

few days of life and pain control. There is still evidence of reluctance among some in the medical profession to request palliative care for patients, regarding death as a medical failure. But palliative care is more than the last few days of life and can last for weeks, months, even a year or more. Palliative care is more than pain control, more than only cancer – palliative care is a whole of community affair.

Again, a by-product of awareness-raising is an increased ability to conduct advocacy through generating an increased number of people who understand the issues and through providing a mechanism for them to participate and make a difference.

Conclusion

This paper has described the advocacy challenges ahead for the palliative care sector. Success will rely on measured management of skills and investments, timing to correspond with funding cycles, evidence to support arguments and maintain credibility, and an ability to harness the support of others to take the argument forward to decision-makers.

SPECIALIST PALLIATIVE CARE USE FOR PEOPLE DYING OF CANCER IN WESTERN AUSTRALIA

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Abstract

The Western Australian Data Linkage System was used to study patterns of specialist palliative care delivery during the last 12 months of life, comparing use between different socio-demographic groups and causes of death. In the two and half year study period, 8007 people had either cancer alone, or cancer and another condition considered amenable to palliative care recorded in part one of the death certificate. Of this group, 56.3% received some form of specialist palliative care. Particular groups of people were disadvantaged in relation to access to specialist palliative care, with those single or widowed, aged over 85 years, or those living in a region other than a major city significantly less likely to receive specialist palliative care services. The vast majority of people in the last year of life had at least one hospital admission. Those receiving specialist palliative care community-based services were more likely to die in their own homes. The population-based data in this study provides a unique picture of palliative care provision in WA, suggests areas of need and helps to lay the groundwork for future research.

Population-based research in palliative care

Population-based research in Australian palliative care is still in its infancy, though the national body, Palliative Care Australia, has proposed using this approach to guide future service provision.¹ Much can be learned from tracing the provision of palliative care services and documenting exactly who does and does not receive these important end-of-life supportive services. However, this kind of epidemiological research is complex and reliant on methods which can be time-

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consuming and frustrating, as access to reliable records is not always feasible. Our Western Australian study was able to deal with these methodological problems by using the unique Data Linkage System available in WA, which spans 20 years and contains core datasets including cancer registrations, inpatient hospital morbidity data and death records. The linking of a large number of administrative health records enables patterns of healthcare service use to be investigated in relation to a variety of socio-demographic variables. For

the purposes of our study we also linked residential and community specialist palliative care services (SPCS) to the other relevant core datasets, enabling us to describe all SPCS use across the whole WA population.^{2,3}

The population was identified from the Australian Bureau of Statistics Mortality Register as all people who died in the period 1 July 2000 to 31 December 2002 in WA and whose underlying cause of death, as recorded on part one of the death certificate, was from either cancer or selected non-cancer conditions considered amenable to palliative care (heart failure, renal failure, chronic obstructive pulmonary disease, Alzheimer's disease, liver failure, Parkinson's disease, Motor Neurone Disease, HIV/AIDS and Huntington's disease).⁴ The outcome variables in the study were cause of death, place of death, use of SPCS in the last 12 months of life and demographic information (age, gender, marital status, Aboriginality, geographical remoteness and socio-economic disadvantage). The following discussion focuses upon those who died of cancer (ICD 10 codes C00 – D 48), as recorded on part one of the death certificate, as this group constitutes the vast majority of people who have symptoms and needs warranting SPCS.

Specialised palliative care services in WA

Specialist palliative care services in WA, like other states and territories, provide a coordinated, integrated and patient-focused model of care, including respite and other supportive services to carers.⁵ In WA these services are provided by tertiary and non-tertiary public hospitals, hospices and community-based agencies. Silver Chain provides the vast majority of specialist palliative care community service in WA.

