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# Who provides care for people dying of cancer? A comparison of a rural and metropolitan cohort in a South Australian bereaved population study

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## **Abstract**

**Background:** People in the rural and remote areas often have disparities in access to services and specific challenges when called upon to provide care. In order to plan and resource palliative care services, it is important to know what levels of service are available and what are the perceived unmet needs of caregivers for people at the end of life.

**Purpose:** To examine and compare urban and rural palliative care service availability and patterns of care from randomised, population-based surveys of caregivers of people at the end of life.

**Methods:** Survey responses on the death of ‘someone close’ from 23,588 interviews of South Australians conducted between 2001 and 2007 are analysed exploring palliative care service availability, caregiving provided, and characteristics of the deceased and caregivers.

**Results:** There was no difference in reported rates of accessing specialist palliative care services between rural and urban respondents (in unadjusted and adjusted analyses) nor did the proportion of people for whom cancer was their life-limiting illness. There was greater reliance on friends than first degree relatives in hands-on care provided at the end of life in rural settings. The rates of reported need for more support did not differ between urban and rural respondents for caregivers of people at the end of life.

## **Conclusion**

Use of palliative care services was similar for rural and urban caregivers for someone close at the end of life with similar levels of met and unmet needs.

## **Introduction**

There are disparities reported in health service delivery and in health outcomes for people who live in rural, remote and very remote settings. Although the differential in health outcomes is well recognised, there is a need to understand any differences in the health services that are available to people and their caregivers, especially at the end of life. Despite the disparities that have been described, semi-structured interviews in Western Australia amongst a range of rural patients identified an overarching theme of ‘implicit faith’ in the health system, despite known delays and inconveniences (1). The contribution of families and friends in providing care and social support is also a critical component in rural health (2,3).

Given the emergence of palliative and supportive care over the last three decades, it is timely to understand from the view point of caregivers the present level of provision of palliative care services in rural areas and their perceived unmet needs when compared to urban respondents. Extensive work has been done to ensure that palliative care services are provided locally wherever possible in line with the national policy frameworks for palliative care (4, 5).

Evaluating the net impact of service provision cannot rely only on surveying people who have successfully sought out or been referred to palliative care services given the wide variation in timing of such referrals, the threshold of perceived needs that triggers these referrals or the models of care subsequently delivering services. In a referral based discipline such as palliative and supportive care, it is imperative to have a mechanism to contact systematically those patients and caregivers who have *not* had contact with specialist palliative care services. In order to make contact with caregivers who had not been referred to specialist palliative care services, this current research team has used the annual South Australian Health Omnibus Survey to ask questions about people’s experience of providing care for someone at the end of life in the five years preceding each respondents participation in the survey.

The aim of the current study was to describe differences in proportions of people accessing specialist palliative care service between urban and rural settings, describe any difference in the population of the deceased or their caregivers and report caregivers’ perception of needs when stratified by the level of care that was given. The null hypotheses were that there would be no differences in these parameters between rural and urban respondents.

## Methods

These data were collected through the South Australian Health Omnibus Survey (HOS), a state government-associated health survey administered annually since 1991 to approximately 3,000 different residents each year aged 15 years and over. The full survey methodology is detailed elsewhere (6,7). Country areas with a population of 1,000 or more (based on Australian Bureau of Statistics (ABS) 1996 Census information) are included in proportion to the size of their population. This research group previously verified the content and construct validity supporting the use of this survey tool in palliative care service planning (8) and in assessing the impact of palliative care services on caregiver needs (9). While there is ongoing discussion on the definition of rural (10, 11), for the purposes of this analysis rural is defined as the postcode areas outside the Adelaide metropolitan area. Data from thirty nine non-metropolitan postcode areas is included in the rural cohort.

*Setting and subjects.* HOS is a multi-stage, systematic, clustered area sample of households conducted by face-to-face interview. A total of 23,706 responded to the survey, conducted annually during September to November in 2000 to 2007. Verbal consent and continued participation is accepted consent given the face-to-face nature of the interview with members of the public in their own homes. Those identified as bereaved comprised 6849 respondents of whom 2205 were from rural areas (Figure 1).

*Survey methodology:* In brief, test questions were piloted with 50 members of the general public annually. The survey is approved by the Human Research Ethics Committee, Department of Health, South Australia.

