölves K. Experiences of parental suicide-bereavement: a longitudinal qualitative analysis over two years. *Int J Environ Res Public Health*. (2021) 18:564. doi: 10.3390/ijerph18020564
- Oliffe JL, Broom A, Kelly MT, Bottorff JL, Creighton GM, Ferlatte O. Men on losing a male to suicide: a gender analysis. *Qual Health Res*. (2018) 28:1383–94. doi: 10.1177/1049732318769600
- Kaspersen SL, Kalseth J, Stene-Larsen K, Reneflot A. Use of health services and support resources by immediate family members bereaved by suicide: a scoping review. *Int J Environ Res Public Health*. (2022) 19:10016. doi: 10.3390/ijerph191610016
- Stroebe M, Stroebe W, Schut H. Gender differences in adjustment to bereavement: an empirical and theoretical review. *Rev Gen Psychol*. (2001) 5:62–83. doi: 10.1037/1089-2680.5.1.62
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. (2007) 19:349–57. doi: 10.1093/intqhc/mzm042
- Guest G, Namey E, Taylor J, Eley N, McKenna K. Comparing focus groups and individual interviews: findings from a randomized study. *Int J Soc Res Methodol*. (2017) 20:693–708. doi: 10.1080/13645579.2017.1281601
- Heath J, Williamson H, Williams L, Harcourt D. “It's just more personal”: using multiple methods of qualitative data collection to facilitate participation in research focusing on sensitive subjects. *Appl Nurs Res*. (2018) 43:30–5. doi: 10.1016/j.apnr.2018.06.015

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declare that no Gen AI was used in the creation of this manuscript.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

- Andriessen K, Krysinaka K, Rickwood D, Pirkis J. “Finding a safe space”: a qualitative study of what makes help helpful for adolescents bereaved by suicide. *Death Stud*. (2022) 46:2456–66. doi: 10.1080/07481187.2021.1970049
- Andriessen K, Krysinaka K, Rickwood D, Pirkis J. The reactions of adolescents, parents and clinicians to participating in qualitative research interviews regarding adolescents bereaved by suicide and other traumatic death. *Int J Environ Res Public Health*. (2022) 19:452. doi: 10.3390/ijerph19010452
- Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. (2016) 26:1753–60. doi: 10.1177/1049732315617444
- Kallio H, Pietilä AM, Johnson M, Kangasniemi M. Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *J Adv Nurs*. (2016) 72:2954–65. doi: 10.1111/jan.13031
- Lumivero. NVivo 14 for windows [computer software]. Denver, CO: Lumivero (2023).
- Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis In: P Liamputtong, editor. Handbook of research methods in health social sciences. Singapore: Springer (2019). 843–60.
- DeCuir-Gunby JT, Marshall PL, McCulloch AW. Developing and using a codebook for the analysis of interview data: an example from a professional development research project. *Field Methods*. (2011) 23:136–55. doi: 10.1177/1525822X10388468
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3:77–101. doi: 10.1191/1478088706qp0630a
- Andriessen K, Krysinaka K, Grad O. Current understandings of suicide bereavement In: K Andriessen, K Krysinaka and O Grad, editors. Postvention in action: The international handbook of suicide bereavement support. Göttingen/Boston: Hogrefe (2017). 3–16.
- Jordan JR. Lessons learned: forty years of clinical work with suicide loss survivors. *Front Psychol*. (2020) 11:766. doi: 10.3389/fpsyg.2020.00766
- Creighton G, Oliffe JL, Butterwick S, Saewyc E. After the death of a friend: young men's grief and masculine identities. *Soc Sci Med*. (2013) 84:35–43. doi: 10.1016/j.socscimed.2013.02.022
- Andriessen K, Draper B, Dudley M, Mitchell PB. Pre-and postloss features of adolescent suicide bereavement: a systematic review. *Death Stud*. (2016) 40:229–46. doi: 10.1080/07481187.2015.1128497
- Pitman A, Osborn D, King M, Erlangsen A. Effects of suicide bereavement on mental health and suicide risk. *Lancet Psychiatry*. (2014) 1:86–94. doi: 10.1016/S2215-0366(14)70224-X
- Grad O, Treven M, Krysinaka K. Suicide bereavement and gender In: K Andriessen, K Krysinaka and O Grad, editors. Postvention in action: The international handbook of suicide bereavement support. Göttingen/Boston: Hogrefe (2017). 39–49.

29. Molina N, Viola M, Rogers M, Ouyang D, Gang J, Derry H, et al. Suicidal ideation in bereavement: a systematic review. *Behav Sci.* (2019) 9:53. doi: 10.3390/bs9050053
30. Pitman AL, Osborn DP, Rantell K, King MB. Bereavement by suicide as a risk factor for suicide attempt: a cross-sectional national UK-wide study of 3432 young bereaved adults. *BMJ Open.* (2016) 6:e009948. doi: 10.1136/bmjopen-2015-009948
31. Burrell LV, Mehlum L, Qin P. Parental death by external causes and risk of hospital-treated deliberate self-harm in bereaved offspring. *Eur Child Adolesc Psychiatry.* (2021) 30:539–48. doi: 10.1007/s00787-020-01534-3
32. Cain AC. Introduction In: AC Cain, editor. *Survivors of suicide.* Springfield, IL, USA: Charles C Thomas (1972). 5–33.
33. Stroebe M, Schut H. Family matters in bereavement: toward an integrative intra-interpersonal coping model. *Perspect Psychol Sci.* (2015) 10:873–9. doi: 10.1177/1745691615598517
34. Andriessen K, Krysinska K, Rickwood D, Pirkis J. “It changes your orbit”: the impact of suicide and traumatic death on adolescents as experienced by adolescents and parents. *Int J Environ Res Public Health.* (2020) 17:9356. doi: 10.3390/ijerph17249356
35. Howard Sharp KM, Meadows EA, Keim MC, Winning AM, Barrera M, Gilmer MJ, et al. The influence of parent distress and parenting on bereaved siblings’ externalizing problems. *J Child Fam Stud.* (2020) 29:1081–93. doi: 10.1007/s10826-019-01640-0
36. Pitman AL, King MB, Marston L, Osborn DP. The association of loneliness after sudden bereavement with risk of suicide attempt: a nationwide survey of bereaved adults. *Soc Psychiatry Psychiatr Epidemiol.* (2020) 55:1081–92. doi: 10.1007/s00127-020-01921-w
37. Wilcox HC, Mittendorf-Rutz E, Kjeldgård L, Alexanderson K, Runeson B. Functional impairment due to bereavement after the death of adolescent or young adult offspring in a national population study of 1,051,515 parents. *Soc Psychiatry Psychiatr Epidemiol.* (2015) 50:1249–56. doi: 10.1007/s00127-014-0997-7
38. Levi-Belz Y, Krysinska K, Andriessen K. “Turning personal tragedy into triumph”: a systematic review and meta-analysis of studies on posttraumatic growth among suicide-loss survivors. *Psychol Trauma Theory Res Pract Policy.* (2021) 13:322–32. doi: 10.1037/tra0000977
39. Martin TL, Doka KJ. The influence of gender and socialization on grieving styles In: R Neimeyer, D Harris, H Winokuer and G Thornton, editors. *Grief and bereavement in contemporary society: Bridging research and practice.* New York: Routledge (2011). 69–77.
40. Castelli Dransart DA. Reclaiming and reshaping life: patterns of reconstruction after the suicide of a loved one. *Qual Health Res.* (2017) 27:994–1005. doi: 10.1177/1049732316637590
41. Cacciatore J, Erlandsson K, Rådestad I. Fatherhood and suffering: a qualitative exploration of Swedish men’s experiences of care after the death of a baby. *Int J Nurs Stud.* (2013) 50:664–70. doi: 10.1016/j.ijnurstu.2012.10.014
42. Andriessen K, Mowl J, Lobb E, Draper B, Dudley M, Mitchell PB. “Don’t bother about me.” the grief and mental health of bereaved adolescents. *Death Stud.* (2018) 42:607–15. doi: 10.1080/07481187.2017.1415393
43. Stroebe M, Schut H. The dual process model of coping with bereavement: a decade on. *OMEGA-J Death Dying.* (2010) 61:273–89. doi: 10.2190/OM.61.4.b
44. Goodall R, Krysinska K, Andriessen K. Continuing bonds after loss by suicide: a systematic review. *Int J Environ Res Public Health.* (2022) 19:2963. doi: 10.3390/ijerph19052963
45. Gibson J, Gallagher M, Jenkins M. The experiences of parents readjusting to the workplace following the death of a child by suicide. *Death Stud.* (2010) 34:500–28. doi: 10.1080/07481187.2010.482879
46. Goulah-Pabst DM. Suicide loss survivors: navigating social stigma and threats to social bonds. *OMEGA-J Death Dying.* (2021) 87:769–92. doi: 10.1177/00302228211026513
47. Feigelman W, Jordan JR, Gorman BS. Personal growth after a suicide loss: cross-sectional findings suggest growth after loss may be associated with better mental health among survivors. *OMEGA-J Death Dying.* (2009) 59:181–202. doi: 10.2190/OM.59.3.a
48. Kearns M, Muldoon OT, Msetfi RM, Surgenor PW. Darkness into light? Identification with the crowd at a suicide prevention fundraiser promotes well-being amongst participants. *Eur J Soc Psychol.* (2017) 47:878–88. doi: 10.1002/ejsp.2304
49. Oulanova O, Séguin M. Peer counseling in suicide bereavement: characteristics and pitfalls In: K Andriessen, K Krysinska and O Grad, editors. *Postvention in action: The international handbook of suicide bereavement support.* Göttingen/Boston: Hogrefe (2017). 139–49.
50. Putri AK, Armstrong G, Setiyawati D, Andriessen K. Unveiling studies on self-healing practices for suicide loss survivors: a scoping review. *Death Stud.* (2024) 48:1107–20. doi: 10.1080/07481187.2024.2304773
51. Honeycutt A, Praetorius RT. Survivors of suicide: who they are and how do they heal? *Illn Crisis Loss.* (2016) 24:103–18. doi: 10.1177/1054137315587646
52. Krysinska K, Ozols I, Fraser T, Banfield M, Hawgood J, Kölves K, et al. ‘Wisdom is knowledge plus experience’: qualitative study of lived experience and researcher perspectives on suicide research co-production. *Int J Ment Health Nurs.* (2025) 34:e13507. doi: 10.1111/inm.13507
53. Oulanova O, Moodley R, Séguin M. From suicide survivor to peer counselor: breaking the silence of suicide bereavement. *OMEGA-J Death Dying.* (2014) 69:151–68. doi: 10.2190/OM.69.2.d
54. Hofmann L, Putri AK, Pitman A, Bantjes J, Castelli Dransart DA, Causer H, et al. Perceived effectiveness of components of interventions to support people bereaved by suicide: a metareview of systematic reviews. *Crisis.* (2025) 46:106–20. doi: 10.1027/0227-5910/a000978
55. Kiselica MS, Englar-Carlson M. Identifying, affirming, and building upon male strengths: the positive psychology/positive masculinity model of psychotherapy with boys and men. *Psychother Theory Res Pract Train.* (2010) 47:276–87. doi: 10.1037/a0021159
56. Andriessen K. Can postvention be prevention? *Crisis.* (2009) 30:43–7. doi: 10.1027/0227-5910.30.1.43
57. Pirkis J, Bantjes J, Dandona R, Knipe D, Pitman A, Robinson J, et al. Addressing key risk factors for suicide at a societal level. *Lancet Public Health.* (2024) 9:e816–24. doi: 10.1016/S2468-2667(24)00158-0



OPEN ACCESS

EDITED BY

Don Lollar,
Oregon Health and Science University,
United States

REVIEWED BY

Jeanine Young,
University of the Sunshine Coast, Australia
Urwah Ali,
Foundation University, Pakistan

*CORRESPONDENCE

Xiaoyun Wang
✉ wangxy1819@gmail.com

RECEIVED 20 February 2025

ACCEPTED 19 May 2025

PUBLISHED 01 July 2025

CITATION

Cui N, Wu S, Wang X and Sheng L (2025)
Experiences and needs of family members of
perinatal infant deaths: a meta-synthesis.
Front. Public Health 13:1580039.
doi: 10.3389/fpubh.2025.1580039

COPYRIGHT

© 2025 Cui, Wu, Wang and Sheng. This is an
open-access article distributed under the
terms of the [Creative Commons Attribution
License \(CC BY\)](https://creativecommons.org/licenses/by/4.0/). The use, distribution or
reproduction in other forums is permitted,
provided the original author(s) and the
copyright owner(s) are credited and that the
original publication in this journal is cited, in
accordance with accepted academic practice.
No use, distribution or reproduction is
permitted which does not comply with these
terms.

Experiences and needs of family members of perinatal infant deaths: a meta-synthesis

Nana Cui¹, Shasha Wu¹, Xiaoyun Wang^{1*} and Lei Sheng²

¹Neonatal Ward, Jining No.1 People's Hospital, Jining, Shandong, China, ²Nursing Department, Jining No.1 People's Hospital, Jining, Shandong, China

Purpose: This meta-review of qualitative studies aims to explore the experiences and needs of family members following perinatal infant deaths.

Design: A qualitative meta-synthesis was conducted.

Data sources: Four databases, PubMed, CINAHL, EMBASE, and Web of Science, were searched from inception through November 2024. An initial search using the keywords "perinatal death", "family members", and "qualitative research" retrieved 496 articles. Based on predefined inclusion and exclusion criteria, 10 studies were selected for inclusion.

Review methodology: The Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist was used to assess the quality of included studies.

Results: Ten studies from nine countries were analyzed, yielding five overarching themes: negative emotional reactions, searching for the cause of death, rebuilding of life, reconstruction of meaning, and need for support.

Conclusion: Negative emotional responses are an inevitable and profound part of the bereavement process for families experiencing perinatal loss. Identifying the cause of death helps families understand their loss and reduces uncertainty and self-blame. Central to the grieving process is the reconstruction of emotional and psychological meaning, which involves redefining life's purpose and gradually restoring a sense of normalcy. However, many of these families' needs remain unmet. There is an urgent need for multidisciplinary strategies to provide comprehensive, tailored support.

KEYWORDS

experiences and needs, family members, perinatal infant, deaths, meta-synthesis

1 Introduction

Perinatal mortality remains a critical global public health issue. According to the World Health Organization (1), perinatal death encompasses the period from 22 weeks of gestation through to the first 28 days post-birth. In 2019, an estimated two million babies [90% uncertainty interval (UI) 1.9–2.2] were stillborn at 28 weeks of gestation or later, with a global stillbirth rate of 13.9 per 1,000 total births (90% UI 13.5–15.4) (2). Studies from Europe, Australia, and the United States have shown that perinatal loss not only imposes significant emotional and psychological burdens on families but also contributes to increased societal and healthcare costs (3–5). For mothers and their families, the confirmation of fetal death is a psychologically traumatic event with long-term effects extending beyond emotional distress to physical and social dimensions (6). Fathers too, experience substantial emotional trauma, often intensified by witnessing their partner's suffering (7, 8).

Despite international consensus guidelines clearly advocating comprehensive family support for perinatally bereaved families (9), gaps persist between the emotional support needs of bereaved parents and the care provided in clinical practice. Research highlights that the quality of bereavement care significantly influences how parents cope with and recover from their loss (10, 11). However, parents frequently report dissatisfaction with the offered support, citing inadequate healthcare resources and insufficient attention to individual emotional needs (11). Current bereavement care often focuses primarily on physical aspects, neglecting the systematic integration of tailored psychosocial support (10, 12). This incongruity underscores the urgent need to re-evaluate support frameworks by critically analyzing lived experiences. A nuanced understanding of lived experiences is essential in informing effective, empathetic perinatal bereavement interventions. Meta-synthesis offers a valuable method for synthesizing qualitative evidence, allowing for a deeper exploration of complex emotional and psychological processes (10, 13). Qualitative research is particularly well-suited to capturing the multidimensional emotional trajectories and the dynamic process of the bereaved and providing a contextualized framework for clinical practice.

Therefore, this meta-synthesis aims to analyze, interpret, and integrate existing qualitative research on the experiences and needs of families affected by perinatal infant deaths. It seeks to answer the following questions: (1) What are the experiences and needs of family members whose infants die during the perinatal period? (2) What recommendations can be drawn from these studies to inform clinical practice, education, and future research to better support families experiencing perinatal loss?

2 Methods

2.1 Research design

Meta-synthesis is a well-established methodology for integrating qualitative findings in health services research (14–16). It serves as an umbrella term for the synthesis of results derived from various qualitative methods and is commonly used to interpret and contextualize qualitative evidence (17). This methodology allows for a deep understanding of participants' meanings, experiences, and perspectives, made possible by the qualitative nature of the included studies, and a broad synthesis by incorporating findings across diverse healthcare settings and populations (18).

2.2 Search strategy

To identify relevant literature, four electronic databases, PubMed, CINAHL, EMBASE, and Web of Science, were searched from their inception to 30 November 2024. Articles were screened based on predefined inclusion and exclusion criteria formulated using the Population, Intervention, Comparison, Outcomes, and Study (PICOS) framework (19). The search was limited to articles in English or Chinese. A detailed search strategy is provided in [Supplementary Table 3](#). This meta-synthesis followed

the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Additionally, the reference lists of the included articles were manually reviewed to identify further eligible studies.

2.3 Study selection

All search results were imported into EndNote, which was also used to import articles and remove duplicates. Two researchers independently screened titles and abstracts using the inclusion and exclusion criteria, followed by a full-text review to confirm eligibility ([Figure 1](#)).

The inclusion criteria were as follows: (a) The study population included parents who had experienced a perinatal death (fetal/neonatal deaths between the 22nd week of gestation and the 28th day after birth); (b) The study focused on parental experiences needs to be related to perinatal deaths; (c) The context was explicitly related to perinatal deaths; (d) The research design was qualitative, using methods such as phenomenology, ethnography, grounded theory, hermeneutics, narrative analysis, or thematic analysis and primarily analyzed textual data rather than digital data; (e) The publication timeframe extended from database inception to 30 November 2024; and (f) The articles were peer-reviewed and published in English or Chinese. Exclusion criteria were as follows: (a) Conference abstracts, dissertations, or gray literature; (b) Studies from which qualitative data could not be extracted; and (c) Articles with full text literature was unavailable through PubMed LinkOut, LibGen, and the host institution's interlibrary loan system.

2.4 Quality assessment

All included studies were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist, which assesses whether each included study had: A clearly stated aim; An appropriate methodology and study design; A suitable recruitment strategy; Sound data collection and ethical considerations, Rigorous data analysis; Clear presentation of findings; and overall research value. Two researchers (CNN and WXY) independently reviewed each study based on a checklist. In case of disagreement, a third researcher (WSS) facilitated consensus through discussion. Two such disagreements arose during the review and were resolved through this collaborative process. A quality assessment form was created ([Table 1](#)). To enable comparison across studies. This table summarized key quality indicators, including the purpose of the study, appropriate qualitative methods, study design, recruitment strategies, data collection methods, the relationship between the researcher and the participants, consideration of ethical issues, data analysis rigor, findings presentation, and the value of the study.

2.5 Data extraction and analysis

Data were extracted independently by two researchers (WXY, SL), including and included authors, year of publication, sample size, age and sex of participants, time of death, newborn age,

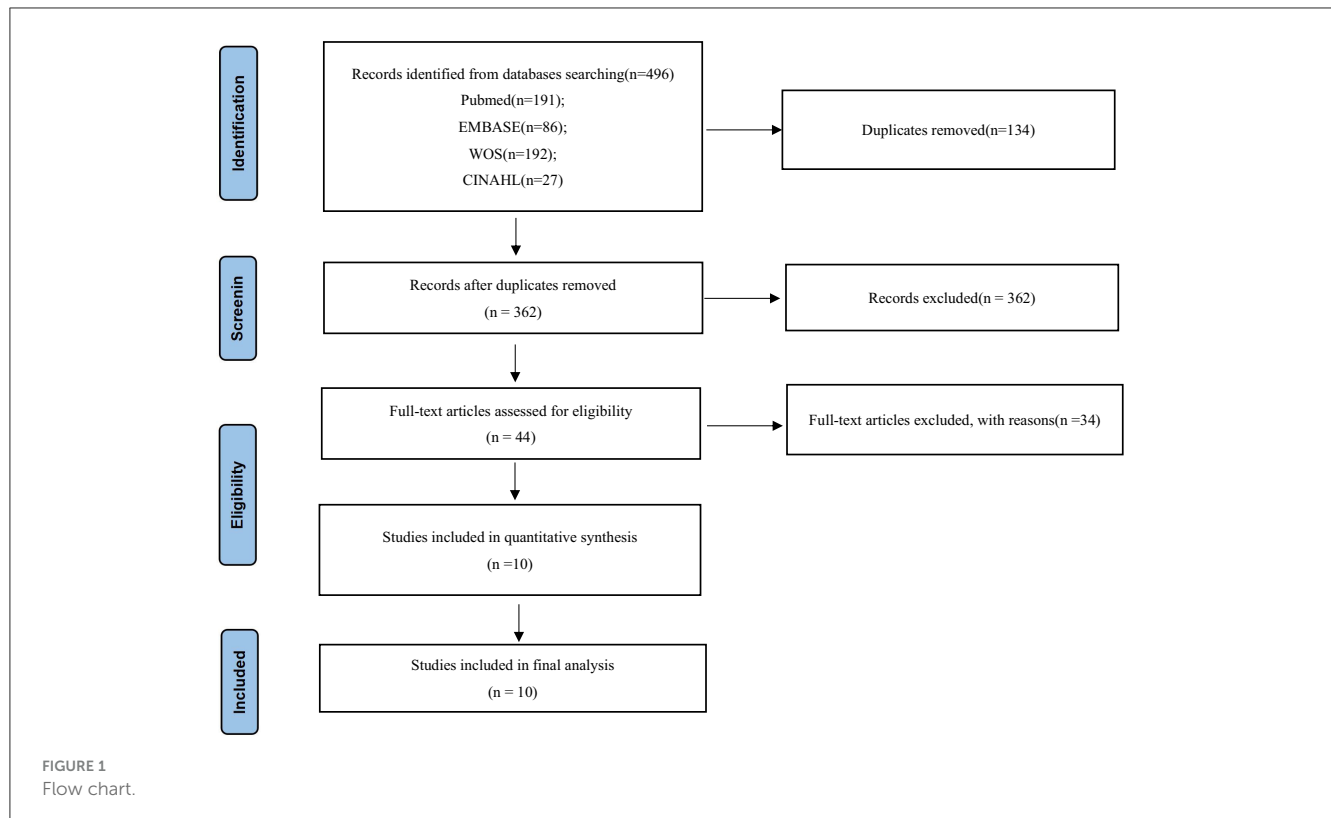


TABLE 1 Use of the critical assessment screening programme (CASP).

No.	Author/Year	CASP-items									
		1	2	3	4	5	6	7	8	9	10
1	Downe et al. (2013)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
2	Camacho-Ávila et al. (2019)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
3	Lizcano et al. (2019)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
4	Kuforiji et al. (2024)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
5	Zheng et al. (2024)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
6	Azeez et al. (2022)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
7	Kavanaugh et al. (2005)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
8	Sutan et al. (2012)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
9	Arach et al. (2022)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
10	Horey et al. (2012)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y

1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research? Y, yes; C, can't tell; N, no.

country of publication, study design and analytical method. The extracted information was compiled in tabular form and cross-checked by a third researcher (WSS). Thematic synthesis followed the framework proposed by Thomas and Harden (24). First, the primary studies were systematically reviewed and iteratively read by CNN and WXY to generate Initial codes. Second, SL and WSS grouped these codes into descriptive themes by

comparing their similarities. Finally, CNN refined these themes to identify overarching analytical constructs, generating new insights and hypotheses. These analytical themes were supported by key findings from the original articles, providing a more comprehensive synthesis of the research field. Any discrepancies encountered during the process were resolved through discussions in group meetings.

3 Results

3.1 Record search results

The study selection process is illustrated in [Figure 1](#). The initial search identified 496 articles, of which 134 duplicates were removed using EndNote software. After title and abstract screening, 362 articles were reviewed, and 318 were excluded based on predefined inclusion and exclusion criteria. Subsequently, 44 full-text articles were assessed, and 34 were excluded for the following reasons: (1) non-qualitative study design ($n = 15$); (2) focus on healthcare providers' perspectives rather than family members ($n = 8$); (3) lack of extractable qualitative data ($n = 6$); and (4) duplicate study populations or contexts already represented in included studies ($n = 5$). Finally, 10 full-text articles met the eligibility criteria and were included in the quality assessment and synthesis.

3.2 Quality assessment of included studies

All 10 included studies fulfilled at least nine out of the 10 criteria on the Critical Appraisal Skills Programme (CASP) qualitative checklist, indicating robust methodological quality. Consequently, all 10 studies were retained for the final qualitative synthesis.

3.3 Basic characteristics of the included studies

The 10 studies employed three principal qualitative methodological approaches: phenomenological design ($n = 5$), exploratory-descriptive design ($n = 3$), generic qualitative methodology ($n = 2$). Analytical methods included inductive thematic analysis and content thematic analysis ([Table 2](#)).

3.4 Demographic characteristics of study participants

Sample sizes in the included studies ranged from 10 to 32 participants ([Table 3](#)). The study populations consisted of family members of neonates who had died, aged between 18 and 63 years, with 125 female and 59 male participants. All 10 studies reported the time since death, ranging from 5 weeks to 12 years. The studies were conducted in a variety of countries: Australia ($n = 2$), the United Kingdom ($n = 1$), Spain ($n = 1$), Colombia ($n = 1$), Nigeria ($n = 1$), China ($n = 1$), the United States ($n = 1$), Malaysia ($n = 1$), and Uganda ($n = 1$). All 10 studies were published between 2005 and 2024.

3.5 Key findings of the meta-synthesis

Thematic analysis of 33 key quotes from the 10 included studies generated five overarching themes: negative emotional reactions, searching for the cause of death, rebuilding life, reconstruction of meaning, and need for support ([Table 4](#)).

3.6 Negative emotional reactions

Perinatal loss evokes complex and intense emotional responses. Mothers who experienced stillbirths often reported feelings of regret and self-blame, attributing the loss to delayed care-seeking, lack of resources, or choosing to give birth at home ([20](#)). The diagnosis of stillbirth during antenatal care was associated with prolonged anxiety and emotional distress ([21](#)). Most participants blamed themselves for the outcome, resulting in deep guilt and psychological trauma ([22](#)). The death of a newborn was described as one of the most devastating experiences in a parent's life, with distress persisting for years ([23](#)). Unlike other types of bereavement, perinatal loss was associated with not only emotional pain but also physical symptoms such as sleep disturbances, nightmares, tingling, and somatic pain ([24](#)). Family members reported feelings of shock, uncertainty, loneliness, loss, guilt, self-blame, and anger ([25–27](#)). The confirmation of a newborn's death marked the beginning of an emotionally taxing grieving process, often worsened by a lack of communication and support from healthcare providers ([27](#)). Almost all mothers mentioned intense loneliness following the loss ([28](#)), especially when the death was sudden and unexpected, leading to profound feelings of helplessness and disbelief ([23, 25, 26](#)). Some women internalized blame for the loss, and the absence of empathetic communication from medical professionals deepened their isolation ([28, 29](#)). This isolation extended beyond emotional

TABLE 2 Basic characteristics of qualitative studies included in the meta-synthesis.

Author/Year	Country	Research design	Data analysis
Downe et al. (2013)	Britain	Phenomenological study design	Inductive thematic analysis
Camacho-Ávila et al. (2019)	Spain	Hermeneutic phenomenology design	Inductive thematic analysis
Lizcano et al. (2019)	Colombia	Descriptive phenomenological design	Inductive thematic analysis
Kuforiji et al. (2024)	Nigeria	Hermeneutic phenomenology design	Inductive thematic analysis
Zheng et al. (2024)	China	Interpretivist constructionist phenomenology	Inductive thematic analysis
Azeez et al. (2022)	Australia	Descriptive, exploratory research	Inductive thematic analysis
Kavanaugh et al. (2005)	America	Descriptive phenomenologic approach	Inductive thematic analysis
Sutan et al. (2012)	Malaysia	Qualitative, exploratory and descriptive analysis	Inductive thematic analysis
Arach et al. (2022)	Uganda	Qualitative study	Content thematic analysis
Horey et al. (2012)	Australia	Qualitative study	Content thematic analysis

TABLE 3 Demographic characteristics of individual study participants included in the meta-synthesis.

Author/Year	Sample size	Age of participants	Sex	Time since loss	Age of baby
Downe et al. (2013)	<i>n</i> = 25	18–44	Female = 19 Male = 6		24–42 weeks
Camacho-Ávila et al. (2019)	<i>n</i> = 21	26–43	Female = 13 Male = 8	3 months–5 years	24 weeks–6 days
Lizcano et al. (2019)	<i>n</i> = 15	18–54	Female = 0 Male = 15		22–38 weeks
Kuforiji et al. (2024)	<i>n</i> = 14	22–41	Female = 14 Male = 0	<5 years	<28 days
Zheng et al. (2024)	<i>n</i> = 28	32.96 ± 4.97	Female = 28 Male = 0	<1 years	≥24 weeks
Azeez et al. (2022)	<i>n</i> = 10	31–42	Female = 0 Male = 10	1–12 years	30 min–27 days
Kavanaugh et al. (2005)	<i>n</i> = 23	>18	Female = 17 Male = 6	5–21 weeks	26, 27 weeks
Sutan et al. (2012)	<i>n</i> = 16	23–37	Female = 16 Male = 0	6–12 months	26–39 weeks
Arach et al. (2022)	<i>n</i> = 32	17–68	Female = 18 Male = 14	<2 years	≥28 weeks
Horey et al. (2012)	<i>n</i> = 17		Female = 14 Male = 3	<7 years	

loneliness, encompassing confusion about the future and shaken sense of identity.

3.7 Finding the cause

Parents expressed a strong desire to understand the cause of their infant's death (26, 29). In seeking explanations, some fathers compared their experiences with those of family and friends, revisiting medical decisions and evaluating the healthcare system's response (23). The need for support and support in understanding the cause was especially acute (20). In many cases, women were blamed by their partners and in-laws, reflecting a broader cultural need to assign responsibility (20). Parents also sought meaning through philosophical or spiritual interpretations of death (26). Autopsies were highlighted as the most definitive method for establishing the cause of death, especially in cases of stillbirths (30–32). However, parents needed detailed, compassionate explanations about autopsy procedures, free from blame, and delivered within a supportive and trusting healthcare environment (32). Across both stillbirth and neonatal death cases, transparent communication from healthcare providers was a recurring need.

3.8 Need for support

Participants frequently reported that not all healthcare professionals were adequately trained to communicate compassionately about perinatal death (28). Mothers desired comprehensive emotional support from healthcare professionals, including opportunities to discuss their feelings openly with doctors and midwives (21). Personalized care from these professionals was seen as particularly comforting (27). Parents reported that they would have coped better if professionals had communicated more transparently during hospitalization (29). In addition to professional support, emotional support from family and friends played a critical role in coping. Parents appreciated those who remained present and comforting after

the loss and expressed a desire for continued support even after the funeral (20, 26). Many fathers reported difficulty balancing their own grief with their perceived responsibilities to support others (23). Many participants also described engaging in activities to stay busy, distract themselves, and seek social support.

3.9 Reconstruction of meaning

Many participants reported that perinatal loss caused them to question the meaning of life. Some sought to reconstruct meaning through reflective practices, spiritual interpretations, and remembrance (33). Creating and conserving memories of the deceased child, such as through keepsakes or rituals, was seen as an important way to cope (29). The experience of loss brought about a shift in participants' worldviews. Parents learned to integrate the child's memory into their ongoing lives and identities, sometimes perceiving the deceased child as a continued spiritual presence (25). Others processed the trauma by making sense of the event and reevaluating their lives in its aftermath (22).

3.10 Rebuilding lives

Perinatal bereavement often leads to a re-evaluation of life priorities and values. Some fathers expressed gratitude for the experience of fatherhood, however brief, and described how the loss had deepened their appreciation for loved ones. When fathers give meaning to perinatal death and acknowledge the spiritual presence of their children in their lives, they can move beyond the pain of losing their children (25). Through meaning-making and spiritual reflection, some parents were able to move forward, regaining a sense of purpose and direction (22). The birth of a healthy child after the loss was often seen as part of the healing process, helping parents recover from grief and renew hope (26).

TABLE 4 Supporting quotes as related to five themes.

Author/Year	Supporting quotes underpinning the five themes				
	Emotional outpouring	Finding cause of death	Need for support	Meaning reconstruction	Rebuilding life
Downe et al. (2013)	Beyond distress: Bowled over by the horror...	Expressed a strong drive to find out why their baby died.	Filling the gap someone to help you and guide you...	Making irretrievable moments precious	Positive caring in the care: 'they hold a special place in our lives
Camacho-Ávila et al. (2019)	The shock of losing a baby and the pain of giving birth to a stillborn baby	Not knowing the cause of death or not having a clear explanation about the causes.	Receiving individualized care from midwives and physicians could become the most important source of comfort for parents.	"We have had a baby."	Saying goodbye to the deceased baby, having the baby's footprint, keeping the memory of the baby alive
Lizcano et al. (2019)	It leaves him devastated, in pain, and feeling shattered.		To give support and strength to their wives or partners	Finding Meaning in Loss	By acknowledging and giving a special meaning to the presence of the deceased child in their lives and home.
Kuforiji et al. (2024)	Caused feeling of anxiety and uncertainty.		Mothers expected comprehensive emotional support from health care professionals		In reassuring mothers of hope for future pregnancies and living babies.
Zheng et al. (2024)	Restrained expressions of grief.		Receiving unexpected levels of help, understanding, an support from family, friends, and colleagues	Reshaping beliefs and views about life and death.	Gained a renewed sense of purpose and direction and felt motivated to make positive changes in their lives.
Azeez et al. (2022)	A complicated grief experience	Disbelief at neonatal death outcome	Disenfranchised grief: lack of social recognition and acknowledgement	It challenging to balance expressing their grief with a desire to support others and attend to responsibilities	
Kavanaugh et al. (2005)	Feeling intense emotions after the death	Parents tried to make sense of their loss and determine why it occurred	Feeling abandoned or unsupported. Seeking diversions and support	Creating and Cherishing Memories of their Infant	Contemplating future pregnancies
Sutan et al. (2012)	Confusion Feeling of emptiness Anger Anger Anxiety over subsequent pregnancy	Parents tried to make sense of their loss and determine why it occurred.	Support during grief.	By practicing religious activities they were able to reduce the pain they suffered and make their mind more accepting of the situation.	
Arach et al. (2022)	Pain, confusion, facing multiple challenging roles, concern about the health of the partners, health care providers' reaction, blame and guilt.	Women were commonly blamed by their partners and in-laws for the perinatal deaths. This could be because family members were searching for the cause of the perinatal deaths.	Family and community support		
Horeyet et al. (2012)	Hazy, emotionally wrecked My biggest fear, and that's what a lot of people would have about it, is 'oh shit, I might have done something wrong and now I'm going to be blamed.	Because I'm not asking questions and I don't have the what if. And even though it was unexplained I did everything I could to find out for myself.	Your doctor makes other decisions for you like. They are quite happy to make those decisions and guide you so why is suddenly when things go wrong... everyone backs off.	It was like another way of reconnecting with him. You get such a level of detail about your child that you wouldn't get in a different setting.	The autopsy did explain the death and gave the parents new information to consider when planning for another baby.

4 Discussion

This review synthesizes findings from 10 qualitative studies on the experiences and needs of families affected by neonatal death. It provides valuable insights that confirm and extend existing knowledge on this important topic.

4.1 Negative emotional reactions

Perinatal bereavement is a deeply traumatic experience, often marked by grief, guilt, and somatic symptoms. These reactions align with established theories of traumatic loss. Stroebe and Schut's Dual Process Model (1999) (34) provides a theoretical framework

to understand the oscillation between loss-oriented and recovery-oriented coping strategies observed in the included studies. Parents often experience profound distress compounded by feelings of loneliness, lack of information, guilt, and self-blame. Unlike other forms of bereavement, perinatal loss represents not just the physical absence of a child, but the chattering of future hopes and imagined lives. Many mothers internalize blame, attributing the death to their actions or decisions, which can lead to lasting psychological trauma. Cultural differences also shape grief expression. Whereas, Western studies emphasize individualized grief (35), participants in Nigeria and Uganda described a communal grief burdened by stigma (20). These findings highlight the importance of culturally sensitive bereavement care. In low-resource settings, structural inequalities often intensify parental guilt, reinforcing the need for context-specific bereavement protocols as advocated by the International Stillbirth Alliance Conference (36, 37). Timely, compassionate communication and the provision of clear information are critical. Healthcare professionals should engage with parents early following a diagnosis of stillbirth, offering both informational and emotional support.

