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Developing a Practice-based Research Agenda for Grief and Bereavement Care

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Practice-based Research Agenda

## **Abstract**

We aimed to identify practitioners' perspectives on current research priorities in grief and bereavement care. Grief and bereavement care providers were invited to participate in a three-phase Delphi study to create expert consensus on the top priorities for grief and bereavement research. A total of 140 participants completed Phase 1, 84 completed Phase 2, and 70 completed Phase 3. These top 10 research priorities form the basis of a practice-based research agenda for grief and bereavement care to enable researchers to respond to key issues in grief and bereavement care that will ultimately improve the lives of bereaved people.

Keywords: research-practice gap; knowledge translation; research dissemination; practice-led research

Developing a Practice-based Research Agenda for Grief and Bereavement Care

Most people adapt well to bereavement and a smaller proportion experiences marked and prolonged distress (Kersting, Brahler, Glaesmer, & Wagner, 2011). It is imperative that there are appropriate frameworks and interventions that are useful to clients and financially feasible on the healthcare system (Stroebe, Stroebe, Schut, & Boerner, 2017). Although there is strong evidence to support indicated intervention outcomes for people experiencing complicated/prolonged grief, there is less support for universal or selective interventions (Currier, Neimeyer, & Berman, 2008; Waller, Turon, Mansfield, Clark, Hobden, & Sanson-Fisher, 2016; Wittouck, Van Autreve, De Jaegere, Portzky, & Van Heeringen, 2011). The evidence base is hampered by methodological issues, particularly in the early studies of bereavement care interventions (Jordan & Neimeyer, 2003), which masked the true effectiveness of interventions.

One important factor that may affect grief and bereavement care is the considerable gap between the science of bereavement care and its application (Breen & O'Connor, 2007; Breen, Aoun, O'Connor, & Rumbold, 2014; Bridging Work Group, 2005; Center for the Advancement of Health, 2004; Neimeyer, Harris, Winokuer, & Thornton, 2011). As new research findings emerge, bereavement care practices must adapt but the evidence must also be applicable to clinical settings (Tieman, Hayman, & Hall, 2015). Rosner (2015) reviewed research findings in grief and bereavement care to establish important areas for research; these were the development of valid measures, prevalence rates of complicated grief, exploration of different treatments, and comorbidity. Although Rosner aimed to develop a research agenda in bereavement, she focused only on the pattern of research findings observed across the grief and bereavement literature and did not engage practitioners.

Many grief and bereavement care practitioners do not have access to the current research findings because these are published in academic journals and, if they do have access, the findings are typically not amenable to ready application in real-world clinical settings (Breen, 2011). Addressing practical, clinical matters is not always a primary consideration for researchers (Center for the Advancement of Health, 2004) whereas practitioners seek readily-applicable research findings to inform their work with bereaved people (Silverman, 2010). Practitioners and academics agree that

research is valuable to inform practice but differ in their assessments of what is relevant and credible, and this tends to position practitioners as the receivers of research rather than its drivers (Brownson, Jacobs, Tabak, Hoehner, & Stamatakis, 2013; Center for the Advancement of Health, 2004). However, a stronger relationship between practice and research would be highly beneficial to both researchers and practitioners. For instance, Neimeyer (2016) highlighted that methods can inform practice, and that practice can (and should) inform the models, measures, and methods that are developed and used in research. These, in turn, inform practice. In this way, no one component is more important than another and each informs another (Neimeyer, 2016).

The development of a research agenda for grief and bereavement care, from the perspectives of practitioners, will provide a shift away from the typical, unidirectional relationship between research and practice and instead will provide a practice-based agenda for researchers to respond to key issues and challenges to those who provide grief and bereavement care (Neimeyer, 2014). Doing so would help address the research-practice gap in grief and bereavement care. By determining grief and bereavement care practitioners' research priorities, researchers can investigate research topics that are likely to be more useful and readily transferable to improving the lives of grieving people.

