

Moving on: Factors associated with caregivers' bereavement adjustment using a random population-based face-to-face survey

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Abstract

Background: Providing care at end of life has consequences for caregivers' bereavement experience. 'Difficulty moving on with life' is an informative and unbiased symptom of prolonged grief disorder. Predictors of bereaved caregivers' ability to 'move on' have not been examined across the population.

Aim: To identify the characteristics of bereaved hands-on caregivers who were, and were not, able to 'move on' 13–60 months after the 'expected' death of someone close.

Design: The South Australian Health Omnibus is an annual, random, cross-sectional community survey. From 2000 to 2007, respondents were asked about providing care for someone terminally ill and their subsequent ability to 'move on'. Multivariable logistic regression models explored the characteristics moving on and not moving on.

Setting: Respondents were aged ≥ 15 years and lived in households within South Australia. They had provided care to someone who had died of terminal illness in the preceding 5 years.

Results: A total of 922 people provided hands-on care. In all, 80% of caregivers (745) had been able to 'move on'. Closeness of relationship to the deceased, increasing caregiver age, caregiver report of needs met, increasing time since loss, sex and English-speaking background were significantly associated with 'moving on'. A closer relationship to the deceased, socioeconomic disadvantage and being male were significantly associated with not 'moving on'.

Conclusion: These results support the relevance of 'moving on' as an indicator of caregivers' bereavement adjustment. Following the outcomes of bereaved caregivers longitudinally is essential if effective interventions are to be developed to minimise the risk of prolonged grief disorder.

Keywords

Population survey, period prevalence, grief, moving on, expected death, palliative care

What is already known about the topic?

- Providing care for someone at the end of life has consequences for the informal caregiver's bereavement experience.
- An important minority of bereaved people will experience prolonged grief disorder (PGD) and this group's characteristics continue to be defined.
- 'Difficulty moving on with life' has been shown to be an informative and unbiased symptom of PGD.

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What this paper adds?

- This paper examined the predictors of 'moving on' in a large population-based community sample over an extended 60-month bereavement period.
- In line with evidence regarding the appropriate timing of diagnosis of PGD, we have explicitly excluded the initial 12-month post-loss period.
- This paper has helped better define the characteristics of bereaved caregivers who follow an adaptive bereavement pathway and those who do not, irrespective of health or social service contact.

Implications for practice, theory or policy

- Defining those at risk of poor bereavement outcomes is essential for improved clinical practice and for efficient resource allocation.
- Those at risk of poor bereavement outcomes require follow-up beyond 12 months to ensure that complications of bereavement are appropriately diagnosed and managed.
- In line with previous findings, Palliative Care Service use was not associated with improved caregiver bereavement outcomes and this requires further investigation

Introduction

A fundamental challenge for both bereavement and caregiver research is to identify those who are at risk of poor bereavement outcomes and those who are not.¹⁻³ This identification is critical when seeking to improve outcomes for bereaved people and planning the efficient allocation of precious health resources.³⁻⁵ It is also critical if we hope to protect and support the informal caregivers who provide care to the sick and dying across our communities.^{1,6,7}

An increasing proportion of deaths in resource-rich countries are preceded by a period of illness requiring the provision of care.^{5,8,9} It is informal caregivers who provide the vast majority of care for such individuals.^{5,8,10} The impact of this caregiving experience on the post-loss bereavement period is the focus of growing interest and research.^{3,8-11} An emerging body of evidence confirms the importance of wide-ranging factors in mediating caregivers' bereavement outcomes including caregiver and patient factors, the caregiver-patient relationship and the availability of formal and informal supports while providing care and subsequently.^{1,4,12-21} More recently, associations have been demonstrated between caregiver bereavement outcomes and end-of-life patient care, patient care-planning and patient quality-of-life.²²⁻²⁵ Nonetheless, much about bereavement after an 'expected' death remains unexplained and unmeasured.^{3,26,27}

