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Terminally-ill people living alone without a caregiver: an Australian national scoping study of palliative care needs

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Home-based palliative care services are facing increasing challenges in servicing the needs of clients who live alone and without a primary caregiver. The findings from the analysis of 721 services' records from three Australian states, and feedback from health professionals in interviews and postal surveys, demonstrated that there were aspects of being on one's own with a terminal illness and living at home that require a specialised approach and support. This study explored the issues of palliative care patients living alone, from a service provider perspective, and provided evidence-based information to assist with service planning. The study made recommendations to the Australian Department of Health and Ageing about services considered important in developing support structures for this growing population. *Palliative Medicine* 2007; **21**: 29–34

Key words: caregiver; community services; living alone; palliative care; place of death

Introduction

An increasing number of people with a progressive terminal illness and who require care, live alone and have no primary caregiver.^{1,2} This group of clients is increasing because a greater proportion of the population is older, prefer to be cared for and die at home, and yet may not have family caregivers available to provide support.^{1,3} According to the study by the National Centre for Social and Economic Modelling in Australia,¹ there will be a four-fold increase between the years 2001 and 2031 in the group projected to be cared for in the community who are likely to be without a caregiver. Also, the ratio of primary caregivers to older persons needing informal care is estimated to drop from 57/100 to 35/100 in the next 30 years.

To date, most studies have examined place of death as an outcome, with the status of caregiver arrangements only considered as a peripheral finding.^{3–13} In these studies, individuals living alone are mentioned as a subgroup of the total study sample, and the absence of a caregiver is cited as one of the factors associated with decreased likelihood of a home death. No studies have examined the service needs of this subgroup. The palliative care literature suggests that living alone or not having access to a primary caregiver is a significant

predictor for admission to an in-patient facility for symptom control or terminal care, and is one of the factors associated with the increased likelihood of hospital admission.^{3,7,14–18}

This study was commissioned by the Australian Government Department of Health and Ageing, Palliative Care Section. This paper reports on the characteristics and service provision of clients without a caregiver from three different community-based services in three Australian states. Differences between clients without a caregiver and those who have a caregiver are highlighted. Directions for the development of support structures are provided based on input from service providers.

Methodology

The settings for this study included three home-based palliative care services in three Australian states: Western Australia (WA), South Australia (SA), and Queensland (QLD). These are predominantly statewide nursing services, with a total catchment population of more than five million people. Ethical approval was obtained from the Ethics Research Committees of the three home-based services, as well as the three universities of the chief investigators, Edith Cowan University, Flinders University and Queensland University of Technology.

The project methodology consisted of:

- A retrospective analysis of all services records of patients without a caregiver during a 15-month period

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in the three participating services. This was undertaken to obtain demographic information, clinical and service use profiles within the Australian palliative home care context. The extraction of data from services records was undertaken by a staff member from the services involved.

- In-depth qualitative telephone interviews with key health professionals in palliative care services in WA, SA and QLD ($n=9$). This was undertaken to investigate the needs, care services and care issues from a provider perspective.
- A postal survey to a sample of health professionals in the three states to elicit a broader, more representative assessment of key issues related to the provision of palliative care for people living at home alone without a caregiver ($n=90$).

Names of health professionals for the interviews and the postal survey were put forward by the project reference group, which had representation from the three participating services.

Results

Profile of clients without a caregiver in three services

A total of 721 client records from the three participating home-based palliative care services were identified for a period of 15 months and analysed (Table 1). Clients living alone with no caregiver and who were receiving palliative care services comprised 7–12% of total clients receiving palliative care services in the three participating services. The analysis of services' records of clients living

Table 1 Profile of clients without a caregiver in three Australian community-based services

Characteristics of clients	Percentage range
Total clients receiving palliative care	7.3–11.8
Male	38.9–45.8
Never married/divorced/separated/widowed	81.8–88.3
Non-English speaking background	6.4–18.6
Mean age at death (years)	72.3–74.4
Service utilisation	
Home death	10.2–35.1
Hospital death	21.2–67.1
Hospitalised during service	19.4–72.6
Median LOS in service (days)	69.5–246.0
Median visits per client	22.0–41.5
Median hours of service/client	12.0–42.5
Support services provided	
Hygiene assistance	19.9–56.4
Equipment	10.8–34.3
Home help or domiciliary care	29.2–45.2
Medication review	3.2–60.2
Counselling	2.1–59.2
Liaison with health professionals	5.3–67.5
Education	29.7–69.1

alone with no caregiver and receiving palliative care services revealed similarities in the profile in terms of gender, marital status and age at death, and differences in terms of the extent of service utilisation and support services provided (Table 1). A percentage range is provided rather than an average due to the diverse differences in the context and practices of the three services. The three most frequent categories of diagnosis were gastro-intestinal cancer (mainly colorectal), respiratory cancer (mainly lung), and genitourinary cancer (mainly prostate).