### Method

# Design

A Delphi study synthesizes group knowledge and recommendations of experts to form a consensus on a topic in a relevant field of inquiry through questionnaires. Each phase of a Delphi method is dependent upon the results of the previous phase of exploration and which influence the next phase of data collection. A systematic review on the Delphi method as used in healthcare research showed that there is no universally-accepted procedure but Delphi studies typically comprise two to four sequential phases (Boulkedid, Abdoul, Loustau, Sibony, & Alberti, 2011). We used a three-phase Delphi method, which enabled the exploration participants' research priorities, which were then reduced and synthesized to identify the most important priorities presented in grief and bereavement research. A summary of the process is provided in Figure 1.

# **Participant Recruitment**

The provision of grief and bereavement care is not discipline-specific so we sought participants who were members of Australian Centre for Grief and Bereavement and identified as practitioners with expertise in the area of grief and bereavement. Potential participants were invited to participate in the study via the Australian Centre for Grief and Bereavement's monthly e-newsletter, which is sent via email to all its members and affiliates (N = 17,956). Delphi samples sizes range from 10 to 2000 with a response rate to opt-in studies averaging 35% (Akard et al., 2013; Akins, Tolson, & Cole, 2005). Participant characteristics are summarized in Table 1.

## **Materials and Procedure**

Ethics approval was obtained from the Curtin University Human Research Ethics Committee (HRE2018-0231). Potential participants who responded to the research invitation clicked on a link to an information sheet hosted on Qualtrics<sup>TM</sup> and advised that, if they wish to be part of this study, they had three weeks to complete Phase 1. Each participant indicated informed consent through a forced-choice question, where participants had to agree to consent before being able to complete the questionnaire. The survey for each phase took no more than 15 minutes to complete.

Phase 1 invited participants to respond to a range of demographics including information on gender, location, role, discipline, years working in grief and bereavement care, and how they keep upto-date with relevant new information. Participants were then asked to write their top five areas or topics they think should be prioritized in future grief and bereavement research. Participants were asked to generate their priorities rather than choose from a pre-determined list. A thematic content analysis (Hsieh & Shannon, 2005) of the responses was conducted to develop priority statements for Phase 2.

Participants who completed Phase 1 were sent an email link to Qualtrics<sup>TM</sup> and invited to complete Phase 2, which involved rating research priority statements on a Likert scale from 1 (very high priority) to 5 (not a priority). Participants who completed Phase 2 were invited to complete Phase 3, which asked them to rank their top 10 priorities extracted from the previous phase. At the completion of all phases, participants who completed Phase 3 were invited to provide an email address to receive a summary of findings and/or to enter the prize draw to win one of four \$25 gift cards. The

winners of four gift cards were drawn through an online random number generator (random.org) and winners contacted by email.

#### Results

The data from Phase 1 was coded and analyzed using a thematic content analysis (Hsieh & Shannon, 2005) where all responses were summarized into broader themes and then collapsed to identify research priorities, eliminate duplication, and group priorities into broader categories. A total of 140 of the 206 participants who started the questionnaire provided at least one research priority (*M* = 4.61); in total, 602 priorities comprising 5898 words were provided for analysis. To increase rigor, two researchers (AH and LJB) independently coded and categorized the priorities and then discussed discrepancies until consensus was achieved. Three grief and bereavement experts (CWH, MS, and EAL) provided detailed feedback on the interim list of research priority statements. This feedback was addressed, and the final analysis yielded 7 broad categories and 62 priority statements (see Table 2).

In Phase 2, 130 participants were emailed, with 93 responses (72.6%) and 84 completed the survey. Consensus was defined a priori as statements that were rated 1 (very high priority) or 2 (high priority) by 85% of participants (Baker, 2015); however, no individual item yielded consensus to this degree. We therefore used the criteria proposed by French et al. (2015) whereby ratings of importance by 70% of participants would be sufficient for consensus. Twenty-three priorities met this criterion and were presented to participants in Phase 3. Means and standard deviations for each priority statement and statement category are presented in Table 2. The categories by priority level (highest to lowest) were "Enriching Health Professionals' Training and Support", "Determining Grief Processes", "Exploring Social/Community Concerns", "Exploring Social/Community Concerns", "Improving Grief Interventions", "Understanding Experiences and Meeting the Needs of Specific Types of Losses and Grievers", and "Investigating Non-Death Losses". The 84 participants from Phase 2 were invited to participate in Phase 3 and 70 responded (response rate of 83%). Mean rankings were used to determine top 10 research priorities (Table 3).