In parallel, there has been significant recent progress in our understanding of abnormal patterns of adjustment to grief. There is now broad consensus that, for a minority of individuals, grief follows an unusually prolonged course and is associated with significant morbidity and mortality.²⁸⁻³⁴ The new diagnosis of prolonged grief disorder (PGD) has been proposed to describe this distinct, disabling response to grief and is likely to be included in the upcoming International Classification of Diseases, 11th edition (ICD-11).^{29,33,34} Targeted therapies have demonstrated effectiveness in this group at reducing suffering across a

range of measures, highlighting that meaningful intervention in PGD is possible.^{4,30,35-40}

In this article, we asked caregivers about their ability to *move on* after the loss of someone close. 'Moving on' has previously been defined as an adaptive process whereby individuals adjust to and integrate their experiences of caregiving and bereavement, allowing satisfactory adjustment or accommodation to the loss so as not to remain stuck in a state of chronic mourning.⁴¹ Metaphors such as *moving on* allow individuals with wide-ranging experiences of grief to describe their own sense of adaptation to loss and reengagement with the post-loss world.⁴² Furthermore, 'difficulty moving on with life' has been found to be an informative and unbiased symptom of PGD and has been retained in the proposed criteria for PGD in ICD-11.^{29,33} Notably, 'difficulty moving on with life' has not been found to have the same association with diagnoses of depression or anxiety.^{29,43}

The aim of this population-based study is to characterise those caregivers who reported that they were able to *move on* after the death of the care recipient and those who were not. In the context of increasing clarity regarding the timing of disordered patterns of adjustment to grief, we have explicitly excluded caregivers who were within 12 months post-loss at the time of survey completion.

Methods**Setting**

The study was undertaken in South Australia, the second smallest state by population in the country, with 7% of the national population. The average age of the population is slightly higher than the rest of Australia, and the proportion who were born overseas, slightly lower.⁴⁴

Sample

Data collection occurred in 2015 through the South Australian Health Omnibus Survey (SAHOS).⁴⁵ SAHOS is a systematic, multi-stage, clustered area sample of households across the state. Annually, interviews are held face-to-face in Spring. Each annual SAHOS sample includes randomly selected households from Australian Bureau of Statistics (ABS) census collector districts (CCDs) across metropolitan Adelaide and non-metropolitan towns with populations ≥ 1000 people. Furthermore, a random starting point is selected in each CCD and a fixed skip pattern used to approach 10 addresses. Six call-back visits were made to each selected household if contact could not be made initially. Non-residential premises formed a proportion of randomly selected properties. Commercial premises, hospitals, hostels and residential care facilities were excluded.

A letter introducing SAHOS was sent to each selected household. The person aged ≥ 15 years who most recently had a birthday was selected for the face-to-face interview. (This cut-off was selected based on Australian government convention when stratifying carers by age.) If the selected respondent declined to participate, another person from the same household could not substitute. Trained interviewers conducted all interviews in the respondent's home.

Data were weighted by 5-year age groups, sex, household size and rurality using estimates from the ABS, 2011 Estimated Residential Population for South Australia.

Measurement tools used in the study

Demographic variables included age (9-year age groups), sex, highest educational attainment and current employment status.

Respondents were asked if 'someone close to them had died of a terminal illness in the last five years'. If yes, respondents were then asked a series of questions relating to the person who died, characteristics of any care provided, perceived unmet needs and whether or not the respondent had been able to *move on* with their lives.²⁹

Statistical methods

The primary variable of interest asked the question whether caregivers had *moved on*. Respondents were asked to identify one of three categories: 'not moved on', 'beginning to move on' or 'moved on'. Two primary analyses were undertaken: whether a respondent between 13 and 60 months post-loss had been able to *move on* and whether a respondent between 13 and 60 months had not been able to *move on*. Our secondary analysis investigated whether a respondent between 13 and 24 months had been able to *move on*. The primary variable was dichotomised as appropriate in each of these situations. Demographic and caregiver variables used descriptive

data. Factors that predict the outcomes in both the primary and secondary analyses were assessed using logistic regression and reported as odds ratios (OR) with 95% confidence intervals (95% CI). All models were assessed for adequacy using the Hosmer–Lemeshow test. A p -value < 0.05 (two-tailed) was deemed to be statistically significant. All analyses were conducted with Stata 14.2 (StataCorp, College Station, Texas).