4.2 Finding the cause

Understanding the cause of death is a central need for bereaved parents. This review suggests that perinatal bereavement not only causes profound emotional trauma but also triggers a deep need to understand why the death occurred. For many parents, discovering the cause becomes one of their most urgent concerns following the loss (26, 29). The “search for meaning” aligns with Neimeyer’s constructivist theory of grief, which emphasizes the importance of sense-making in adapting to loss (38). Parents’ intense need to understand the cause of their infant’s death often includes intense questioning, self-reflection, particularly by fathers, internal attribution of responsibility within the family, and seeking explanations through philosophical and religious perspectives. These reactions reflect not only emotional needs but also reveal the importance of social and cultural factors in dealing with such events. For parents, this need is not only motivated by rational curiosity, but also to find a way to process and accept reality. Understanding the exact cause helps parents reduce feelings of self-blame and uncertainty, focus their grief, and inform future reproductive decisions.

4.3 The need for support

Perinatal bereavement is a complex and multi-layered experience that impacts not only individual mental health but also the wider family and social support network. Research has shown that the quality of care and support received before and after an infant’s premature death is a critical factor in parents’ immediate and long-term wellbeing (39). This support must extend beyond medical care to include emotional, social, and psychological dimensions. Nurses and midwives play a vital role in post-bereavement care and are frequently cited as a primary source of support (40). Their presence, active listening, and emotional responsiveness are key to helping parents navigate their grief. Beyond hospital settings, community-based services, such as

primary care clinics and outreach programmes, are critical in providing ongoing support (30, 39). These community resources can provide both long-term emotional support and practical help as families gradually recover.

Peer support consistently emerges as valued source of comfort and strength. In line with the Sands International Bereavement Care Guidelines (2023) (41), peer networks are recommended as adjuncts to clinical care. Parents often report that connecting with others who have had similar experiences provides affirmation, comfort, hope, and a sense of shared understanding (42, 43). Such support reduces feelings of isolation and helps parents feel less alone in their grief. Personalized care also plays a crucial role in the healing process. Community organizations and professional bodies can provide training and educational resources to help family members better support bereaved families. Healthcare professionals must be equipped with the skills to offer empathetic and culturally sensitive care. However, some relatives may lack sufficient knowledge or skills to engage, which can increase parental isolation and distress (44). Raising public awareness and improving communication skills across the community is therefore essential to ensure that support systems do not inadvertently contribute to feelings of abandonment.

4.4 Reconstruction of meaning

While perinatal bereavement brings profound sorrow, it can also offer an opportunity for families to reframe and redefine their lives. This review shows that, despite overwhelming grief, many parents strive to reconstruct meaning and redefine their values and goals. Acts such as preserving fond memories, collecting meaningful mementoes, reframing life perspectives, and engaging in deep reflection help parents rediscover purpose amid their loss. Parents often continue to acknowledge the presence of their deceased child in their life and family and imbue that presence with lasting meaning. This aligns with Tedeschi and Calhoun’s (45) concept of post-traumatic growth, a process of meaning-making through memorialization and spiritual reframing parallels. Additionally, participants’ efforts to integrate the deceased child into family narratives resonate with Klass’s (46) theory of continuing bonds, challenging earlier grief models that prioritized detachment. Rather than a simple reflection on the past, this process involves reimagining life and forging a future shaped by the child’s enduring influence. Such meaning-making may improve psychological resilience and strengthen family relationships. Many mothers, for example, choose to journal about their thoughts and feelings, allowing them to explore how the experience has transformed them (47). As young women find meaning in their experiences and gain new insights into their loss, the support provided during follow-up may undergo a critical shift. Tools such as the Perinatal Bereavement Care Checklist (48), which incorporates cultural and spiritual assessments into care planning, can help clinicians offer more sensitive and personalized support.

4.5 Rebuilding lives

Perinatal loss is often one of the most devastating experiences a family can endure, consistent with prior research (25). Yet,

this review suggests that such loss can also become a catalyst for personal growth and renewed purpose, in line with Bonanno's resilience theory (49). The emotional upheaval caused by perinatal death can lead to a reassessment of life priorities, fostering greater gratitude, self-awareness, and motivation for positive change. This emotional shift exemplifies the ability of humans to find and appreciate the good in life despite the grief they face. When family members are able to assign meaning to the loss and acknowledge the spiritual presence of the child in their lives, they are often better equipped to cope with grief and embrace life anew. Practices such as meditation, prayer, or other forms of spiritual practice offer valuable coping resources, helping families face life's uncertainties with greater openness and resilience. For many families, a subsequent healthy pregnancy represents a key step in the healing process. It can restore hope and vitality while easing the lingering pain of loss. However, healthcare professionals must be sensitive to acknowledge psychosocial impact of prior loss and support parents accordingly (50). This includes grief education and training to ensure that professionals can respond with both competence and compassion during and after bereavement.

4.6 Strengths and limitations

The strengths of this study lie in its systematic approach to data retrieval and synthesis, as well as the international representativeness of the included studies, which enhance the reliability and relevance of the findings. A comprehensive literature search and rigorous data analysis helped ensure the review's credibility. However, some limitations must be acknowledged. The inclusion of only English and Chinese publications may have introduced language bias, and restricting the review to published studies could have excluded relevant gray literature. Additionally, nine of the ten included studies were conducted in Western countries, which limits the generalisability of the findings to other countries with different cultural backgrounds and healthcare systems. The relatively small number of studies included ($n = 10$) may also reflect publication bias or gaps in qualitative research on perinatal bereavement in non-Western contexts. Future research should explore the experiences and needs of mothers and mothers separately, as the grief responses, coping strategies, and support needs can differ significantly between parents. This would help inform more targeted and effective interventions.

5 Conclusion

Negative emotional reactions are an inevitable part of perinatal bereavement. Understanding the cause of the infant's death is fundamental need for parents, as it provides clarity, reduces self-blame, and supports emotional processing. Equally vital is the reconstruction of meaning on an emotional and psychological level, which involves redefining the meaning of life, finding new purpose and direction, and gradually restoring normality to life. Despite the profound impact of such losses, many needs of bereaved families remain unmet. There is an urgent need

for multidisciplinary strategies to provide comprehensive support during and after bereavement.

5.1 Implications

Firstly, policymakers should develop a standardized and systematic bereavement care protocols to ensure coordinated support for affected families. This includes transparent communication regarding autopsy procedures, timelines, and results. Genetic counseling should be made available to assess future pregnancy risks. Psychological support services, including individual counseling, group therapy and support groups, should be accessible, and health education resources should be developed to enhance parents' knowledge and health literacy related to perinatal bereavement through health talks, pamphlets, and online resources.

Secondly, healthcare teams should include doctors, nurses, psychologists, and social workers, working collaboratively to provide all-round support to families. Specialized training should be provided to nurses and other healthcare professionals to help them acquire skills in communicating with bereaved families, and members of the team should communicate with each other on a regular basis to ensure information sharing and service coordination. Training should include psychological foundations, grief counseling and cultural sensitivity. Post-discharge outreach and partnerships with local community organizations can extend support beyond clinical settings.

Thirdly, healthcare professionals should adopt a personalized care approach that respects unique emotional needs and preferences. Compassionate communication, attentive listening, and flexible support are essential. Respecting parents' emotional expressions and personal choices ensures that they feel valued and understood. Healthcare professionals should demonstrate empathy and support in their interactions with families, listening to them, responding to their specific needs, and helping them find strength and direction in their grief. Nurses, social workers, occupational therapists, and psychologists should provide targeted interventions, which can be done through personalized assessment, whereby each family is assessed in detail to understand their psychological state, social support network and specific needs. Personalized assessments can guide the development of care plans, while continued contact, through regular home visits, telephone counseling, or online support, can help cope and recover over time.

5.2 Recommendations for future research

Perinatal bereavement is both a deeply personal tragedy and a challenge to healthcare systems and communities. Strengthening professional training, improving communication of medical information, establishing a multidisciplinary support system, and fostering the joint participation of all sectors of society are key to supporting grieving families. Future research should continue to explore the complexities of perinatal bereavement and contribute to the evidence base for effective, culturally responsive interventions.

In doing so, we can ensure that no family faces this experience without hope or support.

Data availability statement

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found in the article/Supplementary material.

Author contributions

NC: Writing – original draft, Writing – review & editing, Conceptualization, Data curation, Formal analysis, Methodology, Software. SW: Conceptualization, Formal analysis, Methodology, Software, Writing – original draft. XW: Conceptualization, Formal analysis, Methodology, Validation, Writing – review & editing. LS: Data curation, Methodology, Software, Supervision, Writing – review & editing.

Funding

The author(s) declare that no financial support was received for the research and/or publication of this article.

References

- World Health Organization. (2006). *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10)*. Geneva: WHO Press.
- Hug L, You D, Blencowe H, Mishra A, Wang Z, Fix MJ, et al. Global, regional, and national estimates and trends in stillbirths from 2000 to 2019: a systematic assessment. *Lancet*. (2021) 398:772–85. doi: 10.1097/01.ogx.0000816512.11007.84
- Heazell AEP, Siassakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J, et al. Stillbirths: economic and psychosocial consequences. *Lancet*. (2016) 387:604–16. doi: 10.1016/s0140-6736(15)00836-3
- Quenby S, Gallos ID, Dhillon-Smith RK, Marcelina P, Stephenson MD, Fisher J, et al. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. *Lancet*. (2021) 397:1658–67. doi: 10.1016/S0140-6736(21)00682-6
- Xie J, Hunter A, Biesty L, Grealish A. The impact of midwife/nurse-led psychosocial interventions on parents experiencing perinatal bereavement: an integrative review. *Int J Nurs Stud*. (2024) 157:104814. doi: 10.1016/j.ijnurstu.2024.104814
- Barfield WD. Standard terminology for fetal, infant, and perinatal deaths. *Pediatrics*. (2016) 137:e20160551. doi: 10.1542/peds.2016-0551
- Nguyen V, Temple-Smith M, Bilardi J. Men's lived experiences of perinatal loss: a review of the literature. *Aust N Z J Obstet Gynaecol*. (2019) 59:757–66. doi: 10.1111/ajog.13041
- Shakespeare C, Merriel A, Bakhbakhi D, Baneszova R, Barnard K, Lynch M, et al. Parents' and healthcare professionals' experiences of care after stillbirth in low and middle-income countries: a systematic review and meta-summary. *BJOG*. (2019) 126:12–21. doi: 10.1111/1471-0528.15430
- Froen JF, Cacciatore J, McClure EM, Kuti O, Jokhio AH, Islam M, et al. Stillbirths: why they matter. *Lancet*. (2011) 377:1353–66. doi: 10.1016/S0140-6736(10)62232-5
- Mills TA, Ricklesford C, Cooke A, Heazell AEP, Whitworth M, Lavender T. Parents' experiences and expectations of care in pregnancy after stillbirth or neonatal death: a metasynthesis. *BJOG*. (2014) 121:943–50. doi: 10.1111/1471-0528.12656
- Qian J, Sun S, Wu M, Liu L, Yaping S, Yu X. Preparing nurses and midwives to provide perinatal bereavement care: a systematic scoping review. *Nurse Educ Today*. (2021) 103:104962. doi: 10.1016/j.nedt.2021.104962
- Mariutti MG, de Almeida AM, Panobianco MS. Nursing care according to women in abortion situations. *Rev Lat Am Enfermagem*. (2007) 15:20–6. doi: 10.1590/s0104-11692007000100004
- Lockwood C, Hannes K. *Synthesizing Qualitative Research: Choosing the Right Approach*. Chichester; West Sussex: John Wiley & Sons (2012).
- Zhang D, Liu Y, Chen N, Li Y, Li X. Experiences and needs of family members following sudden cardiac death: a meta-synthesis. *Int J Nurs Stud*. (2024) 160:104872. doi: 10.1016/j.ijnurstu.2024.104872
- Sandelowski M, Docherty S, Emden C. Focus on qualitative methods. Qualitative metasynthesis: issues and techniques. *Res Nurs Health*. (1997) 20:365–71. doi: 10.1002/(sici)1098-240x(199708)20:4<365::aid-nur9>3.0.co;2-e
- Thorne S, Jensen L, Kearney MH, Noblit G, Sandelowski M. Qualitative metasynthesis: reflections on methodological orientation and ideological agenda. *Qual Health Res*. (2004) 14:1342–65. doi: 10.1177/1049732304269888
- Thorne S, Paterson B, Acorn S, Canam C, Joachim G, Jillings C. Chronic illness experience: insights from a metastudy. *Qual Health Res*. (2002) 12:437–52. doi: 10.1177/104973202129120007
- Lachal J, Revah-Levy A, Orri M, Moro MR. Metasynthesis: an original method to synthesize qualitative literature in psychiatry. *Front Psychiatry*. (2017) 8:269. doi: 10.3389/fpsy.2017.00269
- Amir-Behghadami M, Janati A. Population, intervention, comparison, outcomes and study (PICOS) design as a framework to formulate eligibility criteria in systematic reviews. *Emerg Med J*. (2020) 37:387. doi: 10.1136/emermed-2020-209567
- Arach AAO, Kiguli J, Nankabirwa V, Nakasujja N, Mukunya D, Musaba MW, et al. "Your heart keeps bleeding": lived experiences of parents with a perinatal death in Northern Uganda. *BMC Pregnancy Childbirth*. (2022) 22:491. doi: 10.1186/s12884-022-04788-8
- Kuforiji O, Mills TA, Lovell K. An exploration of women's lived experiences of care and support following perinatal death in South-Western Nigeria: a hermeneutic phenomenological study. *Women Birth*. (2024) 37:348–54. doi: 10.1016/j.wombi.2023.11.004
- Zheng Q, Yin X, Liu L, Jevitt C, Dongmei F, Sun Y, et al. The influence of culture and spirituality on maternal grief following stillbirth in China: a

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declare that no Gen AI was used in the creation of this manuscript.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2025.1580039/full#supplementary-material>

qualitative study. *Int J Nurs Stud.* (2024) 160:104863. doi: 10.1016/j.ijnurstu.2024.104863

23. Azeez S, Obst KL, Due C, Oxlad M, Middleton P. Overwhelming and unjust: a qualitative study of fathers' experiences of grief following neonatal death. *Death Stud.* (2022) 46:1443–54. doi: 10.1080/07481187.2022.2030431
24. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol.* (2008) 8:45. doi: 10.1186/1471-2288-8-45
25. Lizcano Pabon LDM, Moreno Fergusson ME, Palacios AM. Experience of perinatal death from the father's perspective. *Nurs Res.* (2019) 68:E1–9. doi: 10.1097/NNR.0000000000000369
26. Kavanaugh K, Hershberger P. Perinatal loss in low-income African American parents. *J Obstet Gynecol Neonatal Nurs.* (2005) 34:595–605. doi: 10.1177/0884217505280000
27. Camacho-Ávila M, Fernández-Sola C, Jiménez-López FR, Granero-Molina J, Fernández-Medina IM, Martínez-Artero L, et al. Experience of parents who have suffered a perinatal death in two Spanish hospitals: a qualitative study. *BMC Pregnancy Childbirth.* (2019) 19:512. doi: 10.1186/s12884-019-2666-z
28. Sutan R, Miskam HM. Psychosocial impact of perinatal loss among Muslim women. *BMC Womens Health.* (2012) 12:15. doi: 10.1186/1472-6874-12-15
29. Downe S, Schmidt E, Kingdon C, Heazell AEP. Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. *BMJ Open.* (2013) 3:e002237. doi: 10.1136/bmjopen-2012-002237
30. Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, Coory M, et al. Stillbirths: recall to action in high-income countries. *Lancet.* (2016) 387:691–702. doi: 10.1016/S0140-6736(15)01020-X
31. Gordijn SJ, Erwich JJHM, Khong TY. Value of the perinatal autopsy: critique. *Pediatr Dev Pathol.* (2002) 5:480–8. doi: 10.1007/s10024-002-0008-y
32. Horey D, Flenady V, Conway L, McLeod E, Khong TY. Decision influences and aftermath: parents, stillbirth and autopsy. *Health Expect.* (2014) 17:534–44. doi: 10.1111/j.1369-7625.2012.00782.x
33. Paljevic ED. A transformative impact of theory in clinical practice: a study in a cardiogenetics clinic. *Res Theory Nurs Pract.* (2020) 34:129–43. doi: 10.1891/RTNP-D-19-00081
34. Fenstermacher KH. Enduring to gain new perspective: a grounded theory study of the experience of perinatal bereavement in Black adolescents. *Res Nurs Health.* (2014) 37:135–43. doi: 10.1002/nur.21583
35. Gozuyesil E, Manav AI, Yesilot SB, Sucu M. Grief and ruminative thought after perinatal loss among Turkish women: one-year cohort study. *Sao Paulo Med J.* (2022) 140:188–98. doi: 10.1590/1516-3180.2021.0148.R1.09062021
36. Kuforiji O, Mills TA, Lovell K. Women's experiences of care and support following perinatal death in high burden countries: a metasynthesis. *Women Birth.* (2023) 36:e195–202. doi: 10.1016/j.wombi.2022.07.170
37. Sands, Stillbirth and Neonatal Death Charity. (2023). Sands bereavement support book. Sands. Available online at: <https://www.sands.org.uk>
38. Neimeyer RA, Baldwin SA, Gillies J. Continuing bonds and reconstructing meaning: mitigating complications in bereavement. *Death Stud.* (2006) 30:715–38. doi: 10.1080/07481180600848322
39. Boyle FM, Horey D, Dean JH, Loughnan S, Ludski K, Mead J, et al. Stillbirth in Australia 5: making respectful care after stillbirth a reality: the quest for parent-centred care. *Women Birth.* (2020) 33:531–6. doi: 10.1016/j.wombi.2020.08.006
40. Finfgeld DL. Metasynthesis: the state of the art—so far. *Qual Health Res.* (2003) 13:893–904. doi: 10.1177/1049732303253462
41. Health Service Executive (HSE). *National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death [R/OL]*. (2022). Available online at: <https://pregnancyandinfantloss.ie/> (accessed June 9, 2025).
42. de Andrade Alvarenga W, deMontigny F, Zeghiche S, Verdon C, Nascimento LC. Experience of hope: an exploratory research with bereaved mothers following perinatal death. *Women Birth.* (2021) 34:e426–34. doi: 10.1016/j.wombi.2020.08.011
43. Schoonover KL, Prokop L, Lapid MI. Valuable informal bereavement support strategies for bereaved parents of stillborn, young children, and adult children: a scoping review. *J Palliat Care.* (2022) 37:381–400. doi: 10.1177/08258597211062762
44. O'Leary J, Thorwick C. Fathers' perspectives during pregnancy, postperinatal loss. *J Obstet Gynecol Neonatal Nurs.* (2006) 35:78–86. doi: 10.1111/j.1552-6909.2006.00017.x
45. Dursun P, Söylemez I. Posttraumatic growth: a comprehensive evaluation of the recently revised model. *Turk Psikiyatri Derg.* (2020) 31:57–68. doi: 10.5080/u23694
46. Klass D. Continuing conversation about continuing bonds. *Death Stud.* (2006) 30:843–58. doi: 10.1080/07481180600886959
47. Fenstermacher KH, Hupcey JE. Support for young black urban women after perinatal loss. *MCN Am J Matern Child Nurs.* (2019) 44:13–9. doi: 10.1097/NMC.0000000000000485
48. Boyle FM, Horey D, Middleton PF, Flenady V. Clinical practice guidelines for perinatal bereavement care - An overview. *Women Birth.* (2020) 33:107–10. doi: 10.1016/j.wombi.2019.01.008
49. Bonanno GA. Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? *Am Psychol.* (2004) 59:20–8. doi: 10.1037/0003-066X.59.1.20
50. Donegan G, Noonan M, Bradshaw C. Parents experiences of pregnancy following perinatal loss: an integrative review. *Midwifery.* (2023) 121:103673. doi: 10.1016/j.midw.2023.103673



OPEN ACCESS

EDITED BY

Toni P. Miles,
Rosalynn Carter Institute for Caregivers,
United States

REVIEWED BY

Mirjam Sophie Rueger,
Goethe University Frankfurt, Germany
Liliane D. Efinger,
University of Texas at San Antonio,
United States

*CORRESPONDENCE

Mette Kjærgaard Nielsen
✉ mette.k.nielsen@ph.au.dk

RECEIVED 28 April 2025

ACCEPTED 18 June 2025

PUBLISHED 25 July 2025

CORRECTED 30 October 2025

CITATION

Nielsen MK, Sparle Christensen K,
Neergaard MA, Bidstrup PE and Guldin M-B
(2025) Grief trajectories and long-term health
effects in bereaved relatives: a prospective,
population-based cohort study with ten-year
follow-up. *Front. Public Health* 13:1619730.
doi: 10.3389/fpubh.2025.1619730

COPYRIGHT

© 2025 Nielsen, Sparle Christensen,
Neergaard, Bidstrup and Guldin. This is an
open-access article distributed under the
terms of the [Creative Commons Attribution
License \(CC BY\)](https://creativecommons.org/licenses/by/4.0/). The use, distribution or
reproduction in other forums is permitted,
provided the original author(s) and the
copyright owner(s) are credited and that the
original publication in this journal is cited, in
accordance with accepted academic practice.
No use, distribution or reproduction is
permitted which does not comply with these
terms.

Grief trajectories and long-term health effects in bereaved relatives: a prospective, population-based cohort study with ten-year follow-up

Mette Kjærgaard Nielsen^{1*}, Kaj Sparle Christensen^{1,2},
Mette Asbjørn Neergaard^{3,4}, Pernille Envold Bidstrup⁵ and
Mai-Britt Guldin¹

¹Department of Mental Health, Research Unit for General Practice, Aarhus, Denmark, ²Department of Public Health, Aarhus University, Aarhus, Denmark, ³Section for Specialist Palliative Care, Department of Oncology, Aarhus University Hospital, Aarhus, Denmark, ⁴Department of Clinical Medicine, Aarhus University, Aarhus, Denmark, ⁵Psychological Aspects of Cancer, Danish Cancer Institute, Copenhagen, Denmark

Background: Bereavement may affect the health of relatives, causing increased use of health care services and increased mortality shortly after the patient's death. However, the long-term consequences for those with a high level of grief symptoms remain largely unexplored. We aimed to investigate associations between grief symptom trajectories and four long-term health outcomes among relatives bereaved by natural death: contacts to general practice and mental health services, use of psychotropic prescription medication, and mortality, over a period of 3–10 years post-bereavement.

Method: We assessed grief symptoms using the Prolonged Grief-13 scale in a cohort of 1,735 bereaved relatives at three different time points (prior to bereavement, 6 months after bereavement, and 3 years after bereavement) and identified five main grief trajectories. The trajectory with persistent low levels of grief symptoms in relatives [n=670 (45%)] was called the low grief trajectory (LGT) and was used as reference. The high grief trajectory (HGT) consisted of 107 (6%) relatives with persistent high grief symptom levels. We investigated associations between grief trajectories and (1) contacts to general practitioner (GP) including out-of-hours using negative binomial regression analysis, (2) contacts to mental health services (GP talk therapy, private-practice psychologist or psychiatrist), (3) use of psychotropic medications (antidepressants, anxiolytics and sedatives) using logistic regression analysis, and (4) mortality using Cox regression analysis. The follow-up period started at 3 years after bereavement and long-term outcome were further followed until 10 years after the patient's death.

Results: Relatives in the HGT had a significantly higher yearly incidence of GP contacts until seven years after bereavement compared to the LGT. The HGT was associated with higher use of mental health services [OR = 2.86 (95% CI 1.58; 5.19)], antidepressants [OR = 5.63 (95% CI 3.52; 9.01)], sedatives and anxiolytics [OR = 2.60 (95% CI 1.63; 4.14)], and excess mortality [HR = 1.88 (95% CI 1.1; 3.2)] compared to the LGT.

Conclusion: This study shows that patients with high and sustained grief symptoms have an increased healthcare use up to 10 years after loss. Future research should assess whether current health care services sufficiently meet the prolonged needs of these relatives.

KEYWORDS

grief, bereavement, relatives, general practice (GP), health care use, mortality, medication use, primary care

Introduction

The death of a close relative due to severe illness is a life-changing event for most people. According to the recently developed integrated process model of loss and grief, the death of a significant other is a multidimensional experience causing suffering and may contain both physical, emotional, cognitive, social, and spiritual dimensions (1). Bereavement may affect the mental and physical health, including development of depression and heart failure (2). Hence, the reactions to loss cause increased use of health care services and higher mortality of relatives immediately after the death of a close relative (3). Register-based studies have shown that bereaved relatives often have a higher use of psychologist sessions after bereavement (4), a higher risk of being hospitalized (4, 5), and being prescribed more psychotropic medication, such as antidepressants and sedatives, compared to their non-bereaved peers (4). However, we lack knowledge of whether the most vulnerable relatives use more health care services and whether there is an impact on their mortality in a long-term perspective.

A large amount of research has been conducted on Prolonged Grief Disorder in recent years and diagnostic criteria have been described (6). However, grief reactions that not necessarily meet these criteria may describe common reactions to loss and may affect the bereaved relative and their long-term reactions to bereavement. A few bereavement studies have included grief symptoms beyond the first year after the death of a close relative and have focused on the prevalence of grief symptoms (7–11). Between 2 and 20% of bereaved relatives experienced prolonged grief symptoms during the 5 years following bereavement (7–10). In a population-based sample, 1/3 of the population reported that they had experienced severe grief due to bereavement measured by a single question (11). Low socio-economic status, low self-reported health, higher symptoms of depression and anxiety and higher use of health care services were associated with more severe grief (11). This is in line with prior studies concerning predictors of adverse outcome (12, 13). The long-term impact on mental and physical health after bereavement was found to be affected, especially in those with limited social contact (14) and may impact the daily life of relatives for years.

Mortality in connection with bereavement has been investigated in register-based studies (15–17). Increased mortality risk has been found after sudden or traumatic bereavement, loss of a child, and prior mental health conditions such as depression (3, 15–17). Yet, reduced mortality has also been found in bereaved relatives (18, 19), and the authors draw attention to

benefits of caregiving as it may buffer the distress of relatives (the stress-buffering effect) (19).

Thus, bereavement has been shown to have a long-term impact on bereaved relatives (3, 15, 20). However, follow-up studies of long-term effects of bereavement have not included data on grief symptoms and short-term psychological reactions. As the reactions of bereaved relatives are heterogeneous (21), we need more knowledge on whether patterns of grief and psychological reactions may predict the long-term wellbeing and psychological consequences.

In a prior study, we examined the development of relative's grief symptoms based on the Prolonged Grief-13 Scale (22) by conducting grief trajectories from short time before to three years after the patient's death in a cohort of 1,735 relatives (23, 24). We identified five distinct grief trajectories that described common reactions to illness and loss. Two of the five trajectories showed minimal differences in symptom level at the three time points of measurements. The *high grief trajectory* (HGT) constituted a small group of 107 persons (6%) who had a consisting of high levels of persistent grief symptoms, whereas 670 persons (38%) had a *low grief trajectory* (LGT) of persistent low levels of grief symptoms (24). The remaining three common grief trajectories were between these extremes and had fluctuating symptom levels. In all, 310 (18%) had a high/decreasing grief trajectory (HDGT) and 526 (29%) had a moderate/decreasing grief trajectory (MDGT), and both of these trajectories had high/moderate symptom levels before the patient's death that decreased after death. The last grief trajectory constituted 122 (9%) who had a late grief trajectory (LaGT) with low levels of grief symptoms before death with a peak at 6 months after the patient's death (23, 24). At 6 months before the death of the patient, we found that the HGT group had more frequent contacts to the GP, more GP talk therapy, and more prescriptions of antidepressants and sedatives compared to the LGT group (24).

In the present study, we aimed to investigate associations between these grief trajectories and the long-term use of primary healthcare, prescription medication and mental health services, as well as mortality from 3 years up to 10-years after bereavement.

We hypothesized that individuals with high grief symptom levels, especially those in the HGT group, would have a higher use of health care services and higher use of psychotropic medications. The HGT group was vulnerable in prior studies regarding reactions to illness and bereavement and we hypothesized that this group would have a higher mortality compared to the LGT group.

Materials and methods

Study design and setting

The study is based on a prospective, population-based cohort established in Denmark in 2012 and followed to 2022. The Danish health care system is tax-funded. Services are free of charge for residents, and GPs serve as gate-keepers to secondary care, including palliative care and psychiatric services (22). However, 40% of the costs of psychotherapy by a psychologist is self-paid after referral from a GP (23). Seven GP talk therapy sessions are free of charge per year, and GPs attending peer supervision may provide 20-min sessions focusing on mental health issues (24).

Study population

In 2012, we obtained register-based information on all patients receiving drug reimbursement due to terminal illness, i.e. patients with a life-expectancy of only a few weeks or months (25). Weekly we sent letters to patients newly registered with drug reimbursement and asked for the patient's closest relative to complete the questionnaire (26). Enrolled relatives completed a questionnaire at the time of inclusion (T0), at 6 months after bereavement (T1), and at 3 years after bereavement (T2), and the outcome variables were followed in individual time periods for up to seven years after T2 (Figure 1). The study period ended December 31, 2022. Information regarding the relation to the patient (partner, adult child, other) was collected in the baseline questionnaire at T0.

Grief trajectory exposures

The Prolonged Grief-13 (PG-13) scale (22) was used to measure grief symptoms at T0, T1, and T2. At baseline (T0), we used an adapted version of the scale (26) including "loss" changed to "illness" to correspond to the time prior to the patient's death in line with prior studies (27).

We have previously identified five specific grief trajectories based on the PG-13 measures at T0, T1, T2 using a semi-parametric group-based trajectory model (GBTM) for repeated measurements (28, 29). Details of the method have been described elsewhere (23, 24).

Healthcare service, prescription medication and mortality outcomes

A unique personal registration number is granted to all Danish citizens. This number allows for linkage between individual-level records in Danish registers and the collected questionnaire data, which was processed at Statistics Denmark.

Contacts to general practice

GP contacts included total daytime contacts (face-to-face, prevention, talk therapy, phone, e-mail, and home visit), daytime

face-to-face consultations, and out-of-hours (OoH) initial contacts (phone and video contacts) obtained from the Danish National Health Service Register (30).

Psychotropic medication

The use of psychotropic medication was measured as registered prescriptions on antidepressants (N06A), sedatives/hypnotics (N05C), or anxiolytics (N05B) according to the Anatomical Therapeutic Chemical (ATC) Classification System obtained from The Danish National Prescription Registry (31).

Mental health services

Mental health services included GP talk therapy (no, yes), psychotherapy sessions with a private-practice psychologist (no, yes) or private-practice psychiatrist (no, yes) after referral from a GP. The categories (GP talk therapy, psychologist and psychiatrist) were merged due to low numbers in the categories (30). The data was retrieved from the Danish National Health Service Register (30).

Mortality

We identified bereaved relatives who had died during follow-up. Data on dates of death was retrieved from the Danish Registry of Causes of Deaths (32).

Covariates in adjusted analyses

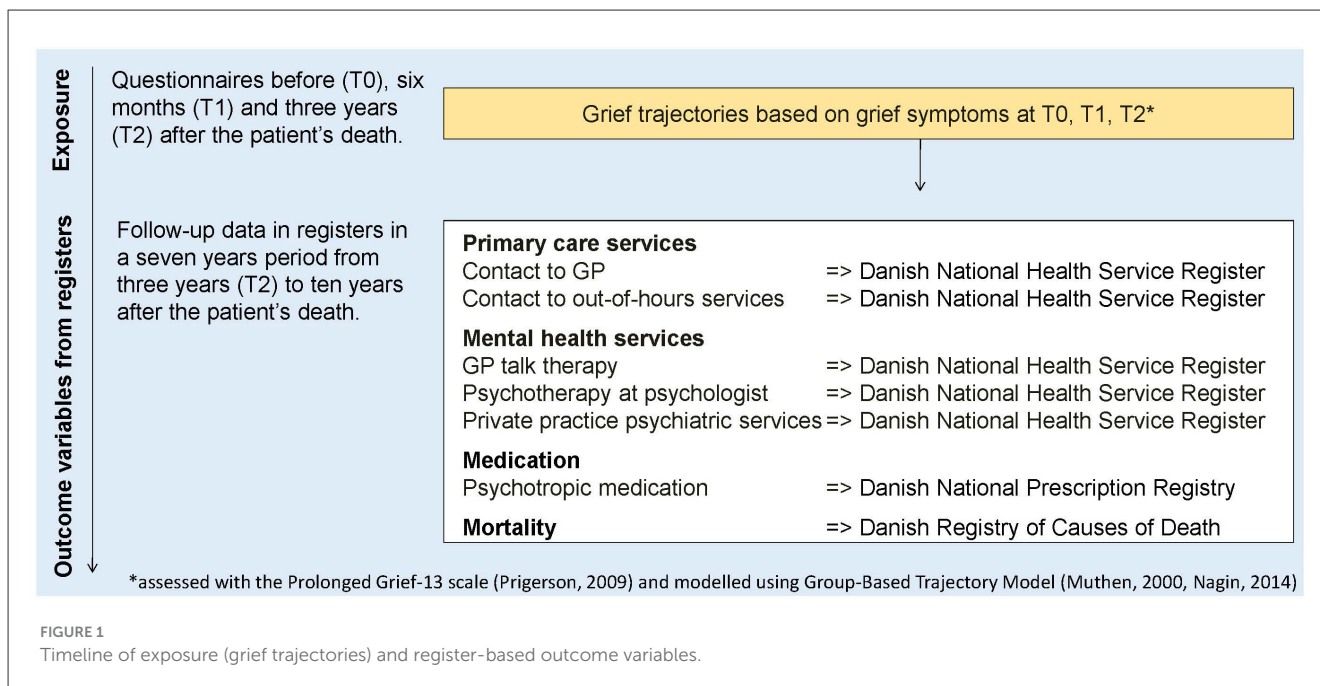
Information on the age of the relative, gender, educational level according to the UNESCO international standard of classification [low (≤ 10 years), intermediate (> 10 and ≤ 15 years), high (> 15 years)] (33). The Danish National Patient Registry (34) provided information of diagnoses registered in connection with a contact to a hospital, which allowed us to adjust for the presence of at least one of the somatic diseases in the Charlson Comorbidity Index (CCI) (35).

Statistical analysis

For all the analyses, we described the association between the five grief trajectories and outcome measures with those in the LGT as the reference group. Relatives contributed with at risk time up until date of death, date of emigration or December 31, 2022, whichever came first.

To examine the incidence rate ratios (IRRs) for GP contacts (daytime face-to-face and out-of-hours) according to grief trajectories (LGT as reference) we applied negative binomial regression analyses to account for overdispersion. Repeated yearly measurements were addressed using cluster robust variance estimation (36) and follow-up time was used as the offset. Cluster robust variance estimation was used to account for the repeated yearly measurements within each relative.

To examine the odds ratios (ORs) for the dichotomous outcomes mental health contacts and medicine use according to



grief trajectories (LGT as reference) we applied logistic regression models. The dichotomous outcomes of mental health contacts and medicine redemptions were analyzed using logistic regression models with follow-up time used as the offset.

Finally, to examine the hazard ratios (HRs) for death according to grief trajectories (LGT as reference) we applied Cox proportional hazards models with age chosen as the underlying time scale. The proportional hazards assumption was assessed graphically using log-minus-log plots and no apparent violation was observed.

The negative binomial regression models yielded incidence rate ratios (IRRs) of yearly GP contacts, the logistic regression models yielded odds ratios (ORs) of medication use and mental health services within the seven-year follow-up period, and the Cox proportional regression model yielded hazard ratios (HRs) of mortality. All regression models were adjusted for the a-priori chosen covariates of age, gender, personal relation to deceased, education and CCI. All estimates were presented with 95% confidence intervals (CIs) and ratio estimates were considered statistically significant if 1 was not included in the CI. All analyses were done using Stata 18 (StataCorp, Texas, USA).