*Data Collection.* One interview by a trained interviewer was conducted per household with the person aged 15 or older who most recently had a birthday. Questions began by identifying a bereaved cohort ('Have you had someone close to you die of a terminal illness in the last 5 years?') and included socio-demographic details of the respondent and some details of the decedent including the relationship of the respondent. Only if someone had experienced such a death did they answer the rest of the questions in this section. The interview then explored: the nature of care provided (daily, intermittent or rare basis); the nature of the experience of caring for a dying person including the perception of the level of comfort for the dying person over the last two weeks; the type of supports that were or were not available; and finally so as

not to pre-empt discussions about end-of-life service use, whether palliative care services had been used, and if not, why not.

*Data analysis.* Each year, the survey data were weighted by sex, age, area of residence and probability of selection within the household to the most recent Australian Bureau of Statistics Census or Estimated Residential Population for South Australia, to provide population estimates. To analyse over multiple survey years, the data were standardised using a macro against all of South Australia for gender, 10-year age group, socioeconomic status, and region of residence in line with the 2001 Australian Census (6, 12, 13)

Descriptive statistics were used to summarise respondent characteristics and responses. Relationships between categorical variables were tested using the chi-squared test and chi-squared test for trend with p values were assumed if  $p < 0.0500$ . A multivariable logistic regression model was created to assess the association between use of palliative care services by people who died using selected respondent and decedent clinical and socio-demographic variables. The SPSS statistical package, 19 was used for analysis (IBM Chicago, IL, USA) (14).

## **Results**

### *Socio-demographic characteristics of caregivers*

Rural respondents were more likely to be born in Australia (85% in rural areas compared to urban areas 76%). The gender of caregivers did not differ between rural and urban respondents. Income levels were significantly lower in rural areas ( $p < 0.001$ ) with 22% earning  $< \$20,000$  and 20% earning  $\$20,000-\$40,000$  compared with 18% and 17% in urban areas. (Table 1)

### *Profile of the deceased and place of death*

More rural respondents (37.0%) than those in metropolitan regions (31.5%;  $p < 0.001$ ) indicated that they had experienced a death of someone close to them in the last 5 years. (Figure 1). Age at death and underlying diagnoses were similar between rural and metropolitan respondents. Place of death was significantly different ( $p < 0.001$ ) for the rural cohort when compared with those in metropolitan settings: while around one fifth of both cohorts died at home, more rural deceased (68%) died in hospital compared with urban

deceased (56%). In rural areas, only half as many people died in a hospice (8%) compared with 16% in urban areas (Table 2).

### *'Hands on' Caregivers*

As a proportion, fewer first degree relatives were the 'hands on' caregivers in rural settings (37% compared to 42% for metropolitan respondents). The difference in proportions was taken up by friends and more distant relatives. While 7.6% of urban friends assisted with daily care, this number rose to 13.2% in rural areas. Similarly, while only 21.2% of urban friends assisted with intermittent care, the numbers roses to 28.8% in rural areas (Table 3).

### *Experiences of caregiving*

There were differences ( $p < 0.035$ ) in the perception of the caregiving experience amongst the two cohorts. Rural people evaluated their caregiving experience much more positively with 19% reporting the experience was 'much better than expected' and 34% reporting it was 'as expected'. By contrast, 14.5% of urban respondents indicated it was 'much better than expected' and 31.4% that it was 'as expected. Of those reporting it was 'worse, or much worse than expected', more were urban (44.7%) than rural (38.5%) respondents (Table 4).

Rural respondents reported differences ( $p < 0.029$ ) in perception of the comfort level of the deceased in their last two weeks of life being 'very comfortable' (18.0%) and comfortable (39%) compared to urban reports of only 10% and 36%. While only one fifth of rural respondents indicated the deceased to be somewhat uncomfortable, this figure was 30.5% for those in urban areas (Table 4).

### *Unmet Needs*

There were ( $p < 0.001$ ) differences in general perception of support: double the numbers of rural (10.4% compared to 4.6% metropolitan) caregivers reported that 'no support (was) needed' (Table 5).

