

Caregiver characteristics and bereavement needs: findings from a population study

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Complete List of Authors:	DiGiacomo, Michelle; University of Technology Sydney, Centre for Cardiovascular and Chronic Care Hatano, Yutaka; Kyoto Prefectural University of Medicine, Department of Psychiatry, Graduate School of Medical Science Phillips, Jane; University of Technology Sydney, Centre for Cardiovascular and Chronic Care Lewis, Joanne; University of Technology Sydney, Faculty of Health, Centre for Cardiovascular and Chronic Care Abernethy, Amy; Duke University Medical Center, Division of Medical Oncology, Department of Medicine Currow, David; Discipline Palliative and Supportive Services; Flinders University, Discipline of Palliative and Supportive Services, Flinders University Centre for Clinical Change
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Abstract:	<p>Background: Globally, most care for people with life-limiting illnesses is provided by informal caregivers. Identifying characteristics of caregivers that may have unmet needs and negative outcomes can help provide better support to facilitate adjustment.</p> <p>Aim: We compared characteristics, expressed unmet needs, and outcomes for spousal caregivers, with other caregivers at the end of life, by gender and age.</p> <p>Design: The South Australian Health Omnibus is an annual, random, face-to-face, cross-sectional survey wherein respondents are asked about end-of-life care.</p> <p>Setting/Participants: Participants were aged over 15, resided in households in South Australia, and had someone close to them die from a terminal illness in the last five years.</p> <p>Results: Of the 1,540 respondents who provided hands-on care for someone close at the end of life, 155 were widows/widowers. Bereaved spousal caregivers were more likely to: be older, female, better educated, have lower incomes, less full-time work, English as second language, sought help with grief, and provided more day-to-day care for longer periods. Spousal caregivers were less likely to be willing to take on caregiving again, less able to 'move on' with life, and needed greater emotional support and information about illness and services. The only difference between widows and widowers was older age of spouse in</p>

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	<p>women. Younger spousal caregivers perceived greater unmet emotional needs and were significantly less likely to be able to 'move on'. Conclusions: Spousal caregivers are different from other caregivers, with more intense needs that are not fully met. These have implications for bereavement, health, and social services.</p>

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Caregiver characteristics and bereavement needs: findings from a population study

Michelle DiGiacomo PhD¹

Yutaka Hatano MD^{2,3}

Jane Phillips PhD¹

Joanne Lewis PhD¹

Amy P Abernethy MD, PhD^{4,5}

David C Currow BMed, MPH, PhD, FRACP^{2,5}

¹University of Technology Sydney, Faculty of Health, Centre for Cardiovascular and Chronic Care, Ultimo, NSW

²Discipline, Palliative and Supportive Services, Flinders University, Adelaide, Australia

³Department of Psychiatry, Graduate School of Medical Science, Kyoto Prefectural University of Medicine, Kyoto, Japan

⁴Division of Medical Oncology, Department of Medicine, Duke University Medical Centre, Durham, North Carolina, USA

⁵Southern Adelaide Palliative Services, Repatriation General Hospital, Daw Park, South Australia, Australia

Corresponding Author:

Professor David Currow

Flinders University

700 Goodwood Road

Daw Park, South Australia 5041 Australia

Phone: +61 8 7221 8235

email: david.currow@flinders.edu.au

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Abstract

Background: Globally, most care for people with life-limiting illnesses is provided by informal caregivers. Identifying characteristics of caregivers that may have unmet needs and negative outcomes can help provide better support to facilitate adjustment.

Aim: We compared characteristics, expressed unmet needs, and outcomes for spousal caregivers, with other caregivers at the end of life, by gender and age.

Design: The South Australian Health Omnibus is an annual, random, face-to-face, cross-sectional survey wherein respondents are asked about end-of-life care.

Setting/Participants: Participants were aged over 15, resided in households in South Australia, and had someone close to them die from a terminal illness in the last five years.