Results

Study population

The study population of 1,735 persons included predominantly females (71%). In all, 1,138 were partners (66%), 476 (27%) were adult children and 121 (7%) had another relation to the patient. The mean age was 62 years, 449 (26%) had a low education and 17% had one or more comorbid diseases (CCI ≥ 1) (Table 1).

TABLE 1 Characteristics of the study cohort.

Characteristics of participants	Participants (n = 1,735)
Age, mean (CI*)	62.0 (61.5; 62.6)
Gender	
Male, n (%)	508 (29.3)
Female, n (%)	1,227 (70.7)
Relation	
Partner, n (%)	1,138 (65.6)
Children, n (%)	476 (27.4)
Other, n (%)	121 (7.0)
Educational level	
Low, n (%)	449 (25.9)
Intermediate, n (%)	828 (47.7)
High, n (%)	458 (26.4)
Comorbidity at baseline**	
No (CCI = 0), n (%)	1,326 (82.7)
Yes (CCI ≥ 1), n (%)	278 (17.3)

*CI, Confidence Interval.

**CCI, Charlson Comorbidity Index.

GP contacts during daytime and out-of-hours and associations with grief trajectories

Relatives in other GT groups than the reference group (LGT) had more GP contacts during the first years of follow-up and the difference seemed to level out toward 10 years of follow-up

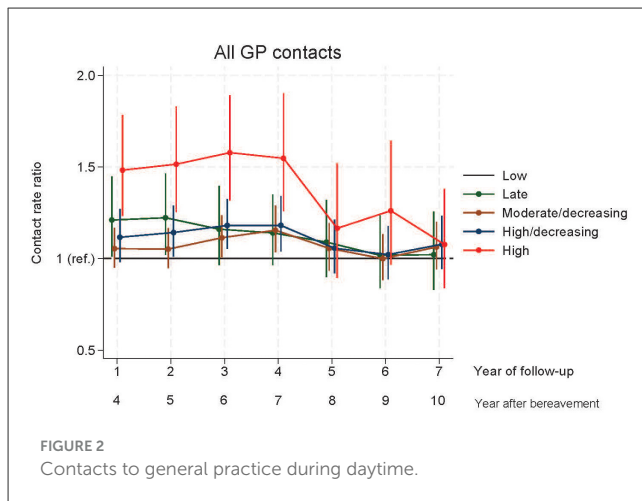


FIGURE 2
Contacts to general practice during daytime.

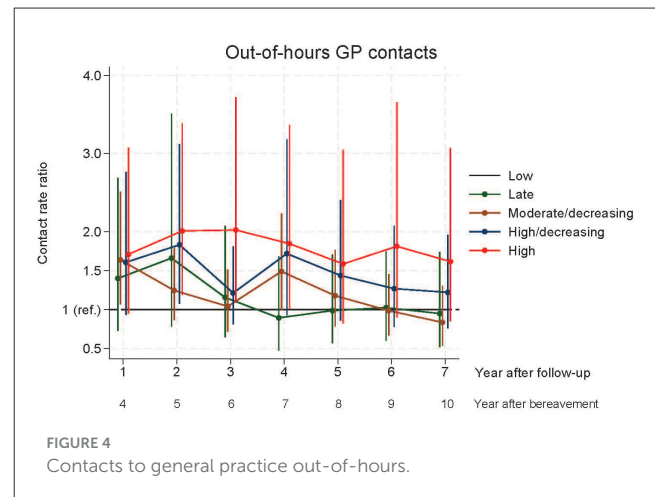


FIGURE 4
Contacts to general practice out-of-hours.

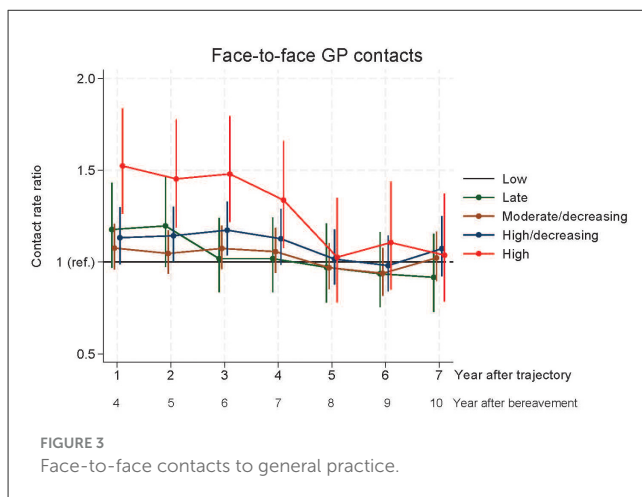


FIGURE 3
Face-to-face contacts to general practice.

(Figures 2, 3). Relatives in the LaGT had more overall contacts 4 and 5 years after bereavement, but no statistically significant excess face-to-face contacts compared to relatives in the LGT.

Relatives in the HDGT had significantly more total contacts in year five to seven and more face-to-face contacts in year six after bereavement, whereas those in the HGT had significantly more GP daytime contacts (face-to-face contact and total contacts) in year four to seven after bereavement compared to the LGT (Figures 2, 3). From year eight to ten after bereavement, no significant difference in contact pattern was found between any of the grief trajectories.

The pattern of initial contact with out-of-hours services showed that in year four after bereavement, the MDGT had significantly more contacts than the LGT, in year five the HDGT had more contacts and in year five and six, the HGT had significantly more contacts than the LGT (Figure 4).

Mental health services and psychotropic medication

In the adjusted logistic regression analysis, the HGT was associated with more mental health services [OR = 2.86 (95% CI:

1.58;5.19)], use of antidepressants [OR = 5.63 (95%CI: 3.52;9.01)] and anxiolytics and sedatives [OR = 2.60 (95%CI: 1.63;4.14)] compared to the LGT (Table 2).

Use of antidepressants was also higher in the LaGT [OR = 2.46 (95% CI: 1.53;3.97)] and HDGT [OR = 1.87 (95%CI: 1.29;2.70)] and use of anxiolytics and sedatives was higher in the HDGT [OR = 1.77 (95%CI: 1.26;2.48)] compared to the LGT (Table 2).

Mortality

In total, 186 (10.7%) died during 3–10 years after the patient's death, and the HGT was associated with mortality [HR = 1.88 (95% CI: 1.11; 3.21)] compared to the LGT. (Table 3).

Discussion

Compared to relatives with a persistent low level of grief symptoms, we found that the grief trajectory groups with higher levels of symptoms had more contact to GP, higher use of mental health care and medication and excess mortality. This was significant for relatives in the HGTs of persistent grief symptoms for all outcome, including contact to GP in the time period until seven years after bereavement. Furthermore, those in the HDGT had a higher use of medication and those in the LaGT had a higher use of antidepressants compared to the LGT.

Comparison with existing literature

Bereavement has consistently been associated with increased use of health care and psychotropic medication (4, 5, 18). The present study establishes that individuals most likely to receive excess health care services beyond 3 years after bereavement were those with high levels of persistent grief symptoms. The long-term findings regarding health care are likely to be impacted by events such as illness of the relative or other losses during the ten-year period after the patient's death. However, such events may also impact the other grief trajectory groups.

TABLE 2 Associations between grief trajectories and use of mental health care and medication.

<i>N</i> = 1,735	Number of events (<i>n</i>)	Follow up years	Adjusted OR ^a	95% CI
Contact to mental health services^{bc}				
Low grief trajectory (<i>n</i> = 670)	71	4,536	1	-
Late grief trajectory (<i>n</i> = 122)	14	798	1.37	0.72; 2.6
Moderate/decreasing grief trajectory (<i>n</i> = 526)	60	3,510	1.18	0.81;1.74
High/decreasing grief trajectory (<i>n</i> = 310)	41	2,072	1.47	0.94; 2.30
High grief trajectory (<i>n</i> = 107)	20	676	2.86	1.58;5.19
Psychotropic medication^b				
Antidepressants				
Low grief trajectory (<i>n</i> = 670)	92	4,536	1	-
Late grief trajectory (<i>n</i> = 122)	35	798	2.46	1.53;3.97
Moderate/decreasing grief trajectory (<i>n</i> = 526)	77	3,510	1.04	0.74; 1.46
High/decreasing grief trajectory (<i>n</i> = 310)	74	2,072	1.87	1.29; 2.70
High grief trajectory (<i>n</i> = 107)	52	676	5.63	3.52; 9.01
Anxiolytics and sedatives^b				
Low grief trajectory (<i>n</i> = 670)	123	4,536	1	-
Late grief trajectory (<i>n</i> = 122)	33	798	1.59	0.99; 2.54
Moderate/decreasing grief trajectory (<i>n</i> = 526)	95	3,510	0.94	0.69;1.28
High/decreasing grief trajectory (<i>n</i> = 310)	91	2,072	1.77	1.26;2.48
High grief trajectory (<i>n</i> = 107)	41	676	2.60	1.63; 4.14

^a Age, gender, personal relation, education, Charlson Comorbidity Index.

^b According to an adjusted^a logistic regression model with the low grief trajectory as reference.

^c GP talk therapy and/or sessions at private-practice psychologist or psychiatrist.

TABLE 3 Associations between grief trajectories and mortality.

<i>N</i> = 1,735	Number of deaths	% of trajectory group	Follow up years	Adjusted HR ^a	95% CI
Mortality^b					
Total	186	10.7			
Low grief trajectory (<i>n</i> = 670)	49	7.3	4,536	1	-
Late grief trajectory (<i>n</i> = 122)	19	15.6	798	1.25	0.70; 2.20
Moderate/decreasing grief trajectory (<i>n</i> = 526)	54	10.3	3,510	1.20	0.80;1.80
High/decreasing grief trajectory (<i>n</i> = 310)	41	13.2	2,072	1.51	0.98; 2.33
High grief trajectory (<i>n</i> = 107)	23	21.5	676	1.88	1.11;3.21

^a Age, gender, personal relation, education, Charlson Comorbidity Index.

^b According to an adjusted^a Cox regression model with the low grief trajectory as reference.

A prior study of health care use before bereavement showed that the HGT was associated with more contacts to GP, medication use, and use of mental health services (24). The relatives in the HGT may have predisposing vulnerabilities and challenges and that severe illness and bereavement pose a high level of distress that they find difficult to handle. Furthermore, relatives with HGT had a lower educational level for both spouses and adult children of the ill person (23). Hence, prior mental health conditions and low educational level are risk factors for long-term psychological distress in bereaved relatives. Nevertheless, the findings of the

present study may be connected with confounding by indication as the persons in the HGT had higher health care use prior to bereavement, but the findings underline that relatives in the HGT are persons who are likely to need additional support from the health care system.

The contact pattern to out-of-hours GP services was diverging. These services are intended for acute situations and available free of charge to all citizens in Denmark (37). Hence, it is at first sight encouraging that persistent grief symptoms may not significantly affect the long-term use of these services as this could indicate

that the supportive services provided during daytime sufficiently support the relatives. However, the connection between daytime consultation and out-of-hours use may be complex and those with need for mental health support might call helplines for mental health. A recent study showed that the use of out-of-hours GP services among citizens above 75 years of age was not lower if the patient had more daytime consultations in general practice (38), and personal characteristics rather than organizational factors were suggested to affect the use of out-of-hours GP services. Hence, out-of-hours contact may not be relevant health care for the participants.

Regarding psychotropic medication, the use of antidepressant and anxiolytics and sedatives was significantly higher in the HDGT and HGT than in the LGT. Approximately 18% used psychotropic medication in the first year after bereavement (39). Our results indicate that early grief patterns may predict health care use is a new finding that extends prior knowledge of higher medication use in bereaved compared to non-bereaved (4, 18). Hence, a specific group of relatives may be recognizable for intervention, especially as the HGT has been found to be associated with higher medication use already before bereavement (24).

We found that relatives with HGT had a higher use of any mental health service after bereavement. Hence, the available services seem to be directed at those with the most severe symptoms. However, the persistent need for mental health service over a long-term period could indicate that the existing interventions may not be sufficient to address the needs of bereaved relatives. Also, the vulnerability of the relatives in the HGT group may also be related to prior health and mental health conditions contributing to their need for individually adapted mental health services.

Talk therapy sessions with the GP and private-practice psychologists early in the bereavement period have been found to reduce the risk of suicide, deliberate self-harm, and reduce psychiatric hospitalization in bereaved persons (40). The HGT was associated with GP talk therapy but not psychotherapy by a psychologist among relatives *before* the death (24). Thus, general practice holds an important task to support those in the HGT, who are more likely to have a low educational level and may not have the economic or mental resources to attend therapy with a psychologist. In recent years, more attention has been drawn at relatives and new knowledge has emerged to inform health professionals, including a supportive intervention in general practice using a dialogue questionnaire (41) and the integrated process model of loss and grief to support the understanding of grief in general (1).

We found that relatives with HGT had a higher mortality compared to relatives with LGT. Previous studies did not compare mortality according to symptoms levels, but excess mortality has been found for bereaved compared to non-bereaved persons in most (3, 17), but not all previous studies (18). Bereaved relatives constitute a heterogeneous group with different risk factors for experiencing adverse bereavement outcomes (3). Caregiving for a close relative have been suggested to buffer the stress reaction in relatives (19). However, if the relative suffers from distress due to their own physical illness this may add to their vulnerability and grief symptoms. Development of persistent high grief symptoms

may be due to several risk factors, and our findings support that comorbidity is likely to play an important role as an intrapersonal risk factor for bereavement outcome (12).

Strengths and limitations

The main advantages of the current study are the follow-up time of 10 years, the longitudinal study design of grief symptom assessment at three time points in 1,735 relatives, and the combination with valid register data on health care services. The Danish registers are considered almost complete, and the data can be linked precisely (42). We used grief trajectories based on repeated grief measurements as exposure, which can be considered a strength as persistent grief reactions were included. The association between having persistent high levels of grief symptoms and higher use of health care services may be considered to be confounding by indication as those in the exposure group HGT with the highest symptom level may have an a priori higher use of health care due to symptoms.

The study was limited by the number of participants and thus lacked power to investigate for instance the different types of mental health services. Also, the follow-up of 10 years may be seen as a limitation to reveal long-term impacts of bereavement on mortality. The study included no comparison group from the background population, which was a limitation. Beyond seven years of bereavement, the association of higher use of primary health care in the HGT seemed to level out. This may indicate that the impact of bereavement diminishes over time. However, it could also be due to the group size as a small group of relatives in the HGT could potentially have had many contacts and this effect would diminish if they had died during follow-up.

The study population was younger and had a higher educational level than non-participants (18, 23). As those with high education may have lower symptom levels, the prevalence of high grief symptoms might have been underestimated in the present study. Still, we believe that the results may be generalizable to bereaved relatives in Denmark and in countries with similar health care systems.

Clinical implications

Despite increased use of health care, including mental health services, those in the HGT had a persistently high level of symptoms. Also, the higher use of medication in the group may indicate a need for further intervention. Bereavement support has been shown to benefit symptomatic persons with psychological distress and need of intervention (43). These findings highlight the importance of identifying those at risk as it may allow for timely intervention, including referral to extended mental health services. For instance, the relatives' symptom levels and needs for support could be systematically assessed by health professionals in primary and secondary care, preferably already before the patient's death.

Individuals with elevated grief symptoms were more likely to engage with general practice in the present study. In contrast, a previous study in the US found that relatives with a high

grief symptom level underutilized healthcare measured as contacts to the health care system (44). These differences suggest that in settings with universal healthcare access, the opportunity for contact with vulnerable relatives may be better. Hence, this enables health professionals to proactively plan a follow-up appointment regarding mental health symptoms.

Future research

To mitigate adverse bereavement reactions, further studies are needed to explore the effects and implementation of targeted intervention in primary care. Such studies should focus on individuals at risk of complications or showing symptoms of distress, such as intensive levels of grief (43). Supportive interventions in general practice starting before bereavement needs further implementation (45), and online interventions show promising results for further implementation to address the increasing demand for mental health support (46). Additionally, we need to further explore the pathways of shared care between health care sectors and the availability of mental health services for bereaved relatives in primary and secondary care and improve collaboration and implementation of evidence-based interventions.

Conclusion

In this follow-up study, we found that relatives with persistently high grief symptoms had more frequent contact with primary care up to seven years after bereavement and higher use of psychotropic medication, mental health services and mortality for at least 10 years after bereavement.

These results extend our earlier findings, showing that relatives in the HGT are vulnerable and already have higher primary care use before the patient's death. Moreover, despite seeking mental health care, these relatives continue to use more medication. Thus, the existing interventions may not be sufficient since this group seems to need long-term support. The present findings highlight the need for targeted interventions of long-term support, particularly in primary care, to adequately address the needs of this high-risk group of bereaved relatives.

Data availability statement

The datasets presented in this article are not readily available because of GDPR. Requests to access the datasets should be directed to the first author.

Ethics statement

The studies involving humans were approved by the Committee on Health Research Ethics of the Central Denmark Region. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MKN: Investigation, Writing – review & editing, Conceptualization, Methodology, Resources, Funding acquisition, Visualization, Project administration, Validation, Formal analysis, Data curation, Writing – original draft. KS: Writing – review & editing, Funding acquisition, Supervision, Conceptualization, Project administration, Validation, Methodology. MAN: Project administration, Funding acquisition, Writing – review & editing, Methodology, Formal analysis, Validation, Resources, Visualization, Investigation, Conceptualization, Supervision, Data curation. PB: Visualization, Formal analysis, Resources, Data curation, Validation, Methodology, Supervision, Investigation, Conceptualization, Funding acquisition, Writing – review & editing. M-BG: Formal analysis, Writing – review & editing, Supervision, Methodology, Investigation, Visualization, Data curation, Conceptualization, Validation, Funding acquisition, Resources.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. This work was supported by the Novo Nordisk Foundation (grant no. NNF17OC0024410) and the Danish Cancer Society (grant no. R160-A10389-16-S3).

Acknowledgments

We wish to extend our profound gratitude to patients and relatives who participated in this study. Thanks to the staff at the Research Unit for General Practice, Aarhus, Denmark, in particular Henrik Schou Pedersen for data management and choice of statistical analyses, data manager Kaare Rud Flarup, and language editor Lone Niedziella. Furthermore, the authors thank statistician Anders Helles Carlsen, Aarhus University Hospital—Psychiatry, Denmark, for his work on grief trajectories.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Correction note

A correction has been made to this article. Details can be found at: [10.3389/fpubh.2025.1678380](https://doi.org/10.3389/fpubh.2025.1678380).

Generative AI statement

The author(s) declare that no Gen AI was used in the creation of this manuscript.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated

organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

References

- Guldin MB, Leget C. The integrated process model of loss and grief - An interprofessional understanding. *Death Stud.* (2023) 48:738–52. doi: 10.1080/07481187.2023.2272960
- Shear MK. Complicated grief. *N Engl J Med.* (2015) 372:153–60. doi: 10.1056/NEJMcp1315618
- Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. *Lancet.* (2007) 370:1960–73. doi: 10.1016/S0140-6736(07)61816-9
- Guldin MB, Jensen AB, Zachariae R, Vedsted P. Healthcare utilization of bereaved relatives of patients who died from cancer a national population-based study. *Psycho-Oncology.* (2013) 22:1152–8. doi: 10.1002/pon.3120
- Miles TP, Allegra JC, Ezeamama A, Simpson C, Gerst-Emerson K, Elkins J, et al. In a longevity society, loss and grief are emerging risk factors for health care use: findings from the health and retirement survey cohort aged 50 to 70 years. *Am J Hosp Palliat Care.* (2016) 33:41–6. doi: 10.1177/1049909114552125
- Simon NM, Shear MK. Prolonged grief disorder. *N Engl J Med.* (2024) 391:1227–36. doi: 10.1056/NEJMcp2308707
- Tsai WI, Prigerson HG, Li CY, Chou WC, Kuo SC, Tang ST, et al. Longitudinal changes and predictors of prolonged grief for bereaved family caregivers over the first 2 years after the terminally ill cancer patient's death. *Palliat MedZ.* (2016) 30:495–503. doi: 10.1177/0269216315603261
- Zordan RD, Bell ML, Price M, Remedios C, Lobb E, Hall C, et al. Long-Term prevalence and predictors of prolonged grief disorder amongst bereaved cancer caregivers: A cohort study. *Palliat Support Care.* (2019) 17:507–14. doi: 10.1017/S1478951518001013
- Guldin MB, Vedsted P, Zachariae R, Olesen F, Jensen AB. Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: a longitudinal cohort study. *Support Care Cancer.* (2012) 20:1679–85. doi: 10.1007/s00520-011-1260-3
- Kim Y, Lucette A, Loscalzo M. Bereavement needs of adults, children, and families after cancer. *Psycho-Oncology.* (2013) 19:444–57. doi: 10.1097/PP0.0b013e3182a5babe
- Thimm JC, Kristoffersen AE, Ringberg U. The prevalence of severe grief reactions after bereavement and their associations with mental health, physical health, and health service utilization: a population-based study. *Eur J Psychotraumatol.* (2020) 11:1844440. doi: 10.1080/20008198.2020.1844440
- Stroebe MS, Folkman S, Hansson RO, Schut H. The prediction of bereavement outcome: development of an integrative risk factor framework. *Soc Sci Med.* (2006) 63:2440–51. doi: 10.1016/j.socscimed.2006.06.012
- Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin MB, et al. Predictors of complicated grief and depression in bereaved caregivers: a nationwide prospective cohort study. *J Pain Symptom Manage.* (2016) 53:540–50. doi: 10.1016/j.jpainsymman.2016.09.013
- Liu WM, Forbat L, Anderson K. Death of a close friend: Short and long-term impacts on physical, psychological and social well-being. *PLoS ONE.* (2019) 14:1–17. doi: 10.1371/journal.pone.0218026
- Moon JR, Kondo N, Glymour MM, Subramanian SV. Widowhood and mortality: A meta-analysis. *PLoS ONE.* (2011) 6:e0023465. doi: 10.1371/journal.pone.0023465
- Prior A, Fenger-Gron M, Davydow DS, Olsen J, Li J, Guldin MB, et al. Bereavement, multimorbidity and mortality: a population-based study using bereavement as an indicator of mental stress. *Psychol Med.* (2017) 48:1437–43. doi: 10.1017/S0033291717002380
- Moller J, Bjorkenstam E, Ljung R, Yngwe MA. Widowhood and the risk of psychiatric care, psychotropic medication and all-cause mortality: a cohort study of 658,022 elderly people in Sweden. *Aging Ment Health.* (2011) 15:259–66. doi: 10.1080/13607863.2010.513041
- King M, Vasanthan M, Petersen I, Jones L, Marston L, Nazareth I, et al. Mortality and medical care after bereavement: a general practice cohort study. *PLoS ONE.* (2013) 8:e52561. doi: 10.1371/journal.pone.0052561
- Roth DL, Brown SL, Rhodes JD, Haley WE. Reduced mortality rates among caregivers: Does family caregiving provide a stress-buffering effect? *Psychol Aging.* (2018) 33:619–29. doi: 10.1037/pag0000224
- Guldin MB, Kjaersgaard MIS, Fenger-Gron M, Parner ET, Li J, Prior A, et al. Risk of suicide, deliberate self-harm and psychiatric illness after the loss of a close relative: a nationwide cohort study. *World Psychiatry.* (2017) 16:193–9. doi: 10.1002/wps.20422
- Bonanno GA, Burton CL. Regulatory flexibility: an individual differences perspective on coping and emotion regulation. *Perspect Psychol Sci.* (2013) 8:591–612. doi: 10.1177/1745691613504116
- Prigerson HG, Horowitz MJ, Jacobs SC, Parkes CM, Aslan M, Goodkin K, et al. Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Med.* (2009) 6:e1000121. doi: 10.1371/journal.pmed.1000121
- Nielsen MK, Carlsen AH, Neergaard MA, Bidstrup PE, Guldin M-B. Looking beyond the mean in grief trajectories: a prospective, population-based cohort study. *Soc Sci Med.* (2019) 232:460–9. doi: 10.1016/j.socscimed.2018.10.007
- Nielsen MK, Christensen KS, Neergaard MA, Bidstrup PE, Guldin M-B. Grief symptoms and primary care use: a prospective study of family caregivers. *BJGP Open.* (2020) 11:537674. doi: 10.3389/fpsy.2020.537674
- Danish Medicines Agency. *The Number of Applications for Individual Drug Reimbursement in 2011.* Copenhagen: The Danish Medicines Agency, the Ministry of Interior and Health (2012). Available online at: <https://laegemiddelstyrelsen.dk/en/reimbursement/individual-reimbursement/reimbursement-for-the-terminally-ill/>
- Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin MB. Psychological distress, health, and socio-economic factors in caregivers of terminally ill patients: a nationwide population-based cohort study. *Support Care Cancer.* (2016) 24:3057–67. doi: 10.1007/s00520-016-3120-7
- Thomas K, Hudson P, Trauer T, Remedios C, Clarke D. Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in palliative care: a longitudinal study. *J Pain Symptom Manage.* (2014) 47:531–41. doi: 10.1016/j.jpainsymman.2013.05.022
- Muthen B, Muthen LK. Integrating person-centered and variable-centered analyses: growth mixture modeling with latent trajectory classes. *Alcohol Clin Exp Res.* (2000) 24:882–91. doi: 10.1111/j.1530-0277.2000.tb02070.x
- Nagin DS. Group-based trajectory modeling: an overview. *Ann Nutr Metab.* (2014) 65:205–10. doi: 10.1159/000360229
- Sahl Andersen J, De Fine Olivarius N, Krasnik A. The Danish national health service register. *Scand J Public Health.* (2011) 39:34–7. doi: 10.1177/1403494810394718
- Wallach Kildemoes H, Toft Sorensen H, Hallas J. The Danish national prescription registry. *Scand J Public Health.* (2011) 39:38–41. doi: 10.1177/1403494810394717
- Helweg-Larsen K. The Danish register of causes of death. *Scand J Public Health.* (2011) 39:26–9. doi: 10.1177/1403494811399958
- UNESCO. *ISCED: International Standard Classification of Education, 2012.* Montreal, QC: UNESCO Institute for Statistics (2012).
- Lynge E, Sandegaard JL, Rebolj M. The Danish National patient register. *Scand J Public Health.* (2011) 39:30–3. doi: 10.1177/1403494811401482
- Thygesen SK, Christiansen CF, Christensen S, Lash TL, Sorensen HT. The predictive value of ICD-10 diagnostic coding used to assess Charlson comorbidity index conditions in the population-based Danish National Registry of Patients. *BMC Med Res Methodol.* (2011) 11:83. doi: 10.1186/1471-2288-11-83
- Williams RL. A note on robust variance estimation for cluster-correlated data. *Biometrics* (2000) 56:645–6. doi: 10.1111/j.0006-341X.2000.00645.x
- Sovsø MB, Laust TJ, Erika FC, Karmark IK, Fredrik F, Backer MC, et al. Reorganization of the Danish out-of-hours primary care - a descriptive study. *Scand J Primary Health Care.* 20:1–10. doi: 10.1080/02813432.2025.2490915
- Olsen JK, Wehberg S, Waldorff FB, Henriksen DP, Lykkegaard J. General practice consultations patterns and patient factors predicting older patients' out-of-hours services. *Br J General Pract.* (2025). doi: 10.3399/BJGP.2024.0798. [Epub ahead of print].

39. Shah SM, Carey IM, Harris T, DeWilde S, Victor CR, Cook DG, et al. Initiation of psychotropic medication after partner bereavement: a matched cohort study. *PLoS ONE*. (2013) 8:e77734. doi: 10.1371/journal.pone.0077734
40. Fenger-Grøn M, Kjaersgaard MIS, Parner ET, Guldin M-B, Vedsted P, Vestergaard M, et al. Early treatment with talk therapy or antidepressants in severely bereaved people and risk of suicidal behavior and psychiatric illness: an instrumental variable analysis. *Clin Epidemiol*. (2018) 10:1013–26. doi: 10.2147/CLEP.S157996
41. Mygind A, Offersen SMH, Guldin M-B, Christensen KS, Nielsen MK. How to support caregivers in general practice: development of the Caregiver Care Model. *Palliat Care Soc Pract*. (2024) 18:26323524241272103. doi: 10.1177/26323524241272103
42. Schmidt M, Schmidt S, Adelborg K, Sundbøll J, Laugesen K, Ehrenstein V, et al. The Danish health care system and epidemiological research: from health care contacts to database records. *Clin Epidemiol*. (2019) 11:563–91. doi: 10.2147/CLEP.S179083
43. Wittouck C, Autreve SV, Jaegere ED, Portzky G, van Heeringen K. The prevention and treatment of complicated grief: a meta-analysis. *Clin Psychol Rev*. (2011) 31:69–78. doi: 10.1016/j.cpr.2010.09.005
44. Lichtenthal WG, Nilsson M, Kissane DW, Breitbart W, Kacel E, Jones EC, et al. Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatr Serv*. (2011) 62:1225–9. doi: 10.1176/ps.62.10.pss6210_1225
45. Nielsen MK, Vinther MC, Guldin M-B, Christensen KS, Mygind A. Implementation and acceptability of the Caregiver Care Model in general practice: a mixed-method feasibility study. *BMC Primary Care*. (2025) 26:142. doi: 10.1186/s12875-025-02833-x
46. van Velsen L, Lotte S, Eva S, Gloria-Mona K, Lena B, Bettina M, et al. Development of an online service for coping with spousal loss by means of human-centered and stakeholder-inclusive design: the case of LEAVES. *Death Stud*. (2024) 48:187–96. doi: 10.1080/07481187.2023.2203680



OPEN ACCESS

EDITED AND REVIEWED BY
Toni P. Miles,
Carter Center, United States

*CORRESPONDENCE
Mette Kjærgaard Nielsen
✉ mette.k.nielsen@ph.au.dk

RECEIVED 02 August 2025
ACCEPTED 16 October 2025
PUBLISHED 30 October 2025

CITATION
Nielsen MK, Sparle Christensen K,
Neergaard MA, Bidstrup PE and Guldin M-B
(2025) Correction: Grief trajectories and
long-term health effects in bereaved relatives:
a prospective, population-based cohort study
with ten-year follow-up.
Front. Public Health 13:1678380.
doi: 10.3389/fpubh.2025.1678380

COPYRIGHT
© 2025 Nielsen, Sparle Christensen,
Neergaard, Bidstrup and Guldin. This is an
open-access article distributed under the
terms of the [Creative Commons Attribution
License \(CC BY\)](https://creativecommons.org/licenses/by/4.0/). The use, distribution or
reproduction in other forums is permitted,
provided the original author(s) and the
copyright owner(s) are credited and that the
original publication in this journal is cited, in
accordance with accepted academic practice.
No use, distribution or reproduction is
permitted which does not comply with these
terms.

Correction: Grief trajectories and long-term health effects in bereaved relatives: a prospective, population-based cohort study with ten-year follow-up

Mette Kjærgaard Nielsen^{1*}, Kaj Sparle Christensen^{1,2},
Mette Asbjoern Neergaard^{3,4}, Pernille Envold Bidstrup⁵ and
Mai-Britt Guldin¹

¹Department of Mental Health, Research Unit for General Practice, Aarhus, Denmark, ²Department of Public Health, Aarhus University, Aarhus, Denmark, ³Section for Specialist Palliative Care, Department of Oncology, Aarhus University Hospital, Aarhus, Denmark, ⁴Department of Clinical Medicine, Aarhus University, Aarhus, Denmark, ⁵Psychological Aspects of Cancer, Danish Cancer Institute, Copenhagen, Denmark

KEYWORDS

grief, bereavement, relatives, general practice (GP), health care use, mortality, medication use, primary care

A Correction on

[Grief trajectories and long-term health effects in bereaved relatives: a prospective, population-based cohort study with ten-year follow-up](#)

by Nielsen, M. K., Sparle Christensen, K., Neergaard, M. A., Bidstrup, P. E., and Guldin, M.-B. (2025). *Front. Public Health* 13:1619730. doi: 10.3389/fpubh.2025.1619730

Author Henrik Schou Pedersen was erroneously included as an author in the published article. The correct author list reads: **Mette Kjærgaard Nielsen, Kaj Sparle Christensen, Mette Asbjoern Neergaard, Pernille Envold Bidstrup, and Mai-Britt Guldin.**

The Author Contributions Statement has been corrected to read:

“MKN: Investigation, Writing – review & editing, Conceptualization, Methodology, Resources, Funding acquisition, Visualization, Project administration, Validation, Formal analysis, Data curation, Writing – original draft. KS: Writing – review & editing, Funding acquisition, Supervision, Conceptualization, Project administration, Validation, Methodology. MAN: Project administration, Funding acquisition, Writing – review & editing, Methodology, Formal analysis, Validation, Resources, Visualization, Investigation, Conceptualization, Supervision, Data curation. PB: Visualization, Formal analysis, Resources, Data curation, Validation, Methodology, Supervision, Investigation, Conceptualization, Funding acquisition, Writing – review & editing. M-BG: Formal analysis, Writing – review & editing, Supervision, Methodology, Investigation, Visualization, Data curation, Conceptualization, Validation, Funding acquisition, Resources.”

The acknowledgments has been updated to acknowledge Henrik Schou Pedersen. The corrected Acknowledgments appears below:

“We wish to extend our profound gratitude to patients and relatives who participated in this study. Thanks to the staff at the Research Unit for General Practice, Aarhus, Denmark, in particular Henrik Schou Pedersen for data management and choice of statistical analyses, data manager Kaare Rud Flarup, and language editor Lone Niedziella. Furthermore, the authors thank statistician Anders Helles Carlsen, Aarhus University Hospital—Psychiatry, Denmark, for his work on grief trajectories.”

In the published article, there were errors in the notation of the odds ratios and hazard ratios.

In the **Abstract**, paragraph Results, the sentence previously read:

“The HGT was associated with higher use of mental health services [OR = 2.86 (95% CI 1.58; 5.19)], antidepressants [OR = 5.63 (95% CI 3.52; 9.01)], sedatives and anxiolytics [OR = 2.60 (95% CI 1.63; 4.14)], and excess mortality [OR = 1.88 (95% CI 1.1; 3.2)] compared to the LGT.”

The corrected sentence appears below:

“The HGT was associated with higher use of mental health services [OR = 2.86 (95% CI 1.58; 5.19)], antidepressants [OR = 5.63 (95% CI 3.52; 9.01)], sedatives and anxiolytics [OR = 2.60 (95% CI 1.63; 4.14)], and excess mortality [HR = 1.88 (95% CI 1.1; 3.2)] compared to the LGT.”

A correction has been made to the section **Materials and methods**, *Statistical analysis*, paragraph 5.

The sentence previously read:

“All estimates were presented with 95% confidence intervals (CIs) and ORs were considered

statistically significant if 1 was not included in the CI.”

This has been corrected to read:

“All estimates were presented with 95% confidence intervals (CIs) and ratio estimates were considered statistically significant if 1 was not included in the CI.”

A correction has been made to the section **Results**, *Mortality*, paragraph 1.

The sentence previously read:

“In total, 186 (10.7%) died during 3–10 years after the patient’s death, and the HGT was associated with mortality [OR = 1.88(95%CI: 1.11;3.21)] compared to the LGT (Table 3).”

This has been corrected to read:

“In total, 186 (10.7%) died during 3–10 years after the patient’s death, and the HGT was associated with mortality [HR = 1.88 (95% CI: 1.11; 3.21)] compared to the LGT (Table 3).”

The original article has been updated.

Publisher’s note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.



OPEN ACCESS

EDITED BY

Toni P. Miles,
Rosalynn Carter Institute for Caregivers,
United States

REVIEWED BY

Stephanie Smith,
Curtin University, Australia

*CORRESPONDENCE

Martin Nagl-Cupal
✉ martin.nagl-cupal@univie.ac.at

[†]These authors have contributed equally to this work

RECEIVED 29 April 2025

ACCEPTED 21 August 2025

PUBLISHED 05 September 2025

CITATION

Schwind B, Visscher R, Haslbeck J, Falkenstein T, Riewoldt C, Griese L, Behrisch B, Metzting S and Nagl-Cupal M (2025) Understanding family caregiving and well-being in adult chronic illness: a call for a more comprehensive perspective. *Front. Public Health* 13:1619672. doi: 10.3389/fpubh.2025.1619672

COPYRIGHT

© 2025 Schwind, Visscher, Haslbeck, Falkenstein, Riewoldt, Griese, Behrisch, Metzting and Nagl-Cupal. This is an open-access article distributed under the terms of the [Creative Commons Attribution License \(CC BY\)](https://creativecommons.org/licenses/by/4.0/). The use, distribution or reproduction in other forums is permitted, provided the original author(s) and the copyright owner(s) are credited and that the original publication in this journal is cited, in accordance with accepted academic practice. No use, distribution or reproduction is permitted which does not comply with these terms.

