

**Original Article**

## Palliative Caregivers Who Would Not Take on the Caring Role Again

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**Abstract**

**Context.** Health and social services rely heavily on family and friends for caregiving at the end of life.

**Objectives.** This study sought to determine the prevalence and factors associated with an unwillingness to take on the caregiving role again by interviewing former caregivers of palliative care patients.

**Methods.** The setting for this study was South Australia, with a population of 1.6 million people (7% of the Australian population) and used the South Australian Health Omnibus, an annual, face-to-face, cross-sectional, whole-of-population, multistage, systematic area sampling survey, which seeks a minimum of 3000 respondents each year statewide. One interview was conducted per household with the person over the age of 15 who most recently had a birthday. Using two years of data ( $n = 8377$ ; 65.4% participation rate), comparisons between those who definitely would care again and those who would not was undertaken.

**Results.** One in 10 people across the community provided hands-on care for someone close to them dying an expected death in the five years before being interviewed. One in 13 (7.4%) former caregivers indicated that they would not provide such care again irrespective of time since the person's death and despite no reported differences identified in unmet needs between those who would and would not care again. A further one in six (16.5%) would only "probably care again." The regression model identified that increasing age lessens the willingness to care again (odds ratio [OR] 3.94; 95% confidence interval [CI] 1.56, 9.95) and so does lower levels of education (OR 0.413; 95% CI 0.18, 0.96) controlling for spousal relationship.

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**Conclusion.** These data suggest that assessment of willingness to care needs to be considered by clinical teams, especially in the elderly. Despite most active caregivers being willing to provide care again, a proportion would not. *J Pain Symptom Manage* 2011;41:661–672. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

### Key Words

*Palliative care, caregivers, outcome assessment (health care), health service planning*

## Introduction

Arguably, the largest sector of the health workforce is informal caregivers—family and friends. The community and clinicians rely simply on the expectation that family and friends will provide care when required.<sup>1</sup> There is a tacit assumption that relatives will be there to fill the role. The likelihood of being expected to take on such a role is increasing as more people experience chronic progressive illnesses. Given the demand on caregivers, the role may be so demanding that caregivers may choose not to provide such care again. Because of the reliance of health and social systems on such caregivers, it is important for future planning to quantify the number and demographic characteristics of people who, having cared, would not take on the role again. Without such help, our health and social systems will fail, given the costs of substituting paid staff for these roles and increasing shortages of health professionals.<sup>2,3</sup>

In the United States, caregiver contributions to the economy were estimated at US \$196 billion annually.<sup>1</sup> Substituting paid care aides at the end of life alone was estimated to be worth \$1.4 billion in 2002.<sup>2</sup> In Australia, the contribution of caregivers to the costs of health and social care was estimated annually to be equal to approximately 50% of the total national government's expenditure on health.<sup>4</sup> If opportunity cost is used in modeling, it is still more than 10% of all direct health spending and as high as 75% of all health spending if replacement costs are used.<sup>2</sup>

Although the net contribution to health care costs by home-based family caregivers has been quantified, the financial impact of caring at home for each individual household is less clear. A number of studies have explored such direct costs incurred, income forgone, and other opportunity costs across a range of chronic or progressive conditions.<sup>5–7</sup>

The caring role may run for short intense periods of time (where formal and informal support networks for the carers may have little time to form) or over long periods of time (where well-formed support networks may become exhausted by the demands generated by such care).<sup>8</sup> In end-of-life care, the role of caregiver is often a subtle transition of growing involvement in increasingly complex care.<sup>9,10</sup> Having a caregiver is still the single most important predictor of home death<sup>11–14</sup> where this is agreed between patient and caregiver.<sup>15,16</sup>

Providing end-of-life care can be a positive experience for many people despite the constancy of demands,<sup>17–19</sup> identified emotional concerns,<sup>1</sup> lack of preparation and inability to effectively negotiate the level of involvement,<sup>20–22</sup> poor support and training, significant stressors,<sup>23</sup> limited respite, and a lack of support in transition from the caring role if the person dies.<sup>7,22</sup> While in the role, there are physical and psychological consequences, and in relinquishing the role, a “hangover” effect that has measurable adverse health outcomes for caregivers, including mortality.<sup>24–26</sup> With measurable mortality for caregivers associated with the role of caregiving at the end of life, anything that can reduce this association needs to be considered. For some people, the experience of providing care is not positive, but to date nothing has been documented at a population level about the characteristics of people who would not care again.

The overall aim of using the Omnibus Survey was to better understand the role of caregivers and specifically to contact people at the end of life who had not used specialist palliative care services. The aim of this substudy was to identify people who had provided active care for someone close to them at the end of life and define the demographic characteristics of the caregiver, the clinical aspects of care, and service

provision in this population. To avoid gatekeeping by health professionals, the study sought direct contact with former caregivers. The null hypothesis was that there were no defining characteristics of people who would and would not care again. Ultimately, there is a need to define whether there is a group that feels unable to take on this role, for only then we can seek to design a better way to support them.