Results: Of the 1,540 respondents who provided hands-on care for someone close at the end of life, 155 were widows/widowers. Bereaved spousal caregivers were more likely to: be older, female, better educated, have lower incomes, less full-time work, English as second language, sought help with grief, and provided more day-to-day care for longer periods. Spousal caregivers were less likely to be willing to take on caregiving again, less able to 'move on' with life, and needed greater emotional support and information about illness and services. The only difference between widows and widowers was older age of spouse in women. Younger spousal caregivers perceived greater unmet emotional needs and were significantly less likely to be able to 'move on'.

Conclusions: Spousal caregivers are different from other caregivers, with more intense needs that are not fully met. These have implications for bereavement, health, and social services.

What is already known about the topic?

- Most care for people with life-limiting illnesses at home is provided by informal caregivers.
- Caregiving for a spouse is considered a chronic stressor and has been linked to psychological distress.
- It is unclear whether gender, age, and relationship differently impact on caregiver bereavement outcomes.

What this paper adds?

- Spousal caregivers were demographically different from non-spousal caregivers and had different outcomes.
- No gender differences were identified in bereaved spousal caregivers.
- Younger bereaved spouses had greater emotional distress upon bereavement.

Implications for practice, theory or policy?

- Older spousal caregivers may have a need for more information about what to expect from services and the disease course.
- Caregiving contexts and bereavement needs for younger widows/widowers may be different from older spousal caregivers.
- Bereavement support should be tailored and offered to spousal caregivers, including those in younger cohorts.

Introduction

Providing care for people with life-limiting illnesses requires substantial effort and impacts on caregivers' lives significantly [1]. Family members and other lay caregivers or carers

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3 ('caregivers') provide a large amount of unpaid care for people with life-limiting illnesses,
4
5 and in many countries, receive little recognition and policy support for their efforts.
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7 Informal caregiving may include emotional support, hands-on care, liaison with formal
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9 services, and financial assistance [2]. Caregiving is generally unplanned with no start or end
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11 date, has unlimited work hours, and little or no respite allocation [2]. Given these
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13 conditions, the literature is replete with reports of negative health and wellbeing outcomes
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15 for caregivers [3]. Common challenges faced by caregivers across cultures include
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17 emotional distress and depression, lessened social contact, and financial hardship [4]. Yet,
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19 many caregivers may experience personal growth and the satisfaction of contributing to the
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21 support and quality of life of a loved one at the end of life [2] and many demonstrate
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23 resilience following the death [5].
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31 *Caregiver and care recipient relationships*

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33 Although not all caregivers are spouses of their care recipient, providing care for a spouse is
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35 considered a chronic stressor and has been linked to psychological distress and caregiver
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37 burden [6]. Outcomes of spousal caregiving upon bereavement have been theorised as
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39 relating to 'relief' of the caregiving stress or as 'wear and tear' due to cumulative effects of
40
41 the stress that eroded the caregiver's mental and physical reserves, thus exacerbating the
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43 impact of the loss [7]. For example, prolonged caregiving has been found to be an
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45 influential predictor of bereaved spouses' depressive symptoms [8] and anxiety [9] six
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47 months after the death. Support for the 'relief' theorisation was evident in Schulz et al's [5]
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49 study wherein bereaved spousal caregivers showed clinically significant reductions in
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51 depressive symptoms within the year after the death, despite demanding caregiving roles.
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3 Non-spousal caregivers may have different experiences and outcomes associated with
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5 caregiving given they are not operating within norms of spousal obligation that may inform
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7 caregiving in couples [10].
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10 11 12 *The impact of gender on spousal bereavement* 13