Profile of clients without a caregiver compared to those with a caregiver

The two groups were similar in gender distribution and mean age at death (Table 2). There were significant differences between the two groups with respect to the place of death. Compared to clients with a caregiver, fewer clients with no caregiver died at home (35 versus 57%, $P=0.0001$) and more died in a hospice (40 versus 20%, $P=0.00001$, twice as many) or a tertiary hospital (11 versus 4%, $P=0.0116$, 2.5 times as many) (Figure 1).

Service utilisation. Compared to clients with a caregiver, clients with no caregiver tended to stay in the service longer (median 70 versus 50 days, $P=0.079$). However, the group with caregiver seemed to have required twice as many visits (median 49 versus 25 days, $P=0.0001$). A higher proportion of clients with no caregiver were admitted to hospital (71 versus 57%, $P=0.0036$) with a slightly longer stay, but not significantly longer.

Support services. Clients with no caregiver needed considerably more assistance with hygiene (24 versus 4%, $P=0.00001$), more home help (27 versus 19%, $P=0.0086$), and more liaison with other health professionals (27 versus 19%, $P=0.0425$). However, clients with a caregiver required more equipment (63 versus 38%, $P=0.00001$), more oxygen (15 versus 5%, $P=0.0007$), and counselling (7 versus 2%, $P=0.0069$).

Feedback from service providers

Telephone interviews were conducted with nine health professionals, three from each participating service. Four main themes emerged from these interviews: care challenges, differences in care provision, appropriate approaches to care, and essentials for an effective service. These themes informed the wider survey that was sent to 90 health professionals in the three states. Participants in the survey were asked to estimate the time they spent in providing nursing care and other support (a list of nine support tasks, such as emotional, financial, social, transportation, medications, housekeeping, mobility, daily living and symptom control) to clients without a

Table 2 Comparison of profile of home alone clients with no caregiver and those with caregiver referred to palliative care in Service A

Demographic	Clients with no caregiver (<i>n</i> = 180)		Clients with caregiver (<i>n</i> = 156)	
	No.	%	No.	%
Gender	<i>n</i> = 180		<i>n</i> = 156	
Male	85	47.2	74	47.4
Female	95	52.8	82	52.6
Country of birth				
Australia	98	55.4	82	52.9
Non-English speaking background	31	16.6	31	19.9
English speaking	51	28.0	43	27.6
Age at death				
Mean	74.7		73.9	
SD	10.9		13.5	
Place of death	<i>n</i> = 142		<i>n</i> = 139	
Home	50	35.2	79	56.8
Hospice	57	40.1	28	20.1
Tertiary hospital	15	10.6	5	3.6
Other hospital	17	12.0	22	15.8
Other location (nursing home)	1	0.7	5	3.6
Unknown	2	1.4	–	–
Service utilisation	Median	Range	Median	Range
Median LOS (days)	69.5	1–897	49.5	1–532
Median visits per client	24.5	1–346	49	1–535
Median hours of service/client	13.5	1–214	16.5	1–296
No. and percent hospitalised	<i>n</i> = 128	% = 71.1	<i>n</i> = 89	% = 57.1
Median No. of hospitalisations	1	1–8	1	1–7
Median hospitalisation days	18	1–178	15	2–123
Hygiene assistance	43	23.9	6	3.8
Provide volunteer support	25	13.9	–	Not available
Provide equipment	68	37.8	98	62.8
Review medication	101	56.1	–	Not available
Counselling	3	1.67	11	7.1
Education (medication, mobility, nutrition, symptom management)	63	35.0	–	Not available
Provide hospice doctor	94	52.2	–	Not available
Provide chaplain	3	1.7	–	Not available
Liaise with other health professionals	49	27.2	–	Not available
Referral to aboriginal home worker	0	0.0	–	Not available
Home help	55	27.2	30	19.2
Oxygen provision	9	5.0	24	15.4
Other services (respite, alarm link, Centrelink, Physio)	6	12.8	4	2.5
Unknown	23	16.1	49	31.4
Type of diagnosis	<i>n</i> = 160		<i>n</i> = 156	
Gastro-intestinal cancer	54	33.8	42	26.9
Respiratory cancer	44	27.5	40	25.6
Genitourinary cancer	24	15.0	21	13.4
Skin cancer	8	5.0	10	6.4
Haematological cancer	8	5.0	2	1.4
Breast cancer	7	4.4	10	6.4
Other cancer	10	6.2	19	12.2
Non-cancer diagnosis	5	3.1	12	7.7

