

# Caregivers for people with end-stage lung disease: Characteristics and unmet needs in the whole population

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**Introduction:** End-stage lung disease (ESLD) (predominantly caused by chronic obstructive pulmonary disease and restrictive lung disease) is a significant cause of death. Little is known about community care for people with ESLD especially in the period leading to death. This paper describes demographic characteristics of caregivers, and key characteristics of the deceased irrespective of specialist service utilization.

**Methods:** The South Australian Health Omnibus is an annual, random, face-to-face, cross-sectional survey conducted statewide. For the last eight years questions about end of life have been asked of 3000 respondents annually (participation rate 77.9%). Directly standardized to the whole population, this study describes people who cared for someone with ESLD until death.

**Results:** One third (6370/18267) had someone die in the last five years from a terminal illness, 644 from ESLD (3.5% of respondents; 10.2% of deaths). One in five (20.8%) provided physical care: 43 respondents provided day-to-day and 63 provided intermittent hands-on care for an average of 40.1 months (SD 56.9). Caregivers were on average 51.2 years old (range 17–85; SD 16.5) and one in five was a spouse. Additional support to provide physical care was an unmet need by 17% of caregivers. The deceased were an average of 73.9 years old (range 47–92; SD 10.4). Only 31.1% were assessed as ‘comfortable’ or ‘very comfortable’ in the last fortnight of life.

**Discussion:** Given the health consequences of caregiving, caregivers of people with ESLD would benefit from prospectively defining their needs given the time for which intense caregiving is provided.

**Keywords:** chronic obstructive pulmonary disease, end-stage lung disease, community care, end-of-life care, palliative care, population survey

## Introduction

Caregiving at the end of life has been identified as having health and social consequences, while in the role and subsequently having relinquished it. These consequences are not trivial especially for caregivers who have not accessed services: excess mortality, psychological morbidity, and unmet needs (Christakis and Iwashyna 2003; Bradley et al 2004; Abernethy et al 2008).

Investigations of the experiences of caregivers for people with end-stage lung disease (ESLD) in qualitative (Bergs 2002; Booth et al 2003; Bailey 2004; Seamark et al 2004) and quantitative studies (Emanuel et al 1999; Hauser et al 2006; Steinhäuser et al 2006; Pinto et al 2007; Kanervisto et al 2007) have occurred. With the exception of Seamark and colleagues (2004), who accessed participants through primary care, studies required contact with tertiary health services (respiratory medicine or palliative care).

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The whole-population methodology of Elkington and colleagues (2004) used death certificates to identify a small number (25) of caregivers who had completed their caring role because of the death of the person in the previous three to six months from ESLD. Service providers must ensure that the needs of caregivers are understood irrespective of service uptake.

ESLD may occur because of changes due to chronic obstructive or restrictive disorders. However, the most common cause of ESLD remains chronic obstructive pulmonary disease (COPD) (emphysema, chronic bronchitis), a leading cause of death worldwide. Although work has been done to identify needs of people with end-stage organ failure at the end of life (Luddington et al 2001; Currow et al 2008), a specific focus on caregivers for people with ESLD is needed given the challenges of uncontrolled breathlessness (Bailey 2004) and increasing social isolation (Leidy and Traver 1996) as death approaches.

The aim of this study is to better understand the whole population of caregivers for people with ESLD leading to death. Objectives include the identification of people who cared for someone with ESLD in the last five years, descriptions of their key demographic characteristics and perceived unmet needs, and description of key factors associated with the death of the person for whom they provided care.

## Methods

The South Australian Health Omnibus (DOH SA 2006) survey is an annual, random, face-to-face, cross-sectional survey conducted statewide in South Australia. The survey explores a number of health issues including smoking, exercise, medication use, and palliative care (Wilson et al 1992; Currow et al 2004). It is administered by a commercial research organization with government support. Trained interviewers collect anonymous data from respondents. There is a cost recovery fee charged to researchers for each question included in the survey. Pilot testing of the questionnaire occurs with 50 members of the general public for comprehension and usability prior to administration of each survey annually.

## Sampling schema

Since the year 2000, a set of core questions have been asked annually about end of life care, with additional questions introduced for a limited number of years (Figure 1). Each year respondents were asked if someone close to them had died of a terminal illness in the last five years (Table 1). Demographic information collected in the survey is about

the respondent and limited demographic and medical information about the person who died. Analyses presented here focused on individuals who died from ESLD and their caregivers.

