
Health Promotion Evaluation Unit

Palliative Care Report



The University of Western Australia

School of Population Health

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Executive Summary

Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹

In 2007 the University of Western Australia's Survey Research Centre performed a telephone audit on behalf of the WA Cancer & Palliative Care Network to ascertain the current palliative care service provision in rural and remote locations. The aims of the survey were:

- To obtain information to guide the implementation of the recommendations of the "Palliative Care in Western Australia. Final Report December 2005".
- To then develop strategies that better support the provision of palliative care in rural and remote Western Australia.

Provision of services and patient care/outcome

- Sixty four percent of organisations contacted indicated that they provided community palliative care services, 58% long term care, 57% in-patient palliative care and 50% hospital services.
- Most organisations cared for between one and five palliative care patients in the past 12 months.
- Twenty three percent of patients did not have a cancer diagnosis, whereas 44% of organisations had between one and five patients who had a cancer diagnosis.

¹ World Health Organization. Definition of Palliative Care [online]. 2006 [cited 2007 Nov 7]. Available from: URL: <http://www.who.int/cancer/palliative/definition/en/>

- Thirty five percent of organisations had between one and five patients with a non-cancer diagnosis, 5% of organisations had between six and ten patients with a non-cancer diagnosis and 12% of organisations had eleven or more patients with a cancer diagnosis.
- Of the patients who had a non- cancer diagnoses, cardiovascular disease (62%), respiratory failure (54%), renal failure (38%), neurological conditions (33%), other non-malignancies (28%) and HIV/AIDS (1%) were reported as the diagnoses
- Seventy percent of respondents reported that their organisation did not care for any Indigenous palliative care patients in the past twelve months, 12% cared for one Indigenous palliative care patient, 6% cared for two and 11% cared for 3 or more. South West respondents reported the lowest proportion of Indigenous palliative care patients (10%), compared with respondents from the Midwest region who reported the highest proportion (57%).
- A large majority of respondents (91%) reported that their organisation had not cared for any babies, children or adolescents in the past 12 months.
- Overall, a large proportion of respondents (87%) reported that that their organisation had not encountered a shortage of beds for their palliative care patients.
- Twenty percent of organisations reported no palliative care deaths in their health service in the past twelve months, 37% had between one and four, 15% between five and nine, 11% between ten and fourteen and 17% had fifteen or more palliative care deaths.
- Seventy percent of these palliative care deaths occurred at the hospital/healthcare centre, 37% occurred within the home, 30% within a nursing home, 9% in a hospice and 1% were unknown.

- Fourteen percent of respondents reported they had experienced problems with the certification of death. When broken down by region, the Midwest region reported the highest proportion of problems with the certification of death (19%), whereas the Kimberley reported lowest proportion of problems with the certification of death (0%).
- Just over one half of respondents reported there was a formal process for allocating people to palliative care (52%), with 81% reporting the process for allocation was written and 60% was verbal.
- Overall, 86% of palliative care referrals came from local or regional sources, 60% came from tertiary sites such as Perth and 3% came from unknown sources. Ninety three percent of referrals from local or regional sources came from medical sources, 57% from nurses, 41% from self referrals and 16% from other sources.
- Eighty eight percent of referrals from tertiary sites such as Perth came from medical sources, 44% from nurses, 23% from self referrals and 10% other sources.

Delivering Palliative Care

- Overall, 71% of respondents reported having a person responsible for coordinating palliative care services in their health area. Of these people, 94% were a nurse, 3% were a doctor and 7% were categorised as other.
- Thirty six percent of respondents reported that the coordination of palliative care services was that person's sole work responsibility. Only 10% of respondents in the Goldfields compared with 54% of respondents in the Great Southern region reported the coordination of palliative care was that person's sole responsibility.
- Forty five percent of respondents reported that they had a multidisciplinary team who meets to discuss the provision of palliative care services for patients. Ninety eight percent of organisations had nurses who made up part of the multi-

disciplinary team, 94% had doctors, 71% had occupational therapists, 66% had physiotherapists, 50% had social workers, 44% had chaplain/religious leaders, 39% had pharmacists, 37% had mental health services and 27% had counsellors, 13% had allied health professionals, 6% had Aboriginal health workers 5% had cancer care coordinators, 3% had HACC coordinators and 3% carers.

- Overall, 99% of organisations had access to doctors to care for the needs of the palliative care patients and their families, 99% to nurses, 89% to physiotherapists, 84% to chaplain/religious leaders, 83% to an occupational therapist, 80% to mental health services, 76% to a pharmacist, 69% to counsellors and 68% to a social worker, 8% to other allied health professionals, 6% to a palliative care provider, 4% to carers, HACC, alternative therapies such as massage, 2% to cancer care coordinator and palliative care coordinator and 1% to ACAT.
- Over one half of respondents reported their staff had trained in palliative care (64%). By region 87% of respondents in the South West reported their staff had trained in palliative care, 67% of respondents from the Great Southern region, 65% from the Midwest, 58% from the Wheat belt, 56% from the Goldfields, 57% from the Kimberley and 27% from the Pilbara.
- Overall, 72% of services provided after hours palliative care support, with 89% of staff being paid for this service. One hundred percent of respondents reported staff were paid for this service in the Goldfields, Great Southern and Kimberley regions as did 96% of respondents from the South West, 83% from the Pilbara, 80% from the Midwest and 79% from the Wheatbelt.
- Majority of respondents agreed or strongly agreed (88%) that there is a need for a clinical nurse consultant to coordinate palliative care across their region.
- Fifty four percent of all respondents were aware of the 2005 “Standards for providing quality care for all Australians (71% from South West, 67% from Great Southern, 58% from Midwest, 46% from Pilbara, 44% from the Goldfields were aware).

- Of those who were aware of these standards, 64% of organisations had implemented these standards (100% of organisations in the Kimberley had implemented these standards, as did 80% of organisations from the Pilbara, 75% from the Great Southern region, 68% from the South West, 60% from the Wheatbelt, 57% in the Goldfields and 46% from the Midwest).
- Respondents were asked if their organisation had a planned bereavement process to support families following the death of a patient. Overall, 47% answered yes. Fifteen percent of these services indicated it was provided for the immediate period, 20% for two weeks to around six months, 15% for around six months to a year and 43% for as long as needed.
- Seventy four percent of all organisations reported having a referral process to another service in place if there was a bereaved family member with problems (100% of organisations in the Great Southern region compared with 46% of organisations in the Pilbara). Thirty five percent of family members were referred to a palliative care unit or team, 28% to a hospital, 16% to Silver Chain, 13% to a health service, 9% to a palliative care coordinator, 8% to a hospice, 7% to a cancer care provider, 6% to a cancer care nurse, 6% to a GP, 5% to a palliative care nurse and 2% to respite care.
- Eighty one percent of respondents refer bereaved families to consult with a counselling service, 76% with a GP, 58% with mental health services, 29% with other support agencies and 6% with none of these.

Assessment and care planning

- Overall, 81% of respondents agreed or strongly agreed that standardised palliative care referral systems, protocols, care plans and clinical pathways would improve care.

- Forty eight percent of respondents said they collected information about their palliative care patients. Of those who did, 88% reported that the information was retained as a hospital record.

Links support to deliver services

- Forty one percent of organisations contacted if there was a clinical problem with a palliative care patient were medical centres (i.e. GP, doctors), 29% palliative care providers, 23% hospitals, 9% a telephone hotline, 9% Silver Chain and 4% the Royal Flying Doctor Service. Overall, 39% were in a GP position, 32% in a nursing position and 31% in a palliative care provider position.
- Approximately three quarters of respondents reported having no formal links in place with a metropolitan specialist service provider (74%).
- Overall, 72% of respondents reported having links in place with palliative care providers in their local health region. The Pilbara reported the lowest proportion of links in place with palliative care providers in their local health region (54%), compared with the Kimberley who reported the highest proportion of links with palliative care providers in their local area (86%).
- The most common linkages in place with palliative care providers in local health regions was with palliative care units/teams (35%), hospitals (28%), Silver Chain (16%) and general health services (13%).
- Forty eight percent of respondents reported occasionally, 8% not really a lot, 28% sometimes and 16% all the time when asked how often they would make contact with these services.
- Sixty three percent of respondents reported that they accessed the Cancer Council WA, to provide care or support, followed by church groups (54%), Indigenous groups (29%), service groups – e.g. Rotary, Lions (19%), miscellaneous services

(5%), HACC (4%), home care (3%), palliative care providers (3%) and grief services (2%).

- Eighty eight percent of respondents reported that in the event of a staff member struggling with issues relating to caring for palliative care patients, their health service provided access to a staff support service.
- Just over one half of all respondents reported that before the time of the survey they had not heard of the 1300 palliative care outreach medical advisory number (56%). Just over one third of these respondents (35%) used this service in the past 12 months, with 17% using it five or more times. Approximately one half (50%) of respondents had heard of the Silver Chain Hospice Care Services' Rural Telephone Nurse Advisory Service number before the time of the survey. Approximately 30% of these respondents had used the service in the last twelve months, 9% of respondents used it once, 7% used it twice, 3% used it 3 times, 1% used it four times and 7% used it more than five times in the last twelve months.
- Just over one half of respondents reported having special local issues relating to palliative care (56%).
- Around 30% of respondents reported, in their clinical opinion, there were patients that their service provided care to who had needs that should normally require referral to a specialist palliative care service, though for some reason a referral was not made.