Understanding family caregiving and well-being in adult chronic illness: a call for a more comprehensive perspective

Bettina Schwind^{1†}, Rosa Visscher^{1,2†}, Jörg Haslbeck¹, Thomas Falkenstein³, Christina Riewoldt^{4,5}, Lennert Griese⁶, Birgit Behrisch⁷, Sabine Metzting⁴ and Martin Nagl-Cupal^{3*}

¹Careum School of Health, Kalaidos University of Applied Sciences, Zurich, Switzerland, ²Department of Medicine, Chair of Public Health and Health Services Research, Institute for Medical Information Processing, Biometry, and Epidemiology, LMU Munich, Munich, Germany, ³Department of Nursing Science, Faculty of Social Sciences, University of Vienna, Vienna, Austria, ⁴School of Nursing Sciences, Witten/Herdecke University, Witten, Germany, ⁵Fließner Fachhochschule, University of Applied Sciences, Düsseldorf, Germany, ⁶School of Public Health, Bielefeld University, Bielefeld, Germany, ⁷Catholic University of Applied Social Sciences, Berlin, Germany

The rising burden of chronic illness, driven by increased life expectancy and an aging population, has amplified the demand for family caregiving and research thereof to assure the well-being of families in the future. Addressing these challenges requires an evaluation of the existing gaps in research on family caregiving and well-being in adult chronic illness. In order to achieve this, seven scholars from various academic disciplines who are researching this topic in Austria, Germany, and Switzerland convened for a two-day workshop in 2024. Discussions were complemented by a set of initial literature searches. The workshop revealed that studies documenting the burdens of informal caregiving have tended to overlook the broader family and social contexts, as well as the well-being of families as a whole, by focusing on single perspectives and improvement of disease management. Thereby, current research fails to address the diverse needs of all family members involved and often neglects intertwined factors like gender, socioeconomic status, and access to the formal health and care system. This results in gaps in how these intertwined factors influence family caregiving and well-being. We propose a more comprehensive, interdisciplinary investigation of family caregiving and well-being in future studies. Further scientific consideration is needed to adequately address the structural and procedural barriers to (in)formal support for families. Understanding the real-life complexities of caregiving can contribute to bridging gaps in research and practice, while promoting family-centered approaches to contribute to health equity. Research and practice recommendations are provided.

KEYWORDS

family caregiving, family well-being, chronic illness, health equity, interdisciplinarity

1 Introduction

The burden of chronic diseases, defined as health conditions that persist and necessitate continuous management over an extended period (1), is increasing in Europe due to improved life expectancy and demographic changes toward an aging population (2, 3). Family members provide substantial support to chronic ill adults, understood as informal care that is characterized by a lack of formal training or financial compensation (4). This informal care provided by families is an important cornerstone of health care (5, 6). Due to the predicted shortage of health professionals, there will be an even greater need for family members to provide care in the future (5,

7–10). However, families are constantly under change. For example, family members are more geographically dispersed which leads to shifts in the set-up of households and what it means to be a family (11, 12). This highlights that what constitutes a family is bound to social change (12), but affecting who is considered to need (formal) support and thus a matter of (intergenerational) health and equity concerns (13, 14). As family caregiving of chronically ill individuals is of critical importance to the functioning of our communities and societies (15, 16), it is of the utmost importance to better understand the complex issues at stake to be best prepared for the challenges ahead.

In light of the complex interplay between adult chronic illness, family caregiving and wellbeing, it is imperative to undertake a comprehensive evaluation of the existing research gaps from an interdisciplinary perspective. This is warranted by the recognition that diverse academic disciplines may approach this subject from various perspectives (17), thereby encouraging innovation, creativity, productivity and overall research success (17, 18). To achieve this, a two-day workshop on “Chronic illness and family over time”, funded by the Swiss National Science Foundation (222885), was held in February 2024 in Zurich, Switzerland. (see the agenda in [Supplementary material S1](#)). The workshop included seven scholars (see authors) from diverse academic backgrounds, including public health, nursing, education, disability studies, sports, social sciences, and gender studies to enhance reflexive problem understanding. The scholars came from research institutions in Austria, Germany, and Switzerland and were of different genders, ages and research seniority to ensure a diversity in perspectives. In preparation for the workshop, various initial literature searches were conducted to support the workshop discussions (details on the review process are provided [Supplemental material S2](#)).

This perspective article focuses exclusively on presenting the workshop discussions on current findings and research gaps in relation to family caregiving and well-being in adult chronic illness. It is important to acknowledge that both terms - family caregiving and well-being - are very broad and lack precise definition, instead representing social and therefore discipline-specific constructs that require careful reflection (19). Given this inherent uncertainty and the breadth of workshop discussions, which included theoretical, methodological and ethical considerations, this article is pertaining to family caregiving and well-being in adult chronic illness only to ensure coherence and actionable insights. This focus enables coherence on aspects that were rich and the insights to be actionable. While broader reflections on theoretical and ethical aspects were invaluable, reporting them would risk to dilute clarity. Aware of this, we will first describe the fragmented evidence on family caregiving in chronic illness from the perspective of health and social sciences. Second, we will present how family well-being in chronic illness is assessed and discuss its strengths and limitations. Third, we will stimulate a discussion on the implications for research and practice, providing recommendations for future directions. Therewith, the authors of this perspective article offer several contributions to the current field of (applied science) research with regard to family caregiving and well-being in chronic illness to ensure the sustainable and equitable promotion of family-centered care to support family well-being.

2 Family caregiving in chronic illness

The health sciences have demonstrated a particular interest in family caregivers as proxies for ill people with the aim of providing support and

managing illness trajectories (20). The challenges and burdens experienced when providing care for a family member with a chronic illness have been the subject of extensive research and documentation (6, 21, 22). Studies have documented the negative impact of caregiving on physical, emotional, financial, relational, educational, occupational, recreational, and social aspects (23, 24), but have also identified potential stress-relieving effects (25, 26). This research has led to a broad consensus that family caregivers need support, based on the assumption that a causal relationship exists between caregiving responsibilities and overburden (27). However, this view overlooks the diversity of skills and competencies of family caregivers (28). For instance, family members have demonstrated the ability to negotiate different caregiving roles and responsibilities within various family networks, a process that is constantly evolving (29). Health literacy has been reported as being unevenly distributed across families' social networks and used as a resource when and where needed (30). Therefore, not all family caregivers possess the same competencies and management styles to cope with different strains and thus may differ in their support needs. Moreover, empirical studies on caregiving in families tend to focus on single perspectives, such as those of adult family caregivers (21), of children and young people as family caregivers (31), or of dyadic relationships between spouses (32, 33), thereby almost decontextualizing caregiving from the family and social context (23, 33, 34). Such studies overlook the importance of family relationships and the ways in which they are part of life courses and distinct biographies, while individuals may be both caregivers and care-receivers at the same time (35).

From a social science perspective, the family, as an intergenerational community has demonstrated resilience despite all changes in the context of illness and caregiving challenges (36) and is still considered as a ‘hidden health system’ (37). Women up until now shoulder the primary responsibility of caregiving for chronic illness in the family (5, 38, 39). While men also give care, they apparently face higher levels of stigma (40). At the same time, families are diversifying, with increases in one-child households and patchwork families (35). These dynamic changes in family caregiving suggest that more comprehensive approaches in chronic illness may be needed (41). This is particularly true given the intricate interweaving of chronic illness into family life, with its attendant influence on and influence from gendered family norms, ambivalences of dependence and independence, and the tension between collective “we” identities and individual autonomy (42–44). In addition, the role of the family in caregiving is shaped by economic, educational, social, and health system contexts (36) and involves interactions between informal and formal care systems (45). These dynamics are further influenced by factors such as socioeconomic status, educational attainment, migration-related barriers, and racial discrimination (46, 47), which require further understanding concerning family caregiving.

3 Family well-being in chronic illness

Despite the absence of a universally accepted definition of family well-being in the health sciences, it is understood to be a multidimensional concept encompassing physical, social, economic, and psychological dimensions (48–50). It is often explored through related concepts such as family functioning, resilience, health, and flourishing (49); it is also treated as a dimension of family functioning (51), which is considered to be a cornerstone for assessing the family quality of life (QoL) (52). There is an overall overlap between the

different concepts, as for example between QoL and well-being, with the latter being typically used more broadly and holistically (53).

Due to the multidimensional nature of family well-being, various tools have been used to measure it in the context of chronic illness, such as those assessing family QoL (48) or family functioning (54). Although these tools differ in focus, a common feature is that they primarily assess the individual perspective of either the ill person, the primary caregiver, or a family member. However, it is questionable whether the perspective of one member can capture the complexity of a family's overall well-being (55).

A growing body of literature demonstrates the reciprocal relationship between individual and family well-being (56, 57), highlighting the need for approaches that consider the family as a whole (48, 58, 59). However, tools that capture the perspectives of multiple family members remain limited (60–62). Those available are predominantly validated for traditional “married with child” families and often lack the capacity to provide an overall family score. Furthermore, as recent reviews have highlighted, most measurement tools have been used in studies with participants who were white or presumed to be white (54). As a result, little is known about family well-being and functioning in families from diverse backgrounds.

Moreover, most family well-being measures originate from the late 1970s and early 1990s, drawing primarily on the McMaster Model or the process Model of Family Functioning as well as findings from family interviews (60, 62, 63). These early tools, listed in Table S3 in the [Supplementary material](#), were intended for screening families in need of support and as research instruments. Scholars typically achieved validation by comparing responses from one family member with findings from interviews. The earlier tools show a focus on family functioning, covering dimensions such as problem-solving, communication, roles, affective response, affective involvement, behavior control, as well as values and norms, but not on how such aspects as, e.g., roles are viewed from different perspectives. Subsequent tools narrow their perspective to specific aspects of the original measures (64, 65) or are more closely aligned with QoL frameworks, incorporating domains such as emotional well-being, physical/material/financial well-being, and support (66, 67). Over time, many family well-being assessment tools have emerged, each varying slightly in focus and domain coverage. This proliferation has led to review articles (48, 54, 61) and initiatives¹ aimed at cataloging and summarizing existing tools. Despite these efforts, a lack of consensus remains, as single tools only cover partial aspects of family well-being (Table 1).

4 Discussion

Our interdisciplinary workshop catalyzed an engaging and mutual beneficial learning experience about strengthening the evidence base for family caregiving and well-being in chronic illness. It brought together diverse perspectives and bodies of knowledge from the health

and social sciences, highlighting the need for an interdisciplinary approach that acknowledges the complexity and heterogeneity of family caregiving realities across different health and care systems.

A substantial proportion of research has focused on family caregivers of individuals with chronic illnesses. However, the broader family and social context in which these caregivers operate has received comparatively less attention than the study of their relationships (23, 33, 34). Consequently, there is an urgent need for a more comprehensive understanding of family well-being, one that transcends the confines of a single perspective as a proxy. This calls for acknowledging the complexities, diversity, and relational reciprocity inherent in caregiving experiences across diverse families and among their members, while recognizing that family caregiving is inextricably intertwined with the formal care services of the broader welfare system (68–71). This type of evidence is paramount for developing effective support strategies tailored to the needs of family members most in need of support. Only thereby, can we contribute to the overall well-being of the family and address social inequalities within the broader health and care systems. Based on this, the following research and practice recommendations are considered of utmost importance in tackling the challenges ahead for our aging societies. Research and practice recommendations are:

1. Call for interdisciplinary research approaches that integrate health sciences, social sciences, and family studies. Emphasize the importance of intersectionality to explore how family caregiving and well-being in chronic illness is shaped by diverse factors such as gender or socioeconomic status (72).
2. Encourage (longitudinal) research that considers a lifespan perspective and/or the complex, lived realities of diverse families that do not necessarily follow linear causality (54). Focus future research on exploring the interrelated experiences of family members as a unit, rather than in isolation, highlighting the necessity of a systems-thinking lens to examine the complexity of informal-formal caregiving interactions across different health and social systems (11). Such research perspectives would allow for a deeper understanding of the diversity and heterogeneity of families, including their ambivalences (35), while considering the specifics of the health and care system (45, 69).
3. Greater participation of individuals/families in research, practice, and policy so that they can influence agendas in ways that are meaningful to them (73, 74), for example through priority setting (73), while accounting for the diversity of families and those in vulnerable situations.
4. Conduct a concept analysis (75) to develop a conceptual understanding of family well-being. This will lay the groundwork for the development of comprehensive tools that assess family well-being with scales that account for the diverse perspectives and meanings. Such scales could be a valuable addition to a nursing practice's toolkit for identifying the most vulnerable family situations and members for support interventions.
5. Stronger acknowledgement and integration of a family-centered approach into primary care services and coordination of support services from health to social care.
6. Introduce policy frameworks that support comprehensive family-centered care interventions, which consider the needs of all: the ill person, informal caregiver, and the entire family as a unit, to mitigate health inequalities.

1 <https://healthychild.ucla.edu/programs/life-course-translational-research-network/resources/family-functioning-measures/>; <https://internationalfamilynursing.org/resources-for-family-nursing/research/measurement-resources/>; https://fam-net.org/instruments-family/page/3/?product_cat=fwb.

TABLE 1 Overview of the different family well-being assessment tools.

Concept	Scale	Domains	Number of items	Target populations	Available languages	Year
Family functioning	Family Environment Scale (FES)	1. Family relationship, 2. Personal growth, 3. System maintenance and change	90	Adult(s) and/or child(ren) from 11 years onwards	>22 languages, incl. Eng, Chi, Jap, Mal, Spa, Por, Gre, Heb	1974
	Family APGAR Index: Family Adaptation, Partnership, Growth, Affection, and Resolve	1. Adaptation, 2. Partnership, 3. Growth, 4. Affection, 5. Resolve	5	Adult or child from the age of 10 onwards, for families with chronically ill person	Eng, Chi, Jap, Spa	1979
	Family Assessment Device (FAD)	1. Problem solving, 2. communication, 3. Affective responsiveness, 4. Affective involvement, 5. Behavior control, 6. General functioning	60	Adult or child from 12 years onwards, for families with chronically ill person	Eng, Ger, Fre, Chi, Gre, Hindi, Ice, Ita, Por, Spa, Swe, Tur	1983
	Family Relationship Index (FRI)	1. Family cohesion, 2. Family expressiveness, 3. Family conflict	12	Adult(s) and/or child(ren) from 11 years onwards, for families with chronically ill person, with and without child(ren), for couples as well as single parents	(see FES)	1983
	Assessment of Strategies in Families-Effectiveness (ASF-E)	1. System maintenance, 2. System change, 3. Coherence, 4. Individuality	18	One person representing the family, unclear if this could be a child	Eng, Ger	1991
	Family Functioning Family Health and Social Support (FAFHES)	1. Affect, 2. Affirmation, 3. Concrete aid	20	Designed for caregiver, with and without child(ren), living in same household	Eng, Ger, Per	2002
	Brief Assessment of Family Functioning Scale (BAFFS)	1. General functioning	3	Adult caregiver with or without child(ren), living in same household	(see FAD)	2019
Family QoL	Beach Family Quality of Life Scale (FQOL)	1. Family Interaction, 2. Parenting, 3. Emotional Well-being, 4. Physical Well-being / Material Well-being, 5. Disability-Related Support.	25	Adult in family with child(ren) with or without disability, also possible for a parent with a disability	Eng, Fre, Spa	2006
	(Canadian) Family Quality of Life survey	1. Health of the family, 2. Financial well-being, 3. Family relationships, 4. Support from other people, 5. Support from disability-related services, 6. Influence of values, 7. Careers and preparing for careers, 8. Leisure and recreation, 9. Community involvement	54	Main adult caregiver with child(ren) with or without intellectual and/or developmental disabilities	Eng, Ger, Bos, Chi, Dut, Fle, Far, Fre, Ita, Jap, Mal, Pol, Por, Slo, Spa, Tel	2006
	Family Reported Outcome Measure (FROM-16)	1. Emotional, 2. Personal and social	16	Adult with (chronic) ill family member of any age	>30 translations, incl. Eng, Ger	2014
Family Health	Family Health Scale	1. social and emotional health processes, 2. family healthy lifestyle, 3. family health resources, 4. family external social supports	32 (short version 10)	Adult(s) in heterosexual relationship with child(ren)	Eng, Chi, Por	2020

Eng, English; Chi, Chinese; Jap, Japanese; Mal, Malay; Spa, Spanish; Por, Portuguese; Gre, Greek; Heb, Hebrew; Ger, German; Fre, French; Per, Persian; Ice, Icelandic; Ita, Italian; Swe, Swedish; Tur, Turkish; Bos, Bosnich; Dut, Dutch; Fle, Flemish; Far, Farsi; Pol, Polish; Slo, Slovenian; Tel, Telugu. Further details of the scales mentioned are given in the, see [Supplementary Table S3](#).

7. Ultimately, such a more comprehensive interdisciplinary approach toward research, policy and practice would enable a more nuanced understanding, which would support the development of targeted and effective interventions for informal caregiving families and improve their overall well-being.

This research perspective integrates evidence, expertise, and knowledge from various disciplines. However, it has some limitations that must be acknowledged. The workshop format encouraged reflective thinking and collaborative learning among scholars of diverse disciplines, ages, and genders. The initial literature searches provided a foundation for the discussions by identifying gaps in the existing literature. Because these searches were not systematic, we may not have considered all available evidence (76), and the discussions may have been influenced by group and power dynamics (77). Nevertheless, the interdisciplinary workshop format enabled us to contextualize the identified evidence within various scholarly traditions (78). This provided a more comprehensive overview than would have been possible otherwise (78), allowing us to generate ideas for innovating research on the matter openly. The discussions also addressed theoretical underpinnings and ethical considerations of family caregiving in adult chronic illness. When discussing ethical aspects in family research from an interdisciplinary perspective, divergent epistemic frames of references were encountered (79), with the emerging complexity extending beyond the scope of this article.

5 Conclusion

The complexities of family well-being in the context of chronic illness are characterized by a fragmentation of focus, with a prevailing emphasis on the perspectives of caregivers within the field of health sciences, who are considered proxies for the chronically ill person. It is imperative to recognize the necessity of an interdisciplinary and more comprehensive approach to understand the complexity of caregiving for chronically ill people within diverse and changing families, as this is the only way to ensure health equity in the context of an aging society undergoing social change.

Data availability statement

The original contributions presented in the study are included in the article/[Supplementary material](#), further inquiries can be directed to the corresponding author/s.

Author contributions

BS: Funding acquisition, Conceptualization, Investigation, Writing – original draft, Writing – review & editing, Supervision. RV: Project administration, Funding acquisition, Conceptualization, Formal analysis, Writing – original draft, Writing – review & editing, Data curation, Investigation, Methodology. JH: Writing – review & editing. TF: Writing – review & editing. CR: Writing – review & editing. LG: Writing – review & editing. BB: Writing – review & editing. SM: Writing – review & editing. MN-C: Writing – review & editing.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. The authors declare that the content of this manuscript is based on a scientific exchange workshop which was funded by the Swiss National Science Foundation (no. 222885). Open access funding was provided by the University of Vienna.

Acknowledgments

The authors acknowledge and thank for the support of Elena Alder, Josip Jurisic, and Sarah Rabhi-Sidler (Careum School of Health, Kalaidos University of Applied Sciences, Switzerland) in preparing, organizing and supporting the successful realization of the workshop. We also are grateful for the academic support of Doris Schaeffer (Hertie School of Governance and University of Bielefeld, Germany). The draft manuscript was written by the two first co-authors who are native speakers of German, respectively Dutch. To ensure that the manuscript was written in correct American English, proofreading assistance was provided by DeepL Write where felt needed to ensure concise use of grammar and wording. A final proofreading was carried out by all co-authors to check for accuracy of content as well as to make and approve linguistic adjustments.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

Any alternative text (alt text) provided alongside figures in this article has been generated by Frontiers with the support of artificial intelligence and reasonable efforts have been made to ensure accuracy, including review by the authors wherever possible. If you identify any issues, please contact us.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2025.1619672/full#supplementary-material>

References

- Theofilou P. Perceived social support among patients and the contribution in the management of the chronic disease: a brief review. *Ser Clin Med Case Rep Rev.* (2023) 1:9. doi: 10.54178/2993-3579.v1i5a2012
- Brennan P, Perola M, van Ommen G-J, Riboli E. Chronic disease research in Europe and the need for integrated population cohorts. *Eur J Epidemiol.* (2017) 32:741–9. doi: 10.1007/s10654-017-0315-2
- Ces S, Hlebce V, Yghemonos S. *Valuing Informal Care in Europe - analytical review of existing valuation methods.* (2019).
- Fischer J, Frisina Doetter L, Rothgang H. Comparing long-term care systems: a multi-dimensional, actor-centred typology. *Soc Policy Adm.* (2022) 56:33–47. doi: 10.1111/spol.12742
- Haley WE, Elayoubi J. Family caregiving as a global and lifespan public health issue. *Lancet Public Health.* (2024) 9:e2–3. doi: 10.1016/S2468-2667(23)00227-X
- Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. *Annu Rev Psychol.* (2020) 71:635–59. doi: 10.1146/annurev-psych-010419-050754
- Nagl-Cupal M, Kolland F, Zartler U, Mayer H, Bittner M, Koller M. *Angehörigenpflege in Österreich. Einsicht in die Situation pflegender Angehöriger und in die Entwicklung informeller Pflegenetzwerke.* Wien: Universität Wien. (2018). Available online at <https://broschuere.service.sozialministerium.at/Home/Download?publicationId=664> (Accessed September 26, 2024).
- O'Gara G, Wiseman T, Doyle A-M, Pattison N. Chronic illness and critical care—a qualitative exploration of family experience and need. *Nurs Crit Care.* (2023) 28:574–84. doi: 10.1111/nicc.12817
- Otto U, Leu A, Bischofberger I, Gerlich R, Riguzzi M, Jans C, et al. *Bedürfnisse und Bedarf von betreuenden Angehörigen nach Unterstützung und Entlastung – eine Bevölkerungsbefragung. Schlussbericht Forschungsprojekt G01a, Förderprogramm Entlastungsangebote für betreuende Angehörige 2017–2020.* Im Auftrag des Bundesamts für Gesundheit (BAG). Zürich/Bern. (2019).
- Statistisches Bundesamt. *Zahl der Pflegebedürftigen steigt bis 2070 deutlich an.* (2024). Available online at <https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Gesundheit/Pflege/aktuell-vorausberechnung-pflegebeduerftige.html> (Accessed September 26, 2024).
- Schulz R, Beach SR, Friedman EM, Martsolf GR, Rodakowski J. A. Everette 3rd James changing structures and processes to support family caregivers of seriously ill patients. *J Palliat Med.* (2018) 21:S36–42. doi: 10.1089/jpm.2017.0437
- Turner LH, West R. The challenge of defining 'family' In: J Reich, editor. *The state of families. Law, policy, and the meanings of relationships.* New York: Routledge (2020). 10–25.
- Devaney C, Donald MM, Holzer J. A social justice perspective on the delivery of family support. *Child Youth Serv Rev.* (2024) 159:107494. doi: 10.1016/j.childyouth.2024.107494
- Kamaryati N, Malathum P. *Family support: A concept analysis*, pp. 403–411. (2020).
- Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. *The Gerontologist.* (2015) 55:309–19. doi: 10.1093/geront/gnu177
- Schönberger C. Familie und Gesundheit In: J Ecarius and A Schierbaum, editors. *Handbuch Familie: Band I: Gesellschaft, Familienbeziehungen und differentielle Felder.* Wiesbaden: Springer Fachmedien Wiesbaden (2022). 589–609.
- Vladova G, Haase J, Friesike S. Why, with whom, and how to conduct interdisciplinary research? A review from a researcher's perspective. *Sci Public Policy.* (2024) 52:165–80. doi: 10.1093/scipol/scae070
- Gardiner P. Learning to think together: creativity, interdisciplinary collaboration and epistemic control. *Think Skills Creat.* (2020) 38:100749. doi: 10.1016/j.tsc.2020.100749
- Thomas PA, Liu H, Umberson D. Family relationships and well-being. *Innov Aging.* (2017) 1:igx025. doi: 10.1093/geroni/igx025
- Zhang Y. Family functioning in the context of an adult family member with illness: a concept analysis. *J Clin Nurs.* (2018) 27:3205–24. doi: 10.1111/jocn.14500
- Choi JY, Lee SH, Yu S. Exploring factors influencing caregiver burden: a systematic review of family caregivers of older adults with chronic illness in local communities. *Healthcare.* (2024) 12:1002. doi: 10.3390/healthcare12101002
- Lim J-w, Zebrack B. Caring for family members with chronic physical illness: a critical review of caregiver literature. *Health Qual Life Outcomes.* (2004) 2:50. doi: 10.1186/1477-7525-2-50
- Golics CJ, Basra MKA, Salek MS, Finlay AY. The impact of patients' chronic disease on family quality of life: an experience from 26 specialties. *Int J Gen Med.* (2013) 6:787–98. doi: 10.2147/IJGM.S45156
- Jika BM, Khan HTA, Lawal M. Exploring experiences of family caregivers for older adults with chronic illness: a scoping review. *Geriatr Nurs.* (2021) 42:1525–32. doi: 10.1016/j.gerinurse.2021.10.010
- Mehri N, Kinney J, Brown S, Rajabi Rostami M. Informal caregiving and all-cause mortality: a meta-analysis of longitudinal population-based studies. *J Appl Gerontol.* (2021) 40:781–91. doi: 10.1177/0733464819893603
- Roth DL, Brown SL, Rhodes JD, Haley WE. Reduced mortality rates among caregivers: does family caregiving provide a stress-buffering effect? *Psychol Aging.* (2018) 33:619–29. doi: 10.1037/pag0000224
- Lindt N, van Berkel J, Mulder BC. Determinants of overburdening among informal carers: a systematic review. *BMC Geriatr.* (2020) 20:304. doi: 10.1186/s12877-020-01708-3
- Jung S, Song J-A, Kim J, Cheon H. Family caregiver competence in managing behavioral and psychological symptoms of dementia: a concept synthesis. *Jpn J Nurs Sci.* (2022) 19:e12462. doi: 10.1111/jjns.12462
- Nagl-Cupal M, Parisot V, Stöhr D, Zartler U. Towards a typology of negotiating care in families: a qualitative multiple perspectives study in Austria. *Int J Care Caring.* (2023) 1:1–21. doi: 10.1332/239788221X16764028221810
- Edwards M, Wood F, Davies M, Edwards A. 'Distributed health literacy': longitudinal qualitative analysis of the roles of health literacy mediators and social networks of people living with a long-term health condition. *Health Expect.* (2015) 18:1180–93. doi: 10.1111/hex.12093
- Lacey RE, Xue B, McMunn A. The mental and physical health of young carers: a systematic review. *Lancet Public Health.* (2022) 7:e787–96. doi: 10.1016/S2468-2667(22)00161-X
- Bertschi IC, Meier F, Bodenmann G. Disability as an interpersonal experience: a systematic review on dyadic challenges and dyadic coping when one partner has a chronic physical or sensory impairment. *Front Psychol.* (2021) 12:624609. doi: 10.3389/fpsyg.2021.624609
- Weitkamp K, Feger F, Landolt SA, Roth M, Bodenmann G. Dyadic coping in couples facing chronic physical illness: a systematic review. *Front Psychol.* (2021) 12:740. doi: 10.3389/fpsyg.2021.722740
- Helgeson Vicki S, Zajdel M. Adjusting to chronic health conditions. *Annu Rev Psychol.* (2017) 68:545–71. doi: 10.1146/annurev-psych-010416-044014
- Jurczyk K. UnDoing family. Bestandsaufnahme und Bezüge des Konzepts In: A Schierbaum, J Ecarius, D Krinninger and U Uhlendorff, editors. *Familie, wozu? Eine Bestandsaufnahme konzeptioneller und theoretischer Perspektiven in der erziehungswissenschaftlichen Forschung zu Familie.* Wiesbaden: Springer Fachmedien Wiesbaden (2023). 15–35.
- Ohlbrecht H. Familie und Krankheit In: J Ecarius and A Schierbaum, editors. *Handbuch Familie: Gesellschaft und differentielle Felder.* Wiesbaden: Springer (2021). 1–19.
- Schönberger C. Gesundheit und Familie In: J Ecarius and A Schierbaum, editors. *Handbuch Familie. Gesellschaft, Familienbeziehungen und differentielle Felder.* Wiesbaden: Springer Fachmedien (2020). 1–21.
- Fratzcher M. *Diese Rentenreform ist für Frauen eine verpasste Chance.* DIW Berlin. (2024). Available online at https://www.diw.de/de/diw_01.c.896494.de/nachrichten/diese_rentenreform_ist_fuer_frauen_eine_verpasste_chance.html (Accessed September 26, 2024).
- Lancet Public Health. Unpaid carers: a silent workforce. *Lancet Public Health.* (2024) 9:e1. doi: 10.1016/S2468-2667(23)00311-0
- Zwar L, Angermeyer MC, Matschinger H, Riedel-Heller SG, König H-H, Hajek A. Are informal family caregivers stigmatized differently based on their gender or employment status?: a German study on public stigma towards informal long-term caregivers of older individuals. *BMC Public Health.* (2021) 21:1868. doi: 10.1186/s12889-021-11955-7
- Dermott E, Fowler T. What is a family and why does it matter? *Soc Sci.* (2020) 9:83. doi: 10.3390/socsci9050083
- Hillcoat-Nallétamby S, Phillips JE. Sociological ambivalence revisited. *Sociology.* (2011) 45:202–17. doi: 10.1177/0038038510394018
- Nave-Herz R. Familiensoziologie. Historische Entwicklung, theoretische Ansätze, aktuelle Themen In: A Wonneberger, K Weidtmann and S Stelzig-Willutzki, editors. *Familienwissenschaft. Grundlagen und Überblick.* Wiesbaden: Springer VS (2018). 119–47.
- Widmer ED. The configurational approach to families: methodological suggestions In: AM Castrén, V Česnuitytė, I Crespi, JA Gauthier, R Gouveia and C Martin, editors. *The Palgrave handbook of family sociology in Europe.* Cham: Springer International Publishing (2021). 107–31.
- Calvó-Pexas L, Vilalta-Franch J, Litwin H, Mira P, Garre-Olmo J. A longitudinal study on public policy and the health of in-house caregivers in Europe. *Health Policy.* (2021) 125:436–41. doi: 10.1016/j.healthpol.2021.02.001
- Amirpur D. *Migrationsbedingt behindert? Familien im Hilfesystem. Eine intersektionale Perspektive.* Bielefeld: Transcript Verlag (2016).
- Engelbert A. *Familien im Hilfenetz. Bedingungen und Folgen der Nutzung von Hilfen für behinderte Kinder.* Weinheim, München: Juventa-Verl (1999).
- Alnahdi GH, Alwadei A, Woltran F, Schwab S. Measuring family quality of life: scoping review of the available scales and future directions. *Int J Environ Res Public Health.* (2022) 19:473. doi: 10.3390/ijerph192315473
- Crandall AA, Holmes EK, Villalon SE, Weiss-Laxer NS, Berge JM. A conceptual model of family well-being: bridging constructs, fields, and practice applications. *J Fam Theory Rev.* (2023) 16:431–48. doi: 10.1111/jftr.12543

50. Wollny I, Apps J, Henricson C. Can government measure family wellbeing? A literature review. London: Family and Parenting Institute (2010).
51. Timmerby N, Cosci F, Watson M, Csillag C, Schmitt F, Steck B, et al. A confirmative clinimetric analysis of the 36-item family assessment device. *Nord J Psychiatry*. (2018) 72:268–72. doi: 10.1080/08039488.2018.1435721
52. Brown I, Brown RI, Bau NT, Isaacs B, Myerscough T, Neikrug SM, et al. *Family quality of life survey. Main caregivers of people with intellectual or developmental disabilities*. (2006). Available online at <http://www.surreyplace.ca/documents/fqls%20files/fqol-survey-id-dd-with-variable-names-may-08.pdf>.
53. Pinto S, Fumincelli L, Mazzo A, Caldeira S, Martins JC. Comfort, well-being and quality of life: discussion of the differences and similarities among the concepts. *Porto Biomed J*. (2017) 2:6–12. doi: 10.1016/j.pbj.2016.11.003
54. Ramaswami SB, Jensen T, Berghaus M, De-Oliveira S, Russ SA, Weiss-Laxer N, et al. Family health development in life course research: a scoping review of family functioning measures. *Pediatrics*. (2022) 149:509. doi: 10.1542/peds.2021-053509
55. Mora CF, Ibáñez A, Balcells-Balcells A. State of the art of family quality of life in early care and disability: a systematic review. *Int J Environ Res Public Health*. (2020) 17:220. doi: 10.3390/ijerph17197220
56. Elizarov E, Konshina T, Benish-Weisman M, Lee TK, van Ryzin M, Vos SR, et al. Family functioning, well-being, and mental health among new immigrant families. *J Fam Psychol*. (2023) 37:806–17. doi: 10.1037/fam0001092
57. Krys K, Capaldi CA, Zelenski JM, Park J, Nader M, Kocimska-Zych A, et al. Family well-being is valued more than personal well-being: a four-country study. *Curr Psychol*. (2021) 40:3332–43. doi: 10.1007/s12144-019-00249-2
58. Hsiao Y-J. Autism spectrum disorders: family demographics, parental stress, and family quality of life. *J Policy Pract Intellect Disabil*. (2018) 15:70–9. doi: 10.1111/jppi.12232
59. Samuel PS, Rillotta F, Brown I. Review: the development of family quality of life concepts and measures. *J Intell Disabil Res*. (2012) 56:1–16. doi: 10.1111/j.1365-2788.2011.01486.x
60. Epstein NB, Baldwin LM, Bishop DS. The McMaster family assessment device*. *J Marital Fam Ther*. (1983) 9:171–80. doi: 10.1111/j.1752-0606.1983.tb01497.x
61. Hamilton E, Carr A. Systematic review of self-report family assessment measures. *Fam Process*. (2016) 55:16–30. doi: 10.1111/famp.12200
62. Moos R. Family environment scale preliminary manual. Palo Alto, CA: Consulting Psychologists Press (1974).
63. Skinner H, Steinhauer P, Sitarenios G. Family assessment measure (FAM) and process model of family functioning. *J Fam Ther*. (2000) 22:190–210. doi: 10.1111/1467-6427.00146
64. Hoge RD, Andrews DA, Faulkner P, Robinson D. The family relationship index: validity data. *J Clin Psychol*. (1989) 45:897–903. doi: 10.1002/1097-4679(198911)45:6<897::AID-JCLP2270450611>3.0.CO;2-T
65. Mansfield AK, Keitner GI, Sheeran T. The brief assessment of family functioning scale (BAFFS): a three-item version of the general functioning scale of the family assessment device. *Psychother Res*. (2019) 29:824–31. doi: 10.1080/10503307.2017.1422213
66. Hoffman L, Marquis J, Poston D, Summers JA, Turnbull A. Assessing family outcomes: psychometric evaluation of the Beach Center family quality of life scale. *J Marriage Fam*. (2006) 68:1069–83. doi: 10.1111/j.1741-3737.2006.00314.x
67. Krecht M. *Familienlebensqualität. Ein Vergleich von Familien mit Kindern mit und ohne intellektuelle Behinderung unter Berücksichtigung der individuellen Lebensqualität und des Copingverhaltens der Hauptbetreuungspersonen*. Universität Wien (2010).
68. Böhm K, Schmid A, Götze R, Landwehr C, Rothgang H. Five types of OECD healthcare systems: empirical results of a deductive classification. *Health Policy*. (2013) 113:258–69. doi: 10.1016/j.healthpol.2013.09.003
69. Cash B, Hodgkin S, Warburton J. A transformative approach to systems theory in caregiving research. *Qual Soc Work*. (2019) 18:710–26. doi: 10.1177/1473325017749988
70. Piel MH, Geiger JM, Julien-Chinn FJ, Lietz CA. An ecological systems approach to understanding social support in foster family resilience. *Child Fam Soc Work*. (2017) 22:1034–43. doi: 10.1111/cfs.12323
71. Reibling N, Arians M, Wendt C. Worlds of healthcare: a healthcare system typology of OECD countries. *Health Policy*. (2019) 123:611–20. doi: 10.1016/j.healthpol.2019.05.001
72. Stadtmann MP, Bischofberger I, Balice-Bourgeois C, Bianchi M, Burr C, Fierz K, et al. Setting new priorities for nursing research: the updated Swiss nursing research agenda—a systematic, participative approach. *Int Nurs Rev*. (2024) 71:504–12. doi: 10.1111/inr.12937
73. Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. *Health Expect*. (2019) 22:785–801. doi: 10.1111/hex.12888
74. Kolade OR, Porat-Dahlerbruch J, Makhmutov R, van Achterberg T, Ellen ME. Strategies for engaging older adults and informal caregivers in health policy development: a scoping review. *Health Res Policy Syst*. (2024) 22:26. doi: 10.1186/s12961-024-01107-9
75. Smith S, Mörelius E. Principle-based concept analysis methodology using a phased approach with quality criteria. *Int J Qual Methods*. (2021) 20:57995. doi: 10.1177/16094069211057995
76. Sutton A, Clowes M, Preston L, Booth A. Meeting the review family: exploring review types and associated information retrieval requirements. *Health Inf Libr J*. (2019) 36:202–22. doi: 10.1111/hir.12276
77. Oberhelman R, Anticona C, Correa M, Malpartida H, Pajuelo M, Paz-Soldan V, et al. Interdisciplinary postdoctoral training in global health through a novel joint project for trainees from diverse disciplines: benefits, risks, and observations. *Am J Trop Med Hyg*. (2016) 96:402. doi: 10.4269/ajtmh.16-0402
78. Mahringer CA, Baessler F, Gerchen MF, Haack C, Jacob K, Mayer S. Benefits and obstacles of interdisciplinary research: insights from members of the young academy at the Heidelberg Academy of Sciences and Humanities. *iScience*. (2023) 26:108508. doi: 10.1016/j.isci.2023.108508
79. Dalton A, Wolff K, Bekker B. Interdisciplinary research as a complicated system. *Int J Qual Methods*. (2022) 21:100397. doi: 10.1177/16094069221100397



OPEN ACCESS

EDITED BY

Qing Zhao,
Chinese Academy of Sciences (CAS), China

REVIEWED BY

Vahid Rashedi,
University of Social Welfare and Rehabilitation
Sciences, Iran
Jessica Barboza,
University of Saint Thomas, United States

*CORRESPONDENCE

Josephine Tognela
✉ josephine.sewell@student.curtin.edu.au

RECEIVED 04 July 2025

ACCEPTED 08 September 2025

PUBLISHED 21 October 2025

CORRECTED 31 October 2025

CITATION

Tognela J, Breen LJ and Rudaizky D (2025)
Reciprocal regulation in social support
interactions between bereaved parents and
their potential supporters: a qualitative study.
Front. Public Health 13:1659628.
doi: 10.3389/fpubh.2025.1659628

COPYRIGHT

© 2025 Tognela, Breen and Rudaizky. This is
an open-access article distributed under the
terms of the [Creative Commons Attribution
License \(CC BY\)](https://creativecommons.org/licenses/by/4.0/). The use, distribution or
reproduction in other forums is permitted,
provided the original author(s) and the
copyright owner(s) are credited and that the
original publication in this journal is cited, in
accordance with accepted academic
practice. No use, distribution or reproduction
is permitted which does not comply with
these terms.