Multiple responses, therefore, percentages do not add up to 100.

The difference between the grand total of records and the totals for individual variables is due to missing data. The records obtained for clients with caregivers were on an Excel spreadsheet and, therefore, less data was available compared to data collected on audit forms for clients with no caregivers, where extra information was sourced from clients' hard files.

caregiver compared to those with a caregiver. They were then asked to prioritise, from a list of 13 items, elements of support that would improve the quality of care for their clients.

The response rate of health professionals to the postal survey was 52%. The median years of work experience was 8.8 years (range: 1–50). The majority of respondents

worked in community-based services (78%), 9% worked in hospital-based services, and 13% in both settings. More than 60% of health professionals who responded to the postal survey reported spending at least 15–30 minutes of additional time per visit providing the following support for clients without a caregiver: symptom control, medications, mobility, transport and social

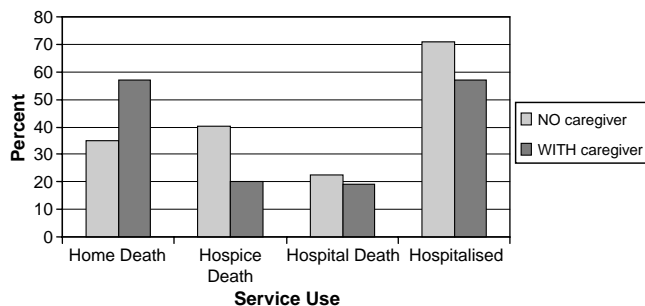


Figure 1 Service Use of clients with NO caregiver and WITH caregiver (Service A)

support. Also, at least a quarter of respondents reported spending 1 hour or more of additional time per visit on activities of daily living (43%), symptom control, housekeeping and emotional support (25%) (Figure 2). On a scale of 1 (very dissatisfied) to 10 (very satisfied), the overall satisfaction median for the level of care they were able to provide for this group of clients was 5.0. Reasons put forward for this average satisfaction ranking were mainly due to limited resources and funding, such as levels of staffing, lack of availability of a social worker, lack of housekeeping support, lack of volunteers, and concerns over safety of clients.

The services considered to be of highest priority by the majority of service providers that responded to the postal survey were:

- Provision of a 24-hour palliative care service, which includes:
 - Provision of a night sitting service
 - Provision of an after-hours support service
 - Pool of volunteers and paid caregivers
- Funded palliative care packages (similar to aged care packages¹);
- Financial support packages for in-house respite (availability of short term, intermittent home care assistance to avoid the need for hospital admission);
- Funded alert link systems (or emergency call systems).

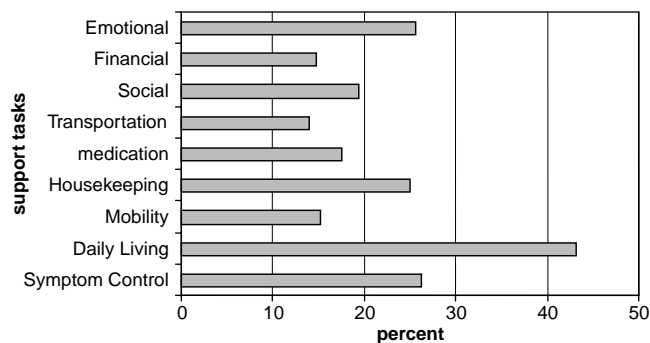


Figure 2 % Survey respondents providing care to clients with NO Caregiver (one hour or more/visit additional to time provided to clients with caregiver)

Discussion

Differences in the type and extent of support between the three services were related to the different structure of the three organisations. Service A has a multidisciplinary team of health professionals, including hospice general practitioners, while the other two services are nursing, but have the backup of specialist interdisciplinary palliative care teams in the community. While home help is provided by Service A, this service is provided in the other two organisations under a separate agency called Domiciliary Care. Service A covers the whole of the metropolitan area in WA and no other community-based or other outreach palliative care services are involved with clients. In contrast, palliative care services in different geographical locations of the city were involved in Service B clients. These services are attached to the main tertiary hospitals in the city, but also provide outreach services to the community.