1. Introduction

Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹

In 2007 the University of Western Australia's Survey Research Centre performed a telephone audit on behalf of the WA Cancer & Palliative Care Network to ascertain the current palliative care service provision in rural and remote locations. The aims of the survey were:

- To obtain information to guide the implementation of the recommendations of the "Palliative Care in Western Australia. Final Report December 2005".
- To then develop strategies that better support the provision of palliative care in rural and remote Western Australia.

2. Method

Sample and Response Rate

The sample for this study was provided by WA Cancer and Palliative Care Network. In total 152 numbers were provided, however 13 numbers were disregarded as they were duplicates, the organisation no longer offered the service or the organisation no longer existed. The response rate for this study was 100% (139 respondents).

¹ World Health Organization. Definition of Palliative Care [online]. 2006 [cited 2007 Nov 7]. Available from: URL: <http://www.who.int/cancer/palliative/definition/en/>

Instrumentation and Analysis

In June 2007 a letter inviting organisations to participate in the Rural Palliative Care Telephone Audit was sent and in July 2007 data were collected by trained interviewers from the Survey Research Centre at the University of Western Australia on behalf of the WA Cancer and Palliative Care Network using a Computer Assisted Telephone Interview (CATI) system.

The survey comprised 40 questions that were split into four sections (provision of services and patient care/outcome, delivering palliative care, assessment and care planning and links support to deliver services).

The data was then exported to SPSS for Windows (Version 15) for analysis via frequency tables and cross tabulations. Open-ended questions were coded using qualitative methodologies, from which descriptive summaries were generated.

3. Results

Sample characteristics

As evidenced in Table 1, the sample comprised of 139 respondents, 12% from the Goldfields, 9% from the Great Southern region, 5% from the Kimberley, 19% from the Midwest, 8% from the Pilbara, 22% from the South West and 26% from the Wheatbelt.

Table 1: Sample characteristics

| | n | % |
|----------------|------------|--------------|
| Goldfields | 16 | 11.5 |
| Great Southern | 12 | 8.6 |
| Kimberley | 7 | 5.0 |
| Midwest | 26 | 18.7 |
| Pilbara | 11 | 7.9 |
| South West | 31 | 22.3 |
| Wheatbelt | 36 | 25.9 |
| Total | 139 | 100.0 |

Provision of services and patient care/outcome

Respondents were asked which of the following services their organisation provided. As shown in Table 2a, 64% of organisations contacted indicated that they provided community palliative care services, 58% long term care, 57% in-patient palliative care and 50% hospital services (multiple response question). Table 2b shows these results by region.

Table 2a: Q1 which of the following services does your organisation provide?

| | % of respondents (n=139) |
|----------------------------|-----------------------------|
| Hospital | 49.6 |
| Long term care | 57.6 |
| Community palliative care | 64.0 |
| In-patient palliative care | 56.8 |

**Multiple response question*

Table 2b: Q1 which of the following services does your organisation provide?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|----------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Hospital | 43.8 | 41.7 | 71.4 | 38.5 | 63.6 | 45.2 | 58.3 |
| Long term care | 56.3 | 66.7 | 57.1 | 42.3 | 36.4 | 64.5 | 66.7 |
| Community palliative care | 62.5 | 75.0 | 28.6 | 69.2 | 72.7 | 45.2 | 77.8 |
| In-patient palliative care | 43.8 | 58.3 | 85.7 | 42.3 | 54.5 | 58.1 | 66.7 |

**Multiple response question*

Overall, most organisations cared for between one and five palliative care patients in the past 12 months (Table 3a). Table 3b breaks this down by region and Appendix Table 1 and 2 presents the individual proportions overall and by regions.

Table 3a: Q2 How many palliative care patients did your organisation care for in the past 12 months

| | n | % |
|--------------|------------|------------|
| 0 | 21 | 15.7 |
| 1 to 5 | 54 | 40.3 |
| 6 to 10 | 21 | 15.7 |
| 11 to 15 | 9 | 6.7 |
| 16 to 20 | 5 | 3.7 |
| 21 to 30 | 10 | 7.5 |
| 31 or more | 14 | 10.4 |
| Total | 134 | 100 |

**Table excludes missing values – 5 respondents said that they did not know*

Table 3b: Q2 How many palliative care patients did your organisation care for in the past 12 months?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 10 | 6 | 26 | 11 | 29 | 36 |
| | % | | | | | | |
| 0 | 31.3 | 0.0 | 0.0 | 26.9 | 36.4 | 6.9 | 8.3 |
| 1 to 5 | 37.5 | 40.0 | 66.7 | 26.9 | 45.5 | 27.6 | 55.6 |
| 6 to 10 | 6.3 | 20.0 | 33.3 | 19.2 | 0.0 | 10.3 | 22.2 |
| 11 to 15 | 0.0 | 10.0 | 0.0 | 7.7 | 9.1 | 10.3 | 5.6 |
| 16 to 20 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 17.2 | 0.0 |
| 21 to 30 | 18.8 | 20.0 | 0.0 | 3.8 | 9.1 | 10.3 | 0.0 |
| 30 or more | 6.3 | 10.0 | 0.0 | 15.4 | 0.0 | 17.2 | 8.3 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

**Table excludes missing values – 5 respondents said that they did not know*

Twenty three percent of patients did not have a cancer diagnosis, whereas 44% of organisations had between one and five patients who had a cancer diagnosis (Table 4a). The results by region are presented in Table 4b.

Table 4a: Q3 How many of these had a cancer diagnosis?

| | n | % |
|--------------|------------|------------|
| 0 | 30 | 22.9 |
| 1 to 5 | 58 | 44.3 |
| 6 to 10 | 18 | 13.7 |
| 11 to 15 | 5 | 3.8 |
| 16 to 20 | 5 | 3.8 |
| 21 or more | 15 | 11.5 |
| Total | 131 | 100 |

**Table excludes missing values – 8 respondents said that they did not know*

Table 4b: Q3 How many of these had a cancer diagnosis?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 10 | 6 | 25 | 11 | 28 | 35 |
| | % | | | | | | |
| 0 | 31.3 | 0.0 | 16.7 | 28.0 | 45.5 | 21.4 | 17.1 |
| 1 to 5 | 43.8 | 50.0 | 66.7 | 36.0 | 45.5 | 25.0 | 60.0 |
| 6 to 10 | 6.3 | 30.0 | 16.7 | 16.0 | 9.1 | 10.7 | 14.3 |
| 11 to 15 | 0.0 | 0.0 | 0.0 | 4.0 | 0.0 | 14.3 | 0.0 |
| 16 to 20 | 12.5 | 10.0 | 0.0 | 0.0 | 0.0 | 7.1 | 0.0 |
| 21 or more | 6.3 | 10.0 | 0.0 | 16.0 | 0.0 | 21.4 | 8.6 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

**Table excludes missing values – 8 respondents said that they did not know*

As evidenced in Table 5a, 35% of organisations had between one and five patients with a non-cancer diagnosis, 5% of organisations had between six and ten patients with a non-cancer diagnosis and 12% of organisations had eleven or more patients with a non-cancer diagnosis. The South West had 25% of respondents reporting eleven or more patients with a non-cancer diagnosis within their organisation (Table 5b).

Table 5a: Q4 How many of these had a non-cancer diagnosis?

| | n | % |
|--------------|------------|--------------|
| 0 | 63 | 48.5 |
| 1 to 5 | 45 | 34.6 |
| 6 to 10 | 7 | 5.4 |
| 11 or more | 15 | 11.5 |
| Total | 130 | 100.0 |

*Table excludes missing values – 9 respondents said did not know

Table 5b: Q4 How many of these had a non-cancer diagnosis?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 10 | 6 | 24 | 11 | 28 | 35 |
| | % | | | | | | |
| 0 | 62.5 | 40.0 | 16.7 | 66.7 | 45.5 | 32.1 | 51.4 |
| 1 to 5 | 25.0 | 40.0 | 83.3 | 25.0 | 36.4 | 32.1 | 51.4 |
| 6 to 10 | 6.3 | 0.0 | 0.0 | 0.0 | 9.1 | 10.7 | 5.7 |
| 11 or more | 6.3 | 20.0 | 0.0 | 8.3 | 9.1 | 25.0 | 5.7 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

*Table excludes missing values – 9 respondents said did not know

Of the patients who had a non- cancer diagnosis, cardiovascular disease (62%), respiratory failure (54%), renal failure (38%), neurological conditions (33%), other non-malignancies (28%) and HIV/AIDS (1%) were reported as the diagnoses (Multiple response question) (Table 6a). Table 6b shows these results by region. Cardiovascular disease was the highest diagnosis in the Great Southern (88%), Goldfields (84%), Pilbara (67%), Wheatbelt (61%) and the Midwest (50%). Renal failure (50%) and respiratory failure (50%) was the highest diagnoses in the Kimberley. In the South West respiratory failure accounted for 65% of the diagnosis.