When respondents reported the death of someone from a terminal illness, information was gathered on the nature of the respondent's relationship to the deceased, their involvement in caregiving, the respondent's perceptions of unmet needs, and the respondents' perceptions of level of comfort in the last fortnight of life.

From September to December 2000–2005, 27,100 households were approached (Figure 2). In metropolitan areas, a starting point was randomly selected for each Australian Bureau of Statistics collector's district, and then 10 dwellings randomly selected using a skip pattern of every fourth household. In nonmetropolitan areas, households were selected using 100 starting points statewide; all towns with a population greater than 10,000 were included and towns above 1000 were randomly included. A cluster size of 10 was used at each nonmetropolitan starting point. One interview per household was conducted with the person over the age of 15 who most recently had a birthday. Prompt cards were provided for selected answers to allow categorization of responses. Data were double entered. Missing responses were followed up by telephone. For quality assurance, 10% of each interviewer's respondents were randomly re-contacted to confirm eligibility and responses.

## Setting

South Australia has a population of 1.54 million people (Anon 2007).

Australia provides free public hospital care for all who elect to use it and universal health care reimbursement for outpatient medical services (Medicare) and for medications (the Pharmaceutical Benefit Scheme), augmented by co-payments and supplemented by private insurance by a significant proportion of the population.

## Data analyses

Data were directly standardized (Curtin and Klein 1995) to the 2001 South Australian population by age, gender, geographic profile (rural or metropolitan) and country of birth (Anon 2007). Multiple year comparisons were enabled by a SAS weighting macro (SAS Inc, Cary, NC, USA) obtained from the South Australian Department of Health to ensure standardized populations were maintained after confirming that there were no significant differences

<p><b>Core questions each year</b></p> <p><b>(2000–2005)</b></p> <p>Demographics of respondent (age, gender, country of birth, marital status, current annual household income, highest level of education, rural/metro), palliative care service use</p>	<p><b>Additional questions asked by year</b></p>
	<p><b>2000–2003, 2005 (n = 15,173)</b></p> <p>Current work status</p>
	<p><b>2001–2005 (n = 15,205)</b></p> <p>Most involved level of care;</p> <p>Time since death;</p> <p>Relationship to the deceased;</p> <p>Expectations between diagnosis and death;</p>
	<p><b>2002, 2003, 2005 (n = 9113)</b></p> <p>Additional supports that would have been of benefit</p>
	<p><b>2003 (n = 2999)</b></p> <p>Financial burden of caregiving</p>
	<p><b>2003–2005 (n = 9163)</b></p> <p>Length of time care for which care was provided</p>
	<p><b>2004 (n = 3051)</b></p> <p>Level of comfort in the last two weeks of life</p>
	<p><b>2004, 2005 (n = 6164)</b></p> <p>Use of bereavement services,</p> <p>Place of death,</p> <p>Age of the person who died</p>

**Figure 1** Questions asked about palliative and end-of-life care in the South Australian Health Omnibus survey 2000–2005.

between annual datasets. Descriptive statistics were used for respondent and patient characteristics. Only weighted data were analyzed.

### Ethics and consent

The Health Omnibus survey received State Ethics Committee approval in 1991, and ethics review continues annually. Verbal consent was obtained from all participants (In South Australia, informed consent can be given by anyone over the age of 15).

## Results

### The Health Omnibus survey

For 2000–2005 inclusive, approximately 3000 respondents per year have participated (participation rate 18,267/23,456; 77.9%) (Figure 2).

### People who had experienced a death following a terminal illness

One in three people who completed the interview (6370/18,267; 34.7%) (Table 1) had 'someone close to them

**Table 1** Characteristics of respondents who identified someone close to them had died of 'emphysema' in the past five years. Core demographic questions asked annually 2000–2005 inclusive (18,224 weighted responses). Participation rate 77.9%. Data directly standardized to the 2001 population. Deaths encountered 6339 (34.7% of 18,224). Deaths from chronic obstructive pulmonary disease (COPD) 644 (10.2% of all deaths; 3.5 % of all respondents)