Reciprocal regulation in social support interactions between bereaved parents and their potential supporters: a qualitative study

Josephine Tognela^{1*}, Lauren J. Breen² and Daniel Rudaizky^{2,3}

¹School of Population Health, Curtin University, Perth, WA, Australia, ²School of Population Health and Curtin enAble Institute, Curtin University, Perth, WA, Australia, ³School of Psychological Science, University of Western Australia, Perth, WA, Australia

Introduction: The death of a child represents one of life's most profound stressors, often resulting in long-term emotional dysregulation and the potential for mental health diagnoses. This qualitative study explores how bereaved parents experience informal social support attempts.

Methods: Sixteen bereaved parents in Australia were recruited through social media and bereavement support networks and participated in in-depth, semi-structured interviews. Reflexive thematic analysis was applied to interpret participant narratives, with data collection and analysis conducted iteratively. Findings revealed that potential support interactions were rarely neutral: they either offered grounding through perceived safety, or heightened distress through judgement or avoidance.

Results: Four overarching themes were developed: *Societal Norms (The Western World)*, articulating societal bereavement norms; *Bereaved Parents' Experiences (The Untethered World)*, describing bereaved parents' internal disruption of identity and coherence; *Potential Support Providers' Perceived Experience (The Uncertain World)*, capturing perceptions of informal social support providers' uncertainty with providing support; and *Quality of Interactions (The Precarious World)*, detailing how support interactions either alleviated or exacerbated bereaved parents' distress. A key mechanism, reciprocal regulation, was identified, whereby bereaved parents mirrored the emotional availability or avoidance of their potential support providers. The findings articulate the complexities of social support done well by affirming the importance of attunement.

Discussion: This study offers an expanded understanding of grief as a relationally co-regulated process and calls for improved grief literacy and societal support.

KEYWORDS

grief, bereaved parents, informal social support, reciprocal regulation, qualitative research

Introduction

The death of a child, often sudden and typically off-time, is widely regarded as one of the most devastating forms of bereavement (1–4). It poses enduring challenges for adaptation and places parents at heightened risk of adverse biopsychosocial outcomes (5, 6). Between 10 and 25% of bereaved parents experience significant emotional dysregulation (7–10), with prolonged grief disorder (PGD) affecting up to 30%, almost 10 times the prevalence in the

general population (11). Common reactions include anxiety, depression, guilt, anger, hopelessness, maladaptive health behaviours (12–14), and diminished workplace participation (15). These persistent stressors demand robust coping strategies.

As one of life's most profound stressors (16, 17), bereavement requires effective coping strategies to facilitate adaptation. Coping, defined as the cognitive and behavioural efforts to manage stress (18), is conceptualised in Lazarus and Folkman's transactional model (19) as an oscillation between problem-focused and emotion-focused strategies. Stroebe and Schut's Dual Process Model (DPM; 20) applied this oscillation to grief, framing adjustment as movement between loss-oriented and restoration-oriented processes. More recently, Guldin and Leget's Integrated Process Model (IPM; 21) presents grief as an ongoing navigation of tensions across physical, emotional, cognitive, social, and spiritual dimensions. Together, these frameworks highlight that adaptation is not linear but involves ongoing negotiation of intrapersonal and interpersonal demands, shaped by social and cultural contexts.

Among the most critical resources in this process is informal social support. Defined by Cobb (22) as the perception of being loved, valued, and part of a mutual network, informal social support is widely recognised as a buffer against psychological distress (23–30). Support from family, friends, colleagues, and community members (31–33) can buffer distress following bereavement generally (34, 35) and child loss specifically (36, 37). Yet, inadequate attempts at support can also intensify distress (38, 39). Around one-third of bereaved individuals report harm from unhelpful or inadequate support (40), with avoidance, platitudes, or lack of empathy, compounded by providers' own distress (41–44), often leaving parents feeling more isolated (41, 42). The mismatch between received support (what is offered) and perceived support (its adequacy) is particularly consequential (45–47).

From a social constructionist perspective (48), grief is shaped by cultural norms that dictate how it should be expressed, its duration, and what constitutes 'healthy' adaptation. In Western societies, these norms are informed by grief denial (49) and death denial (50). Grief denial reflects discomfort with grief's intensity, leading to the suppression and marginalisation of grieving individuals (49). Death denial, rooted in Rank (51) and Becker (52), describes unconscious defences against death anxiety, which is linked to existential distress and compulsive behaviours (53, 54). Death anxiety (55, 56), originating in survival-based neural systems (57), is managed culturally through practices that sanitise death and constrain mourning, pressuring bereaved individuals to resume normative roles quickly (58–61). Meanwhile, support providers are expected to care for others while grappling with their own discomfort and fear (45, 62).

Terror Management Theory (TMT; 63, 64) provides a useful lens for understanding these dynamics. It proposes that both bereaved individuals and supporters may conform to cultural norms to reduce existential anxiety. Although conformity may offer temporary relief, it can reinforce rigid expectations that hinder authentic expression and compassionate support. Over-adherence often results in avoidance, strained communication, and emotional distancing; dynamics that ultimately undermine the support process (65). The Interaction Model of Informal Social Support following Bereavement (IM-ISSB; 66) integrates these perspectives, framing support as reciprocal interactions between bereaved individuals and their networks. Helpful interactions strengthen bereaved and network

relationships, while unhelpful ones weaken them. However, little is known about how these moment-to-moment exchanges unfold for bereaved parents and their networks, and how they are shaped by broader sociocultural scripts.

The present study

Although bereaved parents' support needs are well documented (36, 37), few studies have examined the interactional mechanisms that distinguish helpful from harmful support or explored their embedding in cultural norms. Even fewer apply frameworks such as the IM-ISSB (66), Relational Regulation Theory (RRT; 29), or TMT (63, 64) to interpret these dynamics. Qualitative research is particularly scarce, despite its strength in capturing the lived, moment-to-moment experiences central to understanding support processes in social contexts.

Recent discourse has reframed bereavement support as a community responsibility extending beyond professional care (67). Yet meaningful support cannot be assumed (68). Without adequate skills and confidence, well-intentioned efforts may falter or cause harm (40, 43). Cultivating compassionate communities, therefore, requires transforming the social contexts of grieving and fostering grief literacy, which is a multidimensional skillset encompassing emotional, relational, and cultural competencies (68, 69). This study responds to these gaps by exploring how bereaved parents experience and interpret support interactions following the death of a child. Specifically, it examines parents' lived experiences of grief, their perceptions of supporters' responses, and the interactional and cultural mechanisms that facilitate or hinder adaptation.

Method

This study adhered to the Standards for Reporting Qualitative Research (SRQR; 70) and was cross-referenced against the Consolidated Criteria for Reporting Qualitative Research (COREQ; 71) to ensure comprehensive reporting of study design, researcher reflexivity, context, data collection, analysis, and trustworthiness. The study was conducted from a social constructionist perspective (48) within a constructivist–interpretivist paradigm (72, 73). This paradigm assumes that bereavement experiences are co-constructed through social interaction, embedded within cultural, relational, and contextual frames, and best understood through participants' narratives interpreted alongside the researchers' reflexive engagement (73). This lens acknowledges grief as both intrapsychic and interpersonal, situated in sociocultural contexts where meaning, identity, and expectations are negotiated over time. Researcher positionality and reflexivity are therefore viewed as integral to knowledge production rather than as sources of contamination (74).

A qualitative design was selected to capture the lived, interactional nature of bereaved parents' experiences. Reflexive thematic analysis (75, 76) was chosen for its flexibility and capacity to attend to both semantic and latent meanings, while recognising the researcher's active role in meaning-making. This approach was particularly suited to the aim of examining interactional and relational processes, as it allows exploration of explicit accounts and deeper interpretive layers.

Four theoretical frameworks provided interpretive scaffolding across the study. The DPM (20) sensitised analysis to oscillation between loss- and restoration-oriented coping. The IPM (21) directed attention to existential tensions such as meaning-meaninglessness and hope-despair. The IM-ISSB (66) highlighted the role of sociocultural grief norms in shaping exchanges of support. RRT (27) emphasised relational regulation and emotional synchrony in interactions. Collectively, these frameworks informed interview guide development, sensitised coding, and supported interpretation by situating moment-to-moment interactions within oscillatory, existential, relational, and cultural processes.

Researcher characteristics and reflexivity

The first author (JT), a registered psychologist and PhD candidate with extensive experience in grief counselling and bereavement research, conducted all interviews. She identifies as female and was engaged in both academic and clinical practice at the time of data collection. This background facilitated empathic attunement and rapport-building but also carried risks of interpretive influence. To mitigate these risks, reflexivity was embedded throughout the study (70, 71–77). The first author maintained a reflexive journal from study design through analysis, documenting assumptions, evolving interpretations, emotional responses, and potential influences of prior professional knowledge.

Consultation with co-authors provided opportunities to interrogate assumptions, challenge preliminary interpretations, and ensure coding decisions were grounded in participants' accounts. No prior relationships existed with participants before recruitment. Interviews were conducted as a dedicated research activity, separate from any clinical role, to minimise power differentials and avoid role confusion. Researcher stance was one of interpretive partnership, positioning participants as experts in their own experiences while acknowledging the co-construction of meaning between interviewer and interviewee (74, 75). Rapport was supported through pre-interview check-ins, participant-led choices of timing and modality, and flexibility for pauses or breaks. Emotional safeguards included reminding participants of their right to stop or skip questions, provision of bereavement resource lists at pre-interview and interview conclusion, intentional closing check-ins (“How are you feeling?”; “Do you have support available right now?”), and next-day follow-up where distress was evident. These measures prioritised wellbeing while enhancing integrity and trustworthiness (72, 73).

Sampling and participants

The study was conducted in Australia (Nov 2024–Feb 2025) within a predominantly White, English-speaking cultural context where informal networks are central to bereavement support. Purposive sampling recruited bereaved parents via bereavement organisations and social media, supplemented by snowball sampling to reach parents outside formal networks. Initial participants were approached by bereavement organisation facilitators acting as gatekeepers. Maximum variation was sought across parental gender,

cause of death, age at bereavement, and time since loss to capture a breadth of perspectives.

Eligibility required participants to be aged 18 years or older and to have experienced the death of a child at any time. Sixteen parents participated (13 women, 3 men), all identifying as White Australian (15 in Western Australia, 1 in Victoria). Ages ranged from 35–44 years ($n = 3$), 45–54 ($n = 3$), 55–64 ($n = 3$), to 65+ years ($n = 7$). Causes of death included illness, accident, drug overdose, suicide, sudden death, and stillbirth. Time since the child's death ranged from 4 months to 38 years (median = 8 years). Although purposive sampling captured a wide range of bereavement experiences, the sample was self-selecting and predominantly mothers, which may limit transferability to fathers and non-binary parents. The sample was also culturally homogenous, reflecting structural barriers to research engagement for culturally and linguistically diverse groups (78). Findings should therefore be interpreted within this Western sociocultural context (79, 80). Sample size was determined pragmatically, guided by thematic sufficiency (77) and Malterud et al.'s (81) principle of ‘information power’ rather than data saturation.

Ethical considerations

Approval was obtained from the Curtin University Human Research Ethics Committee (HRE2024-0582). Participation was voluntary, with informed consent secured electronically via Qualtrics. Participants were reminded of their right to withdraw at any stage without consequence. Given the sensitivity of the topic, all participants received pre- and post-interview resources for psychological support. No financial incentives were offered to minimise perceived coercion.

Data collection

Semi-structured interviews were conducted between November 2024 and February 2025 by the first author. Participants chose their preferred timing and modality: eight via Microsoft Teams, seven via telephone, and one in person. Remote options improved accessibility for bereaved parents in metropolitan, regional, and rural locations, reducing barriers to participation. Although video and telephone formats may have influenced rapport, participants reported comfort and openness in sharing through these media. Interviews (60 to 120 min) explored bereavement experiences, perceptions of support, coping, and relational changes.

Initially developed from bereavement literature (62, 82, 83) and theoretical frameworks (20, 21, 27, 66), the interview guide was refined iteratively to allow emerging ideas to shape the inquiry. Doing so is aligned with our epistemology and reflexive thematic analysis. Questions explored participants' bereavement experiences, perceptions of informal support, coping mechanisms, and relational changes. The guide combined open-ended core questions with prompts to elicit concrete examples and reflective meaning-making. These covered experiences of child loss (e.g., “Can you start by telling me something about your experience since the death of your child?”), support perceptions (e.g., “What form of support/help have you received from friends, family and others?”), coping mechanisms (e.g., “Have you experienced any growth and/or changes since you lost

your child?”), and relational changes (e.g., “Have any relationships been lost during your bereavement?”). The format remained flexible to support participant-led narratives, thereby enhancing emotional safety and generating rich, contextualised accounts. Potential power dynamics were mitigated by positioning participants as experts in their experiences and adopting a collaborative, interpretive stance. Interviews were audio-recorded (Microsoft Teams or Otter.ai), transcribed verbatim using Otter.ai, checked for accuracy, anonymised, and securely stored in accordance with university protocols.

Data analysis

Data were analysed using Braun and Clarke’s (75–77) reflexive thematic analysis, situated within a constructivist–interpretivist paradigm (70–71). This approach acknowledges themes as products of co-construction between researcher and participant, shaped by interpretation and reflexivity. Analysis followed six iterative phases: familiarisation through repeated transcript reading; inductive line-by-line coding; clustering codes into conceptual groupings; reviewing candidate themes for coherence; defining and naming themes to capture analytic essence; and producing the final report with illustrative quotes balancing interpretation with participants’ voices.

Three authors contributed to analysis. The first author coded all transcripts, and two co-authors independently reviewed the developing codes to refine categories, check consistency, and challenge assumptions. Differences in interpretations were resolved through iterative discussion and consensus. NVivo 14 was used for data organisation, consistent with reflexive thematic analysis principles (75–77). Themes were generated inductively, though interpretation was sensitised by grief frameworks (e.g., 20, 21, 27, 66). Attention was given to emotional tone, metaphors, and contradictions, with deviant cases actively examined to refine thematic boundaries. Theme refinement involved comparison across transcripts until coherence and distinctiveness were achieved. The development of themes followed an iterative and reflexive process consistent with reflexive thematic analysis. Early interviews highlighted a broad spectrum of positive and negative support experiences, which initially clustered together under general “helpful” and “unhelpful” categories. As interviews progressed, participants elaborated on the nuanced

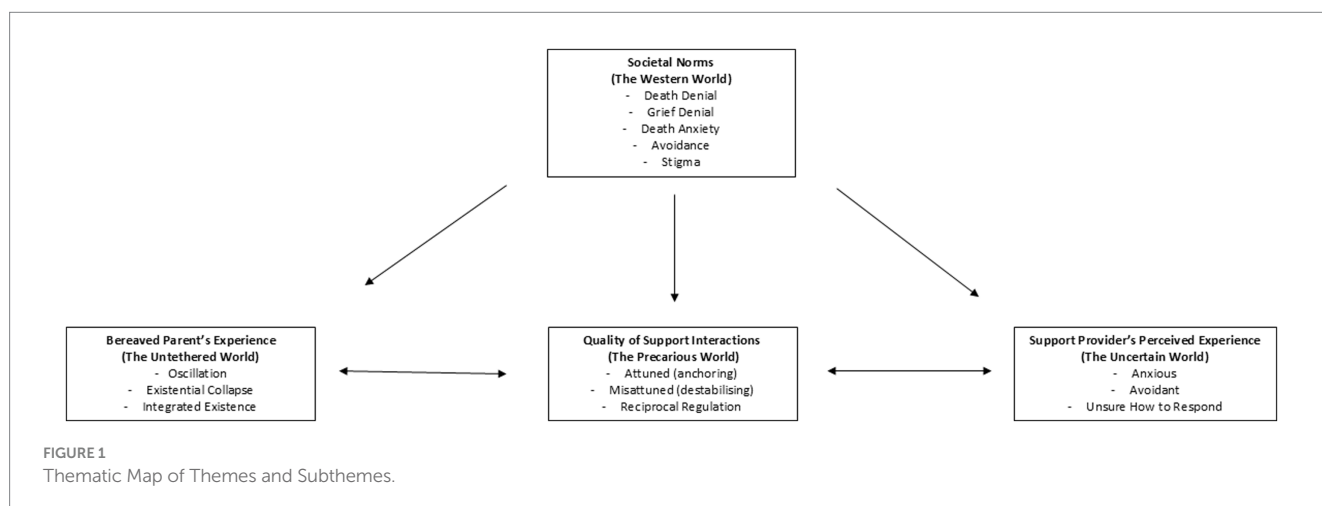
qualities that distinguished attuned support (e.g., presence, validation, and permission to grieve) from misattuned or harmful support (e.g., avoidance, judgement, or platitudes).

These emergent distinctions informed the refinement of the interview guide, with later interviews probing more specifically into how these differences were experienced and negotiated in everyday interactions. This iterative approach allowed the analysis to move beyond descriptive categorisation toward a deeper understanding of the reciprocal processes that shaped bereaved parents’ experiences of support. Thus, themes became valuable not simply through frequency but through their resonance, explanatory power, and recurrence across participants, refined progressively through cycles of coding, memoing, consultation among the team, and participant feedback. The final thematic map has four overarching themes and associated subthemes (Figure 1). An audit trail of memos, coding logs, and thematic maps documented analytic decisions (see [Supplementary materials](#)).

Rigour and trustworthiness

Rigour was supported through strategies consistent with SRQR (70) and COREQ (71) guidelines, with compliance tables provided in the [Supplementary materials](#). Trustworthiness was further addressed using Lincoln and Guba’s (73) criteria. Credibility was enhanced through prolonged engagement with the data, reflexive journaling, triangulation across interviews, field notes, and analytic memos, and member checking of preliminary thematic summaries. Seven participants provided feedback, ranging from affirmation of resonance (e.g., Ethan: “That certainly resonates”) to constructive critique (e.g., Mary: “Some of your statements resonated with me and some others did not...”). This process was treated not as verification but as a reflexive exchange that enriched interpretation; for example, Ruby’s reflection that “sometimes it feels like we live in the shadows of the grief... because it’s easier for those around us” informed the theme on societal discomfort and avoidance. Olivia likewise highlighted shared resonance: “It’s a comfort to know that it’s just not myself who feels the way I do...”

Dependability was supported through detailed documentation of analytic decisions, including reflexive journals, coding logs, and thematic maps. Confirmability was enhanced through reflexive



practice and consultation with co-authors, which challenged assumptions and explored alternative interpretations (70, 71). Transferability was promoted by providing rich description of participant characteristics, contexts, and verbatim quotations to enable readers to assess relevance to other settings (84). Transparency was maintained through detailed documentation of coding iterations, thematic maps, and decision trails. Member checking occurred with preliminary thematic summaries, with participants' feedback significantly informing refinement and contextual sensitivity. Finally, the quality of thematic analysis was benchmarked against Braun and Clarke's (85) 15-point checklist (see [Supplementary materials](#)). Pseudonyms were used throughout to protect identities.

Findings

The findings are organised into four interrelated themes: *Societal Norms (The Western World)*, *Bereaved Parents' Experiences (The Untethered World)*, *Potential Support Providers' Perceived Experience (The Uncertain World)*, and *Quality of Interactions (The Precarious World)*. Member checking confirmed the resonance and validity of this conceptualisation. Olivia wrote, "I think the report absolutely hits the nail right on the head... It's a comfort to know that it's not just myself who feels the way I do, which is beautifully summed up in the report, to the exact letter." Ethan similarly affirmed the framing, noting, "I love the way you have described the experiences as: Untethered, Uncertain, Precarious. That certainly resonates." Mary also highlighted both the challenge and value of thematic condensation: "You have to be commended for finding four common themes... some of your statements resonated with me and some others did not..." These comments affirmed the thematic core while recognising the inherent heterogeneity of individual grief experiences.

Societal norms (the Western world)

Parents consistently described navigating a cultural context characterised by discomfort, avoidance, and a demand for restraint. Their grief often triggered the silence and withdrawal of others, revealing Western norms that prioritise stoicism and productivity over vulnerability. Ethan shared, "It's that silence that almost feels suffocating, because no one knows how to respond... It's totally their anxiety." Zara echoed this sentiment: "I think society sticks their head in the sand... It's just too ugly a topic." This discomfort left many feeling emotionally abandoned. Ruby reflected, "People do not cope with grief... so they pretend it does not exist," while Naomi observed, "They change the subject, or they keep quiet." Stigma, especially around deaths involving suicide or drugs, further isolated parents. Lydia admitted, "I was worried about the opinions of the community," and Isla noted, "If your child dies by suicide, there's a fear of getting close to people like us... that it might be contagious." Liam attributed this avoidance to deeper fears: "They do not want to get the reality because they do not want to think about the possibility of this happening in their own family."

With regard to societal expectations, Liam suggested, "Impermanence and suffering contrast so starkly with societal norms... Our Western idea is to accumulate, to succeed." As such,

many parents faced pressure to resume normalcy. Zara said, "As soon as Paul's funeral was done. I went back to work. I'm not getting the space to heal." Ruby observed, "They give you about a couple of weeks," and Liam summarised societal expectations: "Be sad for a few months... but really, after a year, you should be over it." Emotional expression was often met with discomfort. Mary said, "Australians generally are not comfortable if you cry," and Chloe added, "It's 'you'll be all right, stop that'... just because the other person's uncomfortable."

These accounts were reinforced during member checking, where participants described how societal silence and avoidance reverberated through their everyday lives. Ruby concluded, "Sometimes it feels like we live in the shadows of the grief, not because we want to, but because it's easier for those around us who feel uncomfortable with our grief." Olivia echoed this resonance, explaining, "It's a comfort to know that it's just not myself who feels the way I do..." Together, these cultural scripts shaped how support was offered, withheld, or constrained, intensifying the precarity of the bereaved parent's experience.

Bereaved parents' experiences (the untethered world)

Bereaved parents consistently described their experience as an oscillation between two states: *Existential Collapse* and *Integrated Existence*. Existential Collapse represented profound disintegration across biological, psychological, and social domains. Parents described feeling emotionally paralysed, physically depleted, and existentially disoriented, as though their sense of self, purpose, and identity had been shattered. These moments often involved acute surges of longing, intrusive imagery, and a felt sense of the child's absence that was so overwhelming it eclipsed daily functioning and the ability to connect with others. In contrast, Integrated Existence captured moments of coherence, where parents were able to sustain an enduring bond with their deceased child while simultaneously re-engaging with life, whether through relationships, work, spiritual practice, or creative expression. This state allowed them to carry the loss in a way that fostered meaning-making, connection, and adaptive functioning. The dynamic and constant movement between the two states was often unpredictable and shaped by how viscerally present or absent their child felt in a given moment.

The depth of Existential Collapse was particularly evident in parents' accounts of the immediate aftermath of their child's death, which they experienced as a devastating rupture. Isla captured the cognitive and physical toll: "Deep grief is the inability to think straight," she said, adding, "I got sicker and sicker... you seem to catch every bug that goes past." Sophie described public spaces as triggering: "I have most of my panic attacks in Woolies [a supermarket] or Kmart," and Naomi added, "Everything distresses me. I just walk in the shopping centre, and sometimes I've just got to run out." The enormity of their loss led to overwhelming desolation. Zara reflected, "There's an awful hole in my life," and Olivia described it simply as "hell." Guilt and blame compounded distress. Ethan shared, "It feels like I could not protect him," and Liam noted, "Blaming and anger gave me a strong sense of connection, so I tended to hang on to them." Naomi added, "The guilt goes around and around... but she's dead... there's nothing I can do." Over time, grief became nihilistic. Eliza noted, "A lot of things do not matter anymore," and Mary stated, "Nothing can make up for it... I simply do not care." She continued,

“If I could give every cent that I had... and have Rosie back, I would do it”.

Beyond physical and psychological pain, many described a sense of disorientation. Lydia likened her grief to a phantom limb: “It’s like when someone has an amputee... they still have that connection.” Similarly, Naomi described, “It feels like a piece of my heart has been cut away and I cannot get it.” Some parents described wishing for death or reunion with their child. Freya said, “My hope was death,” and Lydia admitted, “I just want to be with my son. I just do not want to be here anymore.” Similarly, Isla recounted, “You’re wondering how your child is doing... what’s the use of living if they have died?” She summarised this shattered existence as, “We grow up, we have children... and then they die. That’s not right. It turns your order around.” Olivia captured such devastation in her statement, “I’ve had my dark night of the soul.” Time did little to soften this experience. Olivia explained, “People think it gets easier. It does not—it gets worse,” and Liam asserted, “The truth is grief goes on forever.” Social alienation further intensified the psychological collapse. Isla described, “You’re feeling like a stranger in a crowd. normal does not apply anymore,” and Mary exclaimed, “Do not they know the world has changed?” Collectively, these narratives reveal that child loss is a sustained existential crisis that reshapes one’s sense of self, others, and the world. Follow-up reflections during member checking further confirmed this experiential collapse. Freya, despite progress through EMDR therapy, admitted that “all the negative experiences in your summary resonated... unfortunately”.

Despite enduring grief, many parents described ways they integrated grief. Ethan explained, “I made a conscious decision when Kyan passed that I would find grace and beauty in life.” Ilsa described grief as multidimensional: “We have to address the physical, emotional, and spiritual aspects of ourselves, and redefine all three,” and Mary reflected on the transformation process, “You become a deeper, more compassionate, and kind person.” Alongside processing pain, participants described the necessity of continuing daily life, as Ruby noted, “You do not get over it, but you do get on with it”.

Central to this process was maintaining a bond with the deceased child. Jasmine described “doing things that are keeping him alive,” and Liam reframed grief as love: “It’s about love when you flip it around.” Symbolic rituals helped maintain this connection. Freya shared, “We write messages for her, and we send them up with some forget-me-not seeds,” and Ethan emphasised remembrance: “I feel I want to talk about him. I do not want him to be forgotten.” Relationships with their child’s friends also offered a continued connection. Lydia said, “I have a really good relationship with my son’s friends, so I get to see myself grow a bit with them.” Some intimate partnerships strengthened as reflected by Amelia, “The marriage we have is the saving grace... we are just there for each other.” Additionally, peer support was profoundly validating. Jasmine shared, “You hug someone that’s bereaved, and you can just tell by the hug that they get it.” Conversely, many recalibrated their social worlds. Ruby noted, “I have lost a huge circle of friends”.

Grief was described as a non-linear process characterised by oscillation between the states of coherence and collapse. Lydia noted, “You actually do not know how you are feeling... and that feeling can switch from 1 sec to the next,” and Jasmine echoed, “It’s different every day with me.” Social misunderstanding compounded this fluctuation. Jasmine shared, “If you happen to be happy 1 day... then you are down the next, they ask what’s wrong with you.” Meanwhile, grief often

resurfaced unexpectedly. Liam said, “It changes and morphs... then may come back to bite you even 10 years later,” and Ruby added, “You’ll smell a smell, and it can take you right back to that moment”.

Emotional expression varied widely. Sophie noted, “Some days I can talk about Benjamin and not cry at all, and some days I cannot even mention his name.” Olivia explained, “I go backwards and forwards in my grief... I might get a little bit sociable, and then I might retreat.” Metaphors captured this shifting terrain. Amelia said, “The waves hit you... they crash into you at the same intense strength they did right when it happened,” and Jasmine described it as “a rollercoaster.” Despite the pain, moments of gratitude and love coexisted with loss. Zara reflected, “I try to connect to the gratitude and the joy of him... sometimes it’s quite easy... and other times it’s really not.” Ultimately, these fluctuations between the existential presence and physical absence of the child shaped whether parents felt grounded in integrated existence or pulled toward existential collapse.

Alongside oscillation between existential collapse and integrated existence, spirituality emerged as a vital regulating tool. Parents described spiritual encounters and practices as means of restoring coherence when faced with overwhelming grief. Lydia reflected, “I cannot stress enough about the spirituality side of things, because it’s not in the textbooks.” For her, spirituality provided a framework for integration that was not available in formal supports. Several parents described continuing bonds with their child through spiritual connection, dreams, or sensing their presence. Others found solace in legacy-building, such as community rituals or symbolic acts. Legacy-building offered meaning and purpose. Amelia shared, “People love that we do so much in Samuel’s name... fundraising and tree planting,” and Olivia described advocacy as “my life work now.” Spirituality was described as the most transformative element. Naomi recalled, “I could feel her lying next to me,” and Amelia summarised, “I’ve never really been particularly spiritual... but now I believe in a greater universe and signs, and that’s what gets me through my days... Samuel sends me signs... and comes to me in dreams... It’s become a new way of living.” These connections helped bridge the gap between enduring existential presence and physical absence. Ruby described this transformation as “It absolutely is my defining moment, because it is pre and it’s post.” Ultimately, integration was ongoing, shaped by enduring love, spiritual connection, and altered world views. These spiritual experiences enabled parents to remain tethered to their child and find moments of coherence amidst collapse, even when external support faltered.

Lydia, in her member-checking feedback, observed that “most, if not all, bereaved parents have experienced some form of spiritual encounter or connection with their child.” She also highlighted the diversity of responses to continuing bonds, noting that although legacy building is “very important to some, others just want to forget and move on.” At the same time, she highlighted that “commonly parents have contemplated suicide themselves.” Eliza highlighted the enduring gap left by child loss, contrasting it with other types of bereavement: “When a child is lost... there’s not the same opportunity to fill the gap that’s been lost.” Taken together, both the original interviews and the member-checking process underscored that child loss constitutes a sustained existential crisis, punctuated only intermittently by moments of integration anchored in enduring love, spirituality, and meaning-making.

Potential support providers' perceived experience (the uncertain world)

Following the death of a child, bereaved parents became acutely sensitive to how others internally experienced and responded to their grief. Here, parents turned their gaze outward, speculating on the inner states of those around them, whether they seemed grounded, open and attuned to the parent's needs, or uncomfortable, avoidant, and misattuned to the parents' needs. These perceptions shaped how parents navigated their social worlds, informed whom they trusted, and influenced the boundaries they set around emotional exposure.

Some parents described supporters whose inner qualities allowed them to remain steady in the face of profound sorrow. These individuals were perceived as emotionally grounded, authentic, and spiritually open. Lydia appreciated her friend's capacity for honesty and encouragement: "She does not sugar coat things, you know? She encourages me and has helped me, especially spiritually." Freya interpreted her supporter's simple presence as the ability to tolerate grief without fear: "She just held me and I cried, and she just said, you know, just let it go." For Liam, silence itself was evidence of inner composure: "The bereaved person needs silence... to just be sitting there... and maybe bring a bar of chocolate." Zara emphasised the rarity of genuine compassion, explaining: "To be in the company of someone who absolutely gets it is a gift. Really. It's rare." In these accounts, parents attributed helpful support not only to external behaviours, but to the internal steadiness, honesty, or compassion of the provider. This perceived inner capacity created emotional safety, validating grief without judgement or pressure to "move on".

Conversely, many parents described interactions that suggested others were unable to emotionally tolerate their grief. These misattuned responses were interpreted as discomfort, avoidance, or self-centring, which intensified parents' feelings of abandonment. Jasmine reflected on her sister's silence: "[She] will not mention Jason's name, and she does not mention Robert at all. I think she does not know what to say." Zara noted the defensiveness of others: "People do not know what to say, and they are also glad it's not them... and I do kind of get that." Parents often attributed avoidance to supporters' inability to cope, with Lydia observing, "People will cross the street so they do not have to talk to you." Eliza interpreted silence as self-protective: "People do not bring him up... I think it's for them. I think it's to protect them".

Other examples revealed supporters becoming overwhelmed by their *own* grief, leaving parents feeling displaced. Sophie recalled, "My sister-in-law was a bloody mess... acting like it was her child who had died... she'd message me with all her grief problems." Ethan acknowledged the limits of compassion without lived experience: "I do not expect parents that have not lost a child to provide support... but I get it." Sophie added, "If it had not happened to me... I do not know if I would have been the most supportive person." Some interactions went further, where parents perceived supporters' internal states as judgemental or blaming. Lydia confided, "He does not love me anymore if he can think that I was the cause of losing our son." Freya felt silently judged: "I felt like everyone was thinking it was my fault." Such misattuned inner positions were profoundly wounding, compounding guilt and shame, and reinforcing withdrawal.

Ultimately, parents interpreted platitudes, silence, redirection, or judgement as support provider discomfort and avoidance. These interactions challenged the parents' sense of relational safety and

highlighted the difficulty for support providers to effectively navigate the support exchange process. Lydia's member checking feedback summarised the emotional toll of this pattern: "Missattuned support [elicits] feelings of abandonment and invalidation... This I am experiencing".

These perceptions of supporters' internal states, whether marked by openness, avoidance, or emotional paralysis, did not remain abstract impressions. Rather, they became visible and consequential in the lived dynamics of interaction. In other words, the ways supporters managed their own discomfort or steadiness directly shaped the quality of bereavement support interactions. This transition from internal perception to enacted relational experience is explored in the following theme, the Precarious World, where the fragility of social interactions is revealed through moments of attunement that stabilised parents, or misattunement that deepened their sense of isolation.