## Methods

### Setting

South Australia has a population of 1.6 million people (7% of the Australian population), most of whom live in the one metropolitan center (Adelaide, with 1.1 million people) and the rest in small regional centers (maximum population 30,000).<sup>27</sup>

### Study Design

The South Australian Health Omnibus is an annual, face-to-face, cross-sectional, whole-of-population, multistage, systematic area sampling survey where the respondents are interviewed in their own homes. The survey is run each year between September and December. Omnibus is run by a commercial research organization that employs trained interviewers.

### Data Sources: Survey Tool and Questions Included

Researchers submit their own questions on a user-pays basis and in return are provided with de-identified demographic data and the responses to the researchers' own submitted questions. On average, more than 200 questions about health beliefs and behaviors (spanning smoking to childcare and arthritis to exercise habits) are included each year in interviews lasting between 60 and 90 minutes. Before the main survey annually, a pilot study of 50 interviews is conducted to test questions and assess survey procedures.

A question on willingness to care again was included in 2006 and 2007 surveys as part of a larger suite of questions on end-of-life care.<sup>28-30</sup> Only people who had identified that someone close to them had died an expected death (cancer, end-stage organ failure,

neurodegenerative disease, etc.) were asked questions about their caregiving experiences.

### Study Size Power Calculation

This calculation is based on responses over two survey years where at least 10,000 properties were approached, equating with more than 8000 households. With at least a 65% participation rate, data would be available on 5200 respondents. From previous data,<sup>28</sup> close to 10% of respondents would have provided active care for someone close at the end of life in the five years before responding. Given that no study to date has directly explored "willingness to care again," it was proposed that around 10% of caregivers would not wish to provide care again. It was anticipated that two years of survey data would include approximately 500 respondents who had actively provided care, with a 95% confidence interval (CI) of approximately  $\pm 2.6\%$ . A hypothesis test comparing prevalence of unwillingness to care in two subgroups of equal size would have approximately 85% power at a two-tailed Type 1 error of 0.05 to detect a difference in prevalence of 6% vs. 14%.

### Sampling Schema

The survey sampling schema has been detailed elsewhere<sup>28-30</sup> (Fig. 2). Participation rates are calculated on the number of relevant dwellings where a potential participant could be contacted, not the number of properties approached. Where contact could not be made with a household, further five attempts were undertaken to make contact at different times of the day and different days of the week (Fig. 2).

Statewide, a carefully derived algorithm randomly chooses 440 census collector districts (CDs) (approximately 200 dwellings) of a possible 3051, with weighting to larger centers in proportion to the population. From randomly selected starting points in each CD, each trained interviewer uses a skip pattern of every fourth property.

### Participants

One interview was conducted per household with the person over the age of 15 who most recently had a birthday. If this person declined to participate, the household was categorized as having a nonparticipant, and substitution in the household could not be made.