### Rating Comparisons based on Participants' Characteristics

Statistical analyses were conducted using IBM SPSS version 25. Less than 6% of the data was missing per item; a Little's MCAR analysis suggest that these data was missing completely at random

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(df = 935, p = .614) and missing data was replaced using expectation maximization. Mann-Whitney U analyses were conducted due to violations of normality and uneven group sizes. Due to the exploratory nature of this study, and in line with similar conventions used in similar studies, Bonferroni corrections for multiple corrections were not made (Sullivan, Ugalde, Sinclair, & Breen, 2019). Effect sizes were interpreted according to Cohen's (1988) conventions.

Mann-Whitney U tests indicated no significant differences on Phase 2 ratings based on: years working in grief and bereavement care (median split >/< 13 years), country of residence (Australia/other), location (metropolitan/rural), site (inpatient/home-based care), primary role (researcher/practitioner) or sex (male/female). Participants aged 53 and over rated the "Enriching Health Professionals' Training and Support" category items as a higher priority (Mean Rank = 32.82, n = 45), than participants aged under 53 (Mean Rank = 44.76, n = 29) (U = 442.00, p = .019, two tailed), with a "small to medium" (r = .20) effect size. Participants aged 53 and over also rated the "Investigating Non-Death Losses" category items as a higher priority (Mean Rank = 32.98, n = 45), than participants aged under 53 (Mean Rank = 44.52, n = 29) (U = 449.00, p = .024, two tailed), with a "small to medium" (r = .26) effect size. Participants who were not working in a multidisciplinary team rated items in the "Investigating Non-Death Losses" category as a higher priority (Mean Rank = 27.05, n=21) than those who did work in a multidisciplinary team (Mean Rank = 41.64, n=53) (U=337.00, p = .008, two tailed) with a "medium" (r = .30) effect size. Compared to participants from disciplines of social work, counseling, psychology, chaplaincy, and occupational therapy (Mean Rank =38.96, n=72), participants from medicine and nursing disciplines rated the "Determining Grief Processes" category as a higher priority (Mean Rank = 24.21, n = 72) (U = 212.500, p = .026, two tailed) with a "small/medium" (r = .26) effect size. Participants in the medicine and nursing disciplines also rated the "Understanding Experiences and Meeting the Needs of Specific Types of Grievers and Losses" category as a higher priority (Mean Rank = 25.00, n = 72), than the other professionals (Mean Rank = 38.80, n = 72) (U = 222.000, p = .037, two tailed) with a "small/medium" (r = .24) effect size.

### **Discussion**

The current study provides priority areas for future research on grief and bereavement care. To our knowledge, this is the first study to generate research priorities from the perspectives of grief and

bereavement care practitioners. The findings from Phase 2 indicate the categories with the highest overall priority ranking comprised items concerning Enriching Health Professionals' Training and Support, Determining Grief Processes, and Exploring Social/Community Concerns. The top 10 research priorities were drawn from four of the seven categories (Determining Grief Processes, Enriching Health Professionals' Training and Support, Understanding Experiences and Meeting the Needs of Specific Types of Losses and Grievers, and Improving Grief Interventions); 6 of the 10 priorities related to the category Determining Grief Processes.

The first priority identified by the practitioners concerned growth, resilience, and recovery through the grief process. This priority aligns with the knowledge of every individual's mourning process and interactions being unique and generally a normal part of life (Breen, O'Connor, 2007; Stroebe et al., 2017). This priority could also be in response to what has been described by some commentators as the increasing medicalization and pathologization of grief (Bandini, 2015; Granek, 2010) and that a considerable proportion of mental health professionals (Ogden & Simmonds, 2014) and palliative care staff (Davis, Deane, Barclay, Bourne, Connolly, 2018) express concern that a diagnostic category would pathologize "normal" grief. The latter interpretation is likely given that the item "The medicalization of grief and how we can move toward normalizing and destigmatizing grief" was rated as the third highest priority, out of 62 items, in Phase 2. Likewise, Phase 2's ratings showed a consensus of at least one item per category for all categories except "Developing Grief Measures," which could suggest distancing from attempts to measure and potentially pathologize grief (Bandini, 2015).