Ethics, consent and reporting

Ethical approval for the project was obtained from the South Australian Department of Health's Ethics Committee. Respondents were interviewed in their homes and, as such, the Human Research Ethics Committee accepted verbal consent and continuous participation as ongoing consent.

This article reports using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for reporting observational epidemiological studies.⁴⁶

Results

In years 2001–2007, 922 participants in the SAHOS had someone close to them die, were between 13 and 60 months post-bereavement and provided day-to-day hands-on care (52.6%) or intermittent hands-on care (47.4%) to the care recipient. The sociodemographic characteristics of these caregivers and their care recipients are presented in Table 1.

When asked whether they had been able to *move on* since the death of the care recipient, 745 (80.8%) caregivers reported that they had been able to *move on*. A further 146 (15.8%) reported that they were starting to *move on* while 31 (3.4%) respondents had not been able to *move on* in the 13–60 months since the death.

When responses were stratified by 12-month time period (from 13 to 60 months post-loss), the null hypothesis that time and our outcome were independent was rejected ($p = 0.014$; Table 2).

Moved on 13–60 months after death

Six factors were significantly associated with ability to *move on* at 13–60 months post-loss: relationship to the deceased, caregiver age, caregiver report of needs met, time since loss, sex and English-speaking background. Parents/children/siblings (OR, 2.77; 95% CI, 1.68 to 4.56; $p < 0.001$) and other caregivers (OR, 6.23; 95% CI, 3.46 to 11.22) were more likely to have *moved on* than spousal caregivers (Table 3). Likewise, caregivers aged > 65 years (OR, 2.41; 95% CI, 1.46 to 3.97) were more likely to have *moved on* than their younger counterparts. Caregivers who had received enough support (OR, 1.84; 95% CI, 1.22 to

Table 1. Characteristics of 922 hands-on caregivers who had someone close to die in the 5 years before the face-to-face interview for the South Australian Health Omnibus.

<i>Respondents – factors that do not change as care relinquished</i>	
Gender ^a – male	274 (29.7%)
Age – mean (standard deviation (SD))	53.4 (15.9)
Generation	
Pre 1925	41 (4.4%)
1925–1945	311 (33.7%)
1946–1964	380 (41.2%)
1965–1980	157 (17.0%)
1981–1995	33 (3.6%)
Educational attainment ^a – beyond school	489 (53%)
Country of birth ^a – non-English-speaking	96 (10.4%)
Relationship to deceased ^a – spouse/parent/child	529 (57.4%)
<i>Respondents – factors that may change as care relinquished</i>	
Household income ^a ≤AU\$60,000	604 (65.5%)
Current work status ^a – full or part-time	377 (40.9%)
Region of residence ^a – metropolitan	685 (74.3%)
Socio-Economic Indexes for Areas (SEIFA)	
Low (lowest 3 quintiles)	389 (42.2%)
High (highest 2 quintiles)	533 (57.8%)
<i>Caregiving characteristics</i>	
Intensity of care provided	
Day-to-day (hands on)	485 (52.6%)
Intermittent	437 (47.4%)
Length of care less than 1 year	412 (56.5%) ^b
Mean time since death – months (SD)	37.1 (13.8)
<i>Post-care factors</i>	
Perceived needs met/had enough support ^a	268 (29.1%)
Sought help for grief or wished they had ^a – yes	175 (38.2%) ^b
Professional help sought (grief counselling) ^a – yes	60 (13.1%) ^b
<i>Characteristics of the deceased and their deaths</i>	
Age of the deceased (SD)	72.8 (63.2) ^b
Comfortable or very comfortable in last 2 weeks of life ^a	125 (43.4%) ^b
Diagnosis ^a – cancer	720 (78.1%)
Place of death ^a – institution (hospital, care home or hospice)	320 (69.9%) ^b
<i>Service factors</i>	
Palliative care service use ^a – yes	585 (63.4%)

^aDichotomous variable – other results not shown but sums to 100%.

