

Building Community Capacity in Bereavement Support: Lessons Learnt from Bereaved
Caregivers

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Abstract

Background: Most bereaved people do not require specialist intervention, yet building community capacity in providing bereavement support is under-developed. While family caregivers indicate a need for more information about bereavement, there is little evidence to guide what this information might contain.

Objective: The study's purpose was to inform bereavement support by determining the advice people bereaved through expected deaths in palliative care have for others in that situation.

Design: Four funeral providers posted a questionnaire to previous clients who had used their services 6 to 24 months prior and 678 bereaved people responded.

Setting/Subjects: The sample size for this study comprised 265 bereaved people whose relative used palliative care services.

Measurements: The questionnaire comprised 82 questions about caregiving, bereavement support, current bereavement-related distress, and two open-ended questions concerning their bereavement, one of them on advice they have to other people in the same situation.

Results: Family caregivers (n = 140) of people who received palliative care responded to the open-ended question about advice for others. An open content analysis yielded three themes – preparations for bereavement, utilizing social networks, and strategies for dealing with grief.

Conclusions: Bereaved family caregivers' experiential knowledge can be harnessed to progress the development of bereavement care strategies for the good of the community.

These responses could be incorporated into information brochures, posters, and other community education avenues in order to upskill palliative care bereavement volunteers and the wider community so that bereaved family caregivers are best supported.

Building Community Capacity in Bereavement Support: Lessons Learnt from Bereaved Caregivers

There is a limited evidence base for bereavement support in palliative care.¹⁻³ As a consequence, palliative care services grapple with to whom to offer support, for how long, and to what end, given funding and staffing constraints.¹ One emerging approach to bereavement care is the public health model of bereavement support,⁴ which proposes that all bereaved people should have access to information about bereavement and relevant local supports. A smaller proportion of bereaved people, about 30%, should be offered more formal opportunities for reflection provided by volunteer bereavement workers and community bereavement groups. Only a small sub-set of bereaved people (about 10%) would benefit from specialist intervention. The model (Fig. 1) has empirical support and thus provides an evidence-based foundation for determining the types of bereavement services to offer and to whom.⁵

Community engagement increasingly underpins end-of-life care⁶ and palliative care practice⁷ yet advancing the community's capacity to provide bereavement care remains under-developed.⁸ Most of what we know about bereavement is drawn from the experience of people with complex needs⁸ despite only a small proportion requiring specialist intervention.^{5,9,10} Focusing on the experiences of the majority of bereaved people would inform the development of non-professional, community-based bereavement care.⁸

Building the community's capacity to provide bereavement care has three benefits. First, while bereaved caregivers indicate a clear need for more information about bereavement,¹¹ few studies have actually asked bereaved caregivers to reflect on their experiences and provide suggestions for bereavement care strategies in palliative care. One study asked bereaved spouses to indicate their preferences for researcher-determined supports,¹² rather than asking bereaved people to identify their needs. Others have

recommended the development of information brochures without any input from bereaved people.¹³ One study sought advice from bereaved parents and siblings following child death from cancer, but the findings were not specific to palliative care. These participants advised the importance of social support, expressing thoughts and feelings, finding solace in memories, comfort in faith/religion, reaching acceptance, and getting on with life.¹⁴

Second, asking family caregivers about their bereavement experiences may inform the training of palliative care volunteers who provide bereavement support. Trained volunteers are an important and cost-effective component of bereavement care service provision in many palliative care services.^{15,16} However, we know little about how the volunteers are trained or supervised.¹⁷ One study showed that, although the majority of palliative care volunteers providing bereavement support had personal experience of bereavement and were provided with some generic training on the volunteer role, only a third received training in bereavement support.¹⁸ Palliative care services may assume that a personal experience of bereavement is sufficient in order to help others yet there is the potential for harm if they do not receive adequate training and ongoing supervision.^{18,19} A more recent study demonstrated an improvement in the training and supervision of volunteers who provide social support to bereaved caregivers but that this improvement in standards may not apply to volunteer counselors.²⁰

Third, investigating caregivers' bereavement experiences may inform the development of the wider community's capacity to provide bereavement care. While most bereaved people are supported by family and friends,^{5,21} social support typically declines over the first year and a half of bereavement.²² Engaging communities in developing capacity in bereavement support will not only benefit the bereaved but potentially affect attitudes towards dying and death more generally. Such an approach is aligned with the concept of compassionate communities wherein end-of-life care is a collective responsibility.⁶