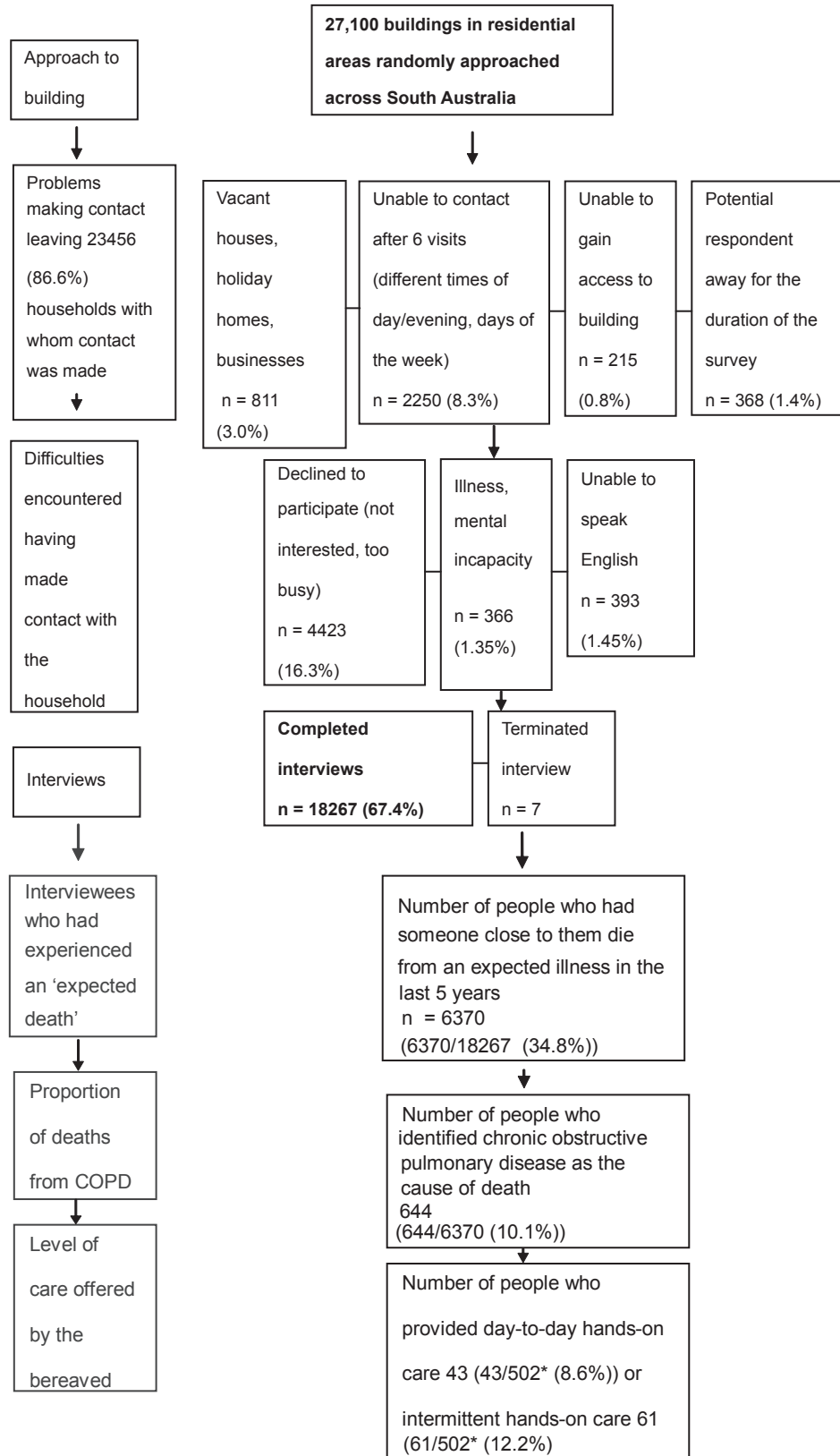
Demographic feature	Factor reported	All people who experienced a death from COPD (n = 644)	Hands-on or intermittent hands-on care for people who died from COPD (n = 104)
Age (years)	Mean	48.4	51.2
	SD	17.2	16.5
	Median	47.5	51.5
	Range	15–89	17–85
Gender	Male	282 (43.8%)	40 (38.9%)
Country of birth	English-speaking countries	588 (91.2%)	101 (96.6%)
Marital status <sup>#</sup>	Married/de facto	443 (68.7%)	61 (58.8%)
Current annual household income <sup>#</sup>	<AU\$60,000 per year	389 (60.4%)	62 (69.5%)
	Declined to answer	62 (9.6%)	14 (13.6%)
Highest education level	School only	341 (52.9%)	53 (51.2%)
Rural/metro <sup>#</sup>	Metropolitan	434 (67.4%)	61 (58.7%)
Relationship to the deceased*	Spouse	21 (4.1%)	17 (15.9%)
	Parent/child	99 (19.8%)	38 (36.9%)
	Sibling	27 (5.4%)	7 (7.2%)
	Other relative	229 (45.7%)	32 (30.4%)
	Friend	111 (22.1%)	10 (9.7%)
	Other	14 (2.8%)	0 (0.0%)
Most involved level of care*	Day-to-day	43 (8.7)	
	Intermittent	61 (9.4%)	
	Rare hands-on care	46 (9.1%)	
	No care, but close	352 (70.1%)	
Palliative care service	Accessed	250 (38.8%)	39 (37.5%)
Bereavement support****	Any	21 (11.7%)	11 (24.6%)
	Professional	4 (2.4%)	3 (8.0%)
Percent who expressed unmet needs***	Any unmet need	109/290	35/66
	percentage	37.6	53.6
	Median	0	1
	Range	0–14	0–14
	Mean	0.82	1.24
	SD	1.37	1.82
Time care provided (months)**N = 62	Mean		40.1
	SD		56.9
	Median		21
	Range		1–300