Specialist palliative care use

In the study period, 8007 people had cancer as one of the conditions listed on part one of the death certificate (29.8% of all deaths). Of this group 7399 people had cancer only and 608 had cancer as well as at least one other condition considered amenable to palliative care. Table 1 shows the kinds of service use for these two groups. Although palliative care is now a well recognised and important subspecialty, many of those who died did not access SPCS. This was particularly so for those who had cancer and one or more co-morbidities considered amenable to palliative care. The study also found that once a patient was referred to specialist palliative care they were more likely to receive other SPCS. In other words once they were in the

system they were well serviced, indicating that referral is crucial to specialised service provision. Of course not all people dying of cancer require or request specialist palliative care. Nevertheless service use is one way of assessing potential unmet need.

Who receives specialist palliative care and who misses out?

Our study used logistic regression to estimate the likelihood of receiving specialist palliative care in the last 12 months of life. Table 2 indicates those who may be disadvantaged by missing out on SPCS and not surprisingly tends to mirror the broader disadvantages in Australian healthcare. Those who died of cancer were significantly less likely to receive SPCS if they were single or widowed, aged over 85 years, or lived in a region other than a major city.

Being married increased the likelihood of accessing SPCS, both in hospital and in the community. Married people with cancer used more community-based services, indicating that the ability to be cared for in their usual place of residence may ease the cost of hospital services.

Those aged over 85 years dying of cancer were less likely to receive SPCS. Compared with those aged 75-84 years, this group was proportionally less likely to have accessed SPCS in both hospital and community settings. It could be argued that this group was more likely to reside in aged care facilities and that a generalist level of palliative care was provided for in this setting. However, this assumption should not mask the broader question the findings suggest: are older people with cancer adequately serviced by palliative care providers?

It is well known that Australians residing in rural and remote areas are less well serviced in relation to healthcare. Our study provides evidence to show that this is particularly so for SPCS provision.

Although numbers were small, when compared with non-Indigenous people, Indigenous Australians were more likely to have used SPC, despite 80% of this group living in rural and remote areas. However, these figures need to be understood in relation to place of death, with only 26 of the 98 dying in their usual place of residence. Of the 72 who died in a place other than their usual residence, 63 died in hospital. As it is culturally very important for Indigenous people to die in their 'own country', the place of SPC delivery is of prime importance.⁶

Table 1. Use of Specialist Palliative Care Services (SPCS) in WA

	Community-based SPCS only	Hospital-based SPCS only	Both community-based SPCS and hospital-based SPCS	No SPCS
Cancer only	23.9%	18.7%	25.1%	32.3%
Cancer + non cancer	20.2%	13.2%	14.8%	51.8%

Table 2. Likelihood of receiving SPCS in the year preceding death for those who died of cancer

Variable	N	% who received SPCS	Crude estimates		Adjusted estimates	
			OR	95%CI	OR	95% CI
Gender						
Male	4191	68	1.00		1.00	
Female	3208	67	0.98	.89 – 1.08	1.07	.96 - 1.19
Marital status						
Married	4171	72	1.00		1.00	
Divorced	691	71	1.05	.88 – 1.26	1.08	.89 - 1.30
Single	345	62	.67**	.54 - .85	.66*	.52 - .84
Widowed	1837	60	.62***	.56 - .70	.79**	.69 - .91
Unknown	355	64	.71**	.57 - .90	.77*	.60 - .99
Age (years)						
0 - 14	30	63	1.67	.78 – 3.53	2.17	.99 – 4.75
15 - 24	27	67	1.93	.86 – 4.33	2.45 *	1.06 – 5.68
25 - 34	75	73	2.65***	1.57 – 4.89	3.06***	1.73 – 5.41
35 - 44	191	73	2.58***	1.83 – 3.62	2.42***	1.69 – 3.46
45 - 54	620	74	2.73***	2.20 – 3.38	2.50***	1.97 – 3.17
55 - 64	1172	74	2.74***	2.29 – 3.28	2.59***	2.12 – 3.16
65 - 74	1974	70	2.22***	1.91 – 2.60	2.14***	1.80 – 2.54
75 - 84	2262	68	2.08***	1.79 – 2.42	1.98 ***	1.69 – 2.32
85+	1047	51	1.00		1.00	
Indigenous status						
No	7007	68	1.00		1.00	
Yes	98	65	.89	.59 – 1.36	1.54	.96 – 2.49
Socio-economic indices for areas (SEIFA), based on 2001 Census						
Most disadvantaged	1391	66	.78**	.66 - .91	.89	.75 – 1.06
More disadvantaged	1449	67	.79**	.67 - .92	.93	.79 – 1.11
Average	1477	66	.77**	.66 - .91	.90	.76 – 1.07
Less disadvantaged	1560	69	.87	.74- 1.01	.93	.79 – 1.10
Least disadvantaged	1457	72	1.00		1.00	
Accessibility remoteness index of Australia (ARIA+)						
Major city	5333	71	1.00		1.00	
Inner regional	1021	64	.73***	.63 0 .84	.72***	.62 - .84
Outer regional	709	58	.57***	.48 - .67	.57***	.48 - .67
Remote	182	47	.37***	.27 - .49	.34***	.25 - .46
Very remote	91	54	.48***	.31 - .72	.39***	.25 - .61
Migratory or missing	63	35	.22***	.13 - .37	.28	.02 – 5.01