Table 6a: Q5 Patient diagnoses of those who did not have cancer

| | % of respondents (n=139) |
|-------------------------|--------------------------|
| Cardiovascular disease | 61.8 |
| Renal failure | 38.2 |
| Respiratory failure | 53.9 |
| Neurological conditions | 32.9 |
| HIV/AIDS | 1.3 |
| Other non malignancy | 27.6 |

*Multiple response question

Table 6b: Q5 Patient diagnoses of those who did not have cancer

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|-------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 6 | 8 | 6 | 10 | 6 | 22 | 18 |
| | % | | | | | | |
| Cardiovascular disease | 83.3 | 87.5 | 33.3 | 50.0 | 66.7 | 59.1 | 61.1 |
| Renal failure | 33.3 | 37.5 | 50.0 | 30.0 | 66.7 | 36.4 | 33.3 |
| Respiratory failure | 50.0 | 62.5 | 50.0 | 50.0 | 66.7 | 63.7 | 38.9 |
| Neurological conditions | 66.7 | 50.0 | 33.3 | 30.0 | 33.3 | 31.8 | 16.7 |
| HIV/AIDS | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 4.5 | 0.0 |
| Other non malignancy | 33.3 | 25.0 | 16.7 | 10.0 | 3.3 | 27.3 | 38.9 |

**Multiple response question*

Seventy percent of respondents reported that their organisation did not care for any Indigenous palliative care patients in the past twelve months, 12% cared for one Indigenous palliative care patient, 6% cared for two and 11% cared for 3 or more (Table 7a). South West respondents reported the lowest proportion of Indigenous palliative care patients (10%), compared with respondents from the Midwest region who reported the highest proportion (57%) (Table 7b).

Table 7a: Q6 How many Indigenous palliative care patients did your organisation care for in the past 12 months?

| | n | % |
|--------------|------------|--------------|
| 0 | 97 | 69.8 |
| 1 | 17 | 12.2 |
| 2 | 8 | 5.8 |
| 3 or more | 15 | 10.8 |
| Don't know | 2 | 1.4 |
| Total | 139 | 100.0 |

Table 7b: Q6 How many Indigenous palliative care patients did your organisation care for in the past 12 months?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| 0 | 75.0 | 50.0 | 28.6 | 57.7 | 54.5 | 90.3 | 77.8 |
| 1 | 12.5 | 33.3 | 0.0 | 15.4 | 0.0 | 6.5 | 13.9 |
| 2 | 6.3 | 0.0 | 0.0 | 15.4 | 9.1 | 3.2 | 2.8 |
| 3 or more | 6.3 | 8.3 | 57.1 | 11.5 | 36.4 | 0.0 | 5.6 |
| Don't Know | 0.0 | 8.3 | 14.3 | 0.0 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

A large majority of respondents (91%) reported that their organisation had not cared for any babies, children or adolescents in the past 12 months (Table 8a). The breakdown by region is presented in Table 8b.

Table 8a: Q7 Has your organisation cared for any babies, children or adolescents in the past 12 months?

| | n | % |
|--------------|------------|--------------|
| No | 126 | 90.6 |
| Yes | 13 | 9.4 |
| Total | 139 | 100.0 |

Table 8b: Q7 Has your organisation cared for any babies, children or adolescents in the past 12 months?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| No | 93.8 | 91.7 | 71.4 | 84.6 | 100.0 | 87.1 | 97.2 |
| Yes | 6.3 | 8.3 | 28.6 | 15.4 | 0.0 | 12.9 | 2.8 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Overall, a large proportion of respondents (87%) reported that their organisation had not encountered a shortage of beds for their palliative care patients (Table 9a). All respondents from the Kimberley reported that they had not encountered a shortage of beds for their palliative care patients in the past twelve months, compared with 74% of respondents from the South West (Table 9b)

Table 9a: Q8 Have you in the last 12 months encountered a shortage of beds for your palliative care patients?

| | n | % |
|--------------|------------|--------------|
| Yes | 18 | 13.0 |
| No | 120 | 87.0 |
| Total | 138 | 100.0 |

Table 9b: Q8 Have you in the last 12 months encountered a shortage of beds for your palliative care patients?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 12.5 | 25.0 | 0.0 | 11.5 | 9.1 | 25.8 | 2.9 |
| No | 87.5 | 75.0 | 100.0 | 88.5 | 90.9 | 74.2 | 97.1 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Overall, 20% of organisations reported no palliative care deaths in their health service in the past twelve months, 37% had between one and four, 15% between five and nine, 11% between ten and fourteen and 17% had fifteen or more palliative care deaths (Table 10a), the results for this question by region are presented in Table 10b.

Table 10a: Q9 How many palliative care deaths occurred in your health service in the past 12 months

| | n | % |
|--------------|------------|--------------|
| 0 | 26 | 19.7 |
| 1 to 4 | 49 | 37.1 |
| 5 to 9 | 20 | 15.2 |
| 10 to 14 | 14 | 10.6 |
| 15 or more | 23 | 17.4 |
| Total | 132 | 100.0 |

**Table excludes missing values – 7 respondents said did not know*

Table 10b: Q9 How many palliative care deaths occurred in your health service in the past 12 months

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 15 | 11 | 6 | 26 | 11 | 27 | 36 |
| | % | | | | | | |
| 0 | 33.3 | 9.1 | 0.0 | 34.6 | 45.5 | 7.4 | 11.1 |
| 1 to 4 | 40.0 | 45.5 | 50.0 | 26.9 | 36.4 | 25.9 | 47.2 |
| 5 to 9 | 6.7 | 0.0 | 33.3 | 11.5 | 9.1 | 14.8 | 25.0 |
| 10 to 14 | 6.7 | 18.2 | 16.7 | 7.7 | 9.1 | 14.8 | 8.3 |
| 15 or more | 13.3 | 27.3 | 0.0 | 19.2 | 0.0 | 37.0 | 8.3 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

**Table excludes missing values – 7 respondents said did not know*

Overall, 70% of palliative care deaths occurred at the hospital/healthcare centre, 37% occurred within the home, 30% within a nursing home, 9% in a hospice and 1% were unknown (Table 11a). In the Kimberley, no palliative care deaths occurred within the home (Table 11b).

Table 11a: Q9a Place where deaths have occurred

| | % of respondents (n=106) |
|------------------------|--------------------------|
| Home | 36.8 |
| Hospital/health centre | 69.8 |
| Nursing home | 30.2 |
| Hospice | 9.4 |
| Don't know | 0.9 |

**Multiple response question*

Table 11b: Q9a Place where deaths have occurred

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 10 | 10 | 6 | 17 | 6 | 25 | 32 |
| | % | | | | | | |
| Home | 30.0 | 60.0 | 0.0 | 58.8 | 33.3 | 36.0 | 28.1 |
| Hospital/health centre | 70.0 | 60.0 | 66.7 | 58.8 | 66.7 | 72.0 | 78.1 |
| Nursing home | 40.0 | 50.0 | 66.7 | 17.6 | 16.7 | 40.0 | 15.6 |
| Hospice | 0.0 | 30.0 | 0.0 | 17.6 | 0.0 | 4.0 | 9.4 |
| Don't know | 0.0 | 0.0 | 0.0 | 5.9 | 0.0 | 0.0 | 0.0 |

**Multiple response question*

Fourteen percent of respondents reported they had experienced problems with the certification of death (Table 12a). When broken down by region, the Midwest reported the highest proportion of problems with the certification of death (19%), whereas the Kimberley reported the lowest proportion of problems with the certification of death (0%) (Table 12b).

Table 12a: Q10 Have you experienced any problems with the certification of death?

| | n | % |
|--------------|------------|--------------|
| Yes | 20 | 14.4 |
| No | 119 | 85.6 |
| Total | 139 | 100.0 |

Table 12b: Q10 Have you experienced any problems with the certification of death?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 6.3 | 16.7 | 0.0 | 19.2 | 18.2 | 12.9 | 16.7 |
| No | 93.8 | 83.3 | 100.0 | 80.8 | 81.8 | 87.1 | 83.3 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Table 13 shows the responses when asked to “please explain the problems which have occurred with the certification of death” among respondents who reported they had experienced problems.

Table 13: Q10a Please explain the problems you have had with the certification of death

-
-
- If it happens at night then we can't get a doctor to come, this has been a problem a few times, also sometimes the patient's doctor is away it can get to be quite a big issue, for example we had a patient pass away at night and we couldn't get a doctor
 - There is no doctor here, royal flying doctor comes once week, last year I was in a position that I had to sign the death certificate
 - We always experience delays because we are so remote and we don't have a doctor here all the time, we only have a doctor here 2 days a week so that makes the certification hard, limited access to a doctor
 - Don't have a doctor on site here and there is no medical cover. I do the certification
 - Cultural problem with a GP who has a problem with death and tends to try to refer them to tertiary hospital even after specialist advice of no further treatment available for their condition, wouldn't listen to nursing staff or wife of dying man
 - There is no doctor in town on weekends and that is when it happens. The nurses need an easier process for them to complete the death certificates
 - We get letters back for further information regarding diagnosis from coroner
 - Problem due to no doctor to certify death
 - One patient didn't get the death certificate written due to no doctor on site then a change over of doctors, no form written
 - Our doctor is often away or over a long weekend there could be a delay
 - Only in the community, if the doctor can't go to the home at the time of death then the police have to attend, the funeral director won't take the body without someone in authority
 - Lack of certifying doctor
 - Getting the GP to the home of the deceased because of the distance
 - We don't have a local doctor so if a death occurs after hours it is hard for us because we need to find a GP to certify the death
 - Problem for home nursing, GPs will not make home visits, the undertaker brings the body into emergency, GP on duty will then do the certificate of death
 - For after hours and weekends its hard to find a doctor to sign the certificate, the after hours only has ED doctors and they are always too busy to do it
 - Well only once when a lady died at home and her GP was overseas we couldn't get anyone to sign her death certificate but we finally managed to find a doctor to come and sign it so that was fine
 - The timing of the death (public holiday) the doctor on call will come and say they have died but not keen on doing death certificate if it was not their patient
 - GPs are reluctant the certification in their own home, very distressing for family having body left in their home, one GP said bring the body to the surgery and I'll see it in the car park
 - Long waiting times for GP to visit and in after hours we have to hold onto bodies for a long time
-

Overall, just over one half of respondents reported there was a formal process for allocating people to palliative care (52%) (Table 14a), with 81% reporting the process for allocation was written and 60% verbal (multiple response question) (Table 15a). The Kimberley had the highest proportion of respondents stating they had a formal process for allocating people to palliative care (71%) (Table 14b). In the Pilbara, 86% of allocation was verbal and 43% was written, whereas in the South West 100% of allocation was written and 43% was verbal (Table 15b).