**Notes:** <sup>#</sup>These are factors that may have changed since the death of someone close to the respondent; \*n = 502 in this cell – this question was not asked in 2000; \*\*n = 182 – questions only asked in 2003–2005; \*\*\*n = 290 – questions only asked in 2002, 2003, and 2005; \*\*\*\*questions only asked in 2004, 2005.

die in the last five years' from a terminal illness. Six hundred and forty four respondents (3.5% of the whole population; 10.2% of all people who experienced death from a terminal illness of someone close to them) reported that the death was due to ESLD (emphysema/other lung disease).

## Caregiver descriptors

In the years 2001–2005, respondents who experienced the death of someone close to them were asked about the extent of their caregiving. A total of 502 respondents in these years had experienced the death of someone from ESLD.



**Figure 2** The flowchart of engaging participants for the South Australian Health Omnibus 2000–2005 to identify caregivers for people who died from chronic obstructive pulmonary disease. Participation rate 77.9% (18,267/23,456). (The denominator for percentages is the total number of households approached (27,100) down to the line of the total number of interviews. Unweighted data).

One in five (104/502; 20.8%) of these respondents provided day-to-day (43/502) or intermittent (61/502) hands-on care for someone who subsequently died from ESLD. Day-to-day and intermittent hands-on caregivers were on average 51.2 years old (range 17–85; SD 16.5) and 40/104 (38.9%) were male. However, caregivers are distributed across the age range with 5/61 people providing intermittent hands on care being under the age of 20 years.

Care was provided for an average of 40.1 months (SD 56.9; median 21; range 1–300) with respondents caring for a spouse (15.9%), parent/child (36.9%), sibling (7.2%), other relative (30.4%), or friend (9.7%: Table 1). The death of the person occurred an average of 27 months before interview (range 0–60 months).

### Perceived unmet needs by caregivers

In 2002, 2003, and 2005, questions were asked about caregivers' perceptions of unmet needs (Table 1). One hundred and nine caregivers (109/290; 37.6%) of someone with ESLD indicated that they had unmet needs. Of those who provided day-to-day or intermittent hands-on care, 35/66 (53.6%) had an average of 1.2 unmet needs (SD 1.8; median 1; range 0–14). Most frequently identified unmet needs included support with physical care (17%), support with symptom control (11%), better information about the future course of the illness (11%), better information about service availability (11%) and better emotional support for the person who died (11%: respondents could identify more than one unmet need).

### Patients' characteristics

The deceased were an average of 73.9 years old (SD 10.4; median 75.5; range 47–92) (Table 2). Two thirds (67.1%) died in hospital and fewer than one in four died in the community (23.2%).

### Comfort at the end of life

In 2004, respondents were asked to reflect on how comfortable the deceased was in the last fortnight of life. Only thirty two of 103 respondents (31.1%) assessed the person dying from end-stage lung disease as 'comfortable' or 'very comfortable' (Table 2).