The second priority concerned distinguishing grief from mental health issues (e.g., depression, PTSD, anxiety, identity disorder and trauma). A recent randomized, controlled trial tested the utility of written information on practitioners' ability to differentially diagnose PGD from normative grief, PTSD, and Major Depressive Disorder (Lichtenthal et al., 2018). The study showed that practitioners can be trained to distinguish between these disorders in order to diagnose PGD accurately, which is important for practitioners to be able to provide appropriate interventions. However, there is still much to be done to understand the relation between complex mental health issues and grief.

The third priority concerned how General Practitioners and other primary care providers could more quickly recognize problematic grief to allow faster referrals to counseling services. This priority is important because people with prolonged grief disorder do not readily seek mental health services (Lichtenthal et al., 2011) but they may have more medical appointments due to the physical health correlates of bereavement (Buckley, Sunari, Marshall, Bartrop, McKinley, & Tofler, 2012; King, Vasanthan, Peterson, Jones, Marston, & Nazareth, 2013). Further, in many countries, General Practitioners occupy a key role in referring patients to mental health professionals (Fredheim, Danbolt, Haavet, Kjønsberg, & Lien, 2011). However, studies have shown that General Practitioners' understandings of grief is limited and not necessarily evidence-based (O'Connor, & Breen, 2014; Wiles, Jarrett, Payne, & Field, 2002). Bereaved people express a desire to receive information on grief (Breen, Aoun, Rumbold, McNamara, Howting, & Mancini, 2017), and such information could be provided to them by primary care providers if the providers are equipped with this information.

Priorities 4, 6, and 7 all concerned aspects of childhood and grief. The fourth priority on the effects of grief on children and adolescents was also established in Rosner's (2015) narrative review. The sixth priority concerned the impact of trauma, including childhood trauma, on the experience of grief. Related to the sixth priority is the eighth priority concerning grief experiences from traumatic losses. Grief experiences are often heightened for people with a history of trauma and/or grieving a traumatic death (Barlé, Wortman, & Latack, 2017). The seventh priority concerned how children process the experience of having a terminal illness, which would be influenced by the child's developmental stage and abilities (O'Halloran & Altmaier, 1996). More information is sought by grief and bereavement care practitioners to support grieving children and adolescents and bereaved people with trauma histories.

The fifth priority concerned the impact of end-of-life caring on family caregivers and their bereavement outcomes. The outcomes of caregiving are known but less is known about the effect of caregiving on bereavement outcomes (Stroebe & Boerner, 2015), due to the dearth of longitudinal studies with data collection at both pre- and post-death time points (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016) and lack of a control group (Breen, Aoun, & O'Connor, 2015). Developing this area of research will guide grief and bereavement care practitioners, particularly those in palliative and

hospice settings, to provide a suite of strategies to meet the varied support needs of caregivers and bereaved caregivers (Hudson, Hall, Boughey, & Roulston, 2018). These strategies would be work well with explicit and careful attention to strategies that also promote informal support (Rumbold & Aoun, 2015).

The ninth priority concerned the development of interventions that can prevent complicated/prolonged grief before it manifests. Most studies have shown that interventions are more likely to be effective for people with high levels of bereavement-related distress or symptoms of complicated/prolonged grief (Currier, et al., 2008; Waller, et al., 2016; Wittouck et al., 2011).

Although protective and risk factors that can influence adaptation to loss are documented (Blackburn & Dwyer, 2016; Lobb, Kristjanson, Aoun, Monterosso, Halkett, & Davies, 2010), how these factors interact and impact individual adaptation to grief is still not well understood and further research into who would best benefit from interventions needs to be conducted and disseminated (Breen, Hall, & Bryant, 2017; Doering, & Eisma, 2016). A recent randomized controlled trial showed that an Internet-based, therapist-assisted intervention may prevent prolonged grief disorder in bereaved people at risk of developing the disorder (Litz et al., 2014).