Table 14a: Q11 Is there a formal process for allocating people to palliative care?

| | n | % |
|--------------|------------|--------------|
| Yes | 72 | 51.8 |
| No | 65 | 46.8 |
| Don't know | 2 | 1.4 |
| Total | 139 | 100.0 |

Table 14b: Q11 Is there a formal process for allocating people to palliative care?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 50.0 | 58.3 | 71.4 | 53.8 | 63.6 | 45.2 | 47.2 |
| No | 50.0 | 41.7 | 14.3 | 42.3 | 36.4 | 54.8 | 52.8 |
| Don't know | 0.0 | 0.0 | 14.3 | 3.8 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Table 15a: Q11 a If yes, is it

| | % of respondents (n=72) |
|---------|-------------------------|
| Verbal | 59.7 |
| Written | 80.6 |

**Multiple response question*

Table 15b: Q11 a If yes, is it

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|---------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 8 | 7 | 5 | 14 | 7 | 14 | 17 |
| | % | | | | | | |
| Verbal | 50.0 | 71.4 | 40.0 | 64.3 | 85.7 | 42.9 | 64.7 |
| Written | 75.0 | 85.7 | 80.0 | 71.4 | 42.9 | 100.0 | 88.2 |

**Multiple response question*

Overall, 86% of palliative care referrals came from local or regional sources, 60% from tertiary sites such as Perth and 3% from unknown sources (Table 16a). Ninety three percent of local or regional referrals came from medical sources, 57% from nurses, 41% from self referrals and 16% from other sources such as ACAT, community health care, family/friends, aged care residence, cancer coordinator and other health care providers/professionals (Table 17a).

Eighty eight percent of referrals from tertiary sites such as Perth came from medical sources, 44% from nurses, 23% from self referrals and 10% other sources such as ACAT, community health care, family/friends, aged care residence, cancer coordinator and other health care providers/professionals (Table 18a).

Tables 17b and 18b show results for these question respectively by region.

Table 16a: Q12 Do palliative care referrals to your organisation come from:

| | % of respondents (n=139) |
|------------------------------|--------------------------|
| Local or regional sources | 85.6 |
| Tertiary sites such as Perth | 60.4 |
| Unknown | 2.9 |
| Not applicable | 6.5 |

**Multiple response question*

Table 16b: Q12 Do palliative care referrals to your organisation come from:

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|------------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Local or regional sources | 93.8 | 100.0 | 85.7 | 80.8 | 54.5 | 93.5 | 83.3 |
| Tertiary sites such as Perth | 62.5 | 58.3 | 85.7 | 50.0 | 45.5 | 48.4 | 77.8 |
| Unknown | 0.0 | 0.0 | 0.0 | 0.0 | 18.2 | 3.2 | 2.8 |
| Not applicable | 0.0 | 0.0 | 0.0 | 19.2 | 18.2 | 3.2 | 2.8 |

**Multiple response question*

Table 17a: Q12a From which of the following sources do local or regional palliative care referrals to your organisation come from?

| | % of respondents (n=119) |
|---------|--------------------------------|
| Medical | 93.3 |
| Self | 41.2 |
| Nurse | 57.1 |
| Other | 16.0 |

**Multiple response question*

***Other includes ACAT, community health care, family/friends, aged care residence, cancer coordinator and other health care providers/professionals*

Table 17b: Q12a From which of the following sources do local or regional palliative care referrals to your organisation come from?

| | Goldfields | Great Southern | Kimberle y | Midwest | Pilbara | South West | Wheatbelt |
|---------|------------|-------------------|---------------|---------|---------|---------------|-----------|
| n | 15 | 12 | 6 | 21 | 6 | 29 | 30 |
| | % | | | | | | |
| Medical | 80.0 | 91.7 | 100.0 | 95.2 | 100.0 | 96.6 | 93.3 |
| Self | 40.0 | 50.0 | 0.0 | 33.3 | 33.3 | 41.4 | 53.3 |
| Nurse | 53.3 | 66.7 | 0.0 | 61.9 | 50.0 | 58.6 | 63.3 |
| Other | 20.0 | 8.3 | 0.0 | 28.6 | 16.7 | 10.3 | 16.7 |

**Multiple response question*

***Other includes ACAT, community health care, family/friends, aged care residence, cancer coordinator and other health care providers/professionals*

Table 18a: Q12b which of the following sources do your palliative care referrals from tertiary sites such as Perth come from?

| | % of respondents (n=84) |
|---------|----------------------------|
| Medical | 88.1 |
| Self | 22.6 |
| Nurse | 44.0 |
| Other | 9.5 |

**Multiple response question*

***Other includes ACAT, community health care, family/friends and other health care providers/professionals*

Table18b: Q12b which of the following sources do your palliative care referrals from tertiary sites such as Perth come from?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|---------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 10 | 7 | 6 | 13 | 5 | 15 | 28 |
| | % | | | | | | |
| Medical | 90.0 | 85.7 | 100.0 | 100.0 | 40.0 | 86.7 | 89.3 |
| Self | 20.0 | 42.9 | 0.0 | 15.4 | 40.0 | 20.0 | 25.0 |
| Nurse | 20.0 | 71.4 | 0.0 | 46.2 | 20.0 | 53.3 | 53.6 |
| Other | 10.0 | 0.0 | 0.0 | 7.7 | 60.0 | 6.7 | 7.1 |

**Multiple response question*

***Other includes ACAT, community health care, family/friends and other health care providers/professionals*

Delivering Palliative Care

Overall, 71% of respondents reported having a person responsible for coordinating palliative care services in their health area (Table 19a), when broken down by region, 92% of respondents from the Great Southern region, 86% from the Kimberley region, 78% from the Wheatbelt, 71% from the South West, 69% from the Midwest, 62% from the Goldfields and 36% from the Pilbara reported there was a person responsible for coordinating palliative care services in their health area (Table 19b).

Table 19a: Q13 Is there a person responsible for coordinating palliative care services in your health area?

| | n | % |
|--------------|------------|--------------|
| Yes | 99 | 71.2 |
| No | 37 | 26.6 |
| Don't know | 3 | 2.2 |
| Total | 139 | 100.0 |

Table 19b: Q13 Is there a person responsible for coordinating palliative care services in your health area?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 62.5 | 91.7 | 85.7 | 69.2 | 36.4 | 71.0 | 77.8 |
| No | 37.5 | 8.3 | 14.3 | 19.2 | 63.6 | 29.0 | 22.2 |
| Don't know | 0.0 | 0.0 | 0.0 | 11.5 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Of the 71% of services that reported having a person responsible for coordinating palliative care services, 94% were a nurse, 3% were a doctor and 7% were categorised as other (i.e. Silver Chain employee or cancer care coordinator) (multiple response question) (Table 20a). Table 20b shows the results by region.

Table 20a: Q13a If yes, what is the person's position?

| | % of respondents (n=99) |
|--------|-------------------------|
| Nurse | 93.9 |
| Doctor | 3.0 |
| Other | 7.1 |

**Multiple response question*

*** Other includes Silver Chain employee, cancer care coordinator*

Table 20b: Q13a If yes, what is the person's position?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 10 | 11 | 6 | 18 | 4 | 22 | 28 |
| | % | | | | | | |
| Nurse | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 81.8 | 92.9 |
| Doctor | 0.0 | 9.1 | 0.0 | 5.6 | 0.0 | 4.5 | 0.0 |
| Other | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 18.2 | 10.7 |

**Multiple response question*

*** Other includes Silver Chain employee, cancer care coordinator*

Thirty six percent of respondents reported that the coordination of palliative care services was that person's sole work responsibility, whereas 57% said it was not and 7% did not know (Table 21a). Only 10% of respondents in the Goldfields compared with 54% of respondents in the Great Southern region reported the coordination of palliative care was that person's sole responsibility (Table 21b).

Table 21a: Q14 Is the coordination of palliative care services their sole work responsibility?

| | n | % |
|--------------|-----------|--------------|
| Yes | 36 | 36.4 |
| No | 56 | 56.6 |
| Don't know | 7 | 7.1 |
| Total | 99 | 100.0 |

Table 21b: Q14 Is the coordination of palliative care services their sole work responsibility

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 10 | 11 | 6 | 18 | 4 | 22 | 28 |
| | % | | | | | | |
| Yes | 10.0 | 54.5 | 50.0 | 50.0 | 25.0 | 22.7 | 39.3 |
| No | 70.0 | 45.5 | 33.3 | 44.4 | 50.0 | 68.2 | 60.7 |
| Don't know | 20.0 | 0.0 | 16.7 | 5.6 | 25.0 | 9.1 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Forty five percent of respondents reported that they had a multidisciplinary team that meets to discuss the provision of palliative care services for patients (Table 22a). Fifty eight percent of respondents from the Great Southern region reported having a multidisciplinary team to discuss patient care compared with 56% from the Goldfields, 55% from the South West, 43% Kimberley, 36% from the Pilbara, 36% from the Wheatbelt and 35% from the Midwest (Table 22b).

