

**Reported experiences of bereavement support in Western Australia:
A pilot study**

Samar M. Aoun¹, BSc(Hons), MPH, PhD

Lauren J. Breen², BSc(Hons), GradCertEd, PhD

Bruce Rumbold³, BD(Hons), MSc, PhD, MA, PhD

Denise Howting¹, BNurs, BSc

¹School of Nursing and Midwifery, Faculty of Health Sciences, Curtin University

²School of Psychology and Speech Pathology, Faculty of Health Sciences, Curtin University

³Palliative Care Unit, School of Public Health, La Trobe University

Corresponding author and requests for reprints: Professor Samar M. Aoun, School of Nursing and Midwifery, Faculty of Health Sciences, Curtin University, GPO Box U1987, Perth 6845.

Email: s.aoun@curtin.edu.au; Telephone: +61 8 9266 9293; Fax: +61 8 9266 2508.

This is the peer reviewed version of the following article: Aoun, S. and Breen, L. and Rumbold, B. and Howting, D. 2014. Reported experiences of bereavement support in Western Australia: a pilot study. *Australian and New Zealand Journal of Public Health*. 38 (5): pp. 473-479., which has been published in final form at <http://doi.org/10.1111/1753-6405.12177>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving at <http://olabout.wiley.com/WileyCDA/Section/id-828039.html>

Abstract

Objective:

This article describes the pilot testing of a community survey aimed to ascertain the experiences and needs of people who were bereaved 6-24 months prior to the survey. The pilot study aimed to assess the feasibility and acceptability of the survey and test the theoretical public health model for bereavement support.

Methods:

A postal survey was used to collect information from clients of three funeral providers in Western Australia in 2012.

Results: The findings confirmed the feasibility and acceptability of the survey questions. The analysis of the demographic characteristics, experience of bereavement, and satisfaction with support revealed differential needs that align with the expectation of low, moderate, and high risk, as articulated in the public health model.

Conclusions:

The data provided tentative empirical support for the public health model of bereavement support. This is the first empirical test of this model nationally and internationally.

Implications:

Considering the lack of evidence to guide development and allocation of bereavement programs in Australia, a larger survey will enable us to determine how the support needs of each of the three groups of bereaved people should be serviced. This is of utmost importance for cost-effective and equitable resource allocation.

Keywords: Bereavement Care, Palliative Care, Family Carers, Health Services, Public Health

Bereavement is a significant life stressor with outcomes across four domains – emotional (e.g., sadness, anger, guilt), physical (e.g., fatigue, agitation, pain), behavioural (e.g., sleep and appetite disturbance, absentmindedness), and cognitive (e.g., disbelief, confusion, hallucinations). Alongside these consequences, bereaved persons must also cope with the secondary losses that can arise as a result of bereavement, including social isolation and stigma,¹ financial loss,² and changes in roles and responsibilities.³ Such disruptions can trigger existential or spiritual issues that present as holistic losses: a fractured sense of identity, the fragmentation of community, or loss of meaning and purpose in living.⁴ Additionally, bereavement is associated with an increased risk of mortality, which is greater for widowed than married, single, or divorced people and greater again for widowers than widows, with risk generally peaking in the first few months following bereavement.⁵

Palliative care services provide the most comprehensive strategy for bereavement support in many communities, as the philosophy of palliative care emphasises support for the patient during illness and support for family carers before and after the patient's death. In Australia, the peak body for palliative care, Palliative Care Australia (PCA),⁶ outlined several standards of palliative care. Standard 8 asserts, "Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services" (p. 33) and that this support should be based on need. Recent clinical practice guidelines for bereavement supports in palliative care also highlight the importance of providing support according to the assessment of need.⁷ A recent audit of Australian palliative care services established bereavement care as the highest priority for improvement; the report based on the findings of this audit, along with the latest national palliative care strategy, recommended a national evidence-based approach to bereavement support.^{7,8}