Finally, the practitioners wanted more research into understanding end-of-life decision-making and the role of Advance Care Planning and Advanced Care Directives on grief. One study showed that bereaved people who prioritized their dying family members' longevity over comfort experienced more grief, guilt, and prolonged grief symptoms that those who prioritized comfort over longevity (Lovell, Smith, & Kannis-Dymand, 2015). Family caregivers' preparedness for death should not be assumed and some are challenged particularly by emotional preparedness (Breen, Aoun, O'Connor, Howting, Halkett, 2018). Caregivers of patients who engage in Advance Care Planning report being more prepared for bereavement (Schulz, Boerner, Klinger, & Rosen, 2015). Advance Care Planning could therefore provide an avenue for promoting caregivers' preparedness for death (Garrido & Prigerson, 2014).

The sample was experienced in the provision of grief and bereavement care and there was a high retention rate through Phases 1 to 3, but there were also some limitations. Phase 1 yielded several terms for describing problematic forms of grief (e.g., complicated grief, Prolonged Grief Disorder,

Persistent Complex Bereavement Disorder), which echoes the lack of consistency and precision in clinical and research language used in grief and bereavement (Stroebe et al., 2017). We tried to keep the priority statements generated in the analysis process as close to the original statements as possible, but this led to inconsistencies in item wording and participants may have had different interpretations of the terms when rating and ranking the items. Interestingly, the participants did not generate items relating to complex social determinant of health such as hardship, poverty, family violence, conflict, and so on, which was especially surprising given that social work was the most-represented discipline in Phases 1 and 2. Although some of the research priorities have been investigated (e.g., the category Developing Grief Measures), the findings from these studies may not have been disseminated to practitioners. Interestingly, however, several of the priorities the practitioners identified have been tackled relatively recently in research, which indicates that the transfer of knowledge from researchers to practitioners may not a central problem in the same way as has been identified in other settings (Brownson et al., 2013; Morris, Wooding, & Grant, 2011), at least for this group of experienced practitioners with membership to a grief and bereavement organization. Instead, the practitioners' priorities indicate an awareness of innovative research topics relevant to practice. Thus, in developing research proposals, we encourage researchers not only to embed pathways for research dissemination and sustainable translation into policy and practice but also to consider ways in which projects could be designed to harness practitioners' research ideas and promote their research capacity (Whitworth, Haining, & Stringer, 2012). While it was our intention to develop a thorough investigation of practitioners' research priorities, it would be helpful to understand grief and bereavement priorities more fully. Future studies could investigate the perspectives of an international sample of bereavement care practitioners, less experienced practitioners and/or those who are not members of a grief and bereavement organization, and of people who are receiving/have received grief and bereavement care, which would be beneficial to furthering the improvement of interventions and understandings of the needs of grieving people.

Formal knowledge exchange processes between grief and bereavement care researchers and practitioners are under-developed. The current study is the first to systematically generate research priorities for grief and bereavement care, from the perspectives of grief and bereavement care

practitioners. We encourage researchers to consider these research priorities, as well as dissemination strategies that promote research translation in policy and practice (e.g., being guided by the participants' common methods of keeping up-to-date with grief and bereavement care information), in designing their future studies, so that the studies may be more likely to be directly relevant to practical application by grief and bereavement care practitioners. These evidence-based priorities should be used to direct programs of research that are relevant to both researchers and practitioners, so that findings are applicable to real-world settings and are more useful and readily transferable to improving the lives of grieving people. Further, the findings could be used to inform priorities for practitioner education. Doing so would help promote evidence-based practice and practice-based evidence in the field of grief and bereavement care.

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Table 1
Summary of Participant Characteristics