^bThe denominator is less than 922 for several factors as not all questions were asked to all respondents every year of the survey.

2.78; $p=0.004$) and those who were further along in time from the loss (OR, 2.46; 95% CI, 1.62 to 3.73; $p<0.001$) were also more likely to have *moved on*. Finally, there was a significant interaction between male gender and English-speaking background. For male caregivers, you were significantly more likely to have *moved on* at 13–60 months if you were of English-speaking background (OR, 3.38; 95% CI, 1.54 to 7.41; $p=0.002$). For females, English-speaking background was irrelevant in *moving on*.

Not moved on 13–60 months after death

Three factors were significantly associated with those who had not *moved on* at 13–60 months post-loss: male gender, a closer relationship to the deceased and socioeconomic disadvantage (Table 4). Male caregivers (OR, 2.62; 95% CI, 1.23 to 5.64; $p=0.012$) were more likely than females to have not *moved on* between 13 and 60 months post-loss. Caregivers whose relationship to the deceased was defined as spousal were less likely to move on than those with any other relationship. Similarly, those from areas of socioeconomic advantage (OR, 0.39; 95% CI, 0.18 to 0.87; $p=0.021$) were less likely to report not *moving on* than their counterparts.

Moved on 13–24 months after death

Six factors were significantly associated with ability to *move on* at 13–24 months post-loss: relationship to the deceased, caregiver age, socioeconomic status, level of care provided, gender and education level (Table 5). Compared with spousally bereaved respondents, parents/children/siblings (OR, 3.09; 95% CI, 1.30 to 7.34; $p=0.011$) and ‘other’ caregivers (OR, 6.32; 95% CI, 2.44 to 16.32; $p<0.001$) were more likely to have *moved on*. Those providing intermittent care (OR, 2.23; 95% CI, 1.13 to 4.40; $p=0.021$) were more likely to have *moved on* than those providing daily care. Respondents from areas of greater socioeconomic advantage (OR, 1.86; 95% CI, 1.05 to 3.30; $p=0.034$) and caregivers aged >65 years (OR, 2.47; 95% CI, 1.10 to 5.54; $p=0.029$) were also more likely to have *moved on* than their counterparts. Finally, there was a significant interaction between male gender and level of education. For males, you were more likely to have *moved on* at 13–24 months if you were educated beyond school (OR, 3.00; 95% CI, 1.05 to 8.58; $p=0.04$). For females, education level was irrelevant in *moving on*.

The Hosmer–Lemeshow tests for each model showed no evidence of model violation.

Discussion

In this large, population-based study, we identified informal caregivers who had experienced the ‘expected’ death of someone close to them and asked them about the caregiver-defined outcome *moving on*. Our results add to the caregiver bereavement literature in three ways. First, we have examined the impact of multiple factors on bereavement outcome in a population-based sample, over an extended period and with explicit exclusion of those respondents who were within 12 months post-bereavement. Second, we have examined the characteristics of those who have *moved on* in two time frames, allowing identification of factors which have particular importance for caregivers in early bereavement. Third, we have confirmed the importance of gender in bereavement outcomes

Table 2. Months since death cross-tabulated with *Ability to move on with life* for 922 hands-on caregivers who had someone close to die in the 5 years before the face-to-face interview for the South Australian Health Omnibus.

		Agreement with a statement about <i>moving on</i>			Total
		'I have been able to move on with my life'	'I am starting to move on with my life'	'I have not been able to move on with my life'	
Months since the person's death at time of response	13–24	228 (74.5)	66 (21.6)	12 (3.9)	306
	25–36	207 (81.8)	38 (15.0)	8 (3.2)	253
	37–48	191 (88.0)	20 (9.2)	6 (2.8)	217
	49–60	119 (81.5)	22 (15.1)	5 (3.4)	146
Total	Total	745 (80.8)	146 (15.8)	31 (3.4)	922

n (%; row percentages).