Quality of interactions (the precarious world)

The fourth theme explores how the quality of social interactions shaped bereaved parents' lived experience of support. Whereas the Potential Support Providers Perceived Experience theme focused on how parents perceived the inner emotional capacities of potential supporters, the Quality of Interactions theme describes how these internal states were enacted in practice and co-regulated in the relational space. Interactions were precarious because they could tip parents toward stability or collapse depending on whether they were experienced as attuned or misattuned.

When supporters' internal steadiness translated into behaviours of openness, honesty, or gentle presence, interactions were described as profoundly anchoring. Lydia captured this sense of attuned synchrony, "Just that connection without even any words." Ethan described the power of minimal but embodied presence, "She just put her hand on my arm. And that's all it took." Letting parents lead the conversation was key. Lydia explained, "You have to let them release what they want to say," and Sophie described helpful conversations as characterised by "ebbs and flows." Ruby valued the freedom to "feel what you need to feel," and Isla reflected, "My grief was being validated." Speaking the child's name was deeply meaningful. Amelia shared, "It brings us so much joy to hear someone say Samuel's name." Naomi added, "It does not hurt if you talk about Julie." Isla remarked, "If you do not talk about Nathan, it's as if he was never here".

Symbolic gestures also offered comfort. Ethan shared, "I carried that poem she gave me for so long," and Amelia appreciated the consistency of a friend: "Sophie has sent me an emoji every single day." Meanwhile, witnessing other bereaved parents' adaptation fostered hope. Isla noted, "If they can do it, so can I." Trust was the foundation of helpful support. Zara expressed, "You just want a safe space... to catch you when you fall." Crucially, these were not abstract perceptions of supporters' capacities, but lived moments where grief was shared, mirrored, and held.

Interactions also carried risk. When perceived discomfort in the supporter manifested outwardly as avoidance, platitudes, or judgement, parents described feeling destabilised. Ruby pleaded, "Why are you avoiding me? I just need a hug." Emotional incompetence compounded the issue. Lydia described awkward

probing: “Some people poke the bear... they start shooting questions at you,” which Liam called “a lack of emotional skills or empathy.” Amelia rejected praise framed as strength: “We do not get a choice to be brave.” Passive offers were also frustrating. Chloe questioned, “They say ‘ring me if you need me.’ Why do I have to reach out to you?” Isla added, “We’re the ones that are hurting”.

Judgement and blame were especially damaging. Lydia worried about stigma. “It was a result of taking drugs... are they going to presume he was a drug addict?” Freya recalled, “My brother said... [if you had done something different] maybe she would have been fixed up early.” Moreover, dismissive responses caused distress, with Isla sharing a colleague’s dismissal: “I do not believe in grieving... I just get on with it.” Mismatched grieving styles also caused friction. Mary explained, “He wanted to talk, but I wanted to be with my own grief,” and Freya observed, “We’re on totally different wavelengths.” During member checking, Eliza remarked, “I know also that loss of a child can cause a marriage to break down. I can understand that from my own experience, as I know I have at times withdrawn into myself a lot, and some partners who grieve differently or at a different rate may find this difficult.” Furthermore, disempowerment occurred when grieving choices were overridden. Amelia warned potential support providers, “Do not give advice... even if you have lost a child, you still cannot give advice to that person.” These misattuned interactions often led parents to withdraw socially, intensifying their sense of vulnerability.

What made interactions precarious was the process of reciprocal regulation - the mutual shaping of emotional states between parent and supporter. Lydia explained, “If someone’s made you feel safe... you open up more, and they open up more.” Mary reflected, “It is my responsibility to tell them... unless you let them know, they will not understand... so, you cannot just blame them.” Chloe described co-regulation: “She just held me and I cried.” Mutual support among bereaved parents was particularly meaningful. Olivia said, “We support each other... we see each other’s souls.” Yet over time, parents became discerning about who could “hold” their grief. Parents sometimes sensed the supporter’s discomfort and responded by shielding or suppressing their own grief to protect the other from distress. In these moments, parents were not being comforted but rather regulating the emotional equilibrium of the supporter. Other times, withdrawal was enacted to preserve their own stability. As Chloe explained, “I’ve got to pull away... for my own sanity.” Sophie echoed this, “I definitely do not have the capacity to try anymore.” Such patterns illustrate that regulation was not a one-way process; bereaved parents actively co-regulated the relational field by modulating what they expressed or withheld.

Ultimately, helpful support was not defined by solutions, but by emotional synchrony. Relationships that offered presence, trust, and attunement became steadying anchors whereas those marked by avoidance and misattunement often dissolved. Reciprocal regulation was always in play, either stabilising or destabilising, depending on the quality of the interaction. Member checking feedback corroborated this theme, with Lydia remarking on the importance of “Finding the right fit.” She added, “Parents are very protective of who they tell their story to [and can be left] feeling vulnerable and isolated.” Ultimately, as Lydia’s feedback affirms, the quality of interactions hinged on emotional synchrony, not solutions. When interpersonal support was misattuned or absent, parents often turned to spirituality as a fallback form of regulation. For some, spiritual practices functioned as a substitute for the safety and anchoring that supportive relationships might otherwise provide. In her member checking statement, Lydia emphasised the

protective value of spirituality: “Spiritually: most if not all bereaved parents have experienced some form of encounter/connection”.

Discussion

Bereaved parents in this study described grief as an oscillating, unpredictable process marked by shifts between existential collapse and moments of coherence. Their experiences align with contemporary grief models, particularly Stroebe and Schut’s DPM (20), which frames adaptive coping as oscillation between loss- and restoration-oriented processes. However, participants’ descriptions extended beyond functional coping strategies, revealing deeper existential instability, where grief disrupted their sense of self, others, and the world. To better account for this experience, Guldin and Leget’s IPM (21) adds nuance by identifying five existential polarities: meaning vs. meaninglessness, connection vs. isolation, order vs. chaos, control vs. helplessness, and hope vs. despair. The IPM views these tensions as persistent, lived polarities that bereaved individuals must continually navigate. Rather than being tasks to complete, these tensions are recurring experiential movements. Importantly, the IPM foregrounds the non-pathological nature of oscillation, presenting it as the very terrain through which adaptation unfolds (21).

Parents navigated these tensions continuously, often expressing competing needs, such as speaking openly versus protecting themselves, or connecting spiritually while simultaneously confronting despair. These existential fluctuations resonate with Relational Dialectics Theory (86), which conceptualises relationships as ongoing negotiations of opposing needs. Consistent with findings by Toller (87) and Hooghe et al. (88), participants oscillated between openness and emotional withdrawal, calibrating their level of expression based on the perceived safety of their relational context. Supportive responses—those marked by compassion and non-judgement—tended to foster emotional openness in the bereaved parents. In contrast, when interactions were coloured by judgement, discomfort, or misunderstanding, the bereaved parents often withdrew or silenced themselves.

Crucially, this study extends existing knowledge by illuminating *why* potential support may fail to help: it is not merely the presence or absence of support that matters, but how well it aligns with the bereaved person’s fluctuating relational and emotional needs. The dynamic interplay between bereaved parents and their informal support networks revealed that even well-intended support could be unhelpful when it fails to attune to these oscillations. This insight highlights the novel contribution of our study, shedding light on the interpersonal micro-dynamics that underlie failed support interactions and offering a nuanced understanding of how and why relational support interactions may both help and harm in the context of grief.

This relational dissonance was not only interpersonal but deeply existential, echoing broader philosophical-phenomenological accounts that frame grief as a fundamental disruption to one’s experience of the world. These accounts, particularly those of Ratcliffe (89), Brison (90), Humphreys (91), and Attig (92), offer further insight into the altered fabric of the bereaved’s existence. Ratcliffe (89) suggested grief alters the very structure of lived experience, creating a world suffused with a “spectral existence” of the deceased. Participants in this study exhibited this phenomenon, describing feeling the presence of their child as a persistent yet intangible absence, neither

fully present nor entirely gone. Meanwhile, Attig (92) defines grief as a process of relearning the world, and participants reported repeated and painful confrontations with a world rendered unfamiliar and devastated by the absence of their child.

Emerging within this existential rupture is our core finding of reciprocal regulation, which is the mutual influence between bereaved parents and support providers. While grief reconfigured participants' worlds, their social interactions with others either anchored them momentarily within that world or exacerbated their distress. Within a broader sociocultural context marked by grief and death denial, these interactions became emotionally charged exchanges. The concept of relational regulation (27) captures this dynamic, where attunement or misattunement functions as a mechanism of emotional mirroring. Attuned social support, defined by emotionally safe presence, validation, and acknowledgment of the parents' continuing bond with their child, helped parents remain anchored in moments of coherence and connection. Conversely, misattuned interactions, characterised by avoidance, incompetence, or discomfort, were typically mirrored by the parent, prompting their silence, withdrawal, or disengagement. Some participants perceived such responses as stemming from unacknowledged death anxiety, which posits that grief can provoke defensive reactions in others when mortality salience is high (56).

Although "attunement" is often used descriptively in bereavement research, our findings highlight the need to unpack what it entails in practice. Attunement refers not simply to the provision of support, but to the supporter's capacity to sense accurately, resonate with, and flexibly respond to the bereaved parent's fluctuating emotional state. Consistent with Barboza et al. (93) and Barboza and Seedall (94), attunement can be understood as a dynamic process of relational resonance, in which compassion, emotional availability, and responsiveness converge to create a sense of being understood and accompanied. Parents described attunement as occurring when supporters were able to be fully present, validate their grief, and tolerate emotional intensity without avoidance, judgement, or pressure to "move on." Mechanisms underpinning attunement included affective compassion, experiential resonance (particularly within peer relationships), and behavioural adaptability that allowed the bereaved to oscillate naturally between silence and disclosure, grief and restoration.

Attunement was often difficult for supporters to sustain because bereaved parents' grief was itself oscillatory and unpredictable. As parents moved between collapse and coherence, their needs for closeness, distance, or silence shifted, sometimes rapidly. Supporters who lacked tolerance for this ambiguity often withdrew or defaulted to platitudes. As Barboza et al. (93) suggested, attunement requires comfort with emotional complexity, ambiguity, and loss of control—qualities not well supported in Western cultures shaped by grief denial and death anxiety. Our findings also suggest that withdrawal can function in two ways: as a self-protective form of regulation (e.g., "I needed to pull away for my sanity") and as a co-regulatory strategy aimed at protecting others (e.g., masking grief to shield supporters from discomfort). These dual roles highlight the fragility of attunement and explain why it is both deeply valued and often absent.

The significance of reciprocal regulation becomes even more apparent when considered alongside the psychological vulnerabilities commonly experienced by bereaved parents. Many parents described symptoms consistent with diagnostic criteria for PTSD, PGD, and depression (95). Regularly co-occurring with the death of a child (8, 11), these disorders

amplify emotional vulnerability and relational sensitivity, rendering the quality of interpersonal interactions especially consequential. Among the parents, symptoms of PTSD, such as hypervigilance, intrusive thoughts, and emotional dysregulation, characteristically increased reactivity to perceived emotional incompetence or relational threat, consistent with prior findings (96, 97). Similarly, the core features of PGD, including persistent yearning, identity disintegration, and existential despair, were frequently intensified by dismissive, invalidating, or judgemental responses, an observation that aligns with established literature (11). Depressive symptoms such as anhedonia, hopelessness, and social withdrawal further constrained parents' capacity to seek and accept support, limiting opportunities for co-regulation, as observed by Vance et al. (13). In contrast, attuned interactions created spaces of safe containment, allowing parents to remain relationally, physically, and spiritually tethered.

A notable nuance in the findings concerns parents' descriptions of wishing for death or reunion with their child. Although some accounts were initially coded as suicidal thoughts (e.g., "I just do not want to be here anymore"), closer reflection suggested that many of these were more accurately *death-related fantasies*. These expressions are well-documented in grief literature, especially among bereaved parents, and reflect a longing for reunion or an escape from suffering rather than an intent or plan to enact self-harm (98–100). Distinguishing between suicidality and fantasies of death is clinically important, as the latter are typically an aspect of the yearning that defines grief rather than indicators of psychiatric crisis. This nuance underscores the need for support providers, clinicians, and researchers to interpret parents' words within the relational and existential context of bereavement, ensuring that expressions of longing are understood and responded to with sensitivity rather than automatically pathologised.

Amid these psychological and relational vulnerabilities, many parents turned to spirituality as a crucial resource for regulation, enabling a continued connection with their child that helped restore coherence in the aftermath of profound loss. Fourteen of the 16 participants described spiritual experiences, such as dreams and signs as vital to sustaining a sense of connection with their child. These experiences are consistent with the continuing bonds (CB) framework (101), which emphasises the symbolic and relational persistence of the deceased in the lives of the bereaved. These spiritually mediated connections resembled *internalised* CB expressions, involving symbolic representations of the deceased maintained through memory, imagination, or felt presence (102). Internalised forms of continuing bonds have been shown to reduce grief intensity and support psychological adjustment, particularly for bereaved parents (103, 104). Spirituality, in this context, functioned both as a regulatory and integrative force, offering a framework for identity reconstruction, existential grounding, and ongoing attachment to the deceased child. While some participants drew on traditional religious narratives, others embraced intuitive, personalised forms of spirituality, consistent with Burke and Neimeyer's (105) findings on individualised coping.

In contrast, *externalised* CB expressions, such as seeing or hearing the deceased, preserving their possessions unchanged, or engaging in ritualistic behaviours, have been linked to heightened distress and poorer grief outcomes, particularly in early or unresolved grief (104, 106–109). These expressions are marked by efforts to sustain a concrete connection with the deceased, reflect difficulty accepting the loss (106), and are common among parents whose children died suddenly or violently (108). Several participants who reported externalised CBs also described symptoms consistent with PTSD and PGD, reinforcing their associations with negative grief outcomes (107–109).

Overall, participants demonstrated use of both internalised and externalised CBs, which corresponded to differing grief trajectories. Consistent with Field et al. (108), spiritual experiences, particularly those involving transcendent or symbolic connections, were frequently perceived by the parents as comforting and stabilising. As such, spirituality may be understood as a protective regulatory process that supports the transformation of externalised grief into an internalised, adaptive, and enduring bond (110–112).

These relational and spiritual findings converge within the IM-ISSB (66), which conceptualises informal social support attempts as a reciprocal process shaped by individual, relational, and sociocultural factors. According to this model, effective support is marked by openness, sensitivity, and self-efficacy. Participants' accounts affirmed the IM-ISSB's core claim that attuned support enables mutual regulation, trust, and reintegration. Conversely, the model also posits that fear, avoidance, or cultural taboos undermine the potential for connection and integration. Congruent with this assertion, most parents described potential support providers as often emotionally paralysed, fearful of saying the wrong thing or overwhelmed by their own discomfort. These responses reflect broad Western cultural scripts that tend to demand rapid adaptation, suppress grief, and reward productivity over presence (49–51).

Such sociocultural dynamics are further illuminated by Terror Management Theory (63, 64), which offers a psychological explanation for the avoidance and discomfort observed in many support providers. It posits that death anxiety elicits defensive reactions such as denial, rationalisation, or retreat into cultural worldviews that promote control, growth, and permanence. When confronted with raw, enduring grief such as the loss of a child, these buffers are threatened, and support providers may instinctively minimise, distract, or withdraw. For bereaved parents, this retreat is often experienced as abandonment or invalidation, further complicating their grief trajectory.

Recognising the influence of these underlying defence mechanisms, it becomes essential to explore how such dynamics manifest across different cultural and demographic groups, and how support providers themselves experience and respond to bereavement-related distress. These future directions emerge within a broader societal context marked by growing interest in compassionate communities (67). Although this framework rightly emphasises the importance of social networks in bereavement support, it risks assuming that individuals and communities already possess the knowledge and emotional resources to provide meaningful and effective social support (68). However, as the present study showed, families and friends are not always well-equipped to meet the complex and evolving needs of the bereaved (40, 41, 68). A paradigm shift is needed that moves beyond rhetorical endorsements of communal care toward meaningful investment in both specialised services and community capacity. This involves expanding the breadth of care so that specialised services are developed and available, while also building the community's capacity to provide responsive and compassionate support (68). Only by fostering relational attunement and transforming the social contexts within which grieving occurs can the ideals of compassionate communities be achieved.

Limitations

Despite employing strategies to enhance trustworthiness, including reflexivity, member checking, and an audit trail, several limitations must be acknowledged. The sample consisted primarily of mothers (13 of 16), potentially overrepresenting

maternal perspectives. Participants were all based in Australia and recruited through bereavement networks and snowballing, possibly attracting parents more engaged in support-seeking and limiting transferability to those who grieve privately. Perspectives from culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander peoples, and parents at very early or prolonged stages of grief were underrepresented. Data were self-reported through in-depth interviews, aligning with the study's focus on subjective meaning-making but not capturing observed behaviours (113). Microsoft Teams meetings and telephone calls may also have shaped rapport, though participants reported feeling comfortable.

Findings were co-constructed within a reflexive thematic analysis framework (75, 76), meaning researcher positionality shaped interpretation. Reflexivity, debriefing, and member checking mitigated this. Although member checking enhanced credibility due to the affirming nature of the feedback, only some participants responded, meaning that our interpretations might not reflect all perspectives. Notably, the findings are situated within a Western sociocultural context where grief is marginalised, and stoicism prioritised. Concepts such as continuing bonds or societal avoidance may not translate across cultures, particularly in collectivist contexts with communal grief practices (114). As such, the findings provide contextually rich insights that may be transferable where resonance is recognised (73). Importantly, the sample consisted entirely of White Australian parents. Although recruitment was open to all, this outcome likely reflects wider barriers to participation for minority and Indigenous populations, including stigma, mistrust, and reduced access to bereavement networks (115). Cultural norms strongly shape grieving practices and support processes; for example, communal and ritualised forms of support common in collectivist contexts may foster different dynamics of reciprocal regulation than those observed here in a Western setting (114, 116, 117). Future research should therefore explore how attunement, misattunement, and continuing bonds manifest across in communities where cultural scripts for grieving may create distinct opportunities and challenges for support.

Finally, this study captured only the perspectives of bereaved parents as recipients of informal social support. While this focus offers valuable insight into their lived experiences, informal support exchanges are inherently relational. Future research should aim to examine both perspectives in these dyadic interactions. Investigating both sides of the exchange (i.e., perspectives of bereaved parents and people who aim to support them) would generate a fuller understanding of how attunement or misattunement arise in practice and illuminate the relational dynamics that either facilitate or hinder meaningful support. Such dyadic approaches would also provide stronger foundations for grief literacy initiatives by directly informing training and resources that are responsive to the needs of both providers and recipients.

Conclusion

This study explored how bereaved parents navigate grief following the death of a child, identifying four intersecting "worlds": the Western World (Societal Norms), the Untethered World (Bereaved Parents'

Experience), the Uncertain World (Perceived Support Provider Experience), and the Precarious World (Quality of Interactions). Across these domains, the process of reciprocal regulation emerged as central. Attuned, consistent, and non-directive support offered grounding, whereas avoidance, judgement, or insensitivity intensified collapse and isolation. Situated within a Western sociocultural context that often silences grief, many parents sought solace in spiritual or symbolic continuing bonds to remain connected to their child. These findings highlight grief as simultaneously individual, relational, and cultural, shaped by the capacity of others to respond with attuned presence rather than misattuned avoidance. Implications extend to policy and practice. Building community grief literacy, equipping support providers with interactional and communication skills, and strengthening peer networks and professional services can create environments where grief is acknowledged rather than marginalised. By fostering reciprocal, attuned support, communities can mitigate isolation and promote long-term well-being for bereaved parents.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Curtin University Human Research Ethics Committee (HREC). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

JT: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Writing – original draft, Writing – review & editing. LB: Conceptualization, Project administration, Resources, Supervision, Validation, Writing – review & editing. DR: Conceptualization, Resources, Supervision, Writing – review & editing.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. Josephine Tognela is

supported by an Australian Government Research Training Program Scholarship.

Acknowledgments

The authors thank the bereaved parents who participated in this study.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Correction note

This article has been corrected with minor changes. These changes do not impact the scientific content of the article.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

Any alternative text (alt text) provided alongside figures in this article has been generated by Frontiers with the support of artificial intelligence and reasonable efforts have been made to ensure accuracy, including review by the authors wherever possible. If you identify any issues, please contact us.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2025.1659628/full#supplementary-material>

References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 3rd ed. Washington, DC: American Psychiatric Association (1987).
2. Dyregrov K, Nordanger D, Dyregrov A. Predictors of psychosocial distress after suicide, SIDS and accidents. *Death Stud.* (2003) 27:143–65. doi: 10.1080/07481180302892
3. Meert KL, Shear K, Newth CJL, Harrison R, Berger J, Zimmerman J, et al. Follow-up study of complicated grief among parents eighteen months after a child's death in the Pediatric intensive care unit. *J Palliat Med.* (2011) 14:207–14. doi: 10.1089/jpm.2010.0291
4. Snaman JM, Kaye EC, Torres C, Gibson D, Baker JN. Parental grief following the death of a child from cancer: the ongoing odyssey. *Pediatr Blood Cancer.* (2016) 63:1594–602. doi: 10.1002/pbc.26046
5. Middleton W, Raphael B, Martinek N, Burnett P. A longitudinal study comparing bereavement phenomena in recently bereaved spouses, adult children and parents. *Aust N Z J Psychiatry.* (1998) 32:235–41. doi: 10.3109/00048679809062734
6. Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B, Hegney D. Who needs bereavement support? A population based survey of bereavement risk and support need. *PLoS One.* (2015) 10:10. doi: 10.1371/journal.pone.0121101

7. Kaltman S, Bonanno GA. Trauma and bereavement: examining the impact of sudden and violent deaths. *J Anxiety Disord.* (2003) 17:131–47. doi: 10.1016/S0887-6185(02)00184-6
8. Kristensen P, Weisæth L, Heir T. Bereavement and mental health after sudden and violent losses: a review. *Psychiatry Interpers Biol Processes.* (2012) 75:76–97. doi: 10.1521/psyc.2012.75.1.76
9. October T, Dryden-Palmer K, Copnell B, Meert KL. Caring for parents after the death of a child. *Pediatr Crit Care Med.* (2018) 19:S61–8. doi: 10.1097/PCC.0000000000001466
10. Wiener L, Rosenberg AR, Lichtenthal WG, Tager J, Weaver MS. Personalized and yet standardized: an informed approach to the integration of bereavement care in pediatric oncology settings. *Palliat Support Care.* (2018) 16:706–11. doi: 10.1017/S1478951517001249
11. Shear MK. Complicated grief. *N Engl J Med.* (2015) 372:153–60. doi: 10.1056/NEJMcip1315618
12. Rubin S, Malkinson R. Parental response to child loss across the life cycle: clinical and research perspectives In: M Stroebe, R Hansson, W Stroebe and H Schut, editors. *Handbook of bereavement research: Consequences, coping, and care.* Washington, DC: American Psychological Association (2001). 219–40.
13. Vance JC, Najman JM, Boyle FM, Embelton G, Foster WJ, Thearle MJ. Alcohol and drug usage in parents soon after stillbirth, neonatal death or SIDS. *J Paediatr Child Health.* (1994) 30:269–72. doi: 10.1111/j.1440-1754.1994.tb00632.x
14. Videka-Sherman L. Coping with the death of a child: a study over time. *Am J Orthopsychiatry.* (1982) 52:688–98. doi: 10.1111/j.1939-0025.1982.tb01458.x
15. van den Berg GJ, Lundborg P, Vikström J. The economics of grief. *Econ J.* (2017) 127:1794–832. doi: 10.1111/econj.12399
16. Holmes TH, Rahe RH. The social readjustment rating scale. *J Psychosom Res.* (1967) 11:213–8. doi: 10.1016/0022-3999(67)90010-4
17. Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. *Lancet.* (2007) 370:1960–73. doi: 10.1016/S0140-6736(07)61816-9
18. Folkman S. Revised coping theory and the process of bereavement In: S Folkman, editor. *Handbook of Bereavement research: Consequences, coping, and care.* Washington, DC: American Psychological Association (2001). 563–84.
19. Lazarus RS, Folkman S. Transactional theory and research on emotions and coping. *Eur J Personal.* (1987) 1:141–69. doi: 10.1002/per.2410010304
20. Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. *Death Stud.* (1999) 23:197–224. doi: 10.1080/074811899201046
21. Guldin MB, Leget C. The integrated process model of loss and grief – an interprofessional understanding. *Death Stud.* (2024) 48:738–52. doi: 10.1080/07481187.2023.2272960
22. Cobb S. Social support as a moderator of life stress. *Psychosom Med.* (1976) 38:300–14. doi: 10.1097/00006842-197609000-00003
23. Barrera M. Distinctions between social support concepts, measures, and models. *Am J Community Psychol.* (1986) 14:413–45. doi: 10.1007/BF00922627
24. Breen LJ. Harnessing social support for bereavement now and beyond the COVID-19 pandemic. *Palliat Care Soc Pract.* (2021) 15:1–4. doi: 10.1177/2632352420988009
25. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull.* (1985) 98:310–57. doi: 10.1037/0033-2909.98.2.310
26. Hupcey JE. Clarifying the social support theory-research linkage. *J Adv Nurs.* (1998) 27:1231–41. doi: 10.1046/j.1365-2648.1998.01231.x
27. Lakey B, Orehek E. Relational regulation theory: a new approach to explain the link between perceived social support and mental health. *Psychol Rev.* (2011) 118:482–95. doi: 10.1037/a0023477
28. Scott HR, Pitman A, Kozhuharova P, Lloyd-Evans B. A systematic review of studies describing the influence of informal social support on psychological wellbeing in people bereaved by sudden or violent causes of death. *BMC Psychiatry.* (2020) 20:1–20. doi: 10.1186/s12888-020-02639-4
29. Taylor S. Social support: a review In: HS Friedman, editor. *The Oxford handbook of Health Psychology.* Oxford: Oxford University Press (2020). 189–214.
30. Wang J, Lloyd-Evans B, Giacco D, Forsyth R, Nebo C, Mann F, et al. Social isolation in mental health: a conceptual and methodological review. *Soc Psychiatry Psychiatr Epidemiol.* (2017) 52:1451–61. doi: 10.1007/s00127-017-1446-1
31. Aoun SM, Breen LJ, White I, Rumbold B, Kellehear A. What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach. *Palliat Med.* (2018) 32:1378–88. doi: 10.1177/0269216318774995
32. Dyregrov A, Dyregrov K. *Effective grief and bereavement support: The role of family, friends, colleagues, schools and support professionals.* London: Jessica Kingsley Publishers (2008).
33. Wills T. Social support and interpersonal relationships In: MS Clark, editor. *Review of personality and social psychology: Prosocial behavior, vol. 12.* Newbury Park, CA: Sage (1991). 265–89.
34. Chen R. Social support as a protective factor against the effect of grief reactions on depression for bereaved single older adults. *Death Stud.* (2022) 46:756–63. doi: 10.1080/07481187.2020.1774943
35. Lobb EA, Kristjanson LJ, Aoun SM, Monterosso L, Halkett GKB, Davies A. Predictors of complicated grief: a systematic review of empirical studies. *Death Stud.* (2010) 34:673–98. doi: 10.1080/07481187.2010.496686
36. Schoonover KL, Prokop L, Lapid MI. Valuable informal bereavement support strategies for bereaved parents of stillborn, young children, and adult children: a scoping review. *J Palliat Care.* (2022) 37:381–400. doi: 10.1177/08258597211062762
37. Wang E, Hu H, He Y, Xu Y. Can social support matter? the relationship between social support and mental health among bereaved parents in an only-child society: evidence from China. *Health Soc Care Community.* (2021) 29:476–86. doi: 10.1111/hsc.13108
38. Bolger N, Amarel D. Effects of social support visibility on adjustment to stress: experimental evidence. *J Pers Soc Psychol.* (2007) 92:458–75. doi: 10.1037/0022-3514.92.3.458
39. Bolger N, Zuckerman A, Kessler RC. Invisible support and adjustment to stress. *J Pers Soc Psychol.* (2000) 79:953–61. doi: 10.1037/0022-3514.79.6.953
40. Aoun SM, Keegan O, Roberts A, Breen LJ. The impact of bereavement support on wellbeing: a comparative study between Australia and Ireland. *Palliat Care Soc Pract.* (2020) 14:132. doi: 10.1177/2632352420935132
41. Breen LJ, O'Connor M. Family and social networks after bereavement: experiences of support, change and isolation. *J Fam Ther.* (2011) 33:98–120. doi: 10.1111/j.1467-6427.2010.00495.x
42. Grindrod A, Rumbold B. Healthy end of life project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia. *Ann Palliat Med.* (2018) 7:S73–83. doi: 10.21037/apm.2018.04.01
43. Breen LJ, Aoun SM, Rumbold B, McNamara B, Howling DA, Mancini V. Building community capacity in bereavement support. *Am J Hosp Palliat Med.* (2017) 34:275–81. doi: 10.1177/1049909115615568
44. Smith KV, Wild J, Ehlers A. The masking of mourning: social disconnection after bereavement and its role in psychological distress. *Clin Psychol Sci.* (2020) 8:464–76. doi: 10.1177/2167702620902748
45. Kaplan J, Block R, Gillard A, Putnam M. Inventory of youth adaptation to loss (IYAL): psychometric testing of a new instrument for bereaved youth to assess social support and coping. *OMEGA.* (2022) 86:503–32. doi: 10.1177/0030222820976299
46. Lehman DR, Ellard JH, Wortman CB. Social support for the bereaved: recipients' and providers' perspectives on what is helpful. *J Consult Clin Psychol.* (1986) 54:438–46. doi: 10.1037//0022-006X.54.4.438
47. Dyregrov K. Experiences of social networks supporting traumatically bereaved. *OMEGA.* (2006) 52:339–58. doi: 10.2190/CLAA-X2LW-JHQJ-T2DM
48. Berger PL, Luckmann T. *The social construction of Reality: A treatise in.* New York: Penguin Books (1966).
49. Macdonald ME. The denial of grief In: M Jacobsen and A Petersen, editors. *Exploring Grief.* Abingdon: Routledge (2019). 125–39.
50. Zimmermann C, Rodin G. The denial of death thesis: sociological critique and implications for palliative care. *Palliat Med.* (2004) 18:121–8. doi: 10.1191/0269216304pm8580a
51. Raphael T. *Seelenglaube und psychologie.* by dr. Otto Rank. (leipzig und Wien: Franz Deuticke). *Am J Psychiatry.* (1930) 88:400–0. doi: 10.1176/ajp.88.2.400
52. Becker E. *The denial of death.* New York: Free Press (1973).
53. Menzies RE, Dar-Nimrod I. Death anxiety and its relationship with obsessive-compulsive disorder. *J Abnorm Psychol.* (2017) 126:367–77. doi: 10.1037/abn0000263
54. Menzies RE, Sharpe L, Dar-Nimrod I. The relationship between death anxiety and severity of mental illnesses. *Br J Clin Psychol.* (2019) 58:452–67. doi: 10.1111/bjc.12229
55. Greenberg J, Pyszczynski T, Solomon S, Simon L, Breus M. Role of consciousness and accessibility of death-related thoughts in mortality salience effects. *J Pers Soc Psychol.* (1994) 67:627–37. doi: 10.1037/0022-3514.67.4.627
56. Pandya A, Kathuria T. Death anxiety, religiosity and culture: implications for therapeutic process and future research. *Religion.* (2021) 12:61. doi: 10.3390/rel12010061
57. Panksepp J. *Affective neuroscience: The foundations of human and animal emotions.* Oxford: Oxford University Press (1998).
58. Gudmundsdottir M, Chesla CA. Building a new experience. *J Fam Nurs.* (2006) 12:143–64. doi: 10.1177/1074840706287275
59. Martz E, Livneh H. Death anxiety as a predictor of future time orientation among individuals with spinal cord injuries. *Disabil Rehabil.* (2003) 25:1024–32. doi: 10.1080/09638280310001596469
60. Umphrey LR, Cacciatore J. Coping with the ultimate deprivation: narrative themes in a parental bereavement support group. *OMEGA.* (2011) 63:141–60. doi: 10.2190/OM.63.2.c
61. Walsh F. Loss and bereavement in families: a systemic framework for recovery and resilience In: BH Fiese, M Celano, KD Deater-Deckard, EN Jouriles and MA Whisman, editors. *APA handbook of contemporary family psychology: Foundations, methods, and contemporary issues across the lifespan, vol. 1.* Washington, DC: American Psychological Association (2019). 649–63.
62. Dyregrov K, Kristensen P, Dyregrov A. A relational perspective on social support between bereaved and their networks after terror: a qualitative study. *Glob Qual Nurs Res.* (2018) 5:2076. doi: 10.1177/2333393618792076