Dependent variable = SPCS from any source (home-based or hospital-based)

* 0.05 > p ≥ 0.01 ** 0.01 > p ≥ 0.001 *** p < 0.001

Hospital admissions in the last 12 months of life

In the last 12 months of life 96.5% of people who died of cancer, or cancer and another condition considered amenable to palliative care, had at least one hospital admission. Of the 3.5% of people dying of cancer who were not admitted to hospital in the last 12 months of life, the vast majority died in their usual place of residence, be it a residential aged care facility (35.0%) or some other location (58.8%). Table 3 summarises hospital admissions in the last year of life for those

people who were: (1) hospital admission only; (2) specialised palliative care admission only; and (3) both specialised palliative care and hospital admission. Those admitted for both SPC and hospital admissions had a lower mean number of hospital admissions (6.3) than those who had hospital admissions only (6.9). More importantly those admitted for both had a lower mean length of hospital stay (29.0 days versus 33.5 days). In Table 3, the large standard deviations in comparison to the means are a reflection of the skewed distribution of the data.

Table 3. Hospital admissions in the last year of life

	Condition listed on part one of the death certificate			
	Cancer N=7399		Cancer + non cancer N=8007	
Hospital admissions in the last year of life (excluding specialised palliative care admissions)				
Number of persons	n = 3897	52.7%	n = 4316	53.9%
Mean number of hospital admissions	6.9	SD=9.4	7.0	SD=9.8
Mean length of hospital stay in the last year of life (days)	33.5	SD=33.3	34.0	SD=34.2
Range of the length of hospital stays in the last year of life (days)	1 – 359		1 – 361	
Specialised palliative care hospital admissions in the last year of life				
Number of persons	198	2.7%	208	2.6%
Mean number of SPCS hospital admissions	1.7	SD=1.8	1.7	SD=1.8
Mean length of SPCS hospital stay in the last year of life (days)	20.6	SD=25.4	20.2	SD=24.9
Range of the length of SPCS hospital stays in the last year of life (days)	1 – 12		1 – 131	
Admission for both hospital and hospital specialised palliative care in the last year of life				
Number of persons	3046	41.2%	3206	40.0%
Mean number of hospital admissions	6.3	SD=6.9	6.4	SD=7.1
Mean length of hospital stay in the last year of life (days)	29.0	SD=25.1	29.2	SD=25.6
Range of the length of hospital stays in the last year of life (days)	1-182		1 – 262	
Mean number of SPCS hospital admissions	1.6	SD=2.0	1.6	SD=2.0
Mean length of SPCS hospital stay in the last year of life (days)	18.1	SD=20.8	17.9	SD=20.6
Range of the length of SPCS hospital stays in the last year of life (days)	1 – 180		1 – 180	

Place of death

Very little is known about where people die despite growing evidence to indicate that many people prefer to die in their usual place of residence.⁷ As the goal of palliative care is to allow patients to die comfortably and, if possible, in a place of their choosing, data about actual place of death is of interest to palliative care practitioners. Our study shows that of those who died of cancer either with or without another condition considered amenable to palliative care: 29.6% died in their usual place of residence; 17.1% died in a hospice; 48.6% died in a hospital; 1.7% died in a residential aged care facility; and 3.0% died in some other place. Multiple logistic regression was used to examine the effects of receiving specialist palliative care on place of death. When considering the effect of receiving SPCS, after adjusting for other factors, there is a seven times higher chance (95% CI 6.1-7.9) of dying in the usual place of residence if the patient received community-based specialist palliative care only, when compared to no specialist palliative care from any source. Receiving SPCS in the home, in particular, potentially allows people to die in a place of their own choosing.