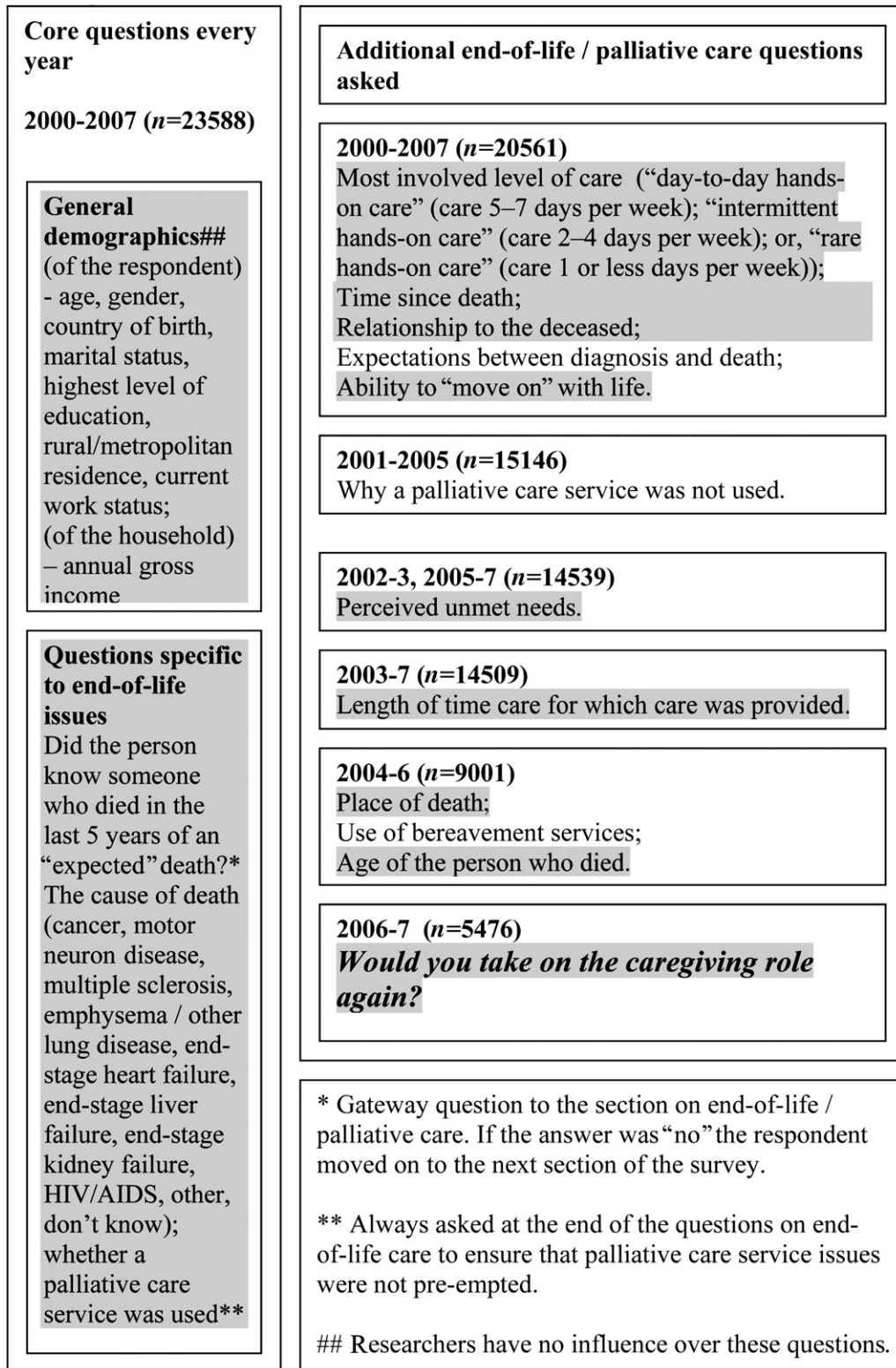


Fig. 1. Questions asked about palliative and end-of-life care in the South Australian Health Omnibus 2000–2007. Gray indicates data used in this analysis (unweighted data).

### *Data Quality*

Data were double entered, and 10% of each interviewer's respondents were selected randomly by a supervisor, recontacted, and asked to confirm their eligibility and reanswer a subset of questions. Aggregated data were then anonymized before release to researchers.

### *Quantitative Statistical Methods*

Data were weighted by the inverse of the respondent's probability of selection for the survey, adjusted for participation rates in metropolitan and rural areas, and then reweighted and directly standardized against the South Australian population (2006) for gender, 10-year age group, country of birth, and region of residence (urban, suburban, outer metropolitan, regional, rural, and remote).<sup>27,29</sup> Before combining the data set for the two years, annual data sets were compared. There were no statistically significant differences between the years in demographics. Direct standardization macros<sup>31</sup> appropriate for combining more than one survey year were applied. Only weighted data were analyzed.

All available demographic data have been used in the analysis, including the only data on income and financial burden of caregiving. Descriptive statistics were used for respondents' demographic characteristics. Cross tabulations were created to analyze demographic characteristics for carers, the deceased and service use with Chi-square comparisons adjusted by a Bonferroni correction for multiple comparisons.

An exploratory logistic regression model was created from the most significant factors from the cross tabulation and plausible factors from the literature that may affect future willingness to care. Based on the estimate that at least 10 cases are required for each single degree of freedom predictor (including intercept),<sup>32</sup> 36 respondents in the dependent group would allow the development of a logistic regression model with up to three dichotomous predictors. This analysis excluded caregiver characteristics that may change as a result of the death of a member of the household, such as place of residence, work status, and household income.<sup>33</sup> Analyses used Predictive Analytics Software version 18.0 (SPSS Inc., Chicago, IL).

Processes to minimize bias include a carefully generated sample size, random starting points (choosing CDs and then randomly choosing starting points within the district), minimizing response bias in question design and piloting, and good geographic coverage across the state to minimize undercoverage. Nonresponse is difficult to assess, but the difference in demographics between the weighted and unweighted data was compared, through a sensitivity analysis, to ensure that the sample included is broadly representative of the whole state.

### *Ethics, Consent, and Reporting*

The survey receives annual South Australian Department of Health Research Ethics Committee approval. Given that this was a community survey in people's own homes, verbal consent and response to questions were acceptable. This study complies with the Strengthening the Reporting of Observational studies in Epidemiology consensus statement on reporting observational studies.<sup>34</sup>

## **Results**

### *Descriptive Data: Participants*

A total of 8377 households were contactable in the two years in which these questions were asked, of which 5476 agreed to proceed, giving a participation rate of 65.4% (Fig. 1). Across this population, 1553 people had someone close to them die an "expected" death in the five years before the interview (1553/5476; 28.3%), of whom 520 (520/5476; 9.5%) responded that they provided active day-to-day (five to seven days per week), intermittent (two to four days per week), or rare (less than one day per week) hands-on care for the person by providing a range of supports (Table 1).<sup>28</sup>

### *Main Results*

Of all respondents who provided any level of active care, 75.7% indicated that they would provide such care again, 16.5% continue to be undecided, and 7.4% would not provide such care again (Table 1). The average age of people who would provide care again was 50.3 years (standard deviation [SD] 14.5 years) and for those who would not care again was 62.3 years (SD 15.4 years;  $P = 0.000$ ). Other demographic factors are outlined in Table 2. Of

*Table 1*  
**Respondents to the 2006 and 2007 South Australian Health Omnibus Face-to-Face Interviews Who Had Someone Die an Expected Death in the Five Years Before Responding, Whether They Provided Hands-On Care, and Whether They Would Care Again (Weighted Data)**