Chi-square = 16.0017, *p* = 0.014.

Table 3. Characteristics identified through multivariable logistic regression reported as odds ratios (OR) (95% confidence interval (CI)) of hands-on caregivers having *moved on* 13–60 months (*n* = 745) after the death of the care recipient.

Factor		Multivariable OR (95% CI)	p value	
Respondents – factors that do not change as care relinquished				
Age	≤65 (reference)	1 ^a	0.001	
	>65	2.41 (1.46 to 3.97)		
Highest educational attainment		School	0.035	
		Beyond school		1.48 (1.03 to 2.13)
Country of birth	Males	Non-ESB	1 ^a	0.002
		ESB	3.38 (1.54, 7.41)	
	Females	Non-ESB	1 ^a	0.86
		ESB	0.94 (0.46, 1.90)	
Relationship of the caregiver to the deceased	Spouse		1 ^a	< 0.001
	Parent/child/sibling		2.77 (1.68 to 4.56)	
	Other		6.23 (3.46 to 11.22)	
Respondents – factors that may change as care relinquished				
Socio-Economic Indexes for Areas (SEIFA)	Low (lowest 3 quintiles)		1 ^a	0.068
	High (highest 2 quintiles)		1.39 (0.98 to 1.98)	
Caregiving characteristics				
Intensity of care provided	Daily		1 ^a	0.065
	Intermittent		1.46 (0.98 to 2.19)	
Time since death	Years (natural log)		2.46 (1.62 to 3.73)	< 0.001
Post-care factors				
Perception of needs met/had enough support	No		1 ^a	0.004
	Yes		1.84 (1.22 to 2.78)	
Characteristics of the deceased and their deaths				
Life-limiting illness diagnosis	Non-cancer		1 ^a	0.203
	Cancer		0.76 (0.49 to 1.16)	
Service factors				
Palliative care service used	No		1 ^a	0.733
	Yes		1.07 (0.74 to 1.54)	

ESB: English-speaking background.

^aReference group.

Bold values are statistically significant.

and highlighted the interaction of gender with other variables in mediating these outcomes.

As Stroebe and Boerner³ recently observed, our current challenge is to further elucidate caregiver subgroups of resilience versus risk with regard to bereavement outcomes. However, caregiver bereavement research faces

well-documented obstacles. Informal caregivers may fail to identify or be identified as a caregiver due to cross-over between the norms of familial roles, especially the spousal role, and those of the caregiver role.⁴⁷ Additionally, those who experience the greatest difficulty with adjustment in bereavement are often least likely to access formal

Table 4. Characteristics identified through multivariable logistic regression reported as odds ratios (OR; 95% confidence interval (CI)) of hands-on caregivers having not *moved on* 13–60 months after the death of the care recipient ($n = 31$).

Factor		Multivariable OR (95% CI)	p value
<i>Respondents – factors that do not change as care relinquished</i>			
Sex	Females	I ^a	0.012
	Males	2.64 (1.23 to 5.64)	
Age	≤65	I ^a	0.158
	>65	0.49 (0.18 to 1.32)	
Highest educational attainment	School	I ^a	0.116
	Beyond school	0.53 (0.24 to 1.17)	
Country of birth	Non-ESB	I ^a	0.150
	ESB	0.50 (0.19 to 1.29)	
Relationship to the deceased	Spouse	I ^a	0.053
	Parent/child/sibling	0.36 (0.13 to 1.01)	
	Other	0.25 (0.08 to 0.84)	
<i>Respondents – factors that may change as care relinquished</i>			
Socio-Economic Indexes for Areas (SEIFA)	Low (lowest 3 quintiles)	I ^a	0.021
	High (highest 2 quintiles)	0.39 (0.18 to 0.87)	
<i>Caregiving characteristics</i>			
Intensity of care provided	Daily	I ^a	0.299
	Intermittent	0.61 (0.24 to 1.55)	
Time since death	Years (natural log)	0.67 (0.28 to 1.60)	0.373
<i>Post-care factors</i>			
Perception of needs met/had enough support	No	I ^a	0.084
	Yes	0.42 (0.15 to 1.13)	
<i>Characteristics of the deceased and their deaths</i>			
Life-limiting illness diagnosis	Non-cancer	I ^a	0.438
	Cancer	1.46 (0.56 to 3.78)	
<i>Service factors</i>			
Palliative care service used	No	I ^a	0.972
	Yes	1.01 (0.45 to 2.28)	