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15 The impact of gender on bereavement outcomes and adaptation to widowhood has been
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17 debated. Due to increasing life expectancies, widowhood has increasingly become an older
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19 person's issue, and in fact, an older women's issue [11]. A variety of demographic and
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21 gender-related socialisation factors influence the ways older men and women experience
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23 caregiving and widowhood. In a meta-analysis of caregivers, Pinquart found that gender
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25 differences varied by caregiver age and year of publication, such that stronger gender
26
27 differences emerged in older samples and in older studies [10]. Regarding costs of
28
29 caregiving, female spouses perceived greater costs than male spouses, potentially due to
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31 respective approaches to caregiving [10]. When comparing post-bereavement survival,
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33 Christaskis and Iwashyna (2003) found that female spousal caregivers benefited more than
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35 their male counterparts from engaging with hospice care [12]. These results indicate
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37 potential for differential impact on male and female spousal caregivers.
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46 In order to better identify caregiver needs for information, support, and services, we
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48 undertook this study to elucidate factors contributing to outcomes in caregivers after death.
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50 The aims of this study were to 1) identify bereaved spousal caregivers and contrast their
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52 characteristics, needs, service use, and outcomes with other bereaved caregivers (non-
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54 spousal); and 2) contrast characteristics, needs, service use, and outcomes of widows and
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56 widowers and 3) younger and older widows and widowers. The null hypothesis was that
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3 there would be no significantly distinguishable socio-demographic factors between the
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5 groups. The null hypothesis was that there would be no significantly distinguishable socio-
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7 demographic factors between the groups.
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10 11 12 **Methods**

13 14 *Setting*

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16 Eight percent of Australia's population reside in South Australia with the majority living in
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18 the capital city, Adelaide, and the balance living in relatively small communities. Key
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20 demographic differences from the rest of the country include a slightly older population
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22 who were more likely to be born in Australia.
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29 30 *Survey methodology and participants*

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32 Data were collected using the South Australian Health Omnibus Survey (HOS), a state-wide,
33
34 cross-sectional, face-to-face health survey administered annually since 1991 to
35
36 approximately 3,000 different respondents each year, aged at least 15 years [13]. The
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38 methodology has been constant across this time and is performed as a multi-stage, self-
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40 weighting, systematic, clustered-area sample of households. Seventy-five per cent of the
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42 sample was drawn from greater Adelaide and, outside Adelaide, the likelihood of a
43
44 community being selected for sampling was proportional to the community's size.
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46 Communities with a population of less than 1000 inhabitants were not included. The HOS
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48 used the Australian Bureau of Statistics Collectors' Districts (CD) as their geographic
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50 divisions. There are approximately 200 dwellings per CD and 340 CDs (from 2,041
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52 metropolitan and 1,010 non-metropolitan) randomly selected annually. A starting point
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3 within each CD was then randomly chosen annually with a standard skip pattern defining
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5 the properties to be approached.
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10 After pilot testing with fifty members of the general public each year, the HOS is conducted
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12 between September and December. The Survey is open for any researchers to purchase
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14 'space' to insert questions that are asked in addition to standard demographic questions.
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16 For the purposes of the current study, data collected from 2001-2006 was analysed. Figure
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18 1 depicts items added between 2001 and 2006. The range of health and social topics
19
20 canvassed are broad and vary from year to year; as such, number of respondents varied
21
22 according to year of inclusion of items. Each face-to-face interview lasts approximately 90
23
24 minutes and is conducted by a trained interviewer. In addition to demographic, context, and
25
26 caregiving characteristics, for purposes of the current analysis, the primary independent
27
28 variables of interest were relationship (spousal caregivers compared with all caregivers);
29
30 gender (widows compared with widowers); and age (younger spousal caregivers (<65 years)
31
32 with older spousal caregivers (≥ 65 years)). Dependent variables included post-caregiving
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34 attitudes and behaviours, service utilisation, and perceived unmet needs.
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40 41 *Data Collection*