Table 22a: Q15 Do you have a multi-disciplinary team that meets to discuss provision of palliative care services for patients?

| | n | % |
|--------------|------------|--------------|
| Yes | 62 | 44.6 |
| No | 76 | 54.7 |
| Don't know | 1 | 0.7 |
| Total | 139 | 100.0 |

Table 22b: Q15 Do you have a multi-disciplinary team that meets to discuss provision of palliative care services for patients?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 56.3 | 58.3 | 42.9 | 34.6 | 36.4 | 54.8 | 36.1 |
| No | 37.5 | 41.7 | 57.1 | 65.4 | 63.6 | 45.2 | 63.9 |
| Don't know | 6.3 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Table 22a shows the overall health professional composition of the multidisciplinary team. Ninety eight percent of organisations had nurses who made up part of the multidisciplinary team, 94% had doctors, 71% had occupational therapists, 66% had physiotherapists, 50% had social workers, 44% had chaplain/religious leaders, 39% had pharmacists, 37% had mental health services and 27% had counsellors, 13% had allied health professionals, 6% had Aboriginal health workers 5% had cancer care coordinators, 3% had HACC coordinators and 3% carers (Table 22a).

Table 22a: Q16 Which of the following health professionals comprise your multidisciplinary team?

| | % of respondents (n=62) |
|----------------------------|-------------------------------|
| Doctor | 93.5 |
| Nurse | 98.4 |
| Social worker | 50.0 |
| Physiotherapist | 66.1 |
| Occupational therapist | 71.0 |
| Pharmacist | 38.7 |
| Counsellor | 27.4 |
| Chaplain/religious leaders | 43.5 |
| Mental health services | 37.1 |
| Other | |
| Allied health professional | 12.9 |
| Aboriginal health worker | 6.5 |
| Cancer care coordinator | 4.8 |
| HACC coordinator | 3.2 |
| Carers/volunteers/respice | 3.2 |

**Multiple response question*

Table 22b shows the composition of the multidisciplinary teams by region.

Table 22b: Q16 Which of the following health professionals comprise your multidisciplinary team?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|----------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 9 | 7 | 3 | 9 | 4 | 17 | 13 |
| | % | | | | | | |
| Doctor | 100.0 | 85.7 | 100.0 | 77.8 | 100.0 | 94.1 | 100.0 |
| Nurse | 88.9 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |
| Social worker | 55.6 | 57.1 | 66.7 | 77.8 | 75.0 | 29.4 | 38.5 |
| Physiotherapist | 55.6 | 42.9 | 100.0 | 77.8 | 100.0 | 52.9 | 76.9 |
| Occupational therapist | 44.4 | 85.7 | 100.0 | 88.9 | 100.0 | 58.8 | 69.2 |
| Pharmacist | 44.4 | 42.9 | 33.1 | 44.4 | 0.0 | 52.9 | 23.1 |
| Counsellor | 33.3 | 57.1 | 0.0 | 44.4 | 0.0 | 17.6 | 23.1 |
| Chaplain/religious leaders | 33.3 | 42.9 | 33.3 | 55.6 | 25.0 | 52.9 | 38.5 |
| Mental health services | 22.2 | 42.9 | 100.0 | 33.3 | 50.0 | 17.6 | 53.8 |
| Other | | | | | | | |
| Allied health professional | 22.2 | 0.0 | 0.0 | 11.1 | 0.0 | 11.8 | 23.3 |
| Aboriginal health worker | 0.0 | 0.0 | 0.0 | 22.2 | 0.0 | 5.9 | 7.7 |
| Cancer care coordinator | 11.1 | 14.3 | 0.0 | 11.1 | 0.0 | 0.0 | 0.0 |
| HACC coordinator | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 5.9 | 7.7 |
| Carers/volunteers/respice | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 5.9 | 7.7 |

**Multiple response question*

Overall, 99% of organisations had access to doctors to care for the needs of the palliative care patients and their families, 99% to nurses, 89% to physiotherapists, 84% to chaplain/religious leaders, 83% to an occupational therapist, 80% to mental health services, 76% to a pharmacist, 69% to counsellors and 68% to a social worker, 8% to other allied health professionals, 6% to a palliative care provider, 4% to carers, HACC and alternative therapies such as massage, 2% to cancer care coordinator and palliative care coordinator and 1% to ACAT (multiple response question) (Table 23a). Table 23b presents the health professionals organisations had access to care for the needs of palliative care patients and their families by region.

Table 23a: Q17 Which of the following health professionals does your organisation have access to care for the needs of palliative care patients and their families?

| | % of respondents (n=139) |
|-----------------------------|--------------------------------|
| Doctor | 99.3 |
| Nurse | 98.6 |
| Social worker | 67.6 |
| Physiotherapist | 89.2 |
| Occupational therapist | 82.7 |
| Pharmacist | 76.3 |
| Counsellor | 69.1 |
| Chaplain/religious leaders | 84.2 |
| Mental health services | 79.9 |
| Other | |
| Allied health professional | 7.9 |
| Palliative care provider | 6.5 |
| Carers | 3.6 |
| HACC | 3.6 |
| Alternative therapies | 3.6 |
| Cancer care coordinator | 2.2 |
| Palliative care coordinator | 2.2 |
| ACAT | 1.4 |

**Multiple response question*

Table 23b: Q17 Which of the following health professionals does your organisation have access to care for the needs of palliative care patients and their families?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|-----------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Doctor | 100.0 | 100.0 | 100.0 | 100.0 | 90.9 | 100.0 | 100.0 |
| Nurse | 100.0 | 100.0 | 100.0 | 100.0 | 81.8 | 100.0 | 100.0 |
| Social worker | 68.8 | 75.0 | 28.6 | 65.4 | 54.5 | 87.1 | 61.1 |
| Physiotherapist | 93.8 | 91.7 | 85.7 | 96.2 | 63.6 | 90.3 | 88.9 |
| Occupational therapist | 87.5 | 91.7 | 85.7 | 73.1 | 45.5 | 87.1 | 91.7 |
| Pharmacist | 87.5 | 75.0 | 71.4 | 80.8 | 36.4 | 74.2 | 83.3 |
| Counsellor | 75.0 | 75.0 | 57.1 | 61.5 | 45.5 | 58.1 | 88.9 |
| Chaplain/religious leaders | 87.5 | 75.0 | 100.0 | 80.8 | 54.5 | 96.8 | 83.3 |
| Mental health services | 81.3 | 83.3 | 85.7 | 73.1 | 54.5 | 77.4 | 91.7 |
| Other | | | | | | | |
| Allied health professional | 6.3 | 8.3 | 0.0 | 7.7 | 18.2 | 6.5 | 8.3 |
| Palliative care provider | 6.3 | 0.0 | 14.3 | 7.7 | 9.1 | 3.2 | 8.3 |
| Carers | 0.0 | 8.3 | 0.0 | 3.8 | 0.0 | 3.2 | 5.6 |
| HACC | 0.0 | 0.0 | 0.0 | 7.7 | 18.2 | 0.0 | 2.8 |
| Alternative therapies | 0.0 | 0.0 | 0.0 | 0.0 | 9.1 | 6.5 | 5.6 |
| Cancer care coordinator | 6.3 | 8.3 | 0.0 | 0.0 | 0.0 | 0.0 | 2.8 |
| Palliative care coordinator | 0.0 | 0.0 | 0.0 | 3.8 | 9.1 | 0.0 | 2.8 |
| ACAT | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 2.8 |

**Multiple response question*

Over one half of respondents reported their staff were trained in palliative care (64%) (Table 24a). As evidenced in Table 24b, 87% of respondents in the South West reported their staff were trained in palliative care, 67% of respondents from the Great Southern region, 65% from the Midwest, 58% from the Wheat belt, 56% from the Goldfields, 57% from the Kimberley and 27% from the Pilbara. Table 25 presents the responses to what type of palliative care training staff have had of those who said their staff had received it.

Table 24a: Q18 Have any of your staff had training in palliative care?

| | n | % |
|--------------|------------|--------------|
| Yes | 89 | 64.0 |
| No | 48 | 34.5 |
| Don't know | 2 | 1.4 |
| Total | 139 | 100.0 |

Table 24b: Q18 Have any of your staff had training in palliative care?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 56.3 | 66.7 | 57.1 | 65.4 | 27.3 | 87.1 | 58.3 |
| No | 43.8 | 33.3 | 42.9 | 34.6 | 72.7 | 9.7 | 38.9 |
| Don't know | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 2.8 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Table 25 presents the responses to what type of palliative care training staff have had of those who said their staff had received it.

Table 25: Q18a If yes, what type?