Despite these guidelines, recent surveys demonstrated that, while almost all Australian palliative care services offer bereavement supports and services to families of deceased patients, these services and supportive strategies may be only loosely linked with assessments of risk or need.^{9, 10} For instance, one survey of Australian palliative care services determined that 95% (of 236 services) offer some form of bereavement support.¹⁰ The authors of this study concluded that there is "lack of clear evidence to guide development and allocation of bereavement programs in palliative care" (p. 230). The most common types of support were a telephone call (offered by 86%), memorial service, (66%), letter (55%), anniversary card (53%), group sessions (31%), information package (5%), and informal gatherings (4%). Approximately two-thirds of the services reported engaging in some form of bereavement risk assessment at the time of death, with two-thirds relying on multidisciplinary team opinion, more than half using a formal tool to assess bereavement risk, and approximately half relying on a single staff member's opinion (some services reported using more than one method). However, in practice the majority of bereaved people manage their grief with the support of family, friends and neighbours. It is only a small proportion, about 10 to 20%, who experience persistent psychiatric difficulties, including Prolonged Grief Disorder (PGD), previously known as complicated grief.^{11, 12} This group exhibits higher levels of distress and is most likely to benefit from targeted psychological interventions,^{13, 14} whereas such interventions may be of marginal benefit, or even counter-productive, for others.¹⁵ Given all this, we question the approach of some palliative care services, in Australia and overseas, that attempt to provide blanket support to bereaved clients. This is neither an effective nor economical use of their limited resources,^{16, 17} and can compound health professionals' stress and burnout.^{18, 19}

Conceptual Framework and Rationale

Our research team developed the conceptual framework of the public health approach to bereavement support,¹⁶ summarised in Table 1. The public health literature typically identifies three levels of intervention that target different populations: Level 1 – universal (for the whole population of interest, i.e. all bereaved people); Level 2 – selective (for groups at risk of developing more complex needs e.g. complications of bereavement) and Level 3 – indicated (for people showing signs of disorder e.g. PGD). These levels are congruent with those proposed for preventive intervention for bereavement care – primary (for all bereaved people), secondary (for people at-risk of complications of bereavement), and tertiary (for people with complicated bereavement)²⁰ and the call for applying a public health perspective to end-of-life care services.²¹

The National Institute for Clinical Excellence (NICE)²² in the United Kingdom proposed a similar three-tiered approach to bereavement in palliative care according to the needs of carers and families and approximated the proportions in each tier. Based on cancer or expected deaths, the model advocates that all the bereaved people should have access to information about bereavement and relevant available supports (first tier). The information would be delivered by the palliative care service involved in the care of the patient and family, with much of the support coming from the bereaved person's social networks, including compassionate family and friends. However just over one-third would in addition need more formal opportunities to consider their loss (second tier). The support for this tier would be provided by non-specialist social and therapeutic support such as volunteer bereavement workers, bereavement mutual-help groups, and faith-based and other community groups. This middle-tiered proportion is reflected in the UK Sobell House's analysis of retrospective data on risk assessment and type of support provided for its bereaved carers (1989-2002).²³ Face-to-face consultations with palliative care services identified this group as causing challenges for services in meeting support needs where timely and adequate support could potentially reduce the proportion of the population experiencing prolonged grief.²⁴ The third tier comprises 10-12% who would need specialist intervention such as counselling, mental health services, bereavement services, or psychotherapy to supplement the first two tiers, or because these levels of support are not available to them. Thus, there are about 45% of bereaved people in the second and third tier who would benefit from either targeted or indicated interventions.

Therefore, in order to develop an evidence base for interventions that can target the level of risk and need of the bereaved population in Australia, we need to map the baseline situation through a survey. To guide any work in this field, an understanding of the experience and needs of bereaved people, whether they have or have not used services, is essential.

This article describes the pilot testing of such a survey aimed to ascertain the experiences of people who were bereaved 6-24 months prior to the survey, identify their perceived needs and make recommendations for service provision based on the level of need. We chose this time period as 6 months post-bereavement is the earliest time period required for diagnosis of PGD while 24 months is not likely to compromise the accuracy of recalled information.²⁵ The objectives of the pilot study were to assess:

- the feasibility and acceptability of the survey by the bereaved community
- the appropriateness of the recruitment strategy, and
- the support for the theoretical public health model of bereavement care

METHODS

A postal survey was used to collect information from clients of three funeral providers in metropolitan and rural Western Australia, 6 to 24 months after the death of their family member. Ethics approval was granted by the Human Research Ethics Committee of Curtin University.