Characteristic	Phase 1 (N = 176)	Phase 2 (N = 84)	Phase 3 (N = 70)	
	N (%)	N (%)	N (%)	
Gender	` ,	•		
Female	149 (84.7)	71 (84.5)	57 (85.1)	
Male	15 (8.5)	9 (10.7)	8 (11.9)	
Another Gender	2(1.1)	0	0	
Missing	10 (5.7)	4 (4.7)	5 (7.1)	
Primary role in grief and bereavement care				
Practitioner	154 (87.5)	72 (85.7)	57 (81.4)	
Researcher	15 (8.5)	6 (7.1)	6 (8.6)	
Missing	7 (4.0)	6 (7.1)	7 (10.0)	
Country				
Australia	137 (77.8)	67 (79.8)	56 (80.0)	
Other (e.g., Ireland, Jamaica, Malaysia, New	8 (4.5)	5 (6.0)	4 (5.7)	
Zealand, United Kingdom United States)				
Missing	31 (17.6)	12 (14.3)	10 (14.3)	
Location				
Metropolitan	128 (72.7)	52 (61.9)	45 (64.2)	
Rural	43 (24.4)	27 (32.1)	19 (27.1)	
Missing	5 (2.8)	5 (6.0)	6 (8.6)	
Site				
Other (e.g., consultative, community services,	74 (42.1)	33 (39.3)	28 (41.8)	
government)				
Inpatient	46 (26.1)	18 (21.4)	15 (21.4)	
Home-based services	25 (14.2)	13 (15.5)	9 (12.8)	
Private practice	19 (10.8)	12 (14.3)	9 (12.8)	
University/Research center	8 (4.5)	4 (4.8)	4 (5.7)	
Missing	4 (2.3)	4 (4.8)	5 (7.1)	
Discipline				
Social Worker	53 (30.1)	23 (27.4)	16 (23.9)	
Counselor	41 (23.3)	22 (26.2)	20 (29.9)	
Nurse	25 (14.2)	13 (15.5)	9 (13.4)	
Psychologist	16 (9.1)	7 (8.3)	7 (10.4)	
Chaplain/Pastoral Care Worker	13 (7.4)	7 (8.3)	7 (10.4)	
Other	12 (6.8)	4 (4.8)	3 (4.5)	
Doctor	8 (4.5)	1 (1.2)	1 (1.5)	
Occupational Therapist	1 (.6)	1 (1.2)	1 (1.5)	
Missing	15 (8.5)	6 (7.1)	4 (5.7)	
Member of a multidisciplinary team				
Yes	128 (72.7)	58 (69.0)	46 (68.7)	
No	43 (24.4)	22 (26.2)	19 (28.4)	
Missing	5 (2.8)	4 (4.8)	5 (7.1)	
Most common methods of keeping up-to-date with grief and bereavement care information <sup>a</sup>				
Journal articles	135 (76.7)			
Workshops	112 (63.6)			
Webinars	95 (54.0)			
Books	88 (50.0)			
Conferences	80 (45.4)			
Other (e.g., peer supervision, case	31 (17.6)			

management meetings, workplace training, ResearchGate, Australian Centre for Grief and Bereavement newsletter)

Missing	7 (4.0)		
	M(SD)	M(SD)	M (SD)
Age (years)	51.1(11.4)	52.6 (10.9)	52.9 (11.1)
Years working in grief and bereavement care	13.7 (11.5)	15.1 (10.2)	15.6 (10.4)

<sup>\*</sup>Note: aparticipants could indicate more than one method.

Table 2 Means and Standard Deviations of Phase 2 Priority Ratings

Priority statements in Categories	M	SD
Determining Grief Processes.		
Bereavement trajectories and why people grief differently.	2.36	.89
Long-term outcomes (physical, psychological, social, financial) of bereavement.	2.10	.92
Whether current thinking about grief (e.g., dual process model, continuing bonds) makes sense and is helpful to grieving people.	2.35	.85
**Growth, resilience, and recovery through the grief process.	2.10	.80
How pre-existing factors and attachment style affect adjustment to and coping with grief.	2.22	.81
**The impact of end-of-life caring on family caregivers and their bereavement outcomes.	1.74	.79
The impact of bereavement on families.	2.11	1.03
The role of remembrance grief (e.g., funerals, life review, meaning-making).	2.34	.87
**Distinguishing grief from mental health issues (e.g., depression, PTSD, anxiety, identity disorder, trauma).	1.88	.84
*The impact of trauma, including childhood trauma, on the experience of grief.	1.85	.88
How place of death affects grief outcomes in the long-term.	2.61	.94
** Understanding end-of-life decision making and the role of Advance Care Planning and Advance Care Directives on grief.	2.09	.94
Exploring anticipatory grief arising from terminal illness.	2.23	.79
**How children process the experience of having a terminal illness.	1.90	.89
Developing Grief Measures.		
Γο assess grief/trauma/traumatic grief for children and adults.	2.17	.92
For effective bereavement risk assessment that capture protective factors as well as risk factors.	2.16	.94
Γο use in perinatal and neonatal bereavement.	2.27	.91
Improving Grief Interventions.		
The "key ingredients" of different types of interventions to identify the factors that make the intervention effective or otherwise.	2.24	.82
*Effective brief, non-specialist interventions for acute grief and in acute care settings (e.g., emergency department).	2.15	.85
Effectiveness of grief counseling across modalities (e.g., telephone, online 'chat' Skype and other social media, individual vs group).	2.38	.89
Effectiveness of non-traditional therapies (e.g., art therapy, play therapy, drama therapy, music therapy, animal engagement) for grief.	2.51	.92
Whether current practice is evidence-based.	2.26	.88