Goldfields

- 2 weeks of palliative training in Perth about 4 years ago, training to up skill to doctors and nurses from rural areas
- General palliative care training, grasby pumps for pain control
- PEPA programme, annual palliative care services seminars for Registered Nurses, education for care staff
- Onsite training, palliative care workshops
- Research for care in hospice, as part of degree
- Short courses in palliative care, in-service
- Short in-service courses and teleconferences
- Through the Cancer Council
- Through the Cancer Council, study day, pain management

Great Southern

- 50% of the staff here have done the accredited palliative care course
- A PEPA training course run by the Cancer Council
- Conference / workshops
- I've attended workshops, we also have a lot of books on it
- Palliative care short course and medication management courses
- Pharmacology MSOAP, palliative care standards, general up skilling in palliative care especially aged residential care standards
- We've had people come down from palliative care in Perth to talk to us about palliative care, we also have a regional cancer nurse that has spoken with us recently, also we always get involved in tele-conferencing
- Workshops - by w.a.c.h., Cancer Council, tele-health, in-house training, post grad certificate

Kimberley

- Some of the nurses have done workshops in Perth
- General in-service training
- In-service course, general palliative

Midwest

- Because we don't deal with palliative patients we don't actually have any formal training but we did have a registered nurse here once who taught the staff how to handle the situation if they came across it
 - During their nursing course they have studied areas specific to palliative care and personal care
 - I have worked in hospital setting, private and teaching hospitals
 - In-service training
 - Just a few study days
 - Nurses have attended short professional development courses and we have experienced senior nurses here
 - Pain management course and palliative care courses
 - Palliative care course from the Cancer Council
 - Palliative course through rotary hospice palliative education centre in 1990's by correspondence
 - Palliative reg. coordinator provides in-service on any issue. e.g. medication, documentation, two day courses on palliative, Cancer Council palliative courses, video conferencing in service, electronic monitoring systems use 2 day course
 - PEPA
 - Pharmacology unit, palliative care course teleconference 6 years ago
 - Some units of a course, local course, PEPA training which was in the metro area for two weeks
 - The rural medical palliative care program that is funded through the Cancer Foundation, tele-health conferences, just general different programs that are offered by the Cancer Foundation
 - They attend study days and conferences but no they don't have any formal studies
 - WACCRM, palliative conference, palcis course, regional palliative and age care course
 - We do tele-health services from Perth, short day services, MSOAP [GP training]
-

South West

- 2-3 days training a few years ago by Silver Chain
- Department of health and aging workshops, cancer councillor workshops
- External education sessions run by palliative care professionals
- Formal training, conferences for palliative care, in-service training with Silver Chain
- I have done study days at RPH, St John of God
- Lectures put on at the hospital, private providers workshops in Perth
- Mainly training about how to deal with medications
- PEPA programs, monthly education in the ward, tertiary education in palliative care
- Medication
- One day courses in palliative care
- Palliative approach training, the organisation does this training, Church of Christ, WA PEPA programme by the Cancer Council, staff spent a week at a hospice, training for palliative care training
- Palliative care courses
- Palliative care courses offered by the Cancer Council
- PEPA courses offered by the Cancer Council, few of the nurses have had many years of experience so they help the other staff learn
- Residential care, pain management course
- Short courses, external course
- Staff attend seminars conducted by Silver Chain and the large metro hospitals like RPH and they do self learning as well
- Study days
- Study days, in house, hospice training in Perth
- Study days, run by the hospice coordinator, in service training from the hospice
- Through the regional health service, work shops and they now receive information every second month, there are follow up work shops, palliative care in rural areas are the topics in work shops
- Palliative care training, in house short courses through palliative care modules
- We had a tele-conference for training, also a member of our staff did 5 weeks training at hospice
- Workshops, conference in eastern states
- Workshops and conferences on palliative care
- Workshops in local area

Pilbara

- PEPA program, one week program in Perth, palliative care work shops, palliative care specialist came up from Perth and run a workshop
- Attended some seminars on palliative care but not really any formal training, we also have the Cancer Council representative nurse who comes to talk to the staff and that helps

Wheatbelt

- PEPA - a practical palliative care course offered by the Cancer Council, we also have staff who have worked in palliative care for many year and have brought their experiences with them
 - Aged care training, workshops from organisations like the Alzheimer's McKusker Foundation, WA Country Health service workshops
 - Cancer Council in New Zealand
 - Cancer palliative care course
 - Courses over the years, Cancer Council education
 - Day courses at palliative care centre
 - Medication awareness, general palliative care post graduate certificate
 - Palliative care course from Curtin
 - Palliative care courses
 - Palliative care courses, courses at the Cancer Council, tele-health link, tele-conferencing
 - Nurses who have done aged care get palliative training as part of their course
 - Past experience at a tertiary hospital, various study days and placements in the Cancer Council's PEPA program
 - PEPA course, palliative care through Silver Chain
 - PEPA course through Silver Chain, short course in palliative care
 - Post graduate university course, short courses with the palliative care association
 - Short courses at hospitals
 - Two day course at Perth tertiary on palliative course
 - Palliative care training that was run by the cancer council, palliative medication training
 - We have done short courses through the hospice but that was a very long time ago and we would like more training to be available to us
-

Overall, 72% of services provided after hours palliative care support (Table 26a), with 89% of staff being paid for this service (Table 27a). When broken down by region, 92% of respondents from the Great Southern region reported their service provided after hours palliative care supports, compared with 43% of respondents from the Kimberley (Table 26b). One hundred percent of respondents reported staff were paid for this service in the Goldfields, Great Southern and Kimberley regions as did 96% of respondents from the South West, 83% from the Pilbara, 80% from the Midwest and 79% from the Wheatbelt (Table 27b).

Table 26a: Q19 Does your service provide after hours palliative care support?

| | n | % |
|--------------|------------|--------------|
| Yes | 100 | 72.5 |
| No | 38 | 27.5 |
| Don't know | 1 | 0.7 |
| Total | 139 | 100.0 |

Table 26b: Q19 Does your service provide after hours palliative care support?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 75.0 | 91.7 | 42.9 | 57.7 | 54.5 | 80.6 | 77.8 |
| No | 25.0 | 0.0 | 57.1 | 42.3 | 45.5 | 19.4 | 22.2 |
| Don't know | 0.0 | 8.3 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Table 27a: Q20 Are staff paid to deliver this service?

| | n | % |
|--------------|------------|--------------|
| Yes | 89 | 89.0 |
| No | 11 | 11.0 |
| Total | 100 | 100.0 |

Table 27b: Q20 Are staff paid to deliver this service?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 12 | 11 | 3 | 15 | 6 | 25 | 28 |
| | % | | | | | | |
| Yes | 100.0 | 100.0 | 100.0 | 80.0 | 83.3 | 96.0 | 78.6 |
| No | 0.0 | 0.0 | 0.0 | 20.0 | 16.7 | 4.0 | 21.4 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Majority of respondents agreed or strongly agreed (88%) that there was a need for a clinical nurse consultant to coordinate palliative care across their region (Table 28a). One hundred percent of respondents from the Pilbara region agreed or strongly agreed that there was a need, as did 94% of respondents from the South West, 88% from the Midwest, 86% from the Wheatbelt, 86% from the Kimberley, 83% from the Great Southern and 81% from the Goldfields (Table 28b).

Table 28a:Q21 Do you believe that there is a need for a clinical nurse consultant to coordinate palliative care across your region?

| | n | % |
|-------------------|------------|--------------|
| Strongly disagree | 4 | 2.9 |
| Disagree | 10 | 7.2 |
| Agree | 34 | 24.5 |
| Strongly agree | 89 | 64.0 |
| Don't know | 2 | 1.4 |
| Total | 139 | 100.0 |

Table 28b: Q21 Do you believe that there is a need for a clinical nurse consultant to coordinate palliative care across your region?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|-------------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Strongly disagree | 0.0 | 16.7 | 0.0 | 3.8 | 0.0 | 3.2 | 0.0 |
| Disagree | 18.8 | 0.0 | 14.3 | 7.7 | 0.0 | 0.0 | 11.1 |
| Agree | 31.3 | 0.0 | 28.6 | 30.8 | 27.3 | 29.0 | 19.4 |
| Strongly agree | 50.0 | 83.3 | 57.1 | 57.7 | 72.7 | 64.5 | 66.7 |
| Don't know | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 2.8 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Fifty four percent of all respondents were aware of the 2005 “Standards for providing quality care for all Australians (when broken down; 71% from South West, 67% from Great Southern, 58% from Midwest, 46% from Pilbara, 44% from the Goldfields were aware of the 2005 “Standards for providing quality care for all Australians (Table 29a)). Of those who were aware of these standards, 64% of organisations had implemented these standards (Table 29a). Table 30b shows the results by region, 100% of organisations in the Kimberley had implemented these standards, as did 80% of organisations from the Pilbara, 75% from the Great Southern region, 68% from the South West, 60% from the Wheatbelt, 57% in the Goldfields and 46% from the Midwest (Table 30b).

