



Curtin University

Building community capacity in bereavement support: Lessons learnt from bereaved caregivers

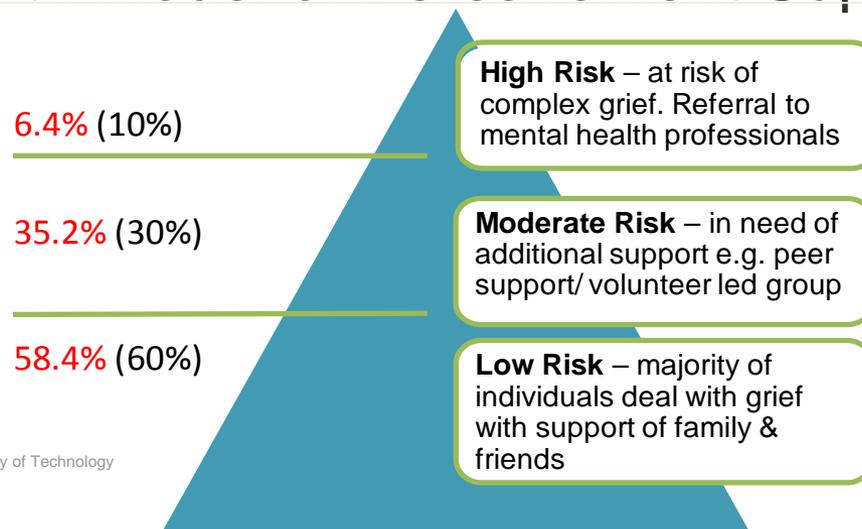
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Introduction

- There is a limited evidence base for bereavement support in PC (Hudson et al 2012, Breen et al 2014)
- PC services tend to grapple with whom to offer support, for how long, and to what end, given funding and staffing constraints (Breen et al 2014)
- Public Health Model of Bereavement Support (Aoun et al 2012, 2015)



Introduction

- Most bereaved people do not require specialist intervention, yet building community capacity in providing bereavement support is under-developed (Rumbold & Aoun 2014)
 - Asking family caregivers to reflect on their experiences and provide suggestions for bereavement care strategies in PC offers 3 benefits:
 - Inform bereavement care strategies in PC
 - Inform the training of PC volunteers who provide bereavement support
 - Inform the development of the wider community's capacity to provide bereavement support
- Kellehear's (2013) concept of compassionate communities wherein end-of-life care is a collective responsibility



Introduction

- Thus, there is a need for information on bereavement experiences from bereaved people themselves
 - In order 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 2 are especially important because bereavement information and volunteer support are two of the most commonly-offered types of support in PC (Foliart et al 2001, Demmer et al 2003, Field et al 2004, Mather et al 2008).
- The objective of the study was to:
 - Inform PC bereavement support by determining the advice people bereaved through expected deaths in PC have for others in that situation



Method

- Four funeral providers posted a questionnaire to previous clients who had used their services 6-24 months prior
 - No follow up to ↑ response rates
 - Information on support services
- 678 bereaved people responded
 - 265 were people whose deceased relative used PC services
- Questionnaire
 - 82 questions about caregiving, bereavement support, current bereavement-related distress, and 2 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 PC responded to the open-ended question about advice for others
- Open content analysis (Hsieh & Shannon 2005)
 - Independent blind-coding of 10% of responses indicated “very good” agreement; Cohen’s kappa = 0.88



Themes	Subthemes
Preparations for bereavement	Advocating for better healthcare Making necessary arrangements Seeking information
Utilising social networks	Seeking and accepting support Expressing yourself Giving permission to grieve before moving forward
Strategies for dealing with grief	Focusing on the present and future Enjoying the memories Being gentle on yourself Recognising grief is unique



Theme 1: Preparations for bereavement

- **Advocating for better healthcare**

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

- **Making necessary arrangements**

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

“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)

- **Seeking information**

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

Theme 2: Utilising social networks

- Seeking and accepting support

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

“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)

- Expressing yourself

“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)

- Giving permission to grieve before moving forward

“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: Preparations for bereavement

- Focusing on the present and future

“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)

- Enjoying the memories

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

- Being gentle on yourself

“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)

- Recognising grief is unique

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

	All palliative care (N=265)		Responders (N=140)		Non-responders (N=125)	
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	50	19.1	25	18.1	25	20.2
Non-English-speaking	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

	All palliative care (N=265)		Responders (N=140)		Non-responders (N=125)	
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



	All palliative care (N=265)		Responders (N=140)		Non-responders (N=125)	
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
	<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

Discussion

- Bereaved people have insights into what may be helpful during the caring phase as well as into bereavement

Many of the suggestions were relevant to the caring stage as well as the post-death stage, indicating that bereavement support should start before the death to help people prepare for the days after the death

There is a need measures that might be used by PC services to identify caregivers at risk of complex bereavement outcomes (Sealey et al under review)



Strengths and limitations

- **Sample size**

Much larger than other studies of family caregivers' coping strategies (Hudson 2006), caring experiences (Philip et al 2014), and perspectives on bereavement support (Diamond et al 2012, Lundberg et al 2013)

- **Few differences between non-responders and responders, therefore findings are likely to reflect the broader sample of people bereaved following PC**

More women responded

More from rural areas

Potential for more community engagement/full participation (e.g., PAR) for sustainable change (Breen & O'Connor 2014)

Conclusion

- Bereaved caregivers are willing and able to provide advice for others in their situation
- This experiential knowledge can be harnessed to progress the development of bereavement care strategies for the good of the community

Information brochures, posters, and other community education avenues to upskill PC bereavement volunteers and the wider community so that bereaved family caregivers are best supported



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