ESB: English-speaking background.

^aReference group.

Bold values are statistically significant.

services or participate in bereavement research.⁴⁸ This is despite evidence that those with bereavement complications would be receptive to treatment and stand to make the greatest gains from intervention.⁴⁹ Finally, while maladaptive grief cannot be diagnosed until 6 months post-bereavement and may not be evident until after 13 months in 1/3 of caregivers, bereavement services are rarely resourced to follow-up for this period.⁵⁰ Furthermore, health systems are ill-equipped to link the array of psychological and somatic presentations that are the sequelae of disordered grief to a loss that may have occurred years before. In this context, there is a particular role for population-based surveys which examine an extended post-loss period and avoid reliance on caregiver self-identification or contact with established services.

Moved on 13–60 months

Our first multivariable regression explored the characteristics of those who were 13–60 months post-loss and had been able to *move on* (Table 3). As could be expected,

those with a closer relationship to the care recipient were less likely to have *moved on* in this period (having controlled for caregiver age), confirming the importance of relational closeness in adjustment to bereavement.^{4,18} Spousal caregivers may be the most vulnerable to cascading losses in bereavement, simultaneously losing their roles as caregiver and spouse, as well as longstanding routines and patterns of communicating.^{51–53} There is also a higher likelihood that other lifestyle factors will be affected: household income, the ability to keep their home and the dynamics of supporting networks. Additionally, if disordered attachment underlies prolonged grief as many have proposed, it is in our closest and most emotionally dependent relationships with others that vulnerabilities in attachment come to the fore.^{4,15,29,54}

Caregiver age >65 years was also associated with ability to *move on* between 13 and 60 months. Older caregivers may well have a better sense of what to expect in death and bereavement and may have provided care previously. Feeling well-prepared for an expected death is associated with better bereavement outcomes in caregiving

Table 5. Characteristics identified through multivariable logistic regression reported as odds ratios (95% CI) of hands-on caregivers having *moved on* 13–24 months after the death of the care recipient ($n=228$).

Factor			Multivariable OR (95% CI)	p value
<i>Respondents – factors that do not change as care relinquished</i>				
Age		≤65 (reference)	I ^a	0.029
		>65	2.47 (1.10 to 5.54)	
Highest educational attainment	Males	School	I ^a	0.040
		Beyond school	3.00 (1.05 to 8.58)	
	Females	School	I ^a	0.660
		Beyond school	0.86 (0.43 to 1.72)	
Country of birth		Non-ESB	I ^a	0.947
		ESB	1.03 (0.40 to 2.66)	
Relationship of the caregiver to the deceased		Spouse	I ^a	
		Parent/child/sibling	3.09 (1.30 to 7.34)	0.011
		Other	6.32 (2.44 to 16.32)	<0.001
<i>Respondents – factors that may change as care relinquished</i>				
Socio-Economic Indexes for Areas (SEIFA)		Low (lowest 3 quintiles)	I ^a	0.034
		High (highest 2 quintiles)	1.86 (1.05 to 3.30)	
<i>Caregiving characteristics</i>				
Intensity of care provided		Daily	I ^a	0.021
		Intermittent	2.23 (1.13 to 4.41)	
<i>Post-care factors</i>				
Perception of needs met/had enough support		No	I ^a	0.083
		Yes	1.78 (0.93 to 3.44)	
<i>Characteristics of the deceased and their deaths</i>				
Life-limiting illness diagnosis		Non-cancer	I ^a	0.176
		Cancer	0.61 (0.30 to 1.25)	
<i>Service factors</i>				
Palliative care service used		No	I ^a	0.702
		Yes	1.13 (0.61 to 2.07)	

OR: odds ratio; CI: confidence interval; ESB: English-speaking background.