Priority statements in Categories	M	SD
The factors that promote or prevent evidence-based practice.	2.47	.92
Effectiveness of current bereavement follow-up initiatives (e.g. palliative care).	2.23	.86
The presence of harm from bereavement interventions so that we can prevent these.	2.20	1.01
If bereaved identified as having complex grief risk factors either do or do not initiate contact with services and in what proportion.	2.31	.85
Self-referral compared to external referral to services (e.g., satisfaction, number of sessions, dropout rates).	2.80	.89
The economic cost-benefit of interventions to inform where to target interventions given the scarcity of resources.	2.59	.99
**Interventions to prevent complicated/prolonged grief, before it develops.	1.96	.84
Barriers to accessing professional grief and bereavement support for grievers who would most benefit.	2.16	.92
**Evidence-based grief interventions to specific groups (e.g., Indigenous peoples, culturally and linguistically diverse [CALD] groups).	1.93	.83
**Evidence-based supports for bereaved children and adolescence.	1.95	.91
Enriching Health Professionals' Training and Support.		
**The effect on staff of increased knowledge of grief and bereavement care in the workplace.	2.11	.88
The awareness amongst health care providers of diagnostic criteria for prolonged/complicated grief; its rates as a comorbid diagnoses in mental	2.23	.88
health patients; and of relevant interventions.		
**How General Practitioners and other primary care providers could more quickly recognize problematic grief, to allow faster referrals to	1.91	.75
appropriate counseling services.  The quality of and access to professional development opportunities in grief and loss.	2.21	.94
Supports/interventions for staff (e.g., aged care, hospitals, assisted living, home volunteers) after the death of a resident that staff have come to	2.17	.95
know and care about.	2.17	.73
**Adverse effects on health professionals working with grief and loss (e.g., compassion fatigue, PTSD in traumatic cases) in order to promote	1.95	.84
education on self-care.		
Understanding Experiences and Meeting the Needs of Specific Types of Losses and Grievers.		
**Grief experiences from traumatic losses (e.g., homicide, culpable driving, workplace deaths, suicide, military).	1.93	.91
The effects of perinatal loss (e.g., miscarriage, termination, stillbirth, neonatal death) on the experience of future pregnancies, parenting, current and	2.07	.90
future siblings, couples  **Effects of deaths by euthanasia/voluntary assisted dying on grief outcomes.	1.99	.91
Grief from pet death.	2.97	.93
Grief after the death of an ex-partner.	3.03	.93 .89
·		
Grief after death of same gender partners.	2.38	.99
Grief from specific grieving relationships (e.g., bereaved siblings, mothers, fathers, grandparents, partners, widows/widowers).	2.40	.82