The analysis of services' records confirmed previous reports:^{4,7,12,16,17} that people living alone without a caregiver with a terminal illness have more hospital admissions and are less likely to die at home than those who have a caregiver. However, the group with a caregiver appears to have required twice as many visits and slightly more hours of service from Service A than the group with no caregiver. It could be that caregivers more actively requested support, resulting in more visits to the group with caregivers. Also, there would be an anticipated increase in visits and hours to care for someone who dies at home, as would be the case for those with a caregiver. However, the national survey reported that service providers are spending additional time per visit providing support tasks to those with no caregivers, mainly in daily living, symptom control, housekeeping and emotional support.

In terms of support services provided (from services' records), clients with no caregiver needed considerably more assistance with hygiene, more home help, and management of their care required more liaisons with other health professionals. Clients with a caregiver required more equipment, more oxygen and more counselling. More people with caregivers tended to be at home towards the end stage of their illness, possibly necessitating greater needs for oxygen for the client, and more equipment to help caregivers provide support for lifting and other daily living tasks. Most of the equipment is usually provided for safety reasons to assist the paid and unpaid caregivers; therefore, individuals without a

¹ Aged care packages are individually planned and coordinated packages of care tailored to help older Australians remain living in their own homes. The types of services that may be provided as part of a package include: personal care, social support, transport to appointments, home help, meal preparation and gardening.

caregiver would not require the same equipment. More counselling was given to the caregiver group possibly because two people require counselling, the client and the caregiver. Services need to anticipate these differences and the requirements for support that may be needed.

It is worth acknowledging the significant support that community-based organisations are also providing to caregivers. The increased number of support visits and oxygen provision (for example) are about supporting anxious caregivers as much as the clients. Palliative care clearly targets the patient and the caregiver as the unit of care and, therefore, services have two clients in such circumstances. By consequence, the length of visits provided is related to direct support for caregivers in their role. Likewise, the use of equipment especially oxygen, may be driven by caregivers saying 'I want to be able to do something if my care recipient gets breathless'. Addington-Hall and Altmann,¹⁹ reported that those living alone were less likely to receive community specialist palliative care compared to clients who had a caregiver, thus suggesting that if you have a caregiver, you are more likely to reach out for services.

The groups of clients included in the analysis of records are those referred to services in the first place and, thus, there is no information on those who declined services or who were never referred. In addition, client groups in this study are not representative of people who have non-cancer as their life-limiting illness.

Although the report highlights that people need access to support around the clock, a 24-hour palliative care service does not necessarily mean only a clinical service. A distinction needs to be made between the provision of specialist palliative care and simply the availability of a caregiver/care assistant in the house as a patient's condition deteriorates.

The proportion of home deaths in the three services is comparable to the state levels reported in the Palliative Care Australia National Census:²⁰ 52% in Queensland, 17.2% in South Australia, and 45.1% Western Australia. It is assumed that home death is the 'gold standard'; however, rather than dying at home being such a predominant theme, it could be characterised as place of predominant care being at home.¹⁷ This is an important distinction for planning services.

Conclusion

This study explored the issues of palliative care patients living alone, from a service provider perspective, and provided evidence-based information to assist with service planning for this growing population. The findings from the analysis of services' records and the comments of health professionals demonstrate that there are aspects of being on one's own with a terminal illness

and living at home that require a specialised approach and support. Adequate services to this particular group will lead to more care being able to be delivered at home, a better quality of life, a capacity to die at home and a reduction in hospitalisations. The study made recommendations to the Australian Department of Health and Ageing about services considered important in developing support structures for this growing population. These recommendations included: the provision of a 24-hour palliative care service (a night sitting service, an after hours support service, and a pool of volunteers and paid caregivers), funded palliative care packages, support packages for in-house respite, and funded alert link systems.

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