Instrument

A questionnaire was developed to obtain demographic information; the supports people accessed; supports they would have liked to have been able to access; their needs and whether they were met. The questionnaire has eight sections with a total of 80, predominantly closed, questions with the aim of generating a large set of population-based data amenable to quantitative analysis in a future survey with a larger sample size (larger study). The questionnaire was developed in consultation with a reference group comprising representatives of the funeral industry, bereavement counselors, palliative care services, primary care, and community based services. To encourage responses from people with accessibility impairments and from cultural and linguistically diverse backgrounds, we included a statement at the front of the questionnaire that if anyone needed assistance completing it, they could call our office number.

Section 1 – the carer or closest person to the deceased

Section 2 – their deceased loved one

Section 3 – their experience caring for a loved one with a terminal or life-limiting illness (expected death)

Section 4 – the bereavement support they received from palliative care providers

Section 5 – the overall support they received after their loved one died

Section 6 – their experiences with the funeral provider

Section 7 – exploring their current feelings about the loss of their loved one

Section 8 – further comments and an option for those who wish to participate in an in-depth interview to leave their details so they are contacted in 2-3 months' time.

The questionnaire includes a validated risk assessment screening measure for PGD, the PG-13 in section 7.¹² Compared to other tools reviewed, the PG-13 is short, easy to self-administer, has a theoretical basis and aligns with the criteria proposed for inclusion in the forthcoming World Health Organization's International Classification of Diseases (ICD-11).^{12, 26} The PG-13 measures responses to separation social/functional impairment, and cognitive, emotional and behavioural symptoms over a period of not less than 6 months since bereavement. All 5 criteria must be met to indicate the presence of PGD: event (bereavement); separation distress; duration (i.e., >6 months); cognitive, emotional and behavioural symptoms; and social/occupational impairment. The score range is 11-55 and a score of 36 or more is a clinical indicator of PGD. It should however be noted that PGD was not included in the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5); rather bereavement was removed as an exclusion criterion for both Major Depressive Disorder and Adjustment Disorder and a new subtype of Persistent Complex Bereavement Disorder was included in section III for further study.²⁷ The practical implications of these changes have yet to emerge, but they would seem to increase the likelihood of clinical treatment for people in low to moderate need of such interventions.

Participants and Procedure

The pilot study was undertaken from August to October 2012 in Western Australia. The funeral providers were reached through their professional association (Australian Funeral

Directors Association [AFDA]). Three providers volunteered to take part in the pilot study; the others decided to wait for the results as they were apprehensive about the effect the research might have on their clients. One funeral provider is a large corporate, and conducts about 5,000 funerals a year in the metropolitan area of Perth. The smaller metropolitan provider conducts about 800 funerals a year and the rural provider about 1,000 per year. None of the companies was religiously affiliated.

The criteria for inclusion in the study were that the potential participants were bereaved for at least 6 months and could read and write in English. In selecting clients for the pilot study, funeral providers reported being hesitant about approaching people who experienced a traumatic death or death of a child. The research team agreed to this condition in order to proceed with the study.

The three funeral providers mailed the pilot questionnaire to previous clients. A total of 90 study packs were delivered to the three providers (30 to each), containing a cover letter addressed from the service provider to the family, information and consent forms, the questionnaire, a feedback form on the questionnaire (for participants to indicate if they find any of the questions confusing, upsetting, difficult or irrelevant), a list of support services for the family to use in case the participant became distressed while completing the questionnaire, and a reply paid envelope. The funeral providers then selected the participants from their databases, attached names and address labels on the envelopes and mailed the study packs.

Analysis

The quantitative data were analysed using IBM SPSS (version 20). The participants' PG-13 scores were calculated to determine the proportion meeting diagnostic criteria. Descriptive statistics were calculated for the demographic variables and responses relating to caring and supports and services received. The data for each level were scrutinised and collapsed into narrative vignettes to simulate real events while maintaining the participants' anonymity. The narrative vignettes were based upon the most common variables for each level of risk.