Thus, there is a need for information on bereavement experiences from bereaved people themselves to improve bereavement care, train volunteers to provide bereavement care, and upskill the wider community so that bereaved people are better supported within their natural support networks. The first two strategies are especially important to palliative care services because the provision of information about bereavement and volunteer support are two of the most common types of support they offer.²³⁻²⁶ The purpose of the present study was to explore advice for others in a similar situation drawn from a community-based sample of bereaved people whose deceased family member had accessed palliative care.

Method

Participants

Participants were clients of four funeral providers in two Australian states who completed a questionnaire between May and July 2013. There were 678 respondents to the postal questionnaire (response rate = 21%). The majority (68%) of the decedents had a diagnosed life-limiting disease and 265 (39%) of these had used palliative care services; the data for this paper were drawn only from the respondents who were caregivers of deceased persons who had accessed palliative care.

Measures

A questionnaire was constructed with the assistance of a reference group comprising bereavement counselors, palliative care health professionals, and representatives of the funeral industry. The questionnaire was pilot tested²⁷ and the final version comprised 82 questions concerning the caregiver or closest person to the deceased, the deceased, the experience of caring, bereavement support received, current bereavement-related distress, and two open-ended questions where participants could reflect upon their loss. Results from the closed-ended questions are presented elsewhere⁵ and the responses to the open-ended

question, “Do you have further comments or advice that you would give to other people in your situation?” forms the basis of this paper.

Procedure

Ethics approval for this study was granted by the university human research ethics committee. Study packs included a cover letter addressed from the funeral provider to the family, information and consent forms, the questionnaire, a list of support services in case the participant became distressed while completing the questionnaire, and a reply-paid envelope for the return of the completed questionnaire to the university. The funeral providers identified clients who had used their services in the previous 6 to 24 months, attached name and address labels on the packs, and mailed them.

Results

Demographics

One hundred and forty participants of those whose family member received palliative care responded to the question on advice (53%); of these, the majority were women (74%). Age ranged from 27 to 87 years ($M = 62.6$; $SD = 11.4$) and the deceased were about 12 years older than their caregivers. The majority of the bereaved were spouses or adult children and over 90% of deaths were due to malignant conditions. There were few demographic differences between those who responded to the question, those who did not, and the overall sample of respondents whose deceased family member accessed palliative care (Table 1).

Themes

Ten participants answered “No advice”. The remaining responses were analysed using open content analysis.²⁸ Two researchers independently blind-coded 10% of responses and there was substantial degree of agreement between coders; Cohen’s kappa = 0.88, indicating “very good” agreement.²⁹ One author coded the remaining responses. The responses revealed

three themes – preparations for bereavement, utilizing social networks, and strategies for dealing with grief – each with subthemes (see Table 2).

Theme 1: Preparations for bereavement. This theme comprised subthemes of advocating for better healthcare, making necessary arrangements, and seeking information. In relation to advocating for better healthcare, participants emphasized the need for caregivers to advocate on behalf of the patient, especially when healthcare was suboptimal. Participants emphasized the importance of palliative care focusing on the whole person:

“My husband was my soulmate and I found the doctors treated the man, not the person – the tragedy was nearly doubled.” (ID1355)

Some participants recommended changes to that palliative care be offered earlier in the disease trajectory and in a coordination fashion wherein the caregivers felt listened to:

“Palliative care should have been [offered] much earlier. Need to be a coordinator to bring things together.” (ID1179)

“I felt that I should have been listened to, and that the palliative care team could have taken my evidence that a home visit was needed. I didn't feel the team supported the family in the community setting as well as they should. I did not feel this was a holistic, integrated approach.” (ID1115)

Participants highlighted the importance of attending to the practical necessities required when a death is imminent, such as funeral and financial arrangements, in order to ease bereavement distress:

“Try to prepare yourself by making all the arrangements before their death because it is very stressful to arrange things just after a death.” (ID1624)

“Of course it is still a terrible experience but having things planned well beforehand eases some of the burden.” (ID1321)

Many participants emphasized the importance of open communication with their dying family member:

“It is very important to speak to them about their wishes. Having spoken to Mum about what pain relief/medical care she wanted or didn’t want meant I felt comfortable declining things when she couldn’t.” (ID1475)

However, some were not able to have these conversations with their dying family member.