### *Proportion of caregivers accessing specialist palliative care services*

Caregivers who provided daily or intermittent 'hands on' care reported that 65.4% of the persons who died used palliative care services. The proportion of hands-on caregivers accessing specialist palliative care services was the same in both groups and these figures were stable across the years of the survey in unadjusted rates as well as when adjusting for

age and gender of the respondent, the length of time for which care was provided, the intensity of that care, and the life-limiting illness and age of the decedent ( $\chi^2_{\text{model}}=67.3$ ,  $df=17$ ,  $p<0.001$ ). This model only used data from 2004-2006 inclusive as all the variables for this model were only asked in those three years (Table 6).

## **Discussion**

These data confirm a range of key similarities between death from and expected cause in rural and metropolitan settings in Australia: the cohort who die and their caregivers look very similar as is their uptake of palliative care services. Contrasts include a greater reliance in rural areas on the use of friends and more distant relatives most likely reflecting the demographic of many children moving from rural areas as they move to adulthood. . In previous South Australian reports we noted the differing activities in ‘hands on’ care (15), the important role of friends (16) and the ‘invisible network’ (17). Our rural analysis emphasises these roles.

Rates of home death were identical, but with no hospices outside metropolitan Adelaide in South Australia, the local hospital serves as the palliative care unit often allowing longer periods of inpatient care than may be seen in metropolitan settings. This is a very valuable contribution of the ‘slow stream’ care offered in parts of the network of rural hospitals. Country hospitals increasingly become a social hub in ageing towns, where the social networks of seriously ill patients, in all likelihood, would find it easier to visit a sick friend than in most metropolitan settings.

Over half of rural respondents reported the caregiving experience as better than expected or as expected. However, the reports from other studies were confirmed in our data, with 18% indicating they needed more information and almost a quarter signalling the need for more physical support.

Recent Canadian and Australian research offers an interesting concept of community resilience suggesting two approaches be integrated; one from the social-ecological systems approach and the other from the psychology of development and mental health (18,19, 20). The model of volunteer rural fire services, established Australia-wide in the 1930’s, might also encourage us to take a lateral approach to health policy initiatives in supporting the seriously ill or dying and their myriad of caregivers together with the ideas of a resilient community.

Finally, the Victorian advanced rural nursing practice confirms an improved collaborative practice in rural health care (21). However high priority remains for professional development

programmes in rural palliative care delivery (22,23). Further research could explore rural caregivers' perception of the role of nurses and general practitioners who provide many of the aspects of palliative care. Penman and colleagues highlighted in their rural research the importance of a relational model of compassionate care (24).

#### *Strengths of this study*

These data represent a unique view into the perceptions and experiences of caregivers for people at the end of life. The paper serves as an important baseline against which further work in the area can be compared. While these figures pertain to South Australia only and indeed highlight throughout the State the strengths of family and friends' compassion to the seriously ill, it is likely to reflect the reality for much of Australia.

#### *Limitations*

A key limitation of this study is that any community with less than 1000 inhabitants was not included at any time in the years of the survey. It will be important in future work to understand if there are any systematic differences for care of someone at the end of life in these smaller communities. The other particular concern is that the overall number of respondents from Aboriginal or Torres Strait Islander communities is relatively low. Given higher proportions living in remote and very remote communities, this will be important to understand in future research.

#### **Conclusion**

The differences in palliative care were minimal between metropolitan and rural cohorts. The contribution of rural friends for 'hands on' care is greater. Perhaps these networks of the extended community are a model that we should strive to bring into the metropolitan setting more often (25).

Table 1: Socio-demographic profile of urban and rural caregivers – people who provided active care

Characteristics of population	Urban		Rural		P value
	n	%	n	%	
<b>Sex</b>					
Male	549	39.7	272	42.2	0.298
Female	833	60.3	374	57.8	
<b>Age</b>					
<35	350	25.4	153	23.7	0.799
35-44	267	19.3	118	18.2	
45-54	316	22.9	162	25.0	
55-64	213	15.4	106	16.4	
65-74	144	10.5	62	9.7	
75+	91	6.6	45	7.0	
<b>Marital Status</b>					
Married / De facto	865	62.6	405	62.7	0.231
Separated / Divorced	108	7.8	56	8.6	
Widowed	155	11.2	86	13.3	
Never Married	253	18.3	99	15.3	
<b>Country of birth</b>					
Australia	1047	75.8	552	85.4	<0.001
UK and Ireland	173	12.5	55	8.6	
Other European	99	7.2	20	3.0	
Asia	15	1.1	3	0.5	
New Zealand	4	0.3	3	0.5	
Other	42	3.1	13	2.0	
<b>Work status *</b>					
Full time	423	36.5	182	33.9	0.007
Part-time employment	256	22.1	128	23.8	
Home Duties	143	12.4	77	14.3	
Retired	211	18.2	101	18.7	
Student	68	5.9	12	2.2	
Other, unemployed & injured	57	4.9	38	7.1	
<b>Gross annual household income</b>					
Up to \$20,000	244	17.7	140	21.7	<0.001
\$20,001 - \$40,000	240	17.4	131	20.3	
\$40,001 - \$60,000	227	16.5	122	18.9	
>\$60,000	482	34.9	161	24.9	
Not stated	188	13.6	92	14.3	
Total	1381	100.0	646	100.0	