Priority statements in Categories	M	SD
How grief is experienced in different cultures and religions.	2.25	.82
**The effects of grief on children and adolescents.	1.95	.82
**Grief experiences for people with intellectual disability.	1.97	.80
Exploring Social/Community Concerns.		
**How societal views about grief and bereavement impact people who are grieving.	2.16	.78
**How communities can support grieving people and foster public mourning.	2.06	.79
Community attitudes to children attending funerals.	2.57	.95
Community attitudes to bereavement care interventions.	2.54	.90
**The medicalization of grief and how we can move toward normalizing and destigmatizing grief.	1.87	.89
**Awareness of dying and end-of-life planning on engagement with palliative care services.	1.95	.95
**Education for all ages/communities/workplaces/schools about how to support grieving people.	1.94	.75
Investigating Non-Death Losses.		
Secondary losses (e.g., losses of autonomy, dignity, social connectedness, independence).	2.35	.77
Grief experiences from life transitions (e.g., retirement, migration, divorce).	2.56	.82
**Grief experiences for people living with chronic diseases and other conditions.	2.14	.70
Grief experiences for people with a family member living with disability or chronic disease/condition).	2.23	.75
Experiences of people facing infertility or who wanted to be parents but due to circumstances this did not happen.	2.44	.87
Grief experiences relevant to LGBTIQ communities (e.g., grief experienced when a partner transitions, or when a relationship is not acknowledged by family or community).	2.33	.89
Intergenerational grief and loss in Indigenous communities since colonization.	2.10	.94

*Note:* \*\* = More than 70% of participants rated the item 1-*Very high priority* or 2- *High priority* and was used in Phase 3.

Table 3 Prioritized Research Agenda for Grief and Bereavement Care

Rank	Research Priority	Category	Phase 2	Rated "very	Mean
			Rating	important priority" "important priority" in Phase 2 (%)	Ranking Phase 3 M (SD)
1	Growth, resilience, and recovery through the grief process.	<b>Determining Grief Processes</b>	2.10	(70.4)	3.82 (2.75)
2	Distinguishing grief from mental health issues (e.g., depression, PTSD, anxiety, identity disorder, trauma).	Determining Grief Processes	1.88	(77.8)	4.35 (2.98)
3	How General Practitioners and other primary care providers could more quickly recognize problematic grief, to allow faster referrals to appropriate counseling services.	Enriching Health Professionals' Training and Support	1.91	(79.0)	4.37 (2.72)
4	The effects of grief on children and adolescents.	Understanding Experiences and Meeting the Needs of Specific Types of Losses and Grievers	1.95	(81.5)	4.78 (2.45)
5	The impact of end-of-life caring on family caregivers and their bereavement outcomes.	Determining Grief Processes	2.22	(81.5)	4.91 (2.98)
6	The impact of trauma, including childhood trauma, on the experience of grief.	Determining Grief Processes	1.85	(80.2)	5.16 (2.89)
7	How children process the experience of having a terminal illness.	<b>Determining Grief Processes</b>	1.90	(75.3)	5.18 (2.87)
8	Grief experiences from traumatic losses (e.g., homicide, culpable driving, workplace deaths, suicide, military).	Understanding Experiences and Meeting the Needs of Specific Types of Losses and Grievers	1.93	(76.5)	5.29 (3.24)
9	Interventions to prevent complicated/prolonged grief, before it develops.	Improving Grief Interventions	1.96	(74.1)	5.42 (2.88)
10	Understanding end-of-life decision making and the role of Advance Care Planning and Advance Care Directives on grief.	Determining Grief Processes	2.09	(72.8)	5.56 (2.85)

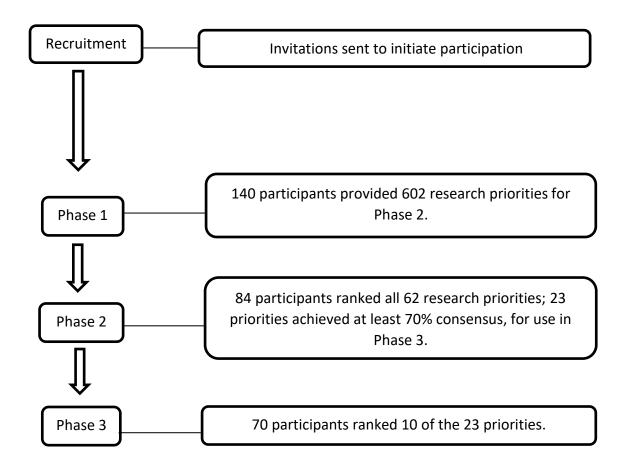


Figure 1: Flow chart of the three-phase Delphi survey.