As a result, the effects of not knowing the patient’s wishes had ongoing effects for caregivers and families:

“As my sister did not wish to discuss any aspect of her journey with us, we did not know her wishes... later never came until it was too late. This loss has torn our family apart! If more help was available things might have been different.” (ID1353)

In attempting to make necessary arrangements, the participants recognized that they did not have the answers and instead needed to seek out the required information and advice from reputable sources, including the patient’s wishes:

“People need to know what questions to ask and who to contact when they have a problem.” (ID1241)

Theme 2: Utilizing social networks. This theme comprised subthemes of seeking and accepting support, expressing yourself, and giving yourself permission to grieve before moving forward. Participants described the importance of seeking and accepting support from others, especially people in their natural support networks such as family and friends:

“If people bring food or items – accept.” (ID1034)

Some noted that not all people are supportive and that it is important to seek out those who are helpful and limit the influence of those who are not:

“Sometimes well-meaning friends and family, in their attempt to comfort, can say hurtful things or make promises they don’t go through with. Don’t let this affect you

too deeply. Surround yourself with the people you love. It's okay to let people help you." (ID1454)

Participants mentioned that they found it helpful to express their thoughts and emotions without worrying about the reactions of others:

"Don't hide your feelings. If you want to cry, do so – no matter who is around. Don't be afraid to talk about the deceased." (ID1129)

Participants expressed an awareness of the "rules of grief," especially in terms of an acceptable time to grieve, and highlighted the importance of bereaved people determining for themselves how long to grieve and when to take the next step:

"Our society is so much about celebrating life and, while I agree with this, I firmly believe it's okay to be sad and to miss the one you love." (ID1431)

Theme 3: Strategies for dealing with grief. This theme comprised subthemes of focusing on the present and future, enjoying the memories, being gentle on yourself, and recognizing grief is unique. Participants commented on the process of negotiating a balance between accepting the past but focusing on their lives now and anticipating how life will change for them as they move beyond their initial grief:

"Nothing can change the past so focus on the present and your future." (ID1009)

"It's all right to hang on to grief; you just have to make room for something else."
(ID1225)

Although it was important not to focus too much on what could not be changed, participants filtered the good memories and the memorable times they spent with the deceased person. These memories were important and the participants took comfort in having and sharing memories of good times and love with the deceased person:

"Remember all the good times and the love for each other." (ID1487)

“Talk openly about memories with each other and also have quiet times to reflect on the memories.” (ID1443)

Participants highlighted the importance of bereaved people looking after themselves physically and emotionally, and not focusing on regrets:

“Don’t beat yourself up thinking, ‘I wish I had done more, I should have done this, if only I hadn’t done something this way’.” (ID1087)

“Exercise and eat healthily. Try and maintain good sleeping patterns. Don’t get overtired and don’t drink alcohol to excess.” (ID1232)

Participants expressed the notion that grief is unique and there is no one or right way to grieve. Some expressed the notion that people will accommodate the losses and manage their grief in their own time rather than on someone else’s schedule:

“It’s a very personal journey and we are all different so we all grieve in our own way.” (ID1290)

Moreover, participants highlighted a need for further information on grief in order to cope with and accommodate the loss:

“It’s very hard! No-one teaches you about grief and the best way to handle it. I am the same person but feel different. I know it is the cycle of life but such a hole is left and the loss is of great sadness.” (ID1526)

Discussion

The findings indicate that bereaved people have insights into what may be helpful during the caring phase as well as into bereavement. They describe practical advice such as making arrangements, advocating for healthcare, and seeking appropriate information and support, as well as guidance on the bereaved person expressing emotions and enjoying memories in their own ways and moving forward in their own time. These findings resonate with established findings that bereaved people often report feeling judged if they are not

grieving the “right” way³⁰ and that the provision of information and encouragement of talking and sharing is helpful.³¹ Most of the advice for coping with bereavement identified by bereaved parents and siblings following child death from cancer,¹⁴ with the exception of acceptance and religion, were highlighted by our sample. Interestingly, many of the suggestions were relevant to the caring stage as well as the post-death stage, which indicates that bereavement support should start before the death to help people prepare for the days after the death. There are several measures that might be used by palliative care services to identify caregivers at risk of complex bereavement outcomes.³² A caregiver-led approach to identifying and addressing support needs has shown a significant reduction in caregiver strain.³³ The findings lend weight to the idea that being empowered to advocate for the dying person as well as one’s own needs may contribute to the wellbeing of bereaved caregivers.