1 Not asked in 2006

Table 2: Reports of characteristics of person who died by area of residence of caregivers (urban and rural)

Characteristics of Population	Urban n=4644 %	Rural n= 2205 %	P value
<b>Illness *</b>			
Cancer	79.9	78.3	0.125
Other	21.6	24.8	<b>0.004</b>
Don't know illness	0.7	0.9	0.359
<b>Age died (n=1816 /894)</b>			
<45	3.6	2.8	0.064
45-54	6.0	8.2	
55-64	13.7	15.3	
65-74	23.1	21.6	
75-84	20.9	23.0	
85+	32.7	29.2	
<b>Place of death (n=1818 /902)</b>			
Home or community	20.0	18.1	<b>&lt;0.001</b>
Hospital	55.5	67.5	
Hospice	16.2	7.9	
RACF	8.4	6.4	

\*Multiple responses sometimes given – this occurred in 3.5% of respondents.

Table 3: Level of 'hands-on' caregivers by role intensity and type of illness of deceased, 2001 to 2007

Characteristics of population	Urban %	Rural %	P value
<b>LEVEL OF CARE</b>			
<b>Daily 'hands on' care ( n=436 /247)</b>			
Cancer	77.3	71.6	0.086
Cancer and at least one other cause	1.7	4.8	
Other causes	20.5	23.0	
First degree relatives	69.1	62.0	0.062
Invisible network of caregivers	30.9	38.0	
Friends	7.6	13.2	<b>0.019</b>
<b>Intermittent 'hands on' care ( n=586 /280)</b>			
Cancer	78.0	72.5	<b>0.004</b>
Cancer and at least one other cause	2.7	7.9	
Other causes	18.8	18.4	
First degree relatives	42.3	36.9	0.141
Invisible network of caregivers	57.7	63.1	
Friends	21.2	28.8	<b>0.016</b>
<b>Rare 'hands on' care (n=383/152)</b>			
Cancer	75.8	66.1	0.122
Cancer and at least one other cause	2.0	3.2	
Other causes	21.9	30.7	
First degree relatives	20.8	21.7	0.824
Invisible network of caregivers	79.2	78.3	
Friends	23.9	16.1	0.052

Table 4: Experiences of ‘hands-on’ (daily, intermittent or rare) caregivers

	<b>Urban % n=1381</b>	<b>Rural % n=646</b>	<b>P value</b>
<b>Relationship</b>			<b>0.050</b>
Spouse/partner	9.6	10.8	
Parent/child	30.1	29.1	
Sibling	5.2	2.8	
Other Family	33.2	34.5	
Friends	17.7	20.2	
Other	4.3	2.7	
<b>Used palliative care services</b>			
Yes	62.9	59.6	0.164
No	37.1	40.4	
<b>Expectations (2001 to 2006)</b>			<b>0.035</b>
Much better than expected	14.6	18.7	
As expected	31.4	34.0	
Worse or much worse than expected	44.7	38.5	
I didn't know what to expect	9.3	8.8	
<b>Comfort level of person in last 2 weeks of life (2004, 2006)</b>			<b>0.029</b>
Very comfortable	9.9	18.0	
Comfortable	35.8	39.0	
Somewhat comfortable	20.3	18.8	
Somewhat uncomfortable	30.5	20.5	
Very uncomfortable	3.5	3.7	

Table 5: General perception of support and unmet need of ‘hands on’ (daily, intermittent or rare) caregivers