Table 29a: Q22 Are you aware of the 2005 “Standards for providing quality care for all Australians”?

| | n | % |
|--------------|------------|--------------|
| Yes | 75 | 54.0 |
| No | 64 | 46.0 |
| Total | 139 | 100.0 |

Table 29a: Q22 Are you aware of the 2005 “Standards for providing quality care for all Australians”?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 43.8 | 66.7 | 42.9 | 57.7 | 45.5 | 71.0 | 41.7 |
| No | 56.3 | 33.3 | 57.1 | 42.3 | 54.5 | 29.0 | 58.3 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Table 30a: Q23 Has your organisation implemented these standards?

| | n | % |
|--------------|-----------|--------------|
| Yes | 48 | 64.0 |
| No | 20 | 26.7 |
| Don't know | 7 | 9.3 |
| Total | 75 | 100.0 |

Table 30b: Q23 Has your organisation implemented these standards?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 7 | 8 | 3 | 15 | 5 | 22 | 15 |
| | % | | | | | | |
| Yes | 57.1 | 75.0 | 100.0 | 46.7 | 80.0 | 68.2 | 60.0 |
| No | 14.3 | 25.0 | 0.0 | 46.7 | 20.0 | 22.7 | 26.7 |
| Don't know | 28.6 | 0.0 | 0.0 | 6.7 | 0.0 | 9.1 | 13.3 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Respondents were asked if their organisation had a planned bereavement process to support families following the death of a patient. Overall, 47% answered yes (Table 31a). Table 31b shows the results broken down by region.

Table 31a: Q24 Does your organisation have a planned bereavement process to support families following the death of a patient?

| | n | % |
|--------------|------------|--------------|
| Yes | 65 | 46.8 |
| No | 65 | 46.8 |
| Don't know | 9 | 6.5 |
| Total | 139 | 100.0 |

Table 31b: Q24 Does your organisation have a planned bereavement process to support families following the death of a patient?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| Yes | 18.8 | 33.3 | 42.9 | 50.0 | 36.4 | 58.1 | 55.6 |
| No | 68.8 | 41.7 | 42.9 | 46.2 | 63.6 | 38.7 | 41.7 |
| Don't know | 12.5 | 25.0 | 14.3 | 3.8 | 0.0 | 3.2 | 2.8 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

If respondents answered yes to provision of a planned bereavement process, they were asked for how long the bereavement support is usually provided. Fifteen percent of the time it was provided for the immediate period, 20% for two weeks to around six months, 15% for around six months to a year, 43% for as long as needed (Table 32a), Table 32b shows how long bereavement support is provided in each region.

Table 32a: Q25 For how long is the bereavement support usually provided?

| | n | % |
|-----------------------|-----------|--------------|
| Immediate period | 10 | 15.4 |
| 2 weeks to 6 months | 13 | 20.0 |
| 6 months to 12 months | 10 | 15.4 |
| As long as needed | 28 | 43.1 |
| Don't know | 4 | 6.2 |
| Total | 65 | 100.0 |

Table 32b: Q25 For how long is the bereavement support usually provided?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|-----------------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 3 | 4 | 3 | 13 | 4 | 18 | 20 |
| | % | | | | | | |
| Immediate period | 33.3 | 0.0 | 33.3 | 15.4 | 25.0 | 11.1 | 15.0 |
| 2 weeks to 6 months | 0.0 | 25.0 | 0.0 | 23.1 | 25.0 | 22.2 | 20.0 |
| 6 months to 12 months | 33.3 | 0.0 | 33.3 | 23.1 | 0.0 | 11.1 | 15.0 |
| As long as needed | 33.3 | 75.0 | 0.0 | 30.8 | 50.0 | 55.6 | 40.0 |
| Don't know | 0.0 | 0.0 | 33.3 | 7.7 | 0.0 | 0.0 | 10.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Seventy four percent of all organisations reported having a referral process in place to another service if there is a bereaved family member with problems (Table 33a). Table 33b shows the proportion of organisations in each region that have a referral process in place for bereaved family members, with 100% of organisations in the Great Southern region compared with 46% of organisations in the Pilbara having a referral process.

Table 33a: Q26 If you have a bereaved family member who has problems is there a referral process in place to another service?

| | n | % |
|--------------|------------|--------------|
| Yes | 103 | 74.1 |
| No | 33 | 23.7 |
| Don't know | 3 | 2.2 |
| Total | 139 | 100.0 |

Table 33b: Q26 If you have a bereaved family member who has problems is there a referral process in place to another service?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 62.5 | 100.0 | 85.7 | 80.8 | 45.5 | 67.7 | 77.8 |
| No | 31.3 | 0.0 | 14.3 | 15.4 | 54.5 | 32.3 | 19.4 |
| Don't know | 6.3 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 2.8 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Thirty five percent of family members were referred to a palliative care unit or team, 28% to a hospital, 16% to Silver Chain, 13% to a health service, 9% to a palliative care coordinator, 8% to a hospice, 7% to a cancer care provider, 6% to a cancer care nurse, 6% to a GP, 5% to a palliative care nurse and 2% to respite care (Table 33).

Table 33c: Q26a If yes, which services are they commonly referred to?

| | % of respondents (n=100) |
|-----------------------------|--------------------------|
| Palliative care unit/team | 35.0 |
| Hospital | 28.0 |
| Palliative care coordinator | 9.0 |
| Palliative care nurse | 5.0 |
| Health service | 13.0 |
| Hospice | 8.0 |
| Silver Chain | 16.0 |
| Cancer care coordinator | 7.0 |
| Cancer care nurse | 6.0 |
| Respite | 2.0 |
| GP | 6.0 |
| Don't know | 5.0 |

**Multiple response question*

As evidenced in Table 34a, 81% of respondents refer bereaved families to consult with a counselling service, 76% with a GP, 58% with mental health services, 29% with other support agencies and 6% with none of these (multiple response question). Table 34b presents results by region.

Table 34a: Q27 Do you refer bereaved families to consult with:

| | % of respondents (n=139) |
|------------------------|--------------------------|
| GP | 75.5 |
| Counselling services | 80.6 |
| Mental health services | 57.6 |
| Other support agency | 28.8 |
| None of these | 5.8 |

**Multiple response question*

Table 34b: Q27 Do you refer bereaved families to consult with:

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| GP | 81.3 | 75.0 | 71.4 | 69.2 | 72.7 | 77.4 | 77.8 |
| Counselling services | 75.0 | 100.0 | 57.1 | 76.9 | 81.8 | 74.2 | 88.9 |
| Mental health services | 68.8 | 66.7 | 71.4 | 61.5 | 72.7 | 35.5 | 58.3 |
| Other support agency | 31.3 | 33.3 | 28.6 | 23.1 | 45.5 | 22.6 | 30.6 |
| None of these | 6.3 | 0.0 | 0.0 | 15.4 | 9.1 | 6.5 | 0.0 |

**Multiple response question*

Assessment and care planning

Overall, 81% of respondents either agreed or strongly agreed that standardised palliative care referral systems, protocols, care plans and clinical pathways would improve care (Figure 1). Eighty eight percent of respondents from the Midwest agreed or strongly agreed with the statement, 87% from the South West, 86% from the Kimberley, 82% from the Pilbara, 80% from the Wheatbelt, 69% from the Goldfields and 67% from the Great Southern region (Table 35).

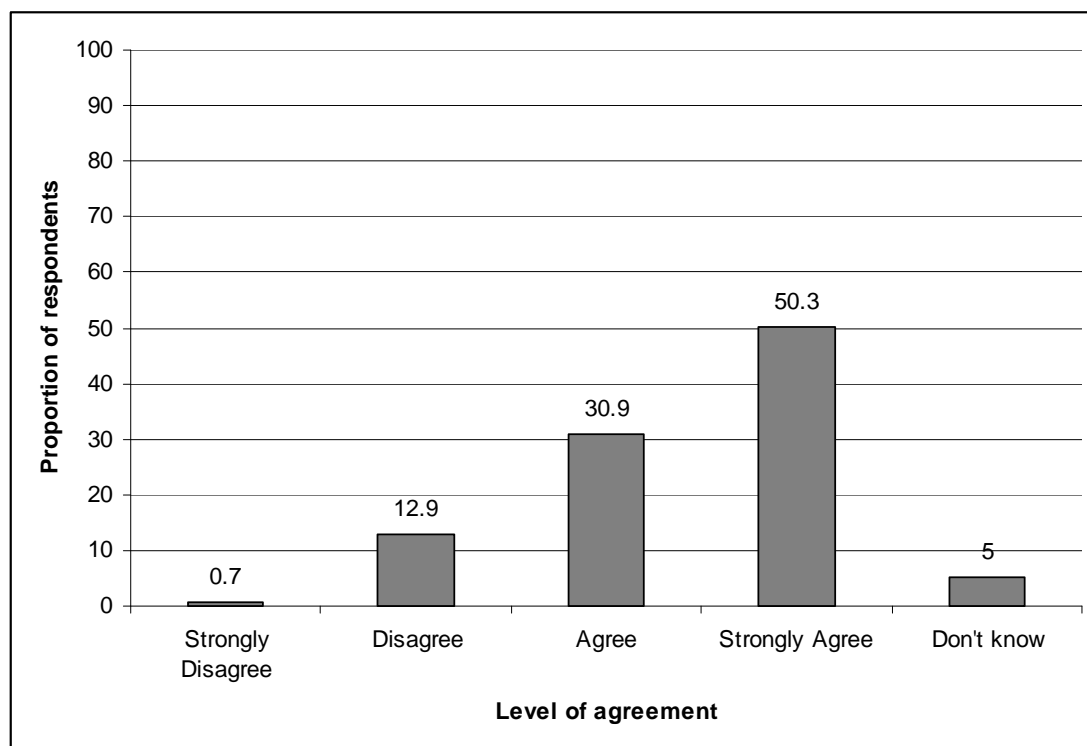


Figure 1 Q28 Do you agree that standardised palliative referral systems, protocols, care plans, and clinical pathways would help improve care?