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43 The person who most recently had a birthday over the age of 15 in each selected household
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45 was interviewed. To avoid missing people who do not self-identify as 'caregivers', the item
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47 targeting relevant respondents asked whether 'someone close to them had died from a
48
49 terminal illness in the last five years'. If they had someone close to them die, they were
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51 asked additional questions asked about the deceased's clinical and demographic
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53 characteristics, caregiver characteristics and experiences, and service utilisation. Topics
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3 were covered in this order to avoid mention of 'palliative care' until the service questions at
4
5 the end of this section. Respondents answered no further questions if they answered 'no'
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7 when asked if someone close to them had died from a terminal illness in the last five years.
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12 Some caregiver characteristics such as household income or place of residence (from which
13
14 socio-economic indices are derived) may change as the result of the death of someone
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16 close, and results in such categories should be interpreted with caution even if statistically
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18 significant [14].
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22 23 24 *Data analysis*

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26 Data were weighted to allow for comparisons over multiple years using sex, 10 year age
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28 groups, rurality, and socio-economic status, based on the most recent national Census to
29
30 inform population estimates [13]. Descriptive data are presented with Chi square
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32 comparison for categorical variables and analysis of variance for continuous variables. Three
33
34 levels of analysis took place: bereaved spousal caregivers compared to other active
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36 caregivers; comparison of the same factors between widows and widowers; and a
37
38 comparison between younger and older bereaved spousal caregivers. A p-value less than
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40 0.05 (two tailed) is considered statistically significant. Given multiple comparisons, a
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42 Bonferroni correction was applied to the final results reported [15]. All analyses were
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44 conducted with SPSS version 20 [16].
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51 52 53 *Ethics approval, consent, and reporting*

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55 The survey is approved annually by the Human Research Ethics Committee, Department of
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57 Health, South Australia. Given that people are surveyed in their own homes, verbal consent
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3 was accepted by the Research Ethics Committee, and continued participation accepted as
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5 continuing consent. This paper complies with the STROBE guidelines for reporting
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7 observational epidemiological studies [17].
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10 11 12 **RESULTS**

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15 The survey results for the years 2001-2006 included 18,060 people of the 24,064 who were
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17 approached (75% response rate). Of these respondents, 6,090 (33.7%) had 'someone close
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19 to them die.' Of the 226 bereaved spouses, 155 (68.6%) provided day-to-day (n=133),
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21 intermittent (n=14) or rare (n=8) hands-on care (hereafter referred to as the active caregiver
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23 group).
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26 27 28 *Differences between spousal and other caregivers*

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30 When compared to other bereaved caregivers, spousal caregivers were older, had a higher
31
32 level of education, were much more likely to provide hands-on care, and were less likely to
33
34 be able to 'move on' with their lives (Table 1). Specific needs were not significantly different
35
36 between the two groups although preferences for information about what to expect from
37
38 services and the likely course of the disease figured prominently for bereaved spousal
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40 caregivers (Table 2).
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45 46 47 *Lack of difference between widows and widowers*

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49 By contrast, there were no demographic, caregiving, moving on, place of death, or service
50
51 utilisation differences between male and female bereaved spousal caregivers (Table 3).
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55 There were no differences in perceived needs between the genders (Table 4).
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3 As shown in Table 5, there were differences between younger spousal caregivers (<65 year
4 old) and older spousal caregivers (65+ year old). In terms of demographic factors, older
5 spousal caregivers were more likely to be: female; born in Australia; have high school as
6 their highest level of education; and in part-time work, at most. In terms of psychosocial
7 factors, younger spousal caregivers: were less likely to 'move on' with their lives (49.0% vs
8 63.8%; $p=0.087$); were more likely to express a need for emotional and bereavement
9 supports for themselves than older spousal caregivers (14.6% vs 4.2%; 12.2% vs 1.4%,
10 respectively) (Table 6). Younger caregivers' spouses were more likely to die in institutions
11 (86.4% vs 68.8%) than at home. There was no difference in the ratio of palliative care
12 service use between the two age groups.
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29 DISCUSSION