<b>General perception of support</b>	<b>Urban n=1012 %</b>	<b>Rural n=450 %</b>	<b>P value</b>
No support needed	4.6	10.4	<b>&lt;0.001</b>
Had enough support	33.8	31.5	
Don’t Know	2.7	2.6	
Yes, needed more support	58.9	55.6	
<b>Type of unmet need <sup>1</sup></b>			
<b>PHYSICAL Support Needs</b>	28.2	23.7	0.071
With physical care	18.7	16.2	0.242
With medications	8.1	3.3	<b>0.001</b>
With symptom control	12.5	10.0	0.171
<b>INFORMATION Support Needs</b>	22.7	18.4	0.064
Information on what to expect	17.7	13.2	<b>0.029</b>
Information on services	14.2	10.8	0.078
<b>EMOTIONAL Support Needs</b>	29.9	24.7	<b>0.045</b>
Emotional support for me	11.9	13.1	0.519
Emotional support for deceased	16.1	12.3	0.060
Other emotional support	5.6	6.2	0.627
Spiritual support	5.2	2.7	<b>0.034</b>
Bereavement support	8.6	6.1	0.106
<b>FINANCIAL Needs</b>	7.5	6.1	0.318
<b>OTHER</b>	22.5	26.5	0.102

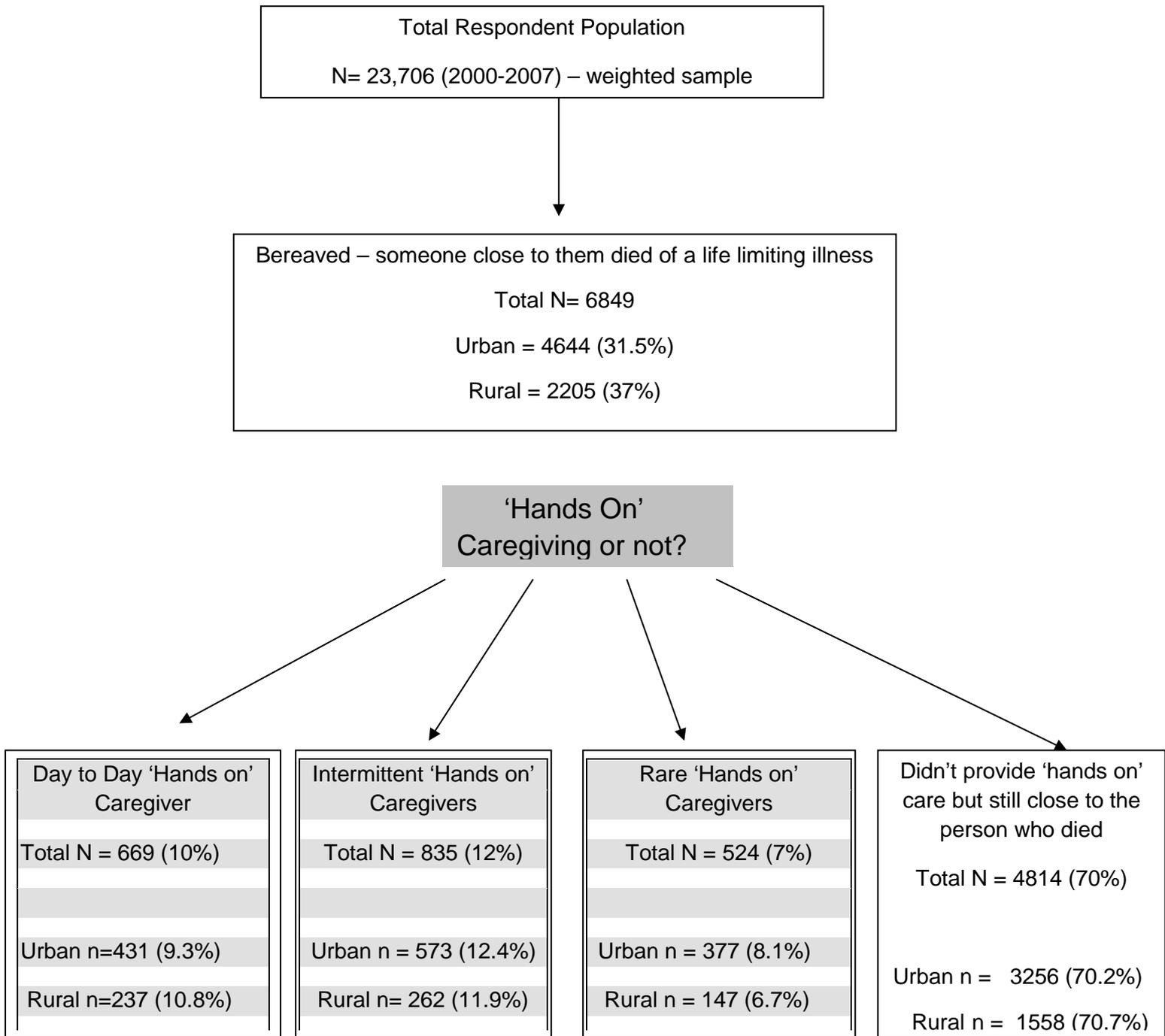
1 Multiple responses

**Table 6: Unadjusted and adjusted logistic regression model for use of palliative care services of person who died, caregiver providing daily or intermittent 'hands on' care, 2004 to 2006**

	% (95% CI)	Crude		Adjusted model *	
		OR (95% OR)	P value	OR (95% OR)	P value
<b>Characteristics of respondent</b>					
Area of residence					
Metropolitan Adelaide	63.5 (58.6 - 68.1)	1.00		1.00	
SA Country	69.2 (62.5 - 75.2)	1.30 (0.90 - 1.87)	0.165	1.25 (0.84 - 1.85)	0.270
Sex of respondent					
Male	60.7 (54.1 - 67.0)	1.00		1.00	
Female	68.2 (63.2 - 72.7)	1.38 (0.98 - 1.96)	0.068	1.16 (0.79 - 1.69)	0.446
Age of respondent					
15-29 years	68.3 (56.5 - 78.2)	1.00		1.00	