RESULTS

Response rate and instrument feasibility and acceptability

Twenty three questionnaires were returned completed along with the feedback form and one was returned indicating that the person was no longer at this address. The response rate was 26% (21% in the rural area and 27% in the metropolitan area). On average the questionnaire took 30 minutes to complete and the majority of participants had no problems completing the survey and did not find the questions upsetting. A few of the questions will require minor fine tuning in the future, and the order of few questions will need to be changed for the questionnaire to have a better flow when the larger survey occurs.

Demographic Characteristics of Respondents

The carers who responded to the survey (Table 2) were bereaved for a median of 12 months ranging from 7 to 25 months. Sixty one percent of carers were female; mean age of 60.52 years (SD 11:40); 44% were married and 39% widowed; 48% were the spouse of the deceased, and 48% were the son or daughter of the deceased; 57% were Australian and 39% from another English speaking background; 44% were Christian (44%), 17% had other religion and 39% had no religion ; A third had finished high school, a third had a diploma or trade qualification and nearly a third had a university degree; 57% were currently employed,

and 43% retired. Sixty four percent of the respondents had diagnosed medical conditions with co-morbidities; the most reported of these were high blood pressure, depression, arthritis and anxiety.

Current feelings about the loss (PG-13)

Of the 23 individuals who responded, only 1 met all 5 criteria. Two respondents (8.7%) met 4 criteria, 10 (43.5%) met 3 criteria, 2 (8.7%) met 2 criteria and 7 (30.4%) met 1 criterion (1 did not complete this section). All met the event criterion (bereavement), 56.5% met the separation criterion, 52.2% met the duration criterion (experiencing symptoms at least daily and after 6 months from loss), 30.4% met the social/functional impairment criterion and 4.3% met the cognitive, emotional and behavioural impairment criterion.

Bereaved participants were grouped into three categories of risk:

- 1) those with low level of risk (meeting up to two PGD criteria): 41% with scores between 11 and 26 (mean=14.6 SD=4.6)
- 2) those with moderate level of risk (meeting up to four PGD criteria): 55% with scores between 18 and 32 (mean=24.9 SD=4.3)
- 3) those with high level of risk (meeting 5 criteria): 4% with a score of 49 (only one person in this pilot study).

The analysis of the demographic characteristics, experience and impact of caring and bereavement, and satisfaction with support received from a variety of services according to the three bereavement levels (mentioned above), tentatively revealed different characteristics of the three groups of bereaved people, allowing for the small sample size. In group 1 (n=9), bereaved people were younger and mainly caring for their dying parents; in group 2 (n=12), bereaved people were older and mainly caring for their dying spouses after a reasonable period of care and support; and group 3 (n=1), this bereaved person cared for his dying spouse during a very short period of illness and support. Details of the predominant variables of the three profiles are presented in Table 3.

Vignettes illustrating the profile of the three levels of risk

The following summary vignettes illustrate the profile in each bereavement level: Level 1- the parental carer; level 2- the widow; level 3- the complicated griever. The three blended vignettes were drawn from the 41% categorised as low risk and the 55% categorised as moderate risk. There was only one person considered high risk for meeting the diagnostic criteria for PGD (4%).

Low Risk: The Parental Carer

Marie is a university-educated, married woman in her 50s in full-time paid employment. Her 75-year-old mother, Olive, died in a nursing home just over a year ago. Olive's death was expected – she had been diagnosed with cancer two years prior and Marie was Olive's primary family carer in her last year of life. Olive received palliative care for 6 months. Since Olive's death, Marie's physical and mental health has stayed the same and her financial situation has improved, due to no longer paying for the nursing home. Overall, she received as much support as she wanted from any health and community service. Following bereavement, Marie did not experience separation distress; cognitive, emotional or behavioural symptoms; or social/occupational impairment. Marie's PGD score is 15.