^aReference group.

Bold values are statistically significant.

populations.^{12,21,55} Older caregivers may also be caring for older care recipients, meaning that death is less likely to be experienced as ‘out of time’ as younger deaths might be.^{14,56,57} Finally, older caregivers may be juggling fewer competing demands such as dependent children and paid employment while providing care. Given that many of us will need to provide care multiple times in our lifetime, the impact of ageing on resilience and risk in bereavement is worthy of further research.⁶

Those respondents who identified that they had received enough support over the 13- to 60-month period were significantly more likely to have *moved on* with their lives than their counterparts. Notably, Aoun et al.⁵⁷ found, in a community sample of bereaved families, that those at high risk of poor bereavement outcome were more likely to perceive lack of support, despite accessing the same supports as lower risk groups.

Finally, caregivers who were further along in bereavement were significantly more likely to report that they had *moved on* than their counterparts. This raises the question of whether there are factors associated with

early adaptation in bereavement and whether such factors would be amenable to targeted intervention.

Gender and English-speaking background were significantly associated with ability to *move on* at 13–60 months post-loss and these variables interacted.

Not moved on 13–60 months

Our second regression model examined the characteristics of those who were between 13 and 60 months post-loss and reported that they had not been able to *move on* (Table 4). Relational closeness was again a significant factor. Those who came from regions of relative socioeconomic advantage were less likely to report not *moving on* than their counterparts, confirming the importance of socioeconomic status in bereavement outcomes. Caregivers’ access to resources ranging from equipment and domestic help to informational resources or specialist services, impacts on both the experience of providing care and of bereavement.^{13,58} A key question for future research is whether some resources are essential to bereavement adaptation

overall and whether certain resources have particular importance in various subgroups.

Arguably, the most notable result from this model was the significant association of male gender with inability to *move on* over 13–60 months post-loss.

Moved on 13–24 months

Our secondary analysis examined the characteristics of those who were 13–24 months post-loss and had been able to *move on* (Table 5). By examining the characteristics of those who had been able to *move on* in this initial time frame, we aimed to shed light on possible differences in factors that impact on caregivers early in bereavement compared with the group as a whole.

Two factors – namely level of care and socioeconomic advantage – were significantly associated with *moving on* at 13–24 months but were not significantly associated with *moving on* at 13–60 months. In line with the findings in other literature, those caregivers who had provided lower care levels were more likely to have *moved on* at 13–24 month post-loss (having controlled for relationship to the deceased).^{5,9,13,56,58,59} The practical demands of increased levels of care come in concert with a range of increased pressures and responsibilities for the caregiver.¹³ It could be argued that those providing higher levels of care enter the bereavement period depleted by their experience,⁶⁰ but that the passage of time allows these individuals the opportunity to move down an adaptive pathway.

Consistent with the previous literature, caregivers from areas of relative socioeconomic advantage were also more likely to have moved on in the 13–24 month post-loss period compared to their counterparts.^{20,61} This association was not apparent when the longer time frame was examined. Again, the passage of time may allow adaptive caregivers more opportunity to mobilise the resources needed to move forward with their life, despite the relative scarcity of (for example) material and service-based resources in disadvantaged regions.

Our results suggest the need for further attention to the changing characteristics of bereaved populations over time. While it was not within the scope of this article to perform additional analyses, comparison of distinct post-loss time frames is indicated to confirm the existence of significant differences between these groups.

Gender and level of education were significantly associated with the ability to *move on* at 13–24 months post-bereavement and these variables interacted.