### Discussion

This study identifies a cohort of people who have cared for someone with lung disease at the end of life, irrespective of health service access. As such, it represents a whole-of-population picture of people who have experienced such

**Table 2** Factors related to the deceased and their deaths

Demographic feature	Factor reported	Respondents who had someone close die of end-stage lung disease
Age of the person who died (years) N = 182 <sup>#</sup>	Mean	73.9
	SD	10.4
	Median	75.5
	Range	47–92
Comfort in the last 2/52 of life* N = 103 <sup>##</sup>	Comfortable or very comfortable	32/103 (31.1%)
Place of death* N = 182 <sup>#</sup>	Community (home, hostel or residential aged care)	44 (23.2%)
	Hospital	122 (67.1%)
	Hospice	14 (7.6%)

**Notes:** \*a small number of respondents in each cell did not reply to this question; <sup>#</sup>Only asked in 2004, 2005; <sup>##</sup>Only asked in 2004.

a death and the sub-group who actually provided care. The cohort identified in this paper also provides key insights into caregiving, the experience of caregivers and the people who died in a way that builds on previous studies that have only accessed participants through hospital records or service attendance.

The age and marital status of caregivers in this study suggest the next generation are the major caregivers, not spouses despite the focus on them in other studies (Bergs 2002; Booth et al 2003; Bailey 2004). The distribution of ages reflects broader caregiving literature that no age is exempt from taking on these tasks, even end-of-life care (Aldridge and Becker 1993, 1999; Levine et al 2005). The range of respondents' ages justifies asking people as young as 15 years of age about their participation in caregiving.

The demographics of society are moving towards more single occupant households raising questions of the availability of caregivers in the future given the large number of family members who provide care. This becomes an important policy question (Aoun et al 2005). Relatively low levels of perceived unmet needs were identified in this study, considering the enormity of the care being undertaken, and the length of time for which that care was provided. It is not immediately clear why the levels of perceived unmet needs were so low but may reflect the long periods of time (mean 40.1 months, median 21 months) for which care was provided allowing people to mobilize formal and informal support networks to support them well.



The overall contribution of ESLD to deaths from a terminal illness in this study is very similar to other large studies with this diagnosis accounting for approximately one in ten deaths (Emanuel et al 1999). The similarity in distribution of causes of such deaths despite differing methods of participant identification (before and after death) adds credibility to these results.

### What are the strengths of the study?

This study employs a method to identify caregivers at a whole-of-population level that allows investigators to by-pass gate-keeping by medical staff (Steinhauser et al 2006), and also access people who have not utilized tertiary services. By this process, the denominator in the current study is as close to representing the whole population as possible.

The findings from caregivers about their roles and perceptions of the care they offered and the benefits it delivered to people dying from ESLD is pivotal to the development of social policy. The breadth of sampling across groups often under-identified in health service utilization (lower socioeconomic status, people from culturally and linguistically diverse populations) is a particular strength of this methodology.

### Limitations: methods

Most responses in this study refer to the respondent directly. In one question, caregivers are asked to report on the comfort of the deceased in the last two weeks of life. However, proxy reports have been previously used in similar settings, especially given the difficulty of any assessment in the terminal phases of care (Addington-Hall and McCarthy 1995; Addington-Hall and McPherson 2001; Tang and McCorkle 2002; Ahmedzai et al 1988; Christianson 1992; Klinkenberg et al 2003; Kutner et al 2006). Retrospective reports by proxies after death compared to actual reports by patients *ante mortem* have confirmed that this is a reasonable approach for key symptoms (Ahmedzai et al 1988; Cartwright and Seale 1990; Higginson et al 1994; Hinton 1996; Klinkenberg et al 2003; Kutner et al 2006) with high correlation to patients' overall scores (Kristjanson et al 1998; Lobchuk et al 1997).

Whilst proxy reports provide useful information, assessment of comfort conducted by relatives is based on behaviors including activity levels, analgesic use and facial expressions (Singer et al 1999; McPherson and Addington-Hall 2004). Family caregivers have greater accuracy identifying more observable symptoms such as breathlessness and vomiting than more subjective symptoms such as

pain and psychological distress (Tang and McCorkle 2002; McPherson and Addington-Hall 2003; McPherson et al 2008). Families may rate symptoms as being more troublesome than patients (Lobchuk and Degner 2002; Redinbaugh et al 2002; McMillan and Moody 2003) and under-recognize emotional distress (Field et al 1995; Lobchuk and Degner 2002; Milne et al 2006).

Despite these concerns, hands-on caregivers have been found to have higher levels of agreement with patients' perceptions of comfort (McPherson and Addington-Hall 2003). However, such observations can be clouded by caregiver stress and the caregivers' skills (Miaskowski et al 1997; Redinbaugh et al 2002; McPherson and Addington-Hall 2003), mood disturbance (McPherson et al 2008) and perceived burden in the role (Miaskowski et al 1997; Kristjanson et al 1998; McPherson et al 2008). Patients may also under-report symptoms to avoid distressing caregivers (McPherson and Addington-Hall 2003; McPherson et al 2007). Proxies are therefore an invaluable and reliable source of information with family members' own perceptions themselves being important and valid endpoints to which health services need to respond (Lynn et al 1997).