Moderate Risk: The Widow

Lorraine is in her early 60s and lives with some medical conditions. Prior to her retirement, she worked as a clerical assistant. Just over a year ago, her 66-year-old husband, Alan, died from cancer; he'd been diagnosed three years earlier. Lorraine had been his primary carer for his last 17 months. Alan received palliative care in the last month of his life. He died at hospital, which was Lorraine's preferred place of death for him. Lorraine received as much support as she wanted from palliative care and other services. Since Alan's death, Lorraine's physical health and financial situation have stayed the same but her mental health is a little worse. Lorraine initially experienced separation distress but this subsided in the first few months. She did not report cognitive, emotional or behavioural symptoms but did experience some social/occupational impairment. Lorraine's PGD score is 25.

High Risk: The Prolonged Griever

Bill is a 65-year-old retiree with a high school education and no diagnosed medical conditions. His 67-year-old wife, Iris, died three months after being diagnosed with cancer. Bill was Iris's primary carer and provided day-to-day, hands-on care during those three months. Iris received palliative care for 7 days. She died at home, which was Iris and Bill's preferred place for her death. Bill received as much support as he wanted from health and community services. He received some support from palliative care but not as much as he would have liked. Since Iris's death, Bill's physical and mental health and financial situation have all got a bit worse. He reflected that he would have wanted professional support. Bill has experienced separation distress for more than 6 months; cognitive, emotional and behavioural symptoms; and social/occupational impairment. Bill's PGD score is 49.

DISCUSSION

The findings of this pilot study and extensive participant feedback support the feasibility and acceptability of the survey questions and provide a good indication that the objectives of the larger population-based study can be achieved, in terms of describing the demographic characteristics of bereaved people, experience and impact of caring and bereavement, and satisfaction with support received from a variety of services. It also provided information as to the participants' perceived needs. Importantly, the data provided tentative empirical support for the public health model of bereavement support. This is the first empirical test of this model nationally and internationally. The three vignettes illustrated how the level of risk of PGD, as measured by the PG-13, i.e. low, moderate and high risk, is congruent with the participants' expressions of met and unmet support needs. For instance, risk may be related to duration of palliative care, ranging from an average of 6 months (low risk), 1 month (moderate risk) and 1 week (high risk). The analysis of the demographic characteristics, experience and impact of caring and bereavement, and satisfaction with support received from a variety of services revealed differential experiences and needs that align with the expectation of low, moderate, and high risk, as articulated in the public health model, despite the small sample size.

Interestingly, the PG-13 scores of our respondents tended to cluster around 15 for those at level 1 and 25 for those at level 2. (There was only one respondent at level 3, with a score well in excess of that required for a diagnosis of PGD.) This suggests a tentative finding that the low and moderate risk categories, levels 1 and 2, may be distinguished fairly clearly on the basis of PG-13 scores as well as the sources from which support needs were met. Additionally, the vignettes provide a context for the scores: low scores typically arose from losses that were expected and less disruptive to daily routines (e.g., the death of an aged parent); moderate scores typically arose from deaths that were both expected and everyday-

disruptive (e.g., the death of an ageing and ill partner); and deaths that are both unexpected or resisted and disruptive may lead to high scores on the PG-13. A much larger sample is needed to verify such a finding, but at the practice level it would be helpful if bereaved people's risk of PGD could be assessed easily and responded to appropriately in accordance with the proposed three service response categories.

Further, in addition to revealing that there might be a difference in type of response between the three levels, the data also show differences in degrees of support need across the three levels. The sources of support listed by respondents indicate that for the most part those in level 1 were satisfied with support provided through everyday interactions. Those at level 2 were also satisfied with the level of support, but most of them were also linked with some sort of bereavement follow-up program, through palliative care, for example. The sole level 3 respondent considered the support he received to be inadequate; his needs necessitate targeted mental health interventions in addition to other forms of support that were effective for people at levels 1 and 2. There is merit in our hypothesis that the support needs of bereaved people at different levels can be met using different combinations of strategies. Again, it needs further exploration with a larger sample, but it is a finding suggesting the need for flexible and targeted bereavement services, many of them informal and within local communities as well as formal offerings of health services.