Table 35: Q28 Do you agree that standardised palliative referral systems, protocols, care plans, and clinical pathways would help improve care?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|-------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Strongly disagree | 0.0 | 8.3 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Disagree | 6.3 | 25.0 | 14.3 | 7.7 | 18.2 | 12.9 | 13.9 |
| Agree | 37.5 | 16.7 | 71.4 | 38.5 | 9.1 | 22.6 | 33.3 |
| Strongly Agree | 31.3 | 50.0 | 14.3 | 50.0 | 72.7 | 64.5 | 47.2 |
| Don't know | 25.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 5.6 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Respondents were asked if they collect information about their palliative care patients. Overall, 48% of respondents said yes, 49% said no and 3% said they did not know (Table 36a). The results by region are shown in Table 36b. The Kimberley had the greatest proportion of respondents reporting yes to collecting specific information about their palliative care patients (71%) compared with the Pilbara who reported the lowest proportion (27%) (Table 36b).

Table 36a: Q29 Do you collect specific information about your palliative care patients?

| | n | % |
|--------------|------------|--------------|
| Yes | 67 | 48.2 |
| No | 68 | 48.9 |
| Don't know | 4 | 2.9 |
| Total | 139 | 100.0 |

Table 36b Q29 Do you collect specific information about your palliative care patients?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 56.3 | 66.7 | 71.4 | 42.3 | 27.3 | 48.4 | 44.4 |
| No | 37.5 | 33.3 | 28.6 | 53.8 | 72.7 | 48.4 | 52.8 |
| Don't know | 6.3 | 0.0 | 0.0 | 3.8 | 0.0 | 3.2 | 2.8 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Overall, of those who said yes, 88% reported that the information was retained as a hospital record (Table 37a). These results by region can be seen in Table 37b.

Table 37a: Q29a If yes, is this information retained as a hospital record?

| | n | % |
|--------------|-----------|--------------|
| Yes | 59 | 88.1 |
| No | 8 | 11.9 |
| Total | 67 | 100.0 |

Table 37b: Q29a If yes, is this information retained as a hospital record?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 9 | 8 | 5 | 11 | 3 | 15 | 16 |
| | % | | | | | | |
| Yes | 77.8 | 75.0 | 80.0 | 90.9 | 66.7 | 100.0 | 93.8 |
| No | 22.2 | 25.0 | 20.0 | 9.1 | 33.3 | 0.0 | 6.3 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Links support to deliver services

Respondents were asked “thinking about your health service, if there is a clinical problem with a palliative care patient, who do you usually contact?” (multiple response question). Overall, 41% of organisations contacted were medical centres (i.e. GP, doctors), 29% palliative care providers, 23% hospitals, 9% a telephone hotline, 9% Silver Chain and 4% the Royal Flying Doctor Service (Table 38a). Overall, 39% were in a GP position, 32% in a nursing position and 31% in a palliative care provider position (Table 39a). The results for this question by region are presented in Table 38b and 39b respectively.

Table 38a: Q30a Thinking about your health services, if there is a clinical problem with a palliative care patient, who do you usually contact - organisation

| | % of respondents (n=139) |
|-----------------------------------|--------------------------|
| Medical centres-GP, doctors | 41.0 |
| Hospital | 23.0 |
| Palliative care service providers | 28.8 |
| Hotlines | 9.4 |
| Silver Chain | 9.4 |
| Royal Flying Doctor Service | 4.3 |

**Multiple response question*

Table 38b: Q30a Thinking about your health services, if there is a clinical problem with a palliative care patient, who do you usually contact - organisation

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|-----------------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Medical centres-GP, doctors | 43.8 | 33.3 | 42.9 | 23.1 | 45.5 | 51.6 | 44.4 |
| Hospital | 31.3 | 33.3 | 42.9 | 26.9 | 27.3 | 6.5 | 22.2 |
| Palliative care service providers | 12.5 | 33.3 | 28.6 | 38.5 | 18.2 | 32.3 | 27.8 |
| Hotlines | 0.0 | 8.3 | 14.3 | 7.7 | 9.1 | 19.4 | 5.6 |
| Silver Chain | 12.5 | 0.0 | 0.0 | 11.5 | 0.0 | 19.4 | 5.6 |
| Royal Flying Doctor Service | 0.0 | 0.0 | 0.0 | 15.4 | 18.2 | 0.0 | 0.0 |

**Multiple response question*

Table 39a: Q30a Thinking about your health services, if there is a clinical problem with a palliative care patient, who do you usually contact – position

| | % of respondents (n=84) |
|--------------------------|-------------------------------|
| Nurse | 32.1 |
| GP | 39.3 |
| Palliative Care Provider | 31.0 |

**Multiple response question*

Table 39b: Q30a Thinking about your health services, if there is a clinical problem with a palliative care patient, who do you usually contact – position

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------------------|------------|----------------|-----------|---------|---------|------------|-----------|
| n | 13 | 9 | 4 | 17 | 5 | 18 | 18 |
| | % | | | | | | |
| Nurse | 23.1 | 22.2 | 50.0 | 35.5 | 40.0 | 38.9 | 27.8 |
| GP | 46.2 | 33.3 | 75.0 | 35.3 | 60.0 | 33.3 | 33.3 |
| Palliative care provider | 30.8 | 44.4 | 0.0 | 29.4 | 0.0 | 33.3 | 38.9 |

**Multiple response question*

Approximately three quarters of respondents reported having no formal links in place with a metropolitan specialist service provider (74%) (Table 40a). When broken down by region, 92% of respondents from the Great Southern reported having no formal links in place with metropolitan specialist service providers, as did 91% of respondents from the Pilbara, 81% from the Wheatbelt, 71% from the South West, 69% from the Midwest, 62% from the Goldfields and 43% from the Kimberley (Table 40b).

Table 40a: Q31 Do you have formal links in place with metropolitan specialist palliative care providers?

| | n | % |
|--------------|------------|--------------|
| Yes | 34 | 24.5 |
| No | 103 | 74.1 |
| Don't know | 2 | 1.4 |
| Total | 139 | 100.0 |

Table 40b: Q31 Do you have formal links in place with metropolitan specialist palliative care providers?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| Yes | 31.3 | 8.3 | 57.1 | 26.9 | 9.1 | 29.0 | 19.4 |
| No | 62.5 | 91.7 | 42.9 | 69.2 | 90.9 | 71.0 | 80.6 |
| Don't know | 6.3 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Overall, 72% of respondents reported having links in place with palliative care providers in their local health region (Table 41a). The Pilbara reported the lowest proportion of links in place with palliative care providers in their local health region (54%), compared with the Kimberley who reported the highest proportion of links in place with palliative care providers in their local area (86%) (Table 41b).

Table 41a: Q32 Do you have any links in place with palliative care providers in your local health region?

| | n | % |
|--------------|------------|--------------|
| Yes | 100 | 71.9 |
| No | 37 | 26.6 |
| Don't know | 2 | 1.4 |
| Total | 139 | 100.0 |

Table 41b: Q32 Do you have any links in place with palliative care providers in your local health region?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 62.5 | 83.3 | 85.7 | 65.4 | 54.5 | 77.4 | 75.0 |
| No | 37.5 | 16.7 | 14.3 | 30.8 | 36.4 | 22.6 | 25.0 |
| Don't know | 0.0 | 0.0 | 0.0 | 3.8 | 9.1 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Overall, the most common linkages in place with palliative care providers in local health regions was with palliative care units/teams (35%), hospitals (28%), Silver Chain (16%) and general health services (13%) (Table 42).

Table 42: Q32a If yes, what are the names of these services?

| | % of respondents (n=100) |
|-----------------------------|--------------------------------|
| Palliative care unit | 35.0 |
| Hospital | 28.0 |
| Palliative care coordinator | 9.0 |
| Palliative care nurse | 5.0 |
| Health service | 13.0 |
| Hospice | 8.0 |
| Silver Chain | 16.0 |
| Cancer nurse coordinator | 7.0 |
| Cancer care nurse | 6.0 |
| Respite | 2.0 |
| GP | 6.0 |
| Don't know | 5.0 |

Respondents were then asked how often they would make contact with these services (Table 43a), 48% reported “occasionally”, 8% “not really a lot”, 28% “sometimes” and 16% “all the time”. Table 43b presents the results by region.

Table 43a: Q32b How often would you make contact with these services?

| | n | % |
|------------------|------------|--------------|
| All the time | 16 | 16.0 |
| Sometimes | 28 | 28.0 |
| Not really a lot | 8 | 8.0 |
| Occasionally | 48 | 48.0 |
| Total | 100 | 100.0 |

Table 43b: Q32b How often would you make contact with these services?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|------------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| N | 10 | 10 | 6 | 17 | 6 | 24 | 27 |
| | % | | | | | | |
| All the time | 10.0 | 30.0 | 16.7 | 23.5 | 0.0 | 12.5 | 14.8 |
| Sometimes | 50.0 | 30.0 | 0.0 | 11.8 | 16.7 | 8.3 | 3.7 |
| Not really a lot | 0.0 | 0.0 | 33.3 | 11.8 | 16.7 | 8.3 | 3.7 |
| Occasionally | 40.0 | 40.0 | 50.0 | 52.9 | 66.7 | 45.8 | 48.1 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Sixty three percent of respondents reported that they access the Cancer Council WA, to provide care or support, followed by church groups (54%), Indigenous groups (29%), service groups – e.g. Rotary, Lions (19%), miscellaneous services (5%), HACC (