Gender and moving on

In their 2001 review, Stroebe and colleagues^{62,63} concluded that there was ‘convergent evidence’ that men do less well in bereavement across a range of health outcomes. Other authors have examined the impact of

gender on bereavement outcomes and reported worse outcomes in women up to 3 years post-bereavement.⁶⁴ Aside from methodological limitations, the findings on gender and bereavement may have been mixed for a number of reasons. Men may do worse later in bereavement, meaning that studies focussing on early bereavement fail to show gendered trajectories of resilience or maladaptation. However, there is not consistent support for this proposal.^{63,65} It may also be that study populations are differentially impacted by the tendency of more distressed men, but not women, to avoid contact with services and avoid study inclusion.⁶³ The SAHOS, as a population-based sample, includes men who may have been overlooked in samples identified by (for example) bereavement service use.

In our study, male gender was associated with inability to *move on* between 13 and 60 months post-loss. Education level proved protective for men in the initial 13–24 months post-loss while English-speaking background proved protective for men over 13–60 months. Women were not similarly impacted by these factors. Interactions between gender and other variables have been noted in bereavement literature across a range of bereavement outcomes. In their 1999 study, Van Grootheest et al.⁶⁶ concluded that depression in widowhood ‘is mediated by different types of environmental strain for men and women’. More recently, it was found that women providing higher care levels were more likely to have a worse-than-expected caregiving experience.⁵⁹ Outcomes for men were not similarly mediated by level of care provided.

Our findings support this more dynamic explanation for the mixed results concerning gender and bereavement – that the experiences of men and women in bereavement are mediated by quite different factors. Our results, situated within an array of related research, challenge us to view men and women as not simply differently impacted by bereavement, but differentially impacted by the constellation of contextual factors which mediate their bereavement experience.

Palliative care service use

The use of a palliative care service (PCS) was not significantly associated with the ability to *move on* in either of the time frames examined. Recent research confirms that factors which impact on patients’ end-of-life experiences have cascading benefits for caregiver bereavement outcomes.²² These factors include end-of-life discussions with health providers, avoidance of aggressive medical interventions, patient quality of life at end of life, and quality and place of death.^{22–34,67,68} These factors arguably represent palliative care’s core business. Yet in line with Wright et al.,²² we found that PCS use was not associated with (improved) caregiver bereavement outcome. Important future questions include whether PCS involvement signifies greater patient/

caregiver complexity, whether other networks and services are filling key roles in the absence of PCS involvement, and whether PCS are appropriately targeting limited resources.

Limitations

The HOS takes the form of a retrospective, structured interview. No data are collected from communities of under 1000 people and there is likely to be under-representation of Aboriginal and Torres Strait Islanders and those from a non-English-speaking background, although data are weighted to population norms to minimise the impact of this. There may be under-representation of those who experience poor bereavement outcomes, as this group have been shown to avoid involvement in research in other settings.⁶⁹ Additionally, those who transitioned to residential aged care facilities (RACF) after the caring role ended are not represented here as RACFs were not surveyed.

All respondents completed the survey in the post-loss period and at a single time point. Information such as baseline caregiver psychopathology was not gathered. Responses were recorded categorically and there was no capacity to record additional details or contextual factors. We do not have a nuanced understanding of the respondents' caregiving experiences, the social networks that supported them or the contribution of competing demands. We do not know how the majority of respondents defined *moving on* and cannot predict how the question was interpreted by those from a non-English-speaking background in particular. *Moving on* is a highly flexible and accessible metaphor and its relevance to bereavement outcomes has been established^{29,41} – yet it may not fit well with everyone's subjective experience of grief.

Conclusion

For ongoing reliance on informal caregivers to be sustained, it is essential that we improve our understanding of the impact of caregiving on bereavement outcomes. Defining the characteristics of those caregivers who follow an adaptive post-bereavement pathway and those who do not is fundamental to effective resource allocation. This study highlights the challenges of the extended time frames during which people experience prolonged grief and the limitations of current systems in recognising such grief. In better defining this group's characteristics, we are provided with an opportunity to intervene in prolonged and intense suffering in people who have contributed immensely to wider health and social networks through their care of the dying.

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