30 This study adds uniquely to our understanding of the bereaved spousal caregivers'
31 experience at a whole-of-population level, without reliance on caregivers self-identifying (as
32 'caregiver') or their engagement in health or social services. In particular, this study
33 highlights the characteristics associated with widows and widowers in a novel way that has
34 not been done before.
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45 The spousal relationship in caregiving has been reported to be an influential factor in
46 relation to the impact of caregiving. Demographic differences between spousal and other
47 types of caregivers were apparent in our findings. Our analysis showed that spousal
48 caregivers were older, had higher levels of education, were much more likely to have
49 provided hands-on care, and were less likely to be able to 'move on' with their lives than
50 non-spousal caregivers.
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5 Of the bereaved spousal caregivers, we found no differences between men and women in
6 regards to demographic characteristics, caregiving, place of death, use of palliative care
7 services, reported ability to 'move on' with life, and expressed unmet need. Similarly, a
8 meta-synthesis on gender differences in caregiver stressors suggests that there are more
9 similarities than differences between female and male caregivers and no difference was
10 found in use of informal and formal support [10]. Yet, our non-significant results may be a
11 consequence of limited precision, which does not allow identification of small differences.
12 Whether such differences would be clinically important is also open to question. However,
13 there are differences for younger and older bereaved spouses in terms of psychosocial
14 factors and preparedness to seek bereavement support. Younger widows/widowers tended
15 to have greater emotional distress and more difficulty 'moving on' with their lives. Our
16 results are supported by previous findings. Tomarken *et al* [18] reported elevated rates of
17 prolonged grief in younger spousal caregivers. Younger spousal caregivers may experience
18 confluence of psychosocial stressors such as parenting, employment, and finances
19 compared to older spousal caregivers. Yet, inconsistencies remain about the effect of age on
20 health outcomes of bereaved spousal caregivers. One study found that older age predicted
21 increasing distress and grief in spousal caregivers [19]. Several other caregiver studies
22 included non-spouse participants in the analysis and provided inconsistent results [20].
23 Bereavement is a complex psychological process. We will need more detailed longitudinal
24 research to understand the effects of age on bereaved spousal caregivers.

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55 There were some demographic differences between the age groups and some of these
56 represent this age differential, such as the older spousal caregivers being more likely to be
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3 female and with lower levels of employment. The preponderance of female older spousal
4 caregivers is likely related to the demographics of partners' ages and differing life
5 expectancies between males and females in the generations where the highest incidence of
6 deaths occurred.
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15 The younger caregiver spouses were more likely to have had the death occur in an
16 institution, but this was not clearly attributed to age. The increased employment
17 commitments for younger spousal caregivers can indicate limits in capacity to achieve a
18 home death. Expressions of difficulties in being able to 'move on' with their lives and the
19 increased desire, compared to the older spousal caregivers, for emotional and bereavement
20 supports, emphasise the unique caregiving contexts and bereavement needs for younger
21 persons.
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34 Characteristics of the disease process, duration, and its impact on the level of care required
35 can impact on psychosocial outcomes of spousal caregivers [21]. Caring for a spouse with
36 cancer may be particularly exhausting due to distressing symptoms and social isolation as
37 one consequence of daily care [22, 23] and the rapidly deteriorating function of the person
38 dying in their last weeks of life [24]. In another study on spousal bereavement following
39 cancer death, distress levels were equal to those of individuals whose spouse died
40 unexpectedly from any cause [25]. The emotional and physical exhaustion experienced by
41 surviving spouses, regardless of whether the death was "expected" or not, may deplete
42 resources needed to cope [26].
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3 The results included bereaved spousal caregivers' desire for more information about what
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5 to expect from services and the disease course. Research has previously noted the need for
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7 improved communication between health professionals, health services staff, and
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9 caregiving spouses regarding illness trajectory, expectations at end-of-life, and services and
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11 supports available [27]. Health professionals should not assume duration of caregiving
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13 equates to caregiver knowledge of care recipients' condition. Outcomes of perceived
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15 inadequate information provision may include more protracted and complicated
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17 bereavement periods [27].
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24 *Strengths and Limitations*