Conclusion

Our study has provided unique information on the healthcare use of WA people in the last year of their lives. While reliant on administrative databases, the data provides a good baseline to determine obvious inequities and areas of need. It is heartening to find that palliative care services are now acknowledged and their influence noticeable, but it is also concerning to find that over 40% of people who died of either cancer or cancer and another condition considered amenable to palliative care did not receive specialist palliative care services. Our study has not investigated non-specialist palliative care service and many people may be receiving a variety of supportive services from general practitioners, other specialists and community organisations. Nevertheless, the holistic, multidisciplinary and family focused care provided by SPCS is a service that should be offered to families as they negotiate the difficult last months of life.

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RURAL PALLIATIVE CARE: EXPLORATION OF THE PIVOTAL ROLE OF PRIMARY HEALTHCARE PROVIDERS

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Abstract

Primary healthcare providers are critical to the delivery of healthcare in Australia. For rural Australians these health professionals play a pivotal role in all aspects of health, from prevention, early diagnosis and treatment through to care at the end of life. The delivery of optimal palliative care for rural Australians is dependant upon a viable, well educated primary healthcare workforce. Recent initiatives by the Commonwealth Department of Health and Ageing, Royal College of General Practitioners and state health departments have made significant inroads into supporting rural palliative care delivery. There is a need for these programs to be extended to other rural healthcare providers.

The Commonwealth Department of Health and Ageing National Palliative Care Strategy identifies three core goals: increase awareness and understanding of palliative care; improve the quality and effectiveness of palliative care delivery; and support and promote partnerships to support delivery of palliative care.¹ To achieve these goals for all Australians requires a knowledge and recognition of the needs of the diversity of the Australian population. This paper focuses on the palliative care needs of rural Australians and recent initiatives undertaken to implement sustainable quality access to palliative care. Not included in this paper are the specific needs and issues associated with provision of palliative care to Indigenous Australians.

Background

In Australia, approximately one third of Australians live in rural areas² and another half a million reside in remote regions of the country. The overall incidence of cancer is similar in metropolitan and rural populations, however, mortality is higher for those individuals who live in rural regions, particularly so for men with prostate cancer and women with cervical or lung cancer. There is recognition that access to healthcare for individuals living in rural and remote areas of Australia has been problematic.^{3,5} Increased costs associated with healthcare delivery, decreasing numbers of rural healthcare providers and a growing trend toward centralisation of services impacted negatively on access to healthcare services

for Australians living in rural and remote areas. Yet, with this decrease of healthcare services the needs for healthcare in rural and remote communities remain high, particularly in the area of palliative care. The need to develop alternative models for providing effective delivery of an appropriate mix and level of health services to rural communities, which differ in size and types, has been acknowledged by government and health authorities.⁶ This article will outline the steps being taken to address these gaps and support the ongoing delivery of palliative care by primary healthcare providers in rural, regional and remote Australia.

Previous work carried out by the author identified a range of unmet needs for palliative care patients and their families in rural and remote areas, including access to palliative care services, information about illness, practical care and support.^{4,7} Rural families have identified problems in accessing practical care, in particular, after hours care, where families reported difficulties associated with the provision of care to an ill family member, especially at night.^{4,7} Difficulties included symptom management, assessment of the patient's condition and uncertainties about how to comfort and solve practical care giving problems. Reduced healthcare provider input and limited choices for home care were identified and families also had limited knowledge of the existing local services. Economic and physical barriers such as distance, lack of transport and the need to travel, as well as reduced