	Level of Hands-On Care			Total (%)
	Daily	Intermittent	Rare	
Willingness to Care Again	<b>163</b>	<b>217</b>	<b>105</b>	<b>488<sup>a</sup> (8.7)</b>
Respondent had someone close to them die in the five years before the survey and provided care				
Would care again	122	177	68	367 (75.7)
Maybe care again	26	32	23	81 (16.5)
Would <i>not</i> care again	14	8	15	37 (7.4)
Respondent had someone close to them die in the five years before the survey but did not provide any care				<b>1070 (19.3)</b>
Other respondents				<b>3989 (72.0)</b>
Total respondents				<b>5547 (100.0)</b>

<sup>a</sup>Three caregivers did not comment on the willingness to care again.

note, although the relationship between the active caregivers and the deceased is dichotomized between spouses and others (5.1%) to allow for comparisons with other studies in the literature, other relationships include parent (11.0%), child (8.2%), sibling (5.5%), other relative (37.5%), friends (26.4%), and others (6.6%).

Using data weighted to the whole state, cross tabulations (Table 2) indicated a future willingness to care ( $n=336$ ). For example, of the people who said they would care again, 18.1% were over the age of 65 whereas of those who would definitely not care again, 44.4% were over the age of 65 ( $P=0.0001$ ). Having used a Bonferroni correction, factors significantly associated with an increased likelihood of taking on the caring role again included younger age and higher levels of education achieved. Factors that bordered on significance for not caring again included spousal relationship to the deceased and having sought help with grief. The involvement of a specialist palliative care service was not a significant predictor of willingness to care again.

Of note, the rates of willingness to care again did not change significantly in the five years after the death. It appears that decisions made soon after relinquishing the role are maintained for the duration of available data (Fig. 3).

Caregivers were asked about perceived unmet needs while in their roles. In all the four broad domains that were questioned, there were no significant differences between

those who would take on the caregiving role again and other respondents (Table 3).

Given the small number of people who indicated that they would be unwilling to provide such care again in the future, the regression analysis used people who were unwilling to provide care again as the dependent variable with age of respondent, highest level of education, and spousal status. The model found two significant factors that helped to explain rates of unwillingness or indecision about caring again: increasing age (odds ratio [OR] 3.94; 95% CI 1.56, 9.95) and lower levels of education (OR 0.413; 95% CI 0.18, 0.96). For this analysis, the Hosmer and Lemeshow goodness of fit ( $P=0.893$ ) suggested that the model adequately fits the data, and the Omnibus Tests of Model coefficients ( $P=0.001$ ) confirmed this. The Nagelkerke  $R$ -square was 0.164.

## Discussion

### Key Results

Given the reliance of health and social systems on caregivers in the community for people at the end of life, most carers would provide such care again. A group of people indicated that they were unlikely to care again, and these people were more likely to be elderly, although specific unmet needs did not distinguish this group.

It could be postulated that rates of willingness to care may improve as time passes after having completed the role. The data do not

Table 2  
**Cross Tabulation: Respondents to the South Australian Health Omnibus 2006, 2007 ( $n = 5547$ ) Who Had Someone Close to Them Die an “Expected” Death in the Five Years Before Responding, Provided a Level of Hands-On Care (Day-to-Day, Intermittent, Rare;  $n = 336$ , weighted data) and Knew Whether or Not They Were Willing to Take on the Caregiving Role Again**

Respondents Who Had Someone Close to Them Die an Expected Death in the Five Years Before Responding Who...					
	...Would Take on the Caregiving Role Again			...Would <i>Not</i> Take on the Caregiving Role Again or Were Undecided	
Factor	Fraction	%	Fraction	%	<i>P</i> -value <sup>a</sup>
<b>Respondents</b>					
Factors that do not change as caregiving is relinquished					
Gender—male	114/300	38.0	11/36	30.6	0.467
Age of respondent—65+	54/300	18.1	16/36	44.4	0.000
Educational attainment—beyond school	178/298	59.7	12/37	32.4	0.002
Country of birth—non-English speaking	39/300	13.0	3/36	8.3	0.596 <sup>b</sup>
Relationship to the deceased—spouse	31/299	10.4	10/36	27.8	0.006
Factors that may change as caregiving is relinquished					
Household income $\leq$ AU \$60,000	148/258	57.4	21/28	75.0	0.104 <sup>b</sup>
Current work status—full or part time	189/298	63.4	12/37	32.4	0.000
Region of residence—metropolitan	213/299	71.2	29/37	78.4	0.440 <sup>b</sup>
SEIFA index—lowest 60%	138/299	46.2	21/37	56.8	0.223
Caregiving characteristics					
Level of care—day-to-day	122/299	40.8	14/37	37.8	0.729
Length of care— $\leq$ one year	143/297	48.1	19/33	57.6	0.532
Had enough support	101/300	33.7	11/36	30.6	0.708
Postcare factors					
Time since death $\leq$ two years	165/298	55.4	19/36	52.8	0.768
Moving on with life—able to move on	236/295	80.0	32/36	88.9	0.263 <sup>b</sup>
Sought help for grief or wished they had—yes <sup>c</sup>	79/156	50.6	6/23	26.1	0.042
The deceased					
Age of the deceased $>65^c$	39/156	25.0	20/23	87.0	0.293 <sup>b</sup>
Comfortable or very comfortable in the last two weeks of life <sup>c</sup>	80/157	51.0	16/22	72.7	0.068
Diagnosis—cancer	233/300	77.7	28/36	77.8	1.000 <sup>b</sup>
Place of death—institution (hospital or hospice) <sup>c</sup>	107/156	68.6	15/23	65.2	0.812 <sup>b</sup>
Service factors					
Palliative care service use—yes	188/300	62.7	23/37	62.2	0.952

SEIFA = Socio-Economic Indexes for Areas.