Limitations and Relevance to the Larger Study

The participants' profiles and experiences are not likely to be representative of those of the general bereaved community, as there was no random selection for this pilot group. It was a convenience sample chosen by the funeral providers. However, despite this small convenience sample, the profile of respondents seems similar to that of bereaved people in the Sobell House Hospice in UK²³.

To be cautious, the providers selected clients who had an expected death which explains the over-representation of death due to cancer in our sample. Hence the vignettes are also a representation of those who had an expected death and received palliative care. The wider group of providers was reassured by the results of the pilot study and understood our concerns about the selection bias. They agreed that for the larger survey, the questionnaires will be mailed to all of their clients who were bereaved between 6 and 24 months from any cause of death. The pilot study appears to have given confidence to the industry partners to be inclusive rather than selective when we conduct the larger study.

The response rate was lower (26%) than we anticipated from initial discussions with one of the funeral providers who reported a 50% response rate for their clients' satisfaction surveys. However, the response rate is comparable to what is expected from anonymous population based postal surveys with no follow-up. It is possible that participants who were not too distressed were comfortable completing the survey, but those who were very distressed found the idea of completing the survey upsetting and did not complete it. As such, risks, needs and scores of PGD could be under-estimated. The length of the survey (mean and median of 30 minutes) may have been burdensome as respondents were asked to also complete a feedback sheet on each section of the questionnaire for the pilot study. This additional requirement will not be part of the larger study and thus we expect a higher response rate.

The survey was constructed to provide information on the population-based experiences of bereavement, including the extent of the alignment of bereavement risk and service need. The validated PG-13 means that we will also be able to determine a population rate of PGD in the

larger survey. Analysis of the larger data set will comprise descriptive statistics of the bereaved population, comparison of data between those who received and those who did not receive palliative care and/or other services, and correlations and hierarchical regressions to explore the individual, environmental and situational factors that are associated with the complications of bereavement (as measured by the PG-13). However, such analyses were not possible with the small sample of the pilot study.

While assistance was offered to complete the surveys, no one took up the offer for assistance in the pilot study. Therefore we need to acknowledge that the pilot study is limited in its assessment of the acceptability of the survey and recruitment methods for those for whom English is not the first language, and particularly those who do not have a good command of the English language, and that the categorisation of bereavement may not be equally applicable. The larger study will be better placed to examine cultural and religious differences in bereavement.

Much of what we know about bereavement care has emerged from research conducted in palliative care settings. In Australia, there are 130,000 deaths per year and 100,000 of these are expected, and only about 30% come to the attention of palliative care services.²⁸ One retrospective cohort study in Western Australia showed that only about 60% of the population of people who died of deaths amenable to palliative care received palliative care services.²⁹ Therefore, we know less about bereavement experiences and needs of people who did not use palliative care services following an expected death, and considerably less about the bereavement experiences of those for whom the death was unexpected. This remains the case following this pilot study, where all three vignettes involved a diagnosis of cancer and access to palliative care.

Therefore, a much larger and a more representative sample is necessary to confirm the tentative trends of needs aligning with risks. As 76% of deaths are expected in Australia,²⁸ and 70% were expected deaths in this pilot study, a public health approach to bereavement services in palliative care offers the foundation for determining the types of bereavement services and supports necessary for carers and families, in line with national and international palliative care policy.

Conclusion

This paper outlines a pilot study providing tentative empirical support for the public health model of bereavement support and provides the basis for a larger, population-based study of the experiences and support needs of bereaved people, the first of its kind nationally and internationally. Appropriate supports and services will ultimately reduce the risk of PGD, through reducing the risk of unmet support needs. Currently there is a lack of clear evidence to guide development and allocation of bereavement programs in palliative care, including programs to develop community capacity. A larger survey will enable us to fill this gap and to determine how the support needs of each of the three groups of bereaved people should be serviced. This is of utmost importance for cost-effective and equitable resource allocation, and for understanding the contribution the community at large makes to bereavement support.