Additionally, the findings provide insights into how the public health model of bereavement support can be operationalised. For instance, while there is an increasing emphasis on identifying and supporting people with persistent or complex grief,^{9,10,34} supports for the majority of bereaved caregivers remains under-developed.⁸ While most bereaved people do not require professional counseling, all would benefit from appropriate information and compassion.^{4,5} This information could be delivered verbally by healthcare professionals and supplemented by brochures, posters, and websites, in order to support bereaved caregivers, who describe written information as providing a sense of certainty and security.³⁵ It could also be used to upskill the wider community to support bereaved caregivers. Additionally, approximately one-third of the bereaved caregivers would benefit from opportunities to reflect upon their loss,^{4,5} which could be provided by trained volunteers and bereavement support groups. For them, a brochure or telephone call alone might not be sufficient, yet they do not require specialist intervention. Without appropriate support, their needs will remain overlooked and that their distress may increase. A program of research on

building the community capacity's to provide bereavement care might also develop the evidence base to allow palliative care services to partner with community-based organisations^{6,8} as well as lobby for resources to assist them to achieve this outcome. Developing referral pathways between all these organisations is promoted by the public health model is next for research.^{4,8} Doing so would promote the community's capacity to provide bereavement care without requiring a huge investment of important resources from within the palliative care sector.

A strength of the study is the sample size for this particular focus on bereaved caregivers' advice, which is much larger than other studies on family caregivers' coping strategies,¹¹ caring experiences,³⁶ advice following pediatric death,¹⁴ and perspectives on bereavement support.^{31,35} Additionally, an analysis of demographic variables between those who did and did not respond showed that non-responders were similar to those who responded. Thus, the findings are likely to reflect the broader sample. It should be noted, however, that the survey response rate, although low, is comparable for 'cold' surveys of bereaved caregivers recruited through palliative care services.^{37,38} Additionally, more women responded, which is in line with other population-based bereavement surveys⁵ and bereavement research in general.³⁹ Because of the location of the participating funeral providers, three-quarters of the respondents were from regional areas yet 76% of Victorians and 78% of Western Australians reside in their respective capital cities.⁴⁰ Finally, the typology of community engagement in end-of-life issues articulates several levels of participation.⁷ In this spectrum of engagement, our results are beneficial in informing bereavement care. However, projects promoting the full participation of participants, through collaboration and empowerment, are more likely to create sustainable change in healthcare service delivery.⁴¹

Conclusion

There remains little focus on developing community capacity for bereavement care. It is through determining the perspectives of bereaved people that appropriate and targeted supports according to need may be developed, offered, and evaluated. The public health model of bereavement support is an inclusive approach that draws upon the resources of the community to deliver this support. This study contributes to our knowledge in building community capacity and particularly for the second tier of the public health model who would benefit from the development of volunteer bereavement workers and bereavement support groups. Through capacity building, people are empowered to make decisions about whether they need support and where to access it, rather than these decisions being directed by the service. Bereaved caregivers are willing and able to provide advice for others in their situation and this experiential knowledge can be harnessed to progress the development of bereavement care strategies for the good of the community. The findings underscore efforts to build community capacity to provide bereavement care and promote the translational potential of the public health model of bereavement support.

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Table 1

Participant Demographics: Overall Sample, Responders and Non-Responders to the Question on Advice

	All palliative care (N=265)		Responders (N=140)		Non-responders (N= 125)	
	N	%	N	%	N	%
Gender						
Female	187	70.8	103	74.1	84	67.2
Male	77	29.2	36	25.9	41	32.8
Cultural background						
Australian	191	72.9	101	73.2	90	72.0
Other English-speaking background	50	19.1	25	18.1	25	20.2
Non-English speaking background	21	8.0	12	8.7	9	7.3
Highest level of education						
Primary school	14	5.3	6	4.3	8	6.4
High school	121	45.8	61	43.9	60	48.0
Diploma/certificate/trade	78	29.5	39	28.1	39	31.2
University degree	51	19.3	33	23.7	18	14.4
Main employment						
Paid employment	95	36.3	51	37.0	44	35.5
Retired	110	42.0	62	44.9	48	38.7
Household duties	33	12.6	16	11.6	17	13.7
Unemployed	6	2.3	3	2.2	3	2.4
Other	18	6.8	6	4.3	12	9.7