63. Solomon S, Greenberg J, Pyszczynski T. A terror management theory of social behavior: the psychological functions of self-esteem and cultural worldviews. *Adv Exp Soc Psychol.* (1991) 24:93–159. doi: 10.1016/S0065-2601(08)60328-7
64. Solomon S, Greenberg J, Pyszczynski T. The worm at the core: On the role of death in life. New York: Penguin Random House (2015).
65. Moreton J, Kelly CS, Sandstrom GM. Social support from weak ties: insight from the literature on minimal social interactions. *Soc Personal Psychol Compass.* (2023) 17:12729. doi: 10.1111/spc3.12729
66. Tognela JA, Rudaizky D, Robinson KT, Mason HM, Breen LJ. Informal social support following bereavement: a scoping review of provider and recipient perspectives of helpful and unhelpful interactions. *Death Stud.* (2025) 2025:1–14. doi: 10.1080/07481187.2025.2454506
67. Mills J, Abel J, Kellehear A, Noonan K, Bollig G, Grindod A, et al. The role and contribution of compassionate communities. *Lancet.* (2024) 404:104–6. doi: 10.1016/S0140-6736(23)02269-9
68. Breen LJ, Kawashima D, Joy K, Cadell S, Roth D, Chow A, et al. Grief literacy: a call to action for compassionate communities. *Death Stud.* (2022) 46:425–33. doi: 10.1080/07481187.2020.1739780
69. Maccallum F, Breen LJ, Ivynian S, DiGiacomo M, Luckett T, Lobb EA. Prolonged grief reactions and help-seeking in bereaved adults during the COVID-19 pandemic. *J Affect Disord.* (2025) 374:467–76. doi: 10.1016/j.jad.2025.01.056
70. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research. *Acad Med.* (2014) 89:1245–51. doi: 10.1097/acm.0000000000000388
71. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* (2007) 19:349–57. doi: 10.1093/intqhc/mzm042
72. Schwandt TA. Constructivist, interpretivist approaches to human inquiry In: NK Denzin and YS Lincoln, editors. *Handbook of qualitative research.* Thousand Oaks, CA: SAGE (1994). 118–37.
73. Lincoln YS, Guba EG. *Naturalistic inquiry.* Thousand Oaks, CA: SAGE (1985).
74. Levitt HM, Motulsky SL, Wertz FJ, Morrow SL, Ponterotto JG. Recommendations for designing and reviewing qualitative research in psychology: promoting methodological integrity. *Qual Psychol.* (2017) 4:2–22. doi: 10.1037/qup0000082
75. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* (2006) 3:77–101. doi: 10.1191/1478088706qp0630a
76. Braun V, Clarke V. *Successful qualitative research: A practical guide for beginners.* Thousand Oaks, CA: SAGE Publications Ltd. (2013).
77. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol.* (2021) 18:328–52. doi: 10.1080/14780887.2020.1769238
78. Australian Government. *Reporting on the health of culturally and linguistically diverse populations in Australia: An exploratory paper, Summary-Australian Institute of Health and Welfare.* (2022). Available online at: <https://www.aihw.gov.au/reports/cald-australians/reporting-health-cald-populations/summary> (Accessed August 19, 2025).
79. What WT. *Death means now: Thinking critically about dying and grieving.* Bristol, UK: Policy Press (2018).
80. Klass D, Silverman PR, Nickman S. *Continuing bonds: New understandings of grief.* Abingdon: Routledge (2014).
81. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies. *Qual Health Res.* (2016) 26:1753–60. doi: 10.1177/1049732315617444
82. Aoun SM, Breen LJ, Rumbold B, Christian KM, Same A, Abel J. Matching response to need: What makes social networks fit for providing bereavement support? *PLoS One.* (2019) 14:14. doi: 10.1371/journal.pone.0213367
83. Morrigan B, Keesing S, Breen LJ. Exploring the social networks of bereaved spouses: phenomenological case studies. *OMEGA.* (2022) 85:268–84. doi: 10.1177/0030222820944062
84. Geertz C. Thick description: toward an interpretive theory of culture. In Geertz C. *The interpretation of cultures: Selected essays.* New York: Basic Books, pp. 3–30. (1973).
85. Braun V, Clarke V. *Thematic analysis: A practical guide.* Thousand Oaks, CA: Sage (2021).
86. Baxter L, Montgomery B. *Relating: Dialogues and dialectics.* New York: Guilford Press (1996).
87. Toller PW. Negotiation of dialectical contradictions by parents who have experienced the death of a child. *J Appl Commun Res.* (2005) 33:46–66. doi: 10.1080/0090988042000318512
88. Hooghe A, Neimeyer RA, Rober P. The complexity of couple communication in bereavement: an illustrative case study. *Death Stud.* (2011) 35:905–24. doi: 10.1080/07481187.2011.553335
89. Ratcliffe M. On feeling unable to continue as oneself. *Eur J Philos.* (2024) 32:1293–303. doi: 10.1111/ejop.12958
90. Brison SJ. *Aftermath: Violence and the remaking of a self.* Princeton, NJ: Princeton University Press (2002).
91. Humphreys H. *True story: On the life and death of my brother.* London, UK: Profile Books (2013).
92. Attig T. *How we grieve: Relearning the experience.* Oxford: Oxford University Press (2011).
93. Barboza J, Seedall R, Hooghe A, Kaplow J, Bradshaw S. Forming our grief rhythm: the relational window of tolerance for bereaved parents. *Fam Process.* (2024) 64:13048. doi: 10.1111/famp.13048
94. Barboza J, Seedall R. Coregulatory responsive strategies in bereaved parents. *J Loss Trauma.* (2025) 1–25:1–25. doi: 10.1080/15325024.2025.2483779
95. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders. 5th ed.* Washington, DC: American Psychiatric Press (2022).
96. Mikulincer M, Shaver PR, Pereg D. Attachment theory and affect regulation: the dynamics, development, and cognitive consequences of attachment-related strategies. *Motiv Emot.* (2003) 27:77–102. doi: 10.1023/A:1024515519160
97. Currier JM, Holland JM, Neimeyer RA. Sense-making, grief, and the experience of violent loss: toward a mediational model. *Death Stud.* (2006) 30:403–28. doi: 10.1080/07481180600614351
98. Worden JW. *Grief counseling and grief therapy: A handbook for the mental health practitioner.* Berlin: Springer Publishing Company (2018).
99. Robinaugh DJ, Mauro C, Bui E, Stone L, Shah R, Wang Y, et al. Yearning and its measurement in complicated grief. *J Loss Trauma.* (2016) 21:410–20. doi: 10.1080/15325024.2015.1110447
100. Maciejewski PK, Zhang B, Block SD, Prigerson HG. An empirical examination of the stage theory of grief. *JAMA.* 297:716. doi: 10.1001/jama.297.7.716
101. Klass D, Silverman PR, Nickman SL. *Continuing bonds: New understandings of grief.* Abingdon: Taylor and Francis (1996).
102. Black J, Belicki K, Emberley-Ralph J, McCann A. Internalized versus externalized continuing bonds: relations to grief, trauma, attachment, openness to experience, and posttraumatic growth. *Death Stud.* (2022) 46:399–414. doi: 10.1080/07481187.2020.1737274
103. Riches G, Dawson P. *An intimate loneliness, supporting bereaved parents and siblings.* Buckingham, UK: Open University. (2002).
104. Scholtes D, Browne M. Internalized and externalized continuing bonds in bereaved parents: their relationship with grief intensity and personal growth. *Death Stud.* (2015) 39:75–83. doi: 10.1080/07481187.2014.890680
105. Burke LA, Neimeyer RA. Complicated spiritual grief I: relation to complicated grief symptomatology following violent death bereavement. *Death Stud.* (2014) 38:259–67. doi: 10.1080/07481187.2013.829372
106. Field NP, Nichols C, Holen A, Horowitz MJ. The relation of continuing attachment to adjustment in conjugal bereavement. *J Consult Clin Psychol.* (1999) 67:212–8. doi: 10.1037/0022-006x.67.2.212
107. Field NP. Continuing bonds in adaptation to bereavement: introduction. *Death Stud.* (2006) 30:709–14. doi: 10.1080/07481180600848090
108. Field NP, Packman JD, Ronen R, Pries A, Davies B, Kramer R. Type of continuing bonds expression and its comforting versus distressing nature: implications for adjustment among bereaved mothers. *Death Stud.* (2013) 37:889–912. doi: 10.1080/07481187.2012.692458
109. Field NP, Gao B, Paderna L. Continuing bonds in bereavement: an attachment theory based perspective. *Death Stud.* (2005) 29:277–99. doi: 10.1080/07481180590923689
110. Laurie A, Neimeyer RA. African Americans in bereavement: grief as a function of ethnicity. *OMEGA.* (2008) 57:173–93. doi: 10.2190/OM.57.2.d
111. Neimeyer RA, Burke LA, Mackay MM, Van Dyke Stringer JG. Grief therapy and the reconstruction of meaning: from principles to practice. *J Contemp Psychother.* (2010) 40:73–83. doi: 10.1007/s10879-009-9135-3
112. Wortmann JH, Park CL. Religion and spirituality in adjustment following bereavement: an integrative review. *Death Stud.* (2008) 32:703–36. doi: 10.1080/07481180802289507
113. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health.* (2019) 11:589–97. doi: 10.1080/2159676X.2019.1628806
114. Klass D. Sorrow and solace: neglected areas in bereavement research. *Death Stud.* (2013) 37:597–616. doi: 10.1080/07481187.2012.673535
115. Australian Institute of Health and Welfare. *Australia's health 2023: data insights.* Canberra: AIHW (2023).
116. Rosenblatt PC. Grief across cultures: a review and research agenda In: MS Stroebe, RO Hansson, H Schut and W Stroebe, editors. *Handbook of bereavement research and practice: Advances in theory and intervention.* Washington, DC: American Psychological Association (2008). 207–22.
117. Valentine C. *Bereavement narratives: continuing bonds in the twenty-first century.* Abingdon: Routledge, (2008).



OPEN ACCESS

EDITED BY

Wendy G. Lichtenthal,
University of Miami, United States

REVIEWED BY

Irene Dudley-Swarbrick,
Edge Hill University, United Kingdom
Alfredo Zamora Mur,
Universidad San Jorge, Spain

*CORRESPONDENCE

Elizabeth Weathers
✉ elizabeth.weathers@ucd.ie

RECEIVED 02 May 2025

ACCEPTED 31 October 2025

PUBLISHED 09 December 2025

CITATION

Weathers E, Cao F, Coughlan H, Easton A and Keegan O (2025) The public health model for bereavement care: learnings from COVID-19 bereavement experiences in Ireland. *Front. Public Health* 13:1611824. doi: 10.3389/fpubh.2025.1611824

COPYRIGHT

© 2025 Weathers, Cao, Coughlan, Easton and Keegan. This is an open-access article distributed under the terms of the [Creative Commons Attribution License \(CC BY\)](https://creativecommons.org/licenses/by/4.0/). The use, distribution or reproduction in other forums is permitted, provided the original author(s) and the copyright owner(s) are credited and that the original publication in this journal is cited, in accordance with accepted academic practice. No use, distribution or reproduction is permitted which does not comply with these terms.

A public health model for bereavement care: learnings from COVID-19 bereavement experiences in Ireland

Elizabeth Weathers^{1*}, Fankun Cao¹, Helen Coughlan², Avril Easton³ and Orla Keegan³

¹School of Nursing, Midwifery, and Health Sciences, University College Dublin, Dublin, Ireland, ²St. Vincent's University Hospital, Dublin, Ireland, ³Irish Hospice Foundation, Dublin, Ireland

Background: The COVID-19 pandemic severely disrupted bereavement care, posing risks of long-term physical and mental health consequences. To ensure the lived experience was captured during this challenging time, a national survey was conducted to examine the Irish population's experiences of dying, death, and bereavement during the pandemic.

Methods: A mixed-methods survey study was conducted between November 2021 and February 2022. Using purposive sampling, a sample of adults completed a 38-question survey. Of the 2,259 participants who completed the survey, 1,223 reported one or more bereavements during the COVID-19 pandemic. This sub-sample of bereaved participants completed the Brief Grief Questionnaire (BGQ). Quantitative data from the sub-sample of 1,223 bereaved individuals were analysed using descriptive and inferential statistics. Qualitative responses were analysed using thematic analysis.

Results: Most participants reported that their bereavement experience was negatively affected by COVID-19, with key themes including loss of connection (including lost opportunities to say goodbye), loss of ritual, and valuing community support. Despite altered funeral structures, many participants found comfort from the efforts made by others to honour the deceased. The BGQ results showed that 59.7% screened negative for Prolonged Grief Disorder (PGD), 26.1% were likely to indicate sub-threshold PGD, and 14.2% were likely to have PGD. Significant associations were found between BGQ scores and several variables including lack of support for bereaved people, relationship to the person that died and being with their loved one at time of death.

Conclusion: The COVID-19 pandemic disrupted traditional end-of-life and mourning practices. The society-wide implementation of public health measures sought to prevent the spread of COVID-19, particularly among our vulnerable populations, but had a deep impact on the dying, death, and bereavement experience in Ireland. This paper gives voice to the bereavement experience of families, friends, and communities and highlights ways to support people who are grieving.

KEYWORDS

bereavement, grief, end-of-life care, funerals, prolonged grief disorder, brief grief questionnaire, public health model, COVID-19

1 Introduction

On 30 January 2020, the World Health Organisation (WHO) declared the novel Coronavirus (2019-nCoV) a global public health emergency (1). Two months later, what soon became known as COVID-19 was declared a global pandemic (2). By 2021, COVID-19 had replaced stroke as the second-leading cause of death globally (3). As of 16 March 2025, over 7 million confirmed COVID-19 deaths have been documented worldwide, including approximately 9.8 thousand in Ireland (4).

The declaration of COVID-19 as a global pandemic began an unprecedented global public health crisis, with cascading effects on individuals, communities and societies across the world. One significant impact was the disruption to end-of-life care and bereavement practices (5, 6). In an effort to reduce the transmission of COVID-19, a range of public health interventions were implemented globally (7). These included travel restrictions, social distancing, lockdowns, bans on mass gatherings, and isolation and quarantining protocols. Concurrently, fear and human interest became the framing patterns of COVID-19 media coverage (8) and news outlets, and social media became saturated with daily stories and statistics about COVID-related deaths. While COVID-19 became the focus of attention, restrictive public health measures such as imposed lockdowns, social restrictions and the banning of hospital visits were universal and did not discriminate by cause of death. As such, the impact of public health measures on end-of-life care and on rituals of mourning were not limited to COVID-19 deaths. They affected end-of-life care and mourning rituals for everyone. COVID-19 has also underscored the crucial role played by family and friend caregivers in the continuum of care. In the face of overwhelmed health services and restricted access to formal support systems, there is a need to recognize family and friend caregiving and community-based support as vital components of bereavement care in public health strategies.

Much of the literature on grief and bereavement in the context of COVID-19 has come from Europe, the USA, Canada, Iran, and China (9, 10). The majority of these studies employed quantitative methodologies, while others took the form of review articles or conceptual discussion papers (9, 10). Empirical research typically involved participants who had lost close family members to COVID-19, focusing on their psychological and emotional responses. Common findings across these studies include heightened levels of prolonged grief, anxiety, and depression among the bereaved, largely attributed to pandemic-related restrictions, such as limits on hospital visitations, funerals, and social gatherings, which disrupted traditional mourning practices and support systems (9, 10). Several authors have argued that the pandemic may have lasting repercussions on how societies experience death, dying, and bereavement, due to the scale and abruptness of the losses involved (11–13). However, some scholars have challenged this view, suggesting that while COVID-19 had a significant immediate impact, its long-term consequences on the societal experience of death, dying, and bereavement may be more limited than initially predicted (14, 15).

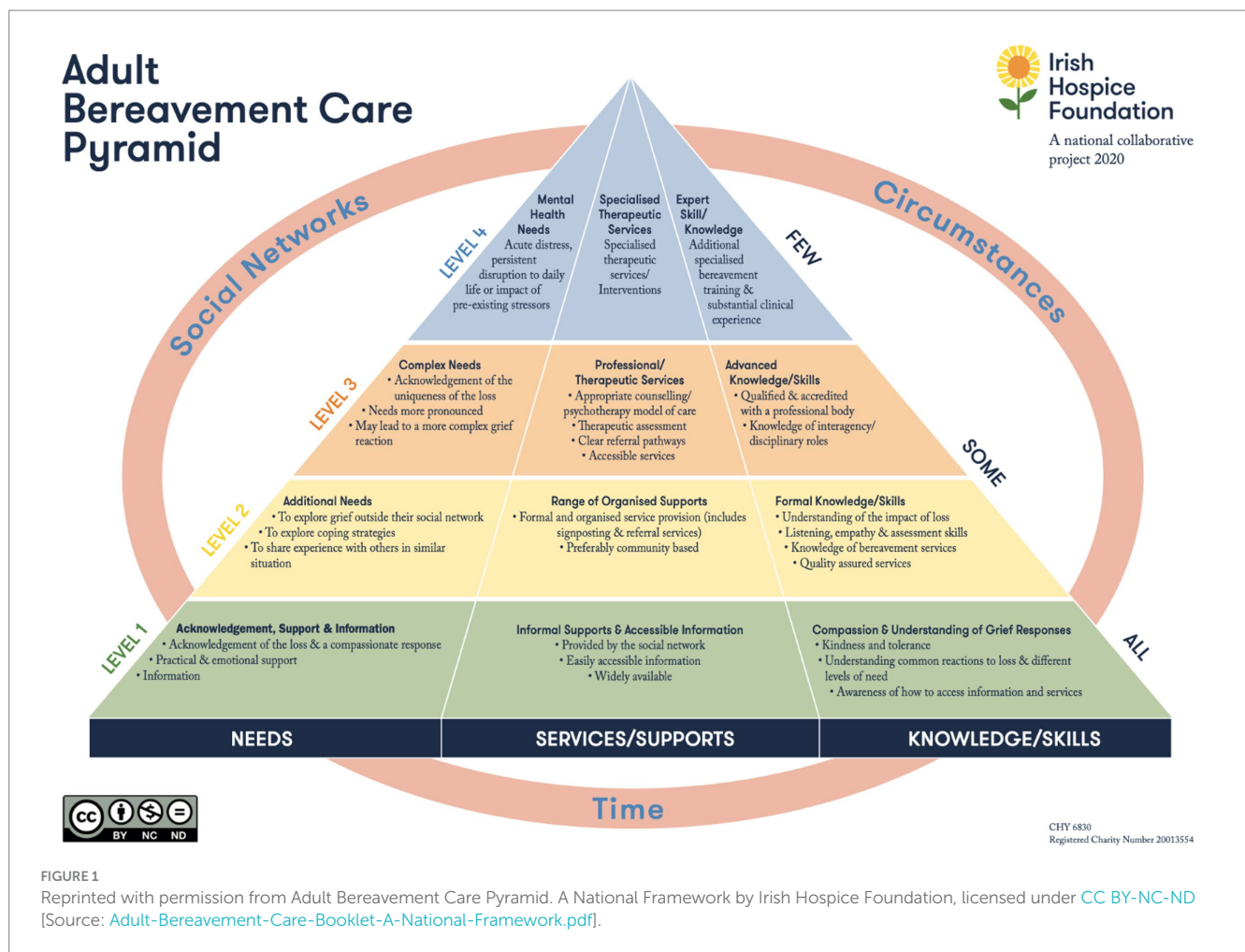
From an Irish perspective, three studies with a focus on bereavement during COVID-19 have been published to date. All these prior studies were conducted with healthcare professionals and support workers. One study describes the implementation and evaluation of a national bereavement helpline by Irish Hospice

Foundation (IHF) in response to the pandemic (16). Results of this study found evidence of high levels of distress among callers to the newly developed bereavement support line. For many callers, their distress was caused by their experiences of hospital visiting restrictions, limitations imposed on rituals of mourning and the absence of meaningful relational connections in the context of these restrictions. The negative impact of disrupted relational connections during COVID-19 was also reported in a study on experiences of midwives providing perinatal bereavement care in one Irish healthcare setting during COVID-19 (17). A further study examined bereavement care provision among people working in hospice, community, and hospital settings across the UK and Ireland (18). The collective experience of participants in that study was of a ‘silent epidemic of grief’, caused by the impact of COVID-19 public health restrictions and the consequent lack of access to meaningful relational bereavement support and services (19).

Findings from the existing literature capture the multi-level impact of COVID-19 public health restrictions on end-of-life care experiences and on bereaved individuals’ subsequent capacity to access meaningful support (5–7). COVID-19 restrictions disrupted a range of bereavement supports, from informal community-based care to specialist clinical services, reflecting challenges across all levels of support outlined in existing public health bereavement frameworks. One such framework is the Adult Bereavement Care Pyramid (19). Developed by IHF and key bereavement stakeholders, the Adult Bereavement Care Pyramid outlines a structured, evidence-based approach to bereavement care that matches support levels to the specific needs of individuals. It advocates for a stratified approach, where the intensity and type of care are informed by assessed need, to ensure resources are used efficiently and effectively (see Figure 1). This framework shares core principles with the three-tiered public health model for bereavement support developed by Aoun and colleagues (20), which emphasises cost-effectiveness, accessibility, and integrated service delivery. Referencing both models helps to contextualize the varied needs of bereaved individuals during the pandemic and underscore the importance of delivering care that is proportional and responsive to those needs, even during crisis situations.

As a public health bereavement framework, the Adult Bereavement Care Pyramid promotes the importance of balancing the needs of bereaved individuals, including emotional, social, and psychological dimensions, with considerations of cost-effectiveness and accessibility, ensuring that support is proportionate to the level of need and delivered through an integrated framework. During the COVID-19 pandemic, bereavement care services were significantly disrupted, and the individualised support needs of bereaved people were deprioritised in favour of broader public health mitigation efforts, such as infection control and service reallocation (16, 17).

Despite emerging international evidence on the negative impacts of the pandemic on bereavement experiences, no study to date has reported findings from individuals living in Ireland who were bereaved during the pandemic. To address this gap in the literature, the study reported on in this paper presents findings from the only national Irish study undertaken on bereavement experiences during COVID-19. Known as Time to Reflect, the study was commissioned by IHF, a national charity that addresses dying, death and bereavement in Ireland. Framed within the Adult Bereavement Care Pyramid, *Time to Reflect* used a mixed methods approach to collect data from a sample of over 1,200 individuals bereaved during the pandemic. This paper



reports on data from the *Time to Reflect* study, i.e., the bereavement experiences of respondents, aiming to quantify the intensity of bereavement reactions experienced by bereaved individuals, exploring how participants described their experiences around the time of death, and to identify factors influencing grief. These findings are then interpreted within a public health framework to consider broader implications for bereavement care and support delivery.

2 Materials and methods

Time to Reflect was a national survey that aimed to explore the impact of COVID-19 on perceptions and experiences of dying, death and bereavement in Ireland. A key objective of the study was to explore if and how the COVID-19 pandemic affected people’s experiences of dying, death, and bereavement.

2.1 Data collection

Data were collected via a survey tool between November 2021 and February 2022. The start date of the survey was 18 months after the declaration of the pandemic and stay-at-home public health mandates in Ireland. It was also one year after the COVID-19 vaccination was made available for vulnerable individuals. Many restrictions remained

in place at the time of the survey, including face mask mandates and hospital visiting restrictions. The peak of the death rate in Ireland for COVID-19 was a year prior to the commencement of the survey, making this an appropriate time to capture the bereavement experiences of people living in Ireland during the pandemic. The survey was delivered in both digital (via Survey Monkey) and paper form.

2.2 Inclusion/exclusion criteria

Individuals over 18 years old in Ireland during the survey period were recruited by purposive, non-probability-based sampling. The survey was disseminated by IHF through different platforms including IHF events, social media, network connections, and relevant programmes. Paper versions of the survey were also distributed to individuals in nursing home settings. Participants were not required to have experienced a bereavement to participate in the national survey. However, the data reported in this manuscript are specific to those who did experience a bereavement.

2.3 Survey instrument

The survey instrument comprised 38 questions across three sections. The first section of the survey Section A examined

perspectives on dying, death, and bereavement since the pandemic began. Participants who indicated they were bereaved during this time proceeded to Section B, which focused on understanding participants' personal experience before and after the death of their loved one. The final section of the survey (Section C) collected demographic and wellbeing information from bereaved and non-bereaved participants. The survey instrument is available to view on the IHF website.¹

Survey responses were predominately presented in the form of Likert scales. Open-ended questions were also asked throughout the survey. This was to ensure that participants had the opportunity to give voice to their subjective experiences that could not be collected through quantitative questions. Bereaved participants, which are the focus of the current paper, were also invited to complete the Brief Grief Questionnaire (BGQ). The BGQ is a 5-item questionnaire developed to screen for symptoms of Prolonged Grief Disorder (PGD) (21, 22), reflecting intense feelings of grief that are long-lasting and interfere with everyday life. It is a screening instrument and not a diagnostic tool. Individuals scoring between 0 and 4 on the BGQ are considered to screen negative for PGD. Scores between 5 and 7 indicate an individual is likely to report sub-threshold symptoms of PGD, and scores 8 or higher indicate the individual is more likely to meet criteria for PGD.

2.4 Data analysis

Quantitative data were analysed using IBM SPSS 27. Descriptive and inferential statistics were used in the analysis. Responses to the five BGQ questions were computed into total scores ranging from 0 to 10. BGQ total scores were grouped into three categories for statistical analysis; negative screen for PGD (0–4), positive screen for sub-threshold symptoms of PGD (5–7), and positive screen for likely PGD (8–10). Relationships between BGQ categories and items reflecting participants' experiences of the death of a relative were explored in the analysis. Chi-square tests were used to examine associations between categorical variables, and independent samples t-tests were employed for comparisons of continuous variables across BGQ categories. The level of significance was set at $p < 0.05$, with Bonferroni correction applied to control for Type I error across multiple comparisons. These categorical cutoffs are meaningful as they reflect established thresholds used to screen for / identify concern around prolonged grief.

Qualitative data derived from the open-ended survey questions were analysed thematically (23). Two researchers independently coded the data. An inductive coding approach was used where the development of themes and sub-themes were derived from interpreting the data and not based on any pre-conceived ideas of what patterns the researchers would like to see in the data. To ensure that qualitative data was analysed successfully, the six phases of thematic analysis as illustrated by Braun and Clarke were used (23). Firstly, the researchers familiarised themselves with the data by reading and documenting initial ideas (phase 1). The relevant text was then imported into NVivo 12 where the researcher

assigned multiple codes using an open and axial coding approach (phase 2). Succeeding this phase, codes were refined and grouped into potential themes along with relevant data/excerpts (phase 3). An in-depth discussion then took place with the extended research team to further review the themes and sub-themes (phase 4), before reaching a collective agreement on the identification and definition of themes and sub-themes (phase 5). Discrepancies in coding were resolved through iterative discussion and consensus, ensuring that interpretations remained grounded in the data and that differing perspectives enriched the analysis. Finally, chosen themes and sub-themes were selected for report inclusion coupled with compelling and relevant excerpts from the open-ended questions.

2.5 Ethical considerations

Participants were provided with an information leaflet prior to completing the survey and contact details of the study team were also provided if participants had any questions or queries about the study. Participation in the study was voluntary, and participants could opt out if they wished to. Ethical approval to carry out the study was granted by the Royal College of Surgeons Ireland (REC approval no: 202105022). IHF acted as the data controller when managing the data and was responsible for the protection, storing, and analysis of the survey. The anonymity of participants was prioritised when storing and analysing survey data.

2.6 Reflexivity statement

As researchers working in the deeply emotive field of death, dying, and bereavement, and during an unprecedented global pandemic, we recognised the importance of reflexivity in acknowledging our own subjectivity and emotional response. Engaging with hundreds of personal, and often heart-breaking, narratives of loss was challenging at times. The intensity and poignancy of participants' accounts evoked empathy, sorrow, and a sense of shared vulnerability. We were not outside observers but situated actors, whose own experiences and bereavements during COVID-19 inevitably shaped how data were interpreted and presented. Personal experiences of bereavement among the research team brought added depth and sensitivity to the research process. These experiences strengthened our commitment to honouring the stories and insights shared by participants. In the context of the emotional depth of the work, regular team debriefings were incorporated, to reflect on the data and analysis, while remaining sensitive to the ethical dimensions of working with such material. This reflexive approach deepened our understanding of the data and helped us remain grounded in the human significance of the stories entrusted to us.

We also recognise that our personal and professional proximity to the topic may have introduced certain interpretive biases. For example, a heightened sensitivity to grief-related distress or an inclination to privilege certain narratives over others. To mitigate this, we engaged in ongoing critical reflection as a team and the diverse experience and background of the research team (nursing, social work, psychology, social policy) ensured varied perspectives during analysis. By making this process visible, we aim to honour the trust placed in us by participants, and to contribute to a more transparent, ethically aware, and emotionally attuned bereavement research practice.

1 https://hospicefoundation.ie/wp-content/uploads/2021/11/IHF_Time-to-Reflect-Survey.pdf

3 Results

A total of 2,259 adults took part in the *Time to Reflect* survey. Of those, a nested sub-sample of 1,223 participants reported experiencing one or more bereavements during the pandemic. This paper presents both quantitative and qualitative findings from the sub-sample of bereaved individuals only ($N = 1,223$). Findings related to bereavement experiences will be presented with a focus on the following themes: bereaved participants' experience of dying and death, funerals and mourning rituals, role of bereavement support and community involvement and screening for indicators of PGD.

3.1 Quantitative findings

3.1.1 Demographics

Among the 1,223 bereaved participants, 1,078 (88.1%) completed the demographic section of the survey (see Table 1). Of these 1,078, a majority were female ($N = 753$, 69.9%) and aged between 45 and 54 years old ($N = 322$, 29.9%). A majority ($N = 1,008$, 93.5%) described their ethnicity as White Irish. Participants were distributed across rural, urban and suburban settings and almost half of bereaved participants were either married or in a civil partnership ($N = 514$, 47.8%). Participants who did not complete the demographic section ($N = 145$, 11.9%) were retained in the analysis of all other sections of the survey, provided they had responded to those relevant items.

3.1.2 Impact of COVID-19 on the experience of dying

Over 86% of participants ($N = 976$, 86.3%) reported that their experience of a loved one's death was negatively affected by COVID-19 (see Table 2). 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 the participants ($N = 717$, 63.7%) were not present with their loved one when they died. Most participants reported receiving the support they needed from the professionals involved in the end-of-life care of their loved one ($N = 273$, 24.2%). Nonetheless, this meant that over one in five 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%) and a further 19.2% ($N = 217$) reported that they somewhat or partly received the support they needed from professionals involved in the end-of-life care.

3.1.3 Funerals and mourning rituals

While most respondents were able to attend the funeral of their loved one, almost one in four were not ($N = 262$, 23.5%). Almost 70% of participants ($N = 765$, 68.6%) reported that family and friends were excluded from funerals due to COVID-19 restrictions (see Table 3). 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%).

Just over half of participants ($N = 608$, 54.6%) reported that, even with the restrictions, some aspects of available funeral rituals were a source of comfort for them. Over half of participants stated that people in their community had found other ways to honour the person who had died ($N = 601$, 53.6%).

TABLE 1 Demographic variables for bereaved participants.

Variable	N	%
Age		
18–24*	73	6.8%
25–34*	115	10.7%
35–44	178	16.5%
45–54*	322	29.9%
55–64*	209	19.4%
65–74*	135	12.5%
75+	27	2.5%
Unknown*	19	1.8%
Total	1,078	100%
Ethnicity		
White Irish	1,008	93.5%
Irish Traveler	1	0.1%
Black Irish	1	0.1%
Any other white background	45	4.2%
Any other black background	1	0.1%
Asian Irish	4	0.4%
Any other Asian background	9	0.8%
Other	9	0.8%
Total	1,078	100%
Gender		
Male	318	29.5%
Female	753	69.9%
Other/non-binary	5	0.5%
Prefer not to say	2	0.2%
Total	1,078	100%
Relationship status		
Single, never married	265	24.6%
Civil partnership or married	514	47.8%
Cohabiting with a significant other	167	15.5%
Separated or divorced	62	5.8%
Widowed	68	6.3%
Total	1,076	100%
Geographic location		
Urban	243	22.5%
Suburban	259	24.0%
Town	227	21.1%
Rural	349	32.4%
Total	1,078	100%

3.1.4 The role of bereavement support and community involvement

Over 60% of participants ($N = 691$, 63.6%) reported that the pandemic made their grieving process more difficult, with almost 40% ($N = 396$, 36.7%) reporting that they did not get the support they needed after the death of a loved one because of the public health measures. Over half of respondents ($N = 580$, 53.6%) reported that,

TABLE 2 Experiences before the death of a loved one.

	Total N	Responses N (%)				
		Yes	Somewhat or partly	No	Do not know	Does not apply
My experience around the time of their death was negatively affected by COVID-19	1,130	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 before they died	1,135	223 (19.6%)	189 (16.7%)	641 (56.5%)	2 (0.2%)	80 (7%)
I was with them at time they died	1,126	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	1,128	273 (24.2%)	217 (19.2%)	246 (21.8%)	29 (2.6%)	363 (32.2%)

TABLE 3 Impact of COVID-19 on funerals and mourning rituals.

	N	Responses N (%)			
		Yes	Somewhat or partly	No	Does not apply
I was unable to attend their funeral in person because of the COVID-19 restrictions	1,116	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	1,115	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	1,119	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	1,121	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	1,114	608 (54.6%)	310 (27.8%)	145 (13.0%)	51 (4.6%)

despite the public health measures, their family and friends found meaningful ways to support them in their grief (see Table 4).

Over half of bereaved participants (N = 496, 53.8%) reported that they did not require extra support from a professional or support service (see Figure 2). For those who did require support services, most sought help from a counsellor, psychotherapist, or private psychologist (N = 138, 15.0%) or from a GP (N = 100, 10.8%). A minority of participants (N = 80, 8.7%) reported that they wanted to get support but did not know where to go.

3.2 Indicators for possible prolonged grief disorder (PGD) and sub-threshold grief

The mean score among participants who completed the BGQ (N = 1,095) was 3.95 (SD = 2.86) (see Table 5). Almost 60% of participants (N = 653, 59.7%) scored between 0 and 4 on the BGQ, indicating a negative screen for PGD. Over one in four (N = 286, 26.1%) scored between 5 and 7, likely to indicate sub-threshold symptoms of PGD. A further 14.2% of participants (N = 156) scored

between 8 and 10, indicating that these individuals were more likely to meet criteria for PGD.

3.2.1 BGQ and place of death

No statistically significant differences in BGQ categories were found based on the place of death of the participant’s loved one (see Table 6).

3.2.2 BGQ and relationship to and time spent with the deceased

A statistically significant association was found between BGQ categories and participants’ relationship to the deceased (see Table 7). Indicators of risk of PGD were more prevalent in participants who lost a parent, a spouse, in-law, or a child compared with those who lost other family members.

No statistically significant associations were found in BGQ categories between those who reported having the time they wanted with their loved one before their death and those who did not (see Table 8). Conversely, significant associations were found between those who were not (p < 0.001). Specifically, those participants who were not with the person who died (10.4%) scored lower on the

TABLE 4 Experiences after the death of a loved one.

	N	Responses N (%)				
		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The Impact of COVID-19 made my grief more difficult	1,086	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	1,082	79 (7.3%)	501 (46.3%)	325 (30%)	127 (11.7%)	50 (4.6%)
I did not get the support I needed after the death because of the COVID-19 restrictions	1,080	128 (11.9%)	268 (24.8%)	389 (36.0%)	220 (20.4%)	75 (6.9%)

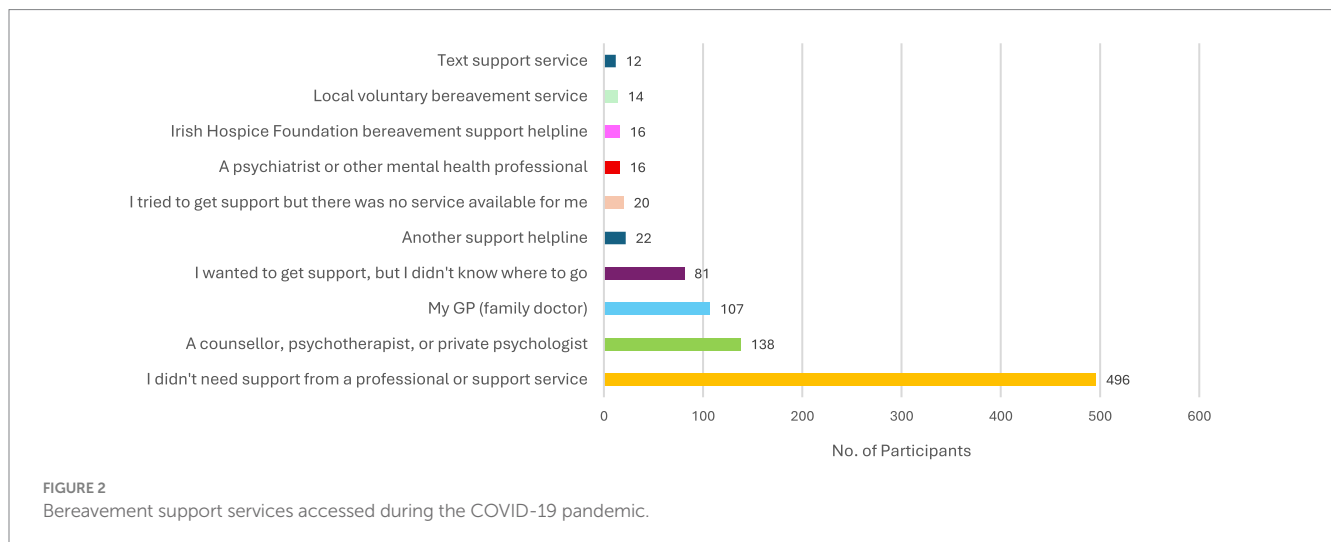


TABLE 5 BGQ scores for bereaved participants.

Variable	Bereaved N = 1,095	
	n	%
BGQ category		
No PGD indicated (0–4)	653	59.6
Sub-threshold PGD indicated (5–7)	286	26.1
PGD indicated (8–10)	156	14.2

BGQ than those that were with the person who died (25.8%) (see Table 9).

3.2.3 BGQ and access to support during COVID-19 pandemic

A statistically significant association was found between BGQ categories and participants' access to support during the pandemic (see Table 10). Bereaved participants were asked to rate their level of

agreement with the following statement: 'I did not get the support I needed because of COVID-19 restrictions'. A higher percentage of those who agreed or strongly agreed with the statement were more likely to report indications of PGD and sub-threshold PGD.

3.2.4 BGQ and experience of death

Chi-square tests were conducted to determine if associations were found between respondents reporting that COVID-19 prevented the person from having the death they would have wished for and their BGQ category (see Table 11). Respondents that felt COVID-19 prevented the person from having the death they would have wished for had significantly higher indications of sub-threshold PGD relative to those who did not feel that way.

3.2.5 BGQ and ability to have a funeral or ritual

Table 12 shows the chi-square results comparing the ability to have the desired funeral or ritual for the death of the loved one and BGQ category. There were no associations between those who did and those who did not have the desired funeral and BGQ category ($p = 0.491$).

TABLE 6 BGQ and place of death.

Place of death	BGQ category						X ² (16)	p
	No PGD indicated (0–4)		Sub-threshold PGD (5–7)		PGD indicated (8–10)			
	N	%	N	%	N	%		
Own home (N = 207)	140	67.6%	45	21.7%	22	10.6%	18.88	0.275
Hospital (N = 245)	139	56.7%	75	30.6%	31	12.6%		
Nursing home (N = 121)	82	67.8%	30	24.8%	9	7.4%		
Hospice (N = 82)	47	57.3%	19	23.2%	16	19.5%		
Other (N = 32)	20	62.5%	9	28.1%	3	9.3%		

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

TABLE 7 BGQ and relationship to deceased.

Relationship	BGQ category						X ² (22)	p
	No PGD indicated N = 639		Sub-threshold PGD indicated N = 279		PGD indicated N = 152			
	N	%	N	%	N	%		
Parent/Steparent (N = 323)*	165*	25.8%	85	30.5%	73*	48.0%	137.59	<0.001
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%		

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

TABLE 8 BGQ and time spent with the deceased before they died.