The timing of the interview about the care of the deceased may be problematic. This study covers a large population over five years to minimize variations in perceptions at the time close to the death deliberately. Any recall bias or response shift over time should be equally distributed across the population given its size. Overall, a mean of 27 months suggests a relatively stable pattern of reporting in relation to the death of the care recipient. The stability of data from year to year also gives confidence in the data reported.

The study stratifies respondents using one aspect of caregiver performance: the time committed to caregiving. Such a process does not encompass other caregiving roles, nor other commitments that caregivers encounter if not only in a caregiving role.

As a survey focusing on past events, recall of key information is crucial to the validity of the results presented. The role of caregiving is one where issues are going to be potentially life-changing and people's subsequent account of the role may reflect such changes.

The diagnosis of the cause of death was necessarily broad and as a result is characterised as 'end-stage lung disease'. The flash card had 'emphysema/lung disease' as this reflects terms commonly used in the community by people other than health professionals. It is likely that respondents

close to the deceased will be aware of a diagnosis leading to death if it were related to chronic pulmonary disease. Further sub-dividing the diagnosis would lead to a level of uncertainty that would be difficult to defend.

### Limitations: sample

People who live in remote settings, those without caregivers, and people from some cultural backgrounds may not be reflected in these data. People who live alone, or whose caregiver subsequently died (Christakis and Iwashyna 2003) will need to be studied by other methodologies.

Key demographic features may change as the result of someone in the household dying: income, place of residence and work status during the caregiving role or after the death of the care recipient.

Income was the question with the most missing data and therefore needs to be treated cautiously.

It is likely that certain small communities whose first language was not English were under-represented in the raw data, and this is an ongoing concern not dealt with entirely by using population-standardized weightings for all analyses. Overall, this is still one of the most effective ways to generate a representative sample across the whole population including people from minority groups.

Despite the period of interest being the last five years the distribution is skewed towards more recent deaths when one would expect that deaths should be distributed evenly across the five-year period. There may be recall error given that life-changing or highly emotional life events may feel more recent than is the case (Christianson 1992; Addington-Hall and McPherson 2001). The time since death may also influence the perceptions of the death and issues such as comfort in the last two weeks of life (McPherson and Addington-Hall 2004).

### Generalizability

Population studies need to be extrapolated with caution to other populations or health and social settings. Given that this study has approached a sizeable population over six years in metropolitan, regional and rural South Australia, it is likely that the findings can be generalised to populations across much of the developed world. The major limit to generalizability is in populations with higher levels of adult smoking or differing occupational exposures that are the most common predispositions to lung disease over the

past 40 years, and will only now be reflected in mortality statistics.

### What are the implications for future research?

Ideally such data could be confirmed with prospective collection in a cohort of people identified as having advancing ESLD. Linking the diagnoses with other co-morbidities would add to the understanding of the total burden of disease experienced by the care recipients. This study has captured perceived needs when subsequently reflecting on those needs. Ideally perceived needs need to be measured while caregivers are actually providing care and again subsequently.

Ultimately interventions that support caregivers better need to be tested in randomized studies compared to current models of care. Such a study should aim to demonstrate improved perceived support while in the role and better health outcomes after having relinquished the role (Christakis and Iwashyna 2003; Aoun et al 2005; Christakis and Allison 2006; Abernethy et al 2008).

Given that caregiving roles differ in societies across the world, studies using population-based methodologies should be repeated in different cultures, health and social systems. Results from other methodologies for identifying this cohort of caregivers would allow triangulation of results with this current study.

### Implications for practice or policy

A significant cohort of people who have provided care for a person at the end of life with ESLD and has been identified through this study. Unmet needs are identified, and the length of time for which care is provided raises concerns about the physical and emotional well being of caregivers, considering the demands that are made on them. Ways of better supporting caregivers is a direct challenge for health and social services, especially given the likely symptom burden that people have with ESLD.

### Conclusions

Ultimately, this study shows that a significant proportion of the population have been affected by the death of someone with ESLD (predominantly COPD) in the recent past, and that many of these people provided care. Meeting unmet needs is an opportunity to improve support for caregivers of people dying from ESLD. How to identify and meet such needs is



a specific task of health care providers given the health and social consequences of caregiving.

## Disclosure

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