ACKNOWLEDGEMENTS

The research team acknowledges the financial support of the Palliative Care Network, WA Health Department, and the cooperation of three funeral providers who assisted with the recruitment of participants. We are grateful to the bereaved families who agreed to complete the survey, especially considering their difficult circumstances. Also many thanks for M. O'Connor's contribution to the project and the reference group members who guided the development of this questionnaire. The second author is supported by the Australian Research Council (DE120101640).

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Table 1: A three-tiered public health model of bereavement care¹⁶

Level of Public Health Interventions	Levels of Risk or Need	Type of Support	Support provided by	Target Population and Level of Support Needed	Proportions Bereaved*
Universal	1	Information about bereavement and relevant supports	Family and friends (information supplied by health and social care professionals)	All bereaved (normal grief) Low need	54%
Selective or Targeted	2	Non-specialist support	Trained volunteers, mutual-help groups, community supports	Those at-risk of developing complex needs Moderate need	33%
Indicated	3	Professional specialist interventions	Mental health services, bereavement services, or psychotherapy	Those with complex needs High need	9%

*(Example of Sobell House Hospice in UK, 1989-2002)

Table 2: Summary of carers' demographics, n=23.

	n(%)
Gender:	
Female	14(61)
Male	9(39)
Age (years):	
mean±SD	60.5±11.40
median[range]	62[31-73]
Marital status:	
Married	10(44)
Widowed	9(39)
Never married/single	4(17)
Relationship to the deceased:	
Spouse	11(48)
Offspring	11(48)
Parent	1(4)
Language/cultural background:	
Australian	13(57)
Other English speaking	8(35)
Non English speaking	2(8)
Religious background:	
Christian	10(44)
No religion	9(39)
Other religion	4(17)
Highest education level:	
High school	8(35)
Diploma/trade qualification	8(35)
Undergraduate degree	7(30)
Employment status:	
Employed	13(57)
Retired	9(39)
Other	1(4)
Comorbidities:	
at least ONE	14(64)
Hypertension	7(30)
Depression	6(26)
Arthritis	5(22)
Anxiety	3(13)
Bereavement length (months):	
mean±SD	13.8±5.17
median[range]	12[7-25]

Table 3: Predominant profile of each level of risk for bereavement support

Variable	Level 1	Level 2	Level 3
Carer/next of kin characteristics			
Sex	Female	Female	Male
Age Median (range)	59 (31-66 years)	64 (42-73 years)	65 years
Marital status	Married	Widowed	Widowed
Education	University education	Diploma/certificate/ trade qualification	High school
Employment	Paid employment	Paid employment/ retired	Retired
Diagnosed medical conditions	No	Yes	No
Time since bereavement	13.5 (8-25) months	11.5 (7-21) months	17 months
Relationship to deceased	Daughter	Spouse	Husband
Satisfaction with support	Received as much support as wanted; main source of support was family/friends	Received as much support as wanted from both palliative care service and family/friends	Received as much support as wanted from health and community services; did not receive as much as wanted from palliative care
Deceased characteristics			
Age Median (range)	76 (65-85) years	66 (56-74) years	67 years
Sex	Female	Male	Female
Place of residence	Nursing home	With bereaved	With bereaved
Place of death	Nursing home	Hospital (median 19 days last hospital admission); preferred place of death of bereaved	Home; preferred place of death of bereaved and deceased
Type of death	Expected (cancer)	Expected (cancer)	Expected (cancer)
Duration of illness Median (range)	1.8 (0.3-7) years	2 (0.1-15) years	3 months
Duration of care Median (range)	11 (3-24) months	10 (1-180) months	3 months
Period received palliative care Median (range)	6 (2-18) months	1 (0.1-12) months	7 days
Since bereavement			
Physical health	Stayed the same	Stayed the same	Got a bit worse
Mental health	Stayed the same	Stayed the same/got a bit worse	Got a bit worse
Financial situation	Improved	Stayed the same	Got a bit worse
PGD criteria met	None (other than event of bereavement)	Separation distress; Duration more than 6	Separation distress; Duration more than 6

		months; Some had social/occupational impairment	months; Cognitive, emotional, behavioural symptoms; Social/occupational impairment
PG-13 mean score (95% CI)	14.6 (10.99-18.12)	24.9 (22.21-27.62)	49