<sup>a</sup>Using a Bonferroni correction, a significant *P*-value should be set at 0.0025. Fisher's exact test used.

<sup>b</sup>Fisher's Exact Test.

<sup>c</sup>Only asked in 2006.

support this hypothesis, with the rates of willingness not increasing as time elapses since being in the role. Views are maintained over five years since caring at a constant rate.

The most surprising aspect of these findings is the factors that are *not* predictive of future unwillingness to care—being the spouse of the deceased (given some of the other associations that have been noted in the literature<sup>24</sup>), the person's diagnosis,<sup>9,24,35–37</sup> perceived levels of unmet needs (despite evidence that caregivers with depression have increased levels of unmet needs<sup>37</sup> and there are specific tasks they would prefer not to undertake<sup>8</sup>), and the use of specialist palliative care services.<sup>30</sup>

### Interpretation

*What Data Do These Findings Support?* There are many positive aspects in the caregiving experience that people have already articulated in the literature.<sup>17–19</sup> Implicit in findings from these studies is that not every caregiver found the role positive, with some evidence of caregiver distress increasing over time.<sup>37</sup>

*Do These Findings Differ From Any Other Reported Data?* The fact that spousal caregiver status does not help to predict a future unwillingness to care is of note, given the health and mortality effects on spouses who have provided care at the end of life without the support of specialist

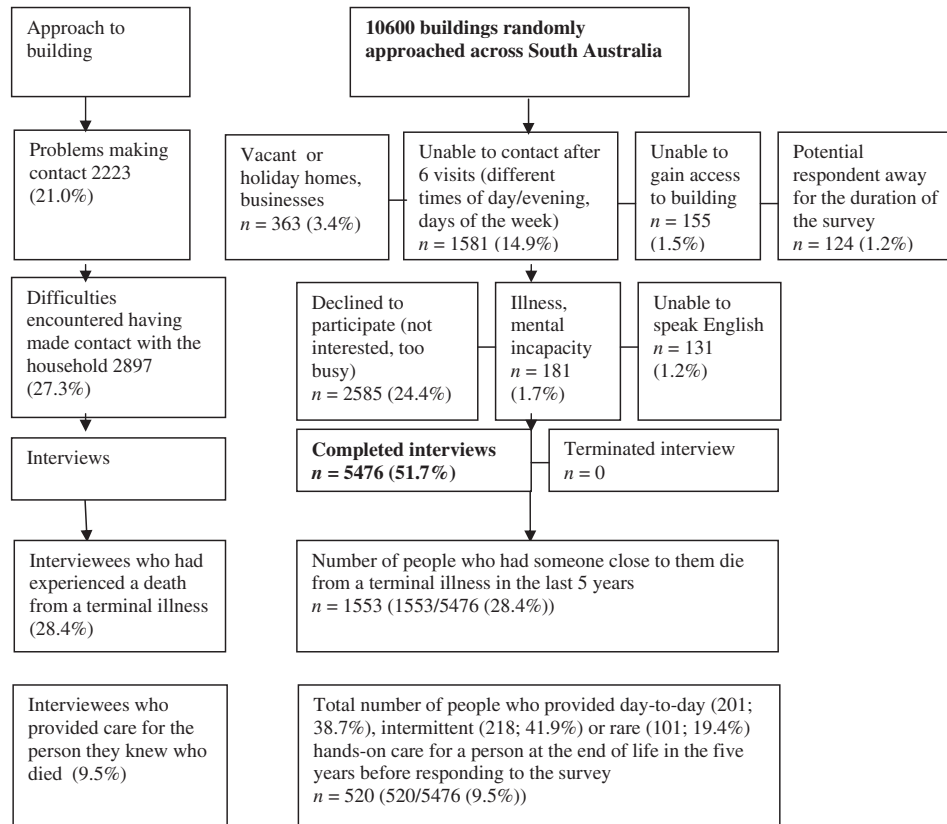


Fig. 2. The flowchart of engaging participants for the South Australian Health Omnibus 2006–2007 to identify caregivers for people who died from chronic obstructive pulmonary disease. Participation rate, 65.4% (5476/8377). (The denominator for percentages is the total number of households approached [10,600] down to the line of the total number of interviews. Unweighted data.)

palliative care services.<sup>24</sup> Excess mortality at 18 months was more likely to be seen in spousal caregivers who had not accessed community palliative care services than in those who had.<sup>25,26</sup> More extensive palliative care service

utilization seen in this study (average time from referral to death is 120 days in South Australia compared with 26 days in the Christakis cohort<sup>24</sup>) has not translated into a demonstrable effect on willingness to care.