Region						
Metropolitan	69	27.1	41	29.9	28	23.7
Regional	186	72.9	96	70.1	90	76.3
Relationship to the deceased						
Spouse/partner	117	44.2	66	47.1	51	40.8
Daughter/son	115	43.4	56	40.0	59	47.2
Parent	10	3.8	8	5.7	2	1.6
Other	23	8.7	10	7.1	13	10.4
Gender of the deceased						
Male	135	51.1	73	52.1	62	50.0
Female	129	48.9	67	47.9	62	50.0
Cause of death						
Malignancy	243	91.7	127	90.7	116	92.8
Non-malignancy	22	8.3	13	9.3	9	7.2
<hr/> <i>M</i> <i>SD</i> <i>M</i> <i>SD</i> <i>M</i> <i>SD</i>						
Age of the bereaved(years)	62.3	12.3	62.6	11.4	62.1	13.3
Age of the deceased (years)	75.6	15.0	74.6	15.7	76.6	14.3

Table 2

Themes and Subthemes

Themes	Subthemes
Theme 1: Preparations for bereavement	Advocating for better healthcare
	Making necessary arrangements
	Seeking information
Theme 2 : Utilizing social networks	Seeking and accepting support
	Expressing yourself
	Giving permission to grieve before moving forward
Theme 3: Strategies for dealing with grief	focusing on the present and future
	Enjoying the memories
	Being gentle on yourself
	Recognizing grief is unique

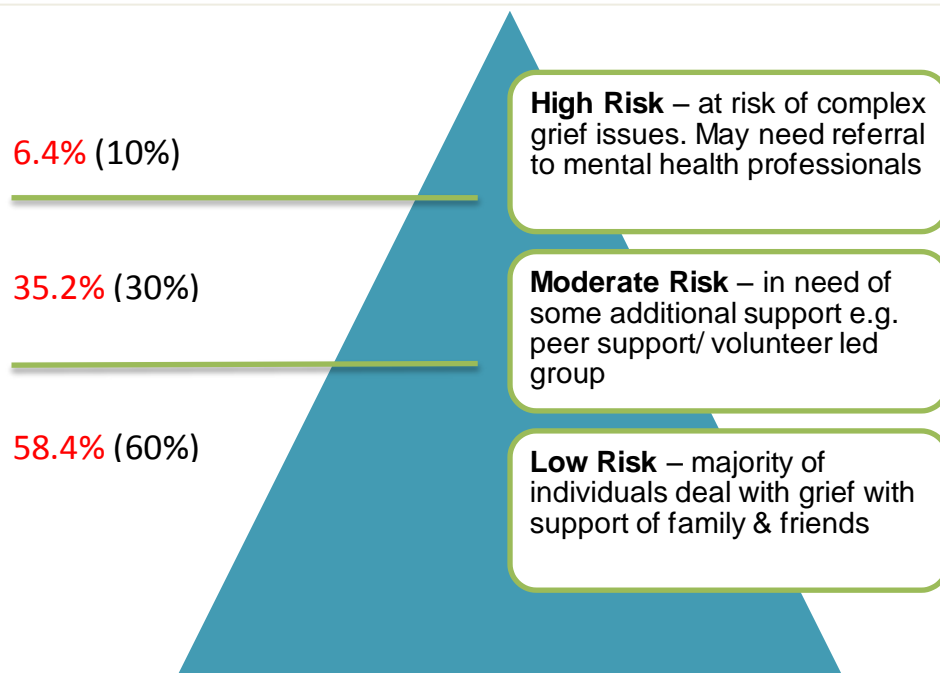


Figure 1. Public health model of bereavement support: Predicted (in parentheses) and actual proportions for the three risk groups. Source: Aoun SM, Breen LJ, Howting D, et al. Who needs bereavement support? a population based survey of bereavement risk and support need. *PLoSOne* 2015; 10(3):e0121101.