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26 Analysis is limited to the (relatively) small number of questions asked of the bereaved. The
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28 study reports caregivers' own perceptions with third party confirmatory elements.
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30 Recipients defined 'someone close' and 'palliative care service use'. Caregivers are defined
31
32 in a practical way without people necessarily having to self-identify with the 'caregiver'
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34 term, as this has been a source of under-reporting given the problems with recognising
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36 oneself as a caregiver as opposed to a spouse [28]. As far as we know, this is the first study
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38 that compared the characteristics of younger and older spousal caregivers from the same
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40 population samples.
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48 The Health Omnibus survey does not engage communities with less than 1000 inhabitants.
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50 Although weighting of data to population norms helps to address under-representation of
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52 Aboriginal and Torres Strait Islander populations and people from culturally and
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54 linguistically diverse backgrounds, direct response from a broader range of respondents
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56 would be ideal to understand better the full implications of providing care to a dying spouse
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3 in these communities. The Omnibus survey is retrospective, but respondents are describing
4
5 significant life events so it is likely that they remember the level of detail sought in these
6
7 questions. Yet, there is potential for recall bias given the death could have taken place up to
8
9 five years prior and perceptions may have shifted in that time.
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12 13 14 15 *Future Research*

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17 These population data suggest that there are differences for bereaved spousal caregivers
18
19 when compared to other caregivers, as well as across age groups. Of the bereaved spousal
20
21 caregivers, there are differences between younger spousal caregivers and older spousal
22
23 caregivers. A more detailed qualitative and quantitative approach to defining bereaved
24
25 spousal caregivers' needs will add to this foundational work. The higher levels of distress
26
27 and increased likelihood of death occurring in hospital in the younger spousal caregiver
28
29 group signals the need for better understanding of this relationship in order to improve care
30
31 outcomes. Following bereaved spousal caregivers longitudinally in order to understand
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33 outcomes progressively over time will also be important, as will collection of pre-loss levels
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35 of psychological distress. Indeed, pre-bereavement data is helpful in understanding the
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37 transition through widowhood [29].
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45 **Conclusions**

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47 Spousal caregivers present real differences to the rest of the caregiver population, with
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49 more intense needs that are not perceived to be met fully. Younger spousal caregivers
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51 additionally report requirements for emotional and bereavement support, beyond those of
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53 older spousal caregivers and may need greater flexibility in support services given multiple
54
55 competing demands of their life stages. The unique needs of spousal caregivers have
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3 implications not only for bereavement services but health and social services which support
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5 these caregivers during the end of life care period.
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Table 1. Spousal and other active caregiver characteristics (weighted data)

Feature	Factor reported	Widows / widowers n = 155	Other active caregivers n = 1385	p value*
Respondent characteristics				
Demographic factors that do not change as the result of someone close dying				
Age of respondent		Mean 68.5 SD 11.5 Range 33- 92	Mean 47.0 SD 15.4 Range 15- 91	0.000#
Gender	Female	105 67.7%	812 58.6%	0.028
Country of birth	non-English speaking	21 13.5%	116 8.4%	0.032
Highest level of education	School at most	101 65.2%	628 45.3%	0.000#
Demographic factors that may change as the result of the death of someone close				
Household income [^]	Up to AU\$60,0000	131 94.9%	734 61.6%	0.000**
Rurality	Country	55 35.5%	462 33.4%	0.595
Current work status ^{^^}	Not in full or part-time work	100 79.4%	427 39.3%	0.000#
The caregiving role				
Level of hands-on care	Day-to-day	133 85.8%	371 26.8%	0.000#
Length of caregiving n = 886	< 1 year	42 46.7%	493 61.9%	0.005
After the caregiving role				
Take on caregiving role again n = 379	Would care again	31 68.9%	268 80.2%	0.080
Moving on with life	Able to move on with my life	90 59.6%	1196 86.9%	0.000#
Grief – help sought, or wished help sought n = 589	Yes	27 48.2%	140 26.3%	0.001#
The deceased and his/her death				
Diagnosis	Cancer	116 74.8%	1094 78.9%	0.239
Place of death n = 588	Institution (hospital, hospice)	43 76.8%	353 66.4%	0.113
Age of the deceased n = 592	>65	38 67.9%	364 67.9%	0.994