Table 3

**Unmet Needs Identified by Respondents to the South Australian Health Omnibus in 2006, 2007 ( $n = 5547$ ) Who Had Actively Provided Care (Day-to-Day or Intermittent) at Some Time in the Five Years Before Responding for Someone at the End of Life and Knew Whether or Not They Would Provide Care Again**

	Respondents Who Had Someone Close to Them Die From an Expected Death in the Five Years Before Responding Who...				P-value
	...Would Take on the Caregiving Role Again ( $n = 300$ )		...Would Not Take on the Caregiving Role Again or Were Undecided ( $n = 36$ )		
	<i>n</i>	%	<i>n</i>	%	
Perceived additional support needed for:					
Physical care, symptom control, medications	95	31.8	13	35.1	0.680
Information about the disease progression or services available	62	20.7	9	25.0	0.524 <sup>a</sup>
Emotional, spiritual, or bereavement support	88	29.4	9	25.0	0.699 <sup>a</sup>
Finances	21	7.0	2	5.4	1.000 <sup>a</sup>

<sup>a</sup>Fisher's Exact Test used.



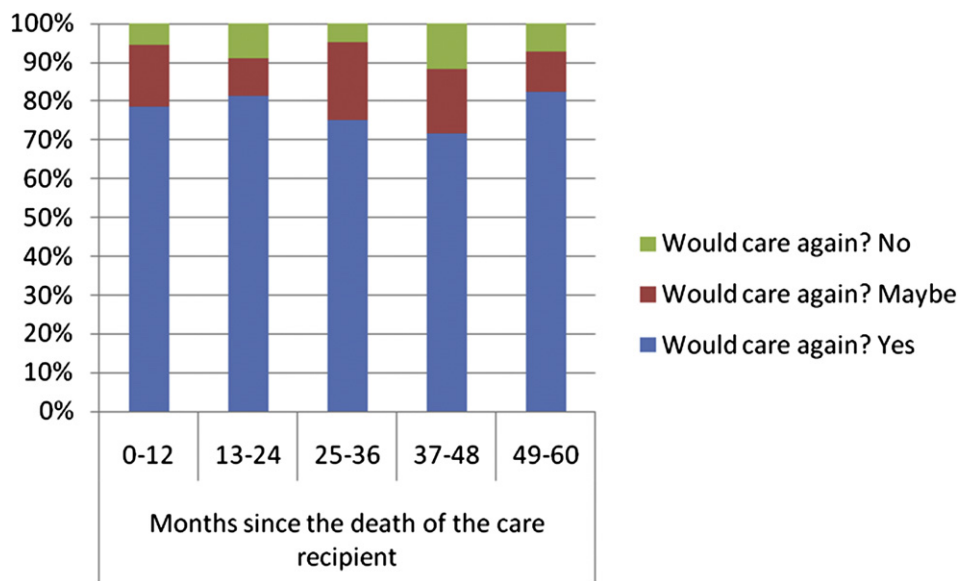


Fig. 3. Percentage of active carers' response to a question about caring again against time since death from 2006 to 2007 South Australian Health Omnibus.

Other studies of caregivers have found a relationship between the intensity of the caregiving role and subsequent negative views of the experience.<sup>24,38</sup> Day-to-day hands-on care in this study was not a predictor of lower likelihood of willingness to care again.

#### *Strengths of the Study*

Bias has been minimized by the design and execution of the study. Using trained interviewers and stringent data entry and checking techniques over two decades ensure the quality of the processes used to collect and collate these data. Most importantly, former caregivers are contacted directly, not relying on health services to identify them. Furthermore, the study did not ask people to identify as "carers," but rather focused on the practical role that someone would have taken. This was done deliberately, given that many people fail to identify themselves as caregivers.<sup>39</sup>

#### *Study Limitations*

*Design.* Where the person died, their comfort in the last two weeks of life and the respondent's perceived need for assistance with or actually accessing bereavement support were only asked in one of the survey years. The actual tasks in care provision are beyond the scope of a population-based survey, but could form the basis of future interviews with caregivers now

that the rates are defined by this study. The data did not capture either the social network supporting the person providing care or whether the caregiver was providing care to more than one person at the time.

*Sample.* The question asked about providing care again assumes that the person would be in the same position in future circumstances. A categorical question does not allow respondents to define the circumstances under which they may provide future care, for example, "I could not provide the same care again for another spouse, but I would be prepared to provide such care for a friend in the future." Given the significant social expectations of families, the ability *not* to take on the role, even if that was the potential caregiver's stated position, was not explored.

Caregiving has been associated with poorer health outcomes. Caregivers who were unable to participate in the interview because of infirmity or their death since relinquishing the role cannot be represented in these data. The findings, therefore, may systematically underestimate the total burden perceived because of caregiving. Other people who may be systematically underrepresented include residents of remote communities, including indigenous communities.

### *Generalizability*

This study represents findings from a single state in a resource-rich country in a pluralist society. Although many of the domains assessed are likely to be similar in countries with similar demographics and health systems, and the disparities in care and access to services mirror other published data, there may be differences in social support and cohesion.

### *Implications for Clinicians and Policymakers*

Health care professionals must assess caregivers' physical and mental well-being as they commence their roles and on a continuing basis<sup>40</sup> because of the consistently identified needs of caregivers.<sup>41</sup> Carers' willingness to continue in the caring role needs to be constantly reassessed, given that some people have indicated that they are reluctant to be in the role.<sup>10</sup> Ultimately, how can unwillingness to care again be minimized?<sup>42</sup> Identifying these people and understanding their concerns will be a major step forward.