I was able to spend the time they I wanted with the person before they died	BGQ category						X ² (6)	p
	No PGD indicated (0–4)		Sub-threshold indicated PGD (5–7)		PGD indicated (8–10)			
	N	%	N	%	N	%		
Yes	123	55.9%	58	26.4%	39	17.7%	8.31	0.216
No	362	59.2%	172	28.2%	77	12.6%		
Somewhat or partly	99	53.7%	45	25.0%	36	20.0%		
Do not know	1	50.0%	1	50.0%	0	0.0%		

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

TABLE 9 BGQ and being with the deceased at the time they died.

I was with them at the time they died	BGQ category						X ² (6)	p
	No PGD indicated (0–4)		Sub-threshold indicated PGD (5–7)		PGD indicated (8–10)			
	N	%	N	%	N	%		
Yes	118*	44.7%*	78	29.5%	68*	25.8%*	47.48	<0.001
No	432*	62.7%*	185	26.9%	72*	10.4%*		
Somewhat or partly	20	58.8%	6	17.60%	8	23.5%		
Do not know	2	50.0%	2	50.0%	0	0.0%		

p-value computed based on chi-square test; * indicates significant differences between yes and no column values.

TABLE 10 BGQ and access to support during COVID-19 pandemic.

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

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

TABLE 11 BGQ and COVID-19 preventing the death the respondent would have wished for the deceased.

COVID-19 prevented them from having the death I wished for them	BGQ category						X ² (6)	p
	No PGD indicated (0–4)		Sub-threshold indicated PGD (5–7)		PGD indicated (8–10)			
	N	%	N	%	N	%		
Yes	244*	50.8%*	155*	32.3%*	81	16.9%	32.67	<0.001
No	166*	66.7%*	45*	18.1%*	38	15.3%		
Somewhat or partly	123	66.1%	44	23.7%	19	10.2%		
Do not know	33	75.0%	9	20.5%	2	4.5%		

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

TABLE 12 BGQ and ability to have funeral or ritual the respondent wanted.

We were able to have the kind of funeral service/ ritual we wanted for them	BGQ category						X ² (6)	p
	No PGD indicated (0–4)		Sub-threshold indicated PGD (5–7)		PGD indicated (8–10)			
	N	%	N	%	N	%		
Yes	126	60.9%	52	25.1%	29	14.0%	3.41	0.491
No	293	56.3%	147	28.3%	80	15.4%		
Somewhat or partly	209	62.4%	82	24.5%	44	13.1%		
Do not know	0	0.0%	0	0.0%	0	0.0%		

p-value computed based on chi-square test.

3.3 Qualitative findings

Open-text responses from participants gave voice to the lived experiences of the sample. Irreparable loss was the superordinate theme identified through thematic analysis, with participants

denied the relational connections they needed and valued in the context of dying, death and bereavement. Nested within this main theme were three sub-themes of loss of connection; loss of ritual; and valuing community support. Each of these themes are presented below.

3.3.1 Loss of connection

Loss of connection was evident in the qualitative accounts of participants. Participants described multiple and layered losses to engage in the end-of-life care and bereavement experience. Sub-themes related to this loss of connection are presented below.

3.3.1.1 Lost opportunities to say goodbye

A theme of loss related to the experience of being unable to say goodbye to loved ones was evident across qualitative accounts. COVID-19 restrictions resulted in people being unable to be with loved ones in the final weeks, days, hours and moments of life. Participants shared stories of loved ones and patients dying alone due to capped visiting numbers in hospital and nursing home settings.

“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 where they allowed at his bedside. They never really got to say goodbye, even worse, they never got to comfort him, tell him they loved him, while he could still hear them. None of us got to say goodbye. There has to be a better way.”

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

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

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

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

3.3.1.2 Alone in grief

Many participants described grieving alone, without access to their informal family, friendship and community supports. Participants reported feelings of loneliness, powerlessness and lack of relational contact as they navigated the period of time after a death:

“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.”

Participants expressed a lack of bereavement support during the pandemic. This included lack of support offered by professionals or generalized difficulties accessing support while grieving. For instance,

one participant recalled their experience of visiting their GP to get support following a bereavement and explained how limited emotional support was given:

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

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

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

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

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

3.3.1.3 Difficulty supporting others

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

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

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

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

The impact of restrictions on people's capacity to be with and support loved ones was captured by one participant who emphasised the difficulty of being unable to comfort his wife at a funeral due to

the restrictions placed on funeral arrangements during the pandemic:

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

3.3.2 Loss of ritual

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

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

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

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

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

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

Participants emphasised that disrupted or absent rituals of mourning negatively affected their grieving process.

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

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

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

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

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

3.3.3 Importance of community support

Alongside people’s experiences of loss and disconnection during the pandemic, data from this study revealed the importance that people place on relational connection and community support at times of death and loss. 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.”

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

“A relative died during the pandemic but not from COVID-19. The family did not have the benefit of the community being able to attend the mass and could not call to houses. Then I realised how important all that is when there is a death.”

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

“The need to be able to share a death with your community was something I took for granted. Having sadly been at a number of close

relatives' funerals, I see that the funerals with restricted numbers do not permit a family to hear lovely stories about the deceased or feel the support of the community."

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

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

4 Discussion

This paper presents compelling findings on experiences of dying, death and bereavement in Ireland during the COVID-19 pandemic. Combining both quantitative and qualitative data from a large survey study in Ireland, findings reveal how relational connections with family, friends and community were restricted, disrupted and, at times severed, at a time when people needed them most. Qualitative findings confirm that the loss of meaningful connection and support was a key source of subjective distress for bereaved persons.

4.1 Deaths during COVID-19 and impact on bereaved people

In line with other published studies, findings from this study demonstrate that some participants who were bereaved during COVID-19 experienced significant distress around the time of their relative's or friend's deaths (24). Many were unable to spend time with the person in the time before they died and only one in five were with the person when they died. Quantitative findings were supported by analysis of qualitative data from the study, providing a window into the meaning of these experiences for participants and their families. Participants spoke of a sense of abandonment, inconsistent with the priorities of caring and family roles before the pandemic. Participants discussed how these experiences gave rise to feelings of guilt, remorse, and moral suffering, which were also captured in the literature (14, 24).

The visiting restrictions in place across the country caused a major disruption in the normal functioning of hospitals and nursing homes during the pandemic. Qualitative findings emphasise the struggle of bereaved participants, who were often denied the opportunity to be present at their loved one's bedside in the last moments of their lives. Being present for a loved one's death is usually desired by family members and is considered an opportunity to say goodbye (25, 26). An interesting finding from this study, was that being present at the time of death was associated with prolonged grief. The reasons for this association are unclear from the data. However, it is possible that the psychological burden of witnessing the death, especially under traumatic and emotionally dysregulated conditions, contributed to dissociative coping responses, which can complicate the grieving process (27). As Diamond argues, trauma that is not mentally processed but instead dissociated can manifest later as unresolved or "repressed" psychological material, intensifying feelings of grief and

loss. In such cases, being physically present does not necessarily equate to psychological preparedness or emotional closure (27). Neither the specific location (hospital versus home) nor the cause of death was associated with poorer bereavement outcomes. This suggests that how the death was managed and supported may have played a more significant role. Given that this study was conducted during an unprecedented public health crisis, which severely impacted healthcare staffing and procedures, other contextual factors may have contributed to the experience of prolonged grief. Further exploration of the lived experiences and surrounding circumstances that may have shaped the grief process in these individuals is warranted. This could include further exploration of the overlap between those who reported their relative died at home and those who were present at the time of death.

Two in five (40%) bereaved people felt they did not get the support they needed at their loved one's time of death. It is possible that protective clothing, limited opportunity for touch, the experiences of uncertainty and communication around what to expect played a role. Also given that the closeness of relationship is associated with PGD it is possible that there is a confounding effect at play. A recent palliative care study also noted the anomalous finding where being present at the time of death was associated with increased use of bereavement support (28). Their findings were not COVID-related and their conclusion about supporting family members to navigate this important time links to the implications of our study.

4.2 The role of funeral and universal support in mourning amid the impact of COVID-19

Findings of a rapid review conducted early in the pandemic showed that research into the functions, processes and impacts of funerals for bereaved people is lacking (29). The importance of funerals as shared, collective and honouring rituals was highlighted through the data presented here. For the majority of respondents, the person who died did not have the funeral they would have wished for, and equally respondents were unable to provide the funeral they would have wanted. There is a poignancy in some of the qualitative comments, which illustrate respondents coming to a realisation of the importance of ritual – something that had not been articulated or understood by them before. This rupturing of cultural scripts (thinking of the funeral as a script) can be viewed from two perspectives, i.e., the destabilising loneliness, and isolation experienced is one perspective however these experiences of limited funerals were not associated with higher grief intensity or risk as measured by the BGQ.

A second perspective is one of adaptation and cultural flexibility (30). Even with restricted attendance most people say they found comfort in funerals. Testament to this flexibility is that the majority of bereaved people note that their community were able to find other ways of honouring the deceased. 'Honouring' in this way is a vital support function of the funeral, and one that plays a vital role in bereavement care at the universal, level 1 of the public health approach to bereavement care. Community bereavement support or 'universal support' extends beyond physical presence to encompass emotional, psychological, and social dimensions. Over half of the respondents said that family and friends were able to

meaningfully support them in their grief, even with restrictions. Evidence shows that social support acts as a protective factor, and meaningful connections within a community can significantly mitigate grief-related distress (28). Similarly, informal social support networks play a vital role in maintaining psychological well-being among those who have lost loved ones due to sudden or violent deaths (31). Natural bereavement support fosters sustained emotional and social engagement (32) and key actions of community members active listening, validation, and sharing experiences need to be privileged.

An important feature of universal support was evident in the qualitative data of this work – it was notable that respondents spontaneously reported the difficulty in supporting others as a disturbing experience. *Bowe et al.* reported on the mental health benefits of community helping during the COVID-19 crisis showing that voluntary caring has benefits for the giver as well as the person supported. While informal bereavement support does not come under this coordinated volunteer support banner, the role of a caring informal supporter, and the subjective impact of being limited in the ability to provide this support should not be underestimated and merits further exploration (33).

4.3 Impact of COVID-19 on bereavement support

The survey found that the majority of participants did not seek formal support from a professional or a support service, which is consistent with prior literature that highlights that informal networks of support are more commonly used and sought by the bereaved (20, 34). However, it is also clear from the literature that those who do seek out bereavement support are in fact those most in need (34). A rapid systematic review to identify effective system-level responses to mass bereavement events, including natural disasters, and pandemics, noted the importance of proactively identifying those in need of support, to ensure need is met (35). Almost half of bereavement service worker participants in an Irish study reported an increase in demand for bereavement support services and many reported more complex needs among service users during COVID-19 (36).

4.4 Impact of COVID-19 on likelihood of PGD and sub-threshold PGD

Findings indicated that 14% of participants screened positive for likely PGD, which is less than prior studies conducted during the pandemic. Indications of 30 to 87% were identified in a recent systematic review (6). While indications of PGD at 14% are lower than proportions reported elsewhere, the relatively large number of individuals with a positive screen for sub-threshold symptoms on the BGQ show that one in four bereaved people may need closer monitoring. This study used the five item Brief Screening Questionnaire (21) in order to minimize participant burden. It is important to note that the BGQ is a screening tool rather than a diagnostic instrument, and none of the 28 studies of PGD during COVID-19 identified by systematic review use the BGQ and therefore there may be a question on the degree of comparability of rates (6).

Many of the higher PGD rates reported in the literature (6) derive from studies conducted in countries with different healthcare systems, cultural mourning practices, and degrees of service disruption during the pandemic. In contrast, Ireland's national response—particularly the role of organisations such as the Irish Hospice Foundation in supporting grief literacy, provision of information to professionals working those who were bereaved and advocating for revised consideration of the public health measures—may have helped buffer some of the adverse impacts of pandemic-related loss. Additionally, cultural norms in Ireland around community-based mourning rituals, spiritual care, and familial cohesion may have played a protective role, even when traditional practices were disrupted.

With respect to risk factors, this study confirmed that closeness of relationship was associated with more intense grief (37). As noted, and discussed above, higher indications of PGD were evident for those present at the time of death and for those who self-reported that they did not get the support they needed because of COVID-19 restrictions (41% of those above thresholds for possible or likely PGD did not get adequate support). There are a number of possible reasons for this finding that may be of interest in further studies. For example, even if a relative was present, for periods of time during the pandemic, loved ones were forced to wear full personal protective equipment in hospitals and unable to hold the hand of a loved one as they died. For others, their care of their loved ones at home happened at a time when restrictions meant they did not have access to the typical levels of palliative care support.

BGQ was chosen as a short, validated screening tool for PGD and the findings presented here should be viewed in that context; diagnosis of PGD rates would require further investigation, including use of validated assessment tools and clinical interview reflecting the multidimensionality of PGD (21, 22). Nevertheless, BGQ as a screening tool has merits; a PGD screening study of 1,015 bereaved patients in a primary care setting (38) concluded that the BGQ performed as well as the Inventory of Complicated Grief and was easier and shorter to administer. Currently in Ireland, despite the recognition of the public health approach to bereavement care, no established screening or clinical pathways for referrals to grief treatment exist. The current study has demonstrated the short five questions are acceptable to an Irish grieving population and some consideration could therefore be given to piloting a screening programme in Ireland.

4.5 Public health framework and planning for bereavement care

Conceptualizing grief as a public health issue is increasingly recommended in order to prevent health impacts and to apportion the most effective supports for those most in need (20, 34, 39, 40). The model promotes communities being grief literate and supportive to all those grieving as a fundamental basis for healthy grief. This extends to the support provided in the lead up to a death, and at the time of death. The need for a public health approach to bereavement was noted as necessary prior to the onset of COVID-19 but was amplified by a time when the focus on dying, death and grief had never been greater.

IHF has long advocated for a strategic and coordinated approach to bereavement care. Developed by IHF, the Adult Bereavement Care

Pyramid provides a national framework for adult bereavement care in Ireland (19). The pyramid suggests that every person who experiences 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.

This structure corresponds closely with the three-tiered model, which divides bereaved individuals into low-risk, moderate-risk, and high-risk categories (39, 41). In both frameworks, the majority of bereaved individuals require only informal or community-based support, while a smaller proportion benefits from structured interventions, and a minority requires specialist care. Aoun's empirical work provides robust validation for the tiered approach to bereavement care as set out in public health models, including the Adult Bereavement Care Pyramid used in Ireland (20, 34).

A pre-COVID 2015 study demonstrates that 58% of bereaved individuals have Level 1 (low level) needs, 35% were at Level 2 (moderate risk), and 6.4% were Level 3, high-risk or demonstrating criterion scores on the Inventory of Complicated Grief (34).

People who are at risk of complications in their grieving need to be identified and matched to the appropriate supports, while those experiencing difficulties should be able to access appropriate professional help.

The data presented here used the five item BGQ to screen for potential indicators of PGD and to approximate the levels of bereavement support need among those who self-reported a bereavement during the COVID-19 pandemic in Ireland. Most (59.6%) of the bereaved survey respondents were categorised as low risk (BGQ score 0–4) with respect to their BGQ, almost identical to Aoun's results (34). Using the screening tool, around one in four (26%) were categorised as likely to have symptoms of sub-threshold PGD and 14% were indicated as possible symptoms of PGD, or as definitely requiring further diagnostic investigation for PGD.

The implications of these results are a mixed picture; a positive was that natural support seemed to remain a protective factor for the majority of bereaved through the pandemic, despite the changes and limited interactions while public health measures were in place. However, a sizeable proportion, approximately one in ten people (14%), presented with possible indications of PGD, higher than Aoun's 6.5% but lower than levels of pandemic bereavements reported in the research literature (24). A further 26% of the Irish sample fit into a moderate risk category and these people require further attention. In summary, approximately 40% of those surveyed were identified by the BGQ as potentially benefiting from additional bereavement support. We use the term "support need" here rather than "bereavement risk" to align with the BGQ's function as a screening tool rather than a predictive risk assessment or diagnostic tool.

The findings of this report are beneficial for public health practitioners, healthcare workers, family carers, policymakers, and the public. The literature review for this survey report highlighted that there is concern globally regarding the detrimental impact of COVID-19 on the grieving process and the provision of bereavement support, particularly considering the public health measures and restrictions placed on society during the pandemic. Several authors have indicated that there is likely to be long-standing consequences on dying, death, and bereavement due to the profound loss of human

life, and that the increase in pathological grief will become a worldwide public health concern, calling it a silent epidemic of grief (14, 42). Others have suggested that the impact may not be as extensive as originally anticipated (29). There is consensus regarding the need for continued research on the topic and close monitoring of people who have been bereaved to identify those most at-risk of developing PGD or other complications, and to intervene early.

Drawing on our findings, which highlighted how restrictions placed on families being with their loved ones, as they approached end of life, was a key source of distress for bereaved individuals, we recommend that future healthcare responses prioritise relational and compassionate care even during public health crises. To mitigate the traumatic experience of bereaved individuals, healthcare systems should facilitate supportive communication that meets the needs of both the dying person and their family, flexible and safe visitation policies wherever possible, and ensure opportunities for loved ones to say goodbye.

Lichtenthal's concept of transitional bereavement care is a guide for how health and social/community contexts need to link (40). The transitional bereavement care model bridges the gap between healthcare institutions and community-based support systems (40). This model emphasises the importance of continuity of care, ensuring that bereaved individuals receive support as they transition from institutional care to community resources (40). Key components include preventive bereavement care, ownership of bereavement services by institutions, allocation of resources for bereavement support, upskilling of support providers, and implementation of evidence-based practices (40). By integrating these elements, the model aims to address the multifaceted needs of the bereaved, promoting a comprehensive and compassionate approach to bereavement care (40). By integrating these elements, many of which respond directly to the gaps in care and support identified by participants in this study, the model promotes a comprehensive and compassionate approach to bereavement care that addresses both pandemic-specific and broader systemic challenges.

Screening and early intervention for PGD or complicated grief should be incorporated into health policy and practices. Recommendations from the literature include the need to find innovative ways for healthcare workers to connect with and support bereaved persons during a public health crisis (43) and the need to ensure continuity of spiritual and religious activities, as well as social support for patients and their families during a public health crisis.

To address the limited access to bereavement support, health services must be equipped with additional resources for patients and families, and healthcare workers should receive training in social-emotional skills to better support grieving families, and bereavement support groups (both online and in-person) should be expanded. Learning from the pandemic demands that, in normal times as well as in crisis, we identify factors that promote healthy grieving, intervene with those at risk of complications and treat people who are intensely suffering from prolonged or other disturbed grieving processes. It is also important to acknowledge the broader ethical complexity of conducting bereavement research during a pandemic, where public health measures aimed at controlling a highly contagious infectious disease may conflict with individual and relational values around end-of-life care, mourning, and grief. This ethical tension, between protecting the collective good and respecting personal and familial

needs, underscores the need for careful ethical reflection on the design and implementation of studies during a public health crises.

4.6 Limitations

The survey was cross-sectional in nature and collected data among participants at one point in time. A cohort study that follows participants over a period of time may yield different findings because views and perceptions may change. In particular, longitudinal follow-up, such as repeating the questionnaire one and two years later, could provide valuable insights into the evolving nature of grief and the longer-term impact of bereavement experiences. This would allow for a deeper understanding of trajectories of adjustment and potential delayed grief responses.

The study had limited representation of younger age groups, male participants, non-Irish ethnic background, and foreign nationals residing in Ireland. However, this is aligned with other similar studies. Future research with diverse populations is warranted. Another limitation of the study was the sensitive nature of the survey questions relating to dying, death, and bereavement. This may have impacted on the missing data throughout the survey responses. While we did collect data on several causes of death, including confirmed and suspected COVID-19 infection, cancer, cardiac conditions, and others; this information was not verified via medical records or death certificates. Future research would benefit from incorporating verified clinical data to explore these patterns further. Nonetheless, this survey study is the only nationwide survey conducted on this topic in Ireland.

While the BGQ was selected as a brief, validated screening tool for PGD, several limitations should be acknowledged. The BGQ is a screening rather than diagnostic instrument and does not capture the full multidimensionality of PGD as defined in recent diagnostic frameworks. Its reliance on self-report introduces the potential for response bias and limits the capacity to distinguish between normative grief reactions and clinically significant PGD. Additionally, although the BGQ has demonstrated good sensitivity and specificity in previous studies, further validation within diverse cultural contexts would strengthen its applicability. Consequently, the findings presented should be interpreted as indicative of probable PGD risk rather than confirmed diagnoses, and future research should incorporate comprehensive diagnostic assessments and longitudinal follow-up.

4.7 Future research

There is a consensus in the literature that further research on the long-term impacts of COVID-19 is warranted and this research should include large population-based samples, as well as studies that focus on specialised groups. Further research monitoring the severity of grief amongst different groups (e.g., healthcare professionals) would also be beneficial to inform public health responses and practices to support those at risk of developing PGD or complicated grief.

5 Conclusion

The COVID-19 pandemic profoundly altered experiences of dying, death, and bereavement, leaving a lasting impact on

individuals and society. Public health measures imposed to control the spread of the virus often prevented families from being present with dying loved ones and disrupted traditional mourning rituals, leading to widespread emotional distress. The *Time to Reflect* study is the only Irish investigation on bereavement experiences in Ireland, providing comprehensive insights into the impact of COVID-19 on end-of-life care, grief, and bereavement support. By capturing data from a broad demographic, it offers a robust evidence base to inform bereavement care policies and interventions.

Findings from this study highlight the significant impact of public health measures on funerals and mourning rituals, and characterize the varied experiences of grief and responses to bereavement among individuals in Ireland during the COVID-19 pandemic. A public health approach to bereavement care involves identifying the diverse needs of the bereaved and mapping out a spectrum of responses, including informal and community-based support and organised and professional interventions. In this survey, it was recognised that all bereaved people need compassion, clear information and 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.

The pandemic heightened public awareness of grief and loss and reinforced the importance of dignified end-of-life care. There is an ongoing global concern about the long-term effects of disrupted grieving processes, highlighting the need for sustained research, early intervention, and enhanced bereavement support within healthcare systems. Future policies must ensure that, even in public health crises, human dignity and the need for connection at the end of life remain a priority. Significantly, the findings highlight the indispensable role of family and friend caregivers, who not only provide practical assistance and emotional comfort but also serve as vital connectors within communities, ensuring that the bereaved are not isolated in their grief.

By capturing data from a broad demographic, this study offers a robust evidence base to inform bereavement care policies and interventions. The study's national scope ensures that findings reflect diverse experiences across different communities, systemic challenges, and the varying support needs of bereaved individuals. Furthermore, as the first large-scale survey of COVID-19-related bereavement in Ireland, it establishes a critical foundation for future research, enabling comparisons over time, which can support the development of evidence-based bereavement care frameworks. Its findings are particularly valuable for public health planning, healthcare service improvement, and policy development, ensuring that bereavement support in Ireland is both inclusive and responsive to the needs of those affected by loss.

Data availability statement

The datasets presented in this article are not readily available because in accordance with the ethical approval granted for this study, all study records including study data will be destroyed in 2026 and therefore, will be unavailable to share. Requests to access the datasets should be directed to OK, orla.keegan@hospicefoundation.ie.

Ethics statement

This study involving humans was approved by Royal College of Surgeons in Ireland (REC approval no: 202105022). The study was conducted in accordance with local legislation and institutional requirements. As the study design ensured complete anonymity written consent was not collected. No identifying information was collected or recorded. In accordance with ethical guidelines, participants were provided with full information about the study. Participants were required to tick a box confirming their informed consent to participate to access the online survey instrument. A tick box confirming informed consent to participate was also included in the paper version of the survey instrument. Only data from participants who ticked this box were included in the study. IHF acted as the data controller when managing the data and was responsible for the protection, storing, and analysis of the survey.

Author contributions

EW: Conceptualization, Formal analysis, Writing – original draft, Writing – review & editing. FC: Writing – original draft, Writing – review & editing. HC: Conceptualization, Methodology, Project administration, Writing – original draft, Writing – review & editing, Data curation, Investigation, Supervision. AE: Conceptualization, Methodology, Project administration, Writing – original draft, Writing – review & editing. OK: Conceptualization, Methodology, Project administration, Writing – original draft, Writing – review & editing.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. Irish Hospice Foundation provided funding for a research assistant to support the write-up of this manuscript.

References

- World Health Organization. WHO director-general's statement on IHR emergency committee on novel coronavirus (2019-nCoV) (2020). Available online at: [https://www.who.int/director-general/speeches/detail/who-director-general-s-statement-on-ihr-emergency-committee-on-novel-coronavirus-\(2019-ncov\)](https://www.who.int/director-general/speeches/detail/who-director-general-s-statement-on-ihr-emergency-committee-on-novel-coronavirus-(2019-ncov))
- World Health Organization. WHO director-general's opening remarks at the media briefing on COVID-19—27 July 2020 (2020). Available online at: <https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---27-july-2020>
- Banach M. Global burden of 288 causes of death and life expectancy decomposition in 204 countries and territories and 811 subnational locations, 1990–2021: a systematic analysis for the global burden of disease study 2021. *Lancet*. (2024) 403:10440. doi: 10.1016/S0140-6736(24)00367-2
- World Health Organization. WHO COVID-19 Dashboard: reported deaths. Available online at: <https://data.who.int/dashboards/covid19/deaths?n=0>
- Lourenço M, Gomes T, Araujo F, Ventura F, Silva R. Challenges for palliative care in times of COVID-19: a scoping review. *Front Public Health*. (2024) 12:1330370. doi: 10.3389/fpubh.2024.1330370
- Reitsma L, Killikelly C, Müller H, Larsen LH, Nijborg LC, Boelen PA, et al. Prevalence and correlates of positive and negative psychological effects of bereavement due to COVID-19: a systematic review. *J Affect Disord*. (2025) 378:19–35. doi: 10.1016/j.jad.2025.02.078
- Ayouni I, Maatoug J, Dhoubi W, Zammit N, Fredj SB, Ghammam R, et al. Effective public health measures to mitigate the spread of COVID-19: a systematic review. *BMC Public Health*. (2021) 21:1015. doi: 10.1186/s12889-021-11111-1

Acknowledgments

Thanks Dr. Carla Perrotta and Vicky Downey (UCD Centre for Safety and Health at Work, School of Public Health, Physiotherapy and Sports Science) for their preliminary analysis of the data. Thanks to Paula O'Reilly and Neil Fullerton (Irish Hospice Foundation), Dr. Ellen Fruijtjer, Lynn Murtagh, Rebecca Lloyd, Gráinne Rogers, and Sharon Foley (formerly Irish Hospice Foundation) for their contribution to the work.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declare that no Gen AI was used in the creation of this manuscript.

Any alternative text (alt text) provided alongside figures in this article has been generated by Frontiers with the support of artificial intelligence and reasonable efforts have been made to ensure accuracy, including review by the authors wherever possible. If you identify any issues, please contact us.

Publisher's note

All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article, or claim that may be made by its manufacturer, is not guaranteed or endorsed by the publisher.

- Ogbodo JN, Onwe EC, Chukwu J, Nwasum CJ, Nwakpu ES, Nwankwo SU, et al. Communicating health crisis: a content analysis of global media framing of COVID-19. *Health Promot Perspect*. (2020) 10:257–69. doi: 10.34172/hpp.2020.40
- Giménez-Llort L, Torres-Lista V, Oghagbon EK, Pereira HV, Gijbsberts MJ, Invitto S. Death and mourning processes in the times of the coronavirus pandemic (COVID-19). *Front Psych*. (2022) 13:922994. doi: 10.3389/fpsy.2022.922994
- Irish Hospice Foundation. Time to reflect: Survey of ECNEs 2023. Dublin: Irish Hospice Foundation (2024).
- Pinto C, Shipsey F, Weston-Stanley P, Martin I, D'arcy A, Standing-Tattersall C, et al. The impact of the COVID-19 pandemic on bereavement and grief. London: National Centre for Social Research.
- Harrop E, Medeiros Mirra R, Goss S, Longo M, Byrne A, Farnell DJ, et al. 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. *Front Public Health*. (2023) 11:1215881. doi: 10.3389/fpubh.2023.1215881
- Sirrine EH, Klinner O, Gollery TJ. College student experiences of grief and loss amid the COVID-19 global pandemic. *OMEGA-J. Death Dying*. (2023) 87:745–64. doi: 10.1177/00302228211027461
- Eisma MC, Tamminga A. Grief before and during the COVID-19 pandemic: multiple group comparisons. *J Pain Symptom Manag*. (2020) 60:e1–4. doi: 10.1016/j.jpainsymman.2020.10.004
- Stroebe M, Schut H. Bereavement in times of COVID-19: a review and theoretical framework. *OMEGA J Death Dying*. (2021) 82:500–22. doi: 10.1177/0030222820966928

16. Bates U, Brennan J, Keegan O. Implementation and evaluation of a National Bereavement Support line in response to the COVID-19 pandemic in Ireland. *J Public Health*. (2023) 45:e296–302. doi: 10.1093/pubmed/fdac119
17. Power A, Atkinson S, Noonan M. “Stranger in a mask” midwives’ experiences of providing perinatal bereavement care to parents during the COVID-19 pandemic in Ireland: a qualitative descriptive study. *Midwifery*. (2022) 111:103356. doi: 10.1016/j.midw.2022.103356
18. Pearce C, Honey JR, Lovick R, Creamer NZ, Henry C, Langford A, et al. A silent epidemic of grief: a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic. *BMJ Open*. (2021) 11:e046872. doi: 10.1136/bmjopen-2020-046872
19. Hospice Foundation of Ireland. Irish Hospice Foundation. Adult bereavement care pyramid: A National Framework. Dublin: Hospice Foundation of Ireland. Irish Hospice Foundation. Available online at: <https://hospicefoundation.ie/our-supports-services/bereavement-loss-hub/i-work-inbereavement/adult-bereavement-care-pyramid/>
20. Aoun SM, Breen LJ, O’Connor M, Rumbold B, Nordstrom C. A public health approach to bereavement support services in palliative care. *Aust N Z J Public Health*. (2012) 36:14–6. doi: 10.1111/j.1753-6405.2012.00825.x
21. Shear KM, Jackson CT, Essock SM, Donahue SA, Felton CJ. Screening for complicated grief among project liberty service recipients 18 months after September 11, 2001. *Psychiatr Serv*. (2006) 57:1291–7. doi: 10.1176/ps.2006.57.9.1291
22. Ito M, Nakajima S, Fujisawa D, Miyashita M, Kim Y, Shear MK, et al. Brief measure for screening complicated grief: reliability and discriminant validity. *PLoS One*. (2012) 7:e31209. doi: 10.1371/journal.pone.0031209
23. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3:77–101. doi: 10.1191/1478088706qp0630a
24. Van Schaik T, Brouwer MA, Knibbe NE, Knibbe HJ, Teunissen SC. The effect of the COVID-19 pandemic on grief experiences of bereaved relatives: an overview review. *OMEGA J Death Dying*. (2022) 91:00302228221143861. doi: 10.1177/00302228221143861
25. Kentish-Barnes N, Cohen-Solal Z, Morin L, Souppart V, Pochard F, Azoulay E. Lived experiences of family members of patients with severe COVID-19 who died in intensive care units in France. *JAMA Netw Open*. (2021) 4. doi: 10.1001/jamanetworkopen.2021.13355
26. Otani H, Yoshida S, Morita T, Aoyama M, Kizawa Y, Shima, Y, et al. Meaningful communication before death, but not present at the time of death itself, is associated with better outcomes on measures of depression and complicated grief among bereaved family members of cancer patients. *J Pain Symptom Manag*. (2017) 54:273–9. doi: 10.1016/j.jpainsymman.2017.07.010
27. Diamond MJ. Return of the repressed: revisiting dissociation and the psychoanalysis of the traumatized mind. *J Am Psychoanal Assoc*. (2020) 68:839–74. doi: 10.1177/0003065120964929
28. Brito MF, Selman LE, Calanzani N, Koffman J, Higginson IJ, Gomes B. Caregiving burden, receipt of palliative care, and the use of bereavement support: secondary analysis of population-based data. *BMC Palliat Care*. (2025) 24:1. doi: 10.1186/s12904-025-01705-6
29. Burrell A, Selman LE. How do funeral practices impact bereaved relatives’ mental health, grief and bereavement? A mixed methods review with implications for COVID-19. *OMEGA J. Death Dying*. (2022) 85:345–83. doi: 10.1177/0030222820941296
30. Kapoor V, Belk R, Goulding C. Ritual revision during a crisis: the case of Indian religious rituals during the COVID-19 pandemic. *J Public Policy Mark*. (2022) 41:277–97. doi: 10.1177/07439156221081485
31. Cacciatore J, Thieleman K, Fretts R, Jackson LB. What is good grief support? Exploring the actors and actions in social support after traumatic grief. *PLoS One*. (2021) 16:e0252324. doi: 10.1371/journal.pone.0252324
32. Lund D, Caserta M, Utz R, De Vries B. Experiences and early coping of bereaved spouses/partners in an intervention based on the dual process model (DPM). *OMEGA J Death Dying*. (2010) 61:291–313. doi: 10.2190/OM.61.4.c
33. Bowe M, Wakefield JR, Kellezi B, Stevenson C, McNamara N, Jones BA, et al. The mental health benefits of community helping during crisis: coordinated helping, community identification and sense of unity during the COVID-19 pandemic. *J Community Appl Soc Psychol*. (2022) 32:521–35. doi: 10.1002/casp.2520
34. Aoun SM, Breen LJ, Howling DA, Rumbold B, McNamara B, Hegney D. Who needs bereavement support? A population based survey of bereavement risk and support need. *PLoS One*. (2015) 10:e0121101. doi: 10.1371/journal.pone.0121101
35. Harrop E, Mann M, Semedo L, Chao D, Selman LE, Byrne A. What elements of a systems’ approach to bereavement are most effective in times of mass bereavement? A narrative systematic review with lessons for COVID-19. *Palliat Med*. (2020) 34:1165–81. doi: 10.1177/0269216320946273
36. Roberts, A, Keegan, O, Holme, I, and Keeting, M. (2023). The impact of Covid-19 on bereavement care in Ireland: A national survey of bereavement care providers. *Bereavement*. 2. doi: 10.54210/bj.2023.1112
37. Buur C, Zachariae R, Komischke-Konnerup KB, Mareello MM, Schierff LH, O’Connor M. Risk factors for prolonged grief symptoms: a systematic review and meta-analysis. *Clin Psychol Rev*. (2024) 107:102375. doi: 10.1016/j.cpr.2023.102375
38. Patel SR, Cole A, Little V, Skritskaya NA, Lever E, Dixon LB, et al. Acceptability, feasibility and outcome of a screening programme for complicated grief in integrated primary and behavioural health care clinics. *Fam Pract*. (2019) 36:125–31. doi: 10.1093/fampra/cmy050
39. Schut H, Stroebe MS. Interventions to enhance adaptation to bereavement. *J Palliat Med*. (2005) 8:s-140–7. doi: 10.1089/jpm.2005.8.s-140
40. National Institute for Clinical Excellence Improving Supportive and Palliative Care for Adults with Cancer. London: National Institute of Clinical Excellence. (2004). Available at: <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>
41. Ward S, Salazano S, Sampson F, Cowan J. Improving supportive and palliative care for adults with cancer. *Econ Rev*. (2004)
42. Gesi C, Carmassi C, Cerveri G, Carpita B, Cremona IM, Dell’Osso L. Complicated grief: what to expect after the coronavirus pandemic. *Front Psych*. (2020) 11:489. doi: 10.3389/fpsy.2020.00489
43. Rabow MW, Huang CH, White-Hammond GE, Tucker RO. Witnesses and victims both: healthcare workers and grief in the time of COVID-19. *J Pain Symptom Manag*. (2021) 62:647–56. doi: 10.1016/j.jpainsymman.2021.01.139

Frontiers in Public Health

Explores and addresses today's fast-moving healthcare challenges

One of the most cited journals in its field, which promotes discussion around inter-sectoral public health challenges spanning health promotion to climate change, transportation, environmental change and even species diversity.

Discover the latest Research Topics

[See more →](#)

Frontiers

Avenue du Tribunal-Fédéral 34
1005 Lausanne, Switzerland
frontiersin.org

Contact us

+41 (0)21 510 17 00
frontiersin.org/about/contact