	Comfort in the last two weeks of life n = 262	Very comfortable or comfortable	7 25.9%	65 27.7%	0.848*
Service utilisation					
	Palliative care service used	No / don't know	64 41.3%	590 42.6%	0.760

* Fisher's exact test ^210 people declined to respond ^^32 people declined to respond

With a Bonferroni correction, a significant p value is 0.002

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Table 2. Spousal and other caregivers' perceived unmet needs (weighted data)

	Factor reported	Widows / widowers n = 116	Other active caregivers n = 1123	p value#
Individual factors				
No additional...				
n	... help with symptom control, physical care and/or medications	97 83.6%	894 79.8%	0.304
	...information about what to expect from the illness, or about services	107 92.2%	914 81.4%	0.003*#
	...emotional support for the carer, the deceased, spiritual or bereavement support	100 86.2%	866 77.1%	0.024
	... support with finances	110 94.0%	1062 94.5%	0.831*
Summary				
	Had enough support	36 31.0%	295 26.3%	0.269

*Fisher's exact test

With a Bonferroni correction, a significant p value is 0.002

Table 3. Widow and widower characteristics (weighted data)

Feature	Factor reported	Widows n = 156	Widowers n = 70	p value#
Respondent characteristics				
Demographic factors that do not change as the result of someone close dying				
Age of respondent		Mean 68.7 SD 11.2 Range 34-99	Mean 66.4 (SD 12.8) Range 33-92	0.190
Country of birth	non-English speaking	25 16.0%	11 15.9%	0.987
Highest level of education	School at most	107 69.0%	39 55.7%	0.053
Demographic factors that may change as the result of the death of someone close				
Household income [^]	Up to AU\$60,0000	126 96.9%	61 92.4%	0.167*
Rurality	Country	55 35.5%	21 34.4%	0.461
Current work status ^{^^}	Not in full or part-time work	108 80.0%	46 78.0%	0.747
The caregiving role				
Level of hands-on care	Day-to-day	119 76.8%	53 76.8%	0.995
Length of caregiving n = 136	< 1 year	54 57.4%	19 45.4%	0.187
After the caregiving role				
Take on caregiving role again n = 48	Would care again	26 72.2%	7 58.3%	0.476*
Moving on with life	Able to move on with my life	100 64.5%	38 57.6%	0.330
Grief – help sought, or wished help sought n = 92	Yes	32 48.5%	12 46.2%	0.840
The deceased and his/her death				
Diagnosis	Cancer	108 69.2%	55 78.6%	0.148
Place of death n = 92	Institution (hospital, hospice)	48 72.7%	21 80.8%	0.594*
Age of the deceased n = 92	>65	53 80.3%	14 53.8%	0.010
Comfort in the last two weeks of life n=60	Very comfortable or comfortable	24 53.3%	8 53.3%	1.000*

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Service utilisation					
	Palliative care service used	No / don't know	71 45.5%	29 42.0%	0.628

* Fisher's exact test

^30 people declined to respond

^^32 people declined to respond

With a Bonferroni correction, a significant p value is 0.002

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Table 4. Perceived unmet needs of male and female bereaved spousal caregivers (weighted data)

	Factor reported	Widows n = 124	Widowers n = 59	p value#
Individual factors				
No additional...				
n	... help with symptom control, physical care and/or medications	103 83.1%	49 83.1%	0.998
	...information about what to expect from the illness, or about services	109 87.9%	56 94.9%	0.186*
	...emotional support for the carer, the deceased, spiritual or bereavement support	106 85.5%	47 79.7%	0.320
	... support with finances	117 95.1%	56 94.9%	0.952
Summary				
	Had enough support	40 32.3%	17 28.8%	0.638