Even if people were prepared to have taken on the role of providing care for someone at the end of life once, it may be that caregiving at the end of life is a once-in-a-lifetime event that exacts such a physical and emotional toll that it cannot be easily repeated. In this situation, caregivers may not reach out for help because of a belief that they should be able to cope with the role.<sup>43</sup> The data suggest that opportunity to provide such care will occur more than once in life. If every time end-of-life care is provided, 7.5% of carers are unable to take on that role again, there is cumulatively a large number of people in the community who will not be able to provide such care despite the community's expectation that they do so.

Nothing from these findings is going to allow an immediate focus on a single issue that will predictably improve a person's willingness to provide care again. The opportunity afforded by these data is that when carers who fit these broad descriptions are encountered in clinical practice, additional care should be taken to ensure that their potential needs are carefully assessed. Of note in univariate analyses is that the group unwilling to care again broadly reflects the people who are generally more disadvantaged in our community.

### *Unanswered Questions and Future Research*

In future research, a key distinction needs to be made between a person feeling unwilling or reticent to provide end-of-life care again and a person who has an absolute inability to take on the role. The strength of that distinction is not drawn out in the current research. The type of care provided on a day-to-day basis and areas of unmet needs not covered by this survey also may influence future willingness to care, and this needs to be the subject of more in-depth study in the future. However, the major areas of concern from the literature have been covered in these questions. Therefore, it may be that unmet needs do *not* drive the decisions about future care, and future research will need to elucidate this question. The specific financial burdens experienced would be one such area for research.

Given the lack of significance in key parameters, including service utilization, caregiver demographic factors, and perceived unmet needs, two questions arise: Are there other factors that need exploring that may help to understand future unwillingness to care again? Would a larger survey sample help to identify key factors to explain the two groups? Other factors that could be examined in the future include how effective a caregiver's social support network was, what they had to forgo while in the role (including workforce participation), the caregivers' ability to "move on,"<sup>29</sup> unmet informational needs,<sup>44</sup> and the perceived suffering of the person who died. These questions need to be answered if ways of better supporting caregivers are to be found.<sup>45</sup> A larger cohort would allow a larger number of factors to be included in the multifactor analysis.

This study defines the population prevalence of unwillingness to care again, thereby helping to demonstrate that it also will be feasible to conduct qualitative studies. Given the differences between those who would and would not be willing to care again, this work will be a crucial step forward. Speaking with former caregivers who are now unwilling to take on the role again is critical and, given these prevalence data, feasible.

Where do the responsibilities of health and social services lie in relation to caregiver well-being while in the role and subsequently?

Ultimately, the community is served well by the tireless support of family and friends providing care at the end of life. Because of the mortality risk for caregivers long after their role has finished, timely referral for support for caregivers is a responsibility of health professionals.<sup>24</sup> At least three-quarters of people would become caregivers again under similar circumstances, but for a small percentage of people, this has been the last time that they would take on this role. The “duality of stress and satisfaction”<sup>8</sup> encountered by caregivers has, for many, long-term consequences. It is a false assumption that caregivers will simply be there when a patient needs them; systems need to be put in place to support caregivers because, as a community, we are going to rely on them again and again.