30-44 years	67.5 (59.5 - 74.6)	0.96 (0.52 - 1.79)	0.908	1.01 (0.52 - 1.97)	0.981
45-59 years	59.1 (52.6 - 65.4)	0.67 (0.38 - 1.20)	0.177	0.76 (0.40 - 1.43)	0.391
60-75 years	73.4 (64.3 - 80.8)	1.28 (0.65 - 2.49)	0.474	1.49 (0.72 - 3.09)	0.288
75+ years	66.8 (51.5 - 79.2)	0.93 (0.41 - 2.14)	0.869	1.04 (0.41 - 2.65)	0.932
<b>Caregiving experiences</b>					
Length of care					
0-3 months	64.9 (57.5 - 71.6)	1.00		1.00	
4-6 months	72.0 (63.1 - 79.5)	1.40 (0.83 - 2.34)	0.207	1.55 (0.90 - 2.68)	0.114
7-9 months	74.0 (55.3 - 86.8)	1.54 (0.62 - 3.86)	0.352	1.36 (0.52 - 3.57)	0.530
10-12 months	71.2 (58.9 - 81.0)	1.34 (0.71 - 2.53)	0.366	1.62 (0.83 - 3.16)	0.154
>12 months	58.0 (51.2 - 64.6)	0.75 (0.49 - 1.14)	0.174	0.93 (0.59 - 1.48)	0.773
Level of care					
Intermittent 'hands on'	61.6 (56.3 - 66.6)	1.00		1.00	
Daily 'hands on'	70.5 (64.6 - 75.8)	1.49 (1.05 - 2.11)	0.025	1.65 (1.12 - 2.43)	0.011
<b>Characteristics of the deceased</b>					
Life-limiting illness					
Other	48.1 (39.3 - 57.1)	1.00		1.00	
Cancer	70.0 (65.7 - 74.0)	2.51 (1.66 - 3.79)	<0.001	2.20 (1.38 - 3.50)	0.001
Age of deceased					
75+ years	58.0 (51.6 - 64.1)	1.00		1.00	
60-74 years	62.5 (55.6 - 69.0)	1.21 (0.82 - 1.78)	0.334	1.02 (0.67 - 1.54)	0.931
45 to 59 years	79.0 (70.3 - 85.6)	2.72 (1.60 - 4.63)	<0.001	2.19 (1.24 - 3.86)	0.007
<45 years	85.0 (72.0 - 92.6)	4.11 (1.75 - 9.64)	0.001	4.10 (1.69 - 9.95)	0.002

\* Adjusted for all variables shown

Figure 1: Distribution of Respondent Population, Bereaved and Caregivers. Caregivers are subdivided into 3 caregiving categories, versus non-caregivers.



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