*Fisher's exact test

With a Bonferroni correction, a significant p value is 0.002

Table 5. Characteristics of younger and older bereaved spousal caregivers (weighted data)

Feature	Factor reported	Widows / widowers		p value#
		<65 year old n = 51	65+ years old n = 96	
Respondent characteristics				
Demographic factors that do not change as the result of someone close dying				
Age of respondent		Mean 54.8 SD 8,2 Median 57.0 Range 33-64	Mean 74.5 SD 6.3 Median 74.4 Range 65-91	
		n	n	
Gender n = 147	Female	29 56.9%	70 72.9%	0.048
Country of birth n = 147	non-English speaking	11 21.6%	9 9.4%	0.047*
Highest level of education n = 147	School at most	26 51.0%	70 72.9%	0.008
Demographic factors that may change as the result of the death of someone close				
Household income [^] n = 132	Up to AU\$60,0000	42 87.5%	83 98.8%	0.009*
Rurality n = 147	Country	18 35.3%	35 36.1%	0.924
Current work status ^{^^} n = 120	Not in full or part-time work	18 43.9%	78 98.7%	0.000*
The caregiving role				
Level of hands-on care n = 147	Day-to-day	44 86.3%	89 92.7%	0.243*
Length of caregiving n = 88	< 1 year	15 45.5%	26 47.3%	0.869
After the caregiving role				
Moving on with life n = 143	Able to move on with my life	24 49.0%	60 63.8%	0.087
Grief – help sought, or wished help sought n = 55	Yes	10 43.5%	16 50.0%	0.633
The deceased and his/her death				
Diagnosis n = 147	Cancer	39 76.5%	71 74.0%	0.738
Place of death n = 54	Institution (hospital, hospice)	19 86.4%	22 68.8%	0.137
Age of the deceased n = 53	>65	5 22.7%	31 100.0%	0.000*
Comfort in the last two weeks of life n = 27	Very comfortable or comfortable	2 15.4%	5 35.7%	0.385*
Service utilisation				
Palliative care service used	No / don't know	19 37.3%	37 38.5%	0.878

* Fisher's exact test [^]15 people declined to respond ^{^^}27 people declined to respond

With a Bonferonni correction, a significant p value is 0.003

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Table 6.* Perceived unmet needs of younger and older spousal caregivers (weighted data)

	Factor reported	<65 years old n = 41	65+ years old n = 72	p value [#]
Individual factors				
No additional...				
		n	n	
n	... help with symptom control, physical care and/or medications	33 80.5%	61 85.9%	0.594*
	...information about what to expect from the illness, or about services	36 90.0%	67 94.4%	0.456*
	...emotional support for the carer, the deceased, spiritual or bereavement support	31 75.6%	67 93.1%	0.018*
	...emotional support for the carer	35 85.4%	69 95.8%	0.070*
	...emotional support for the deceased	37 90.2%	70 98.6%	0.059*
	... spiritual support	39 95.1%	71 98.6%	0.298*
	...bereavement support	36 87.8%	70 98.6%	0.024*
	... support with finances	36 87.8%	70 97.2%	0.097*
Summary				
	Had enough support	31 75.6%	46 64.8%	0.234

*Fisher's exact test

[#] With a Bonferonni correction, a significant p value is 0.010

Figure 1. Items added to the survey from 2001-2006

2001	<ul style="list-style-type: none"> • Length of time since death • Relationship to deceased • Level of care for this person • Ability to move on with life after the person's death
2002	<ul style="list-style-type: none"> • Preference for support for self or person who died
2003	<ul style="list-style-type: none"> • Duration of caregiving
2004	<ul style="list-style-type: none"> • Age of deceased • Level of comfort in last two weeks of life • Place of death • Respondent's meaning of "moving on" • Sought grief support since the death
2006	<ul style="list-style-type: none"> • Take on the role of caring again • Work status

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