### **Disclosures and Acknowledgments**

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### **References**

1. Hauser JM, Kramer BJ. Family caregivers in palliative care. *Clin Geriatr Med* 2004;20:671–688.
2. Rhee YJ, Degenholtz HB, Lo Sasso AT, Emmanuel LL. Estimating the quantity and economic value of family caregiving for community-dwelling older persons in the last year of life. *J Am Geriatr Soc* 2009;59:1654–1659.
3. Access Economics Pty Ltd. The economic value of informal care. Report prepared for Carers Australia. Canberra, Australia: Carers Australia, 2005. Available from <http://www.accesseconomics.com.au/publicationsreports/getreport.php?report=6&id=6>. Accessed March 31, 2010.
4. Australian Institute of Health and Welfare. Australia's welfare 2003. Canberra, Australia: AIHW, 2003.
5. Stommel M, Collins CE, Given BA. The costs of family contributions to the care of persons with dementia. *Gerontologist* 1994;34:199–205.
6. Franks DD. Economic contribution of families caring for persons with severe and persistent mental illness. *Adm Policy Ment Health* 1990;18:9–18.
7. Aoun SM, Kristjanson LJ, Currow DC, Hudson PL. Caregiving for the terminally ill: at what cost? *Palliat Med* 2005;9:551–555.
8. Zapart S, Kenny P, Hall J, Servis B, Wiley S. Home-based palliative care in Sydney, Australia: the carer's perspective on the provision of informal care. *Health Soc Care Community* 2007;15:97–107.
9. Carter P, Chang B. Sleep and depression in cancer caregivers. *Cancer Nurs* 2000;23:410–415.
10. Aoun S. The hardest thing we have ever done. The social impact of caring for terminally ill people in Australia. Full report of the national inquiry into the social impact of caring for terminally ill people. Report prepared for Palliative Care Australia. Deakin, ACT, Australia: Palliative Care Australia, 2004.
11. Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998;7:565–579.
12. Maida V. Factors that promote success in home palliative care: a study of a large suburban palliative care practice. *J Palliat Care* 2002;18:282–286.
13. Cantwell P, Turco S, Brenneis C, et al. Predictors of home deaths in palliative care cancer patients. *J Palliat Care* 2000;16:23–28.
14. Brazil K, Bedard M, Willison K. Factors associated with home death for individuals who receive home support services: a retrospective cohort study. *BMC Palliat Care* 2002;1:2. Available from <http://www.biomedcentral.com/1472-684X/1/2>. Accessed April 7, 2009.
15. Agar M, Currow DC, Shelby-James TM, et al. Preference for place of care and place of death in palliative care: are these different questions? *Palliat Med* 2008;2:787–795.
16. Grande G, Ewing G. Death at home unlikely if informal carers prefer otherwise: implications for policy. *Palliat Med* 2008;22:971–972.
17. Aranda S, Hayman-White K. Home caregivers of the person with advanced cancer. *Cancer Nurs* 2001;24:300–307.
18. Folkman S. Positive psychological states and coping with severe stress. *Soc Sci Med* 1997;45:1207–1221.
19. Hudson P. Positive aspects and challenges associated with caring for a dying relative at home. *Int J Palliat Nurs* 2004;10:58–65.
20. Munck B, Fridlund B, Martensson J. Next-of-kin caregivers in palliative home care—from control to loss of control. *J Adv Nurs* 2008;64:578–586.
21. Wennman-Larsen A, Tishelman C. Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scand J Caring Sci* 2002;16:240–247.
22. Stajduhar KI, Davies B. Variations in and factors influencing family members' decisions for palliative home care. *Palliat Med* 2005;19:21–32.
23. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of

- patients and their caregivers. *Ann Intern Med* 2000; 132:451–459.
24. Christakis NA, Iwashyna TJ. The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving widowed spouses. *Soc Sci Med* 2003;57: 465–475.
25. Nijboer C, Tempelaar R, Sanderman R, et al. Cancer and caregiving: the impact on the caregiver's health. *Psychooncology* 1998;7:3–13.
26. Schulz R, Beach S. Caregiving as a risk factor for mortality. The caregiver health effects study. *JAMA* 1999;282:2215–2219.
27. Australian Bureau of Statistics. Latest issue 3101.0—Australian demographic statistics. Released March 22, 2007. Available from [www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0](http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0). Accessed April 23, 2007.
28. Abernethy AP, Burns C, Wheeler J, Currow DC. Defining distinct caregiver subpopulations by intensity of end-of-life care provided. *Palliat Med* 2009;23: 66–79.
29. Abernethy AP, Currow DC, Fazekas BS, et al. Palliative care services make a difference to short- and long-term caregiver outcomes. *Support Care Cancer* 2008;16:585–597.
30. Currow DC, Agar M, Sanderson C, Abernethy A. Populations who die without specialist palliative care: does lower uptake equate with unmet need? *Palliat Med* 2008;22:43–50.
31. Curtin L, Klein R. Direct standardization (age-adjusted death rates). Statistical notes, no. 6. Hyattsville, MD: National Center for Health Statistics, 1995.
32. Hosmer DW, Lemeshow S. *Applied logistic regression*, 2nd ed. New York: John Wiley & Sons, Inc., 2000.
33. Sun GW, Shook TL, Kay GL. Inappropriate use of bivariable analysis to screen risk factors for use in multivariable analysis. *J Clin Epidemiol* 1996;49: 907–916.
34. von Elm E, Altman DG, Egger M, et al. STROBE initiative. Strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *BMJ* 2007;335:806–808.
35. Clark AM, Reid ME, Morrison CE, et al. The complex nature of informal care in home-based heart failure management. *J Adv Nurs* 2008;61: 373–383.
36. Cain CJ, Wicks MN. Caregiver attributes as correlates of burden in family caregivers coping with chronic obstructive pulmonary disease. *J Fam Nurs* 2000;6:46–68.
37. Dumont S, Turgeon J, Allard P, et al. Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. *J Palliat Med* 2006;9:912–921.
38. Navaie-Waliser M, Feldman P, Gould D, et al. When the caregiver needs care: the plight of vulnerable caregivers. *Am J Public Health* 2002;92: 409–413.
39. Aldridge J, Becker S. Children as carers: the impact of parental illness and disability on children's caring roles. *J Fam Ther* 1999;21:303–320.
40. O'Connell B, Bailey S, Walker A. Promoting the health and well being of older carers: a proactive strategy. *Aust Health Rev* 2003;26:78–86.
41. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs* 2009;18:1379–1393.
42. Grande G, Stajduhar K, Aoun S, et al. Supporting lay carers in end of life care: current gaps and future priorities. *Palliat Med* 2009;23:339–344.
43. Bruce D, Paley G, Underwood P, Roberts D, Steed D. Communication problems between dementia carers and general practitioners: effect on access to community support services. *Med J Aust* 2002; 177:186–188.
44. Docherty A, Owens A, Asadi-Lari M, et al. Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliat Med* 2008;22:153–171.
45. Harding R, Higginson J. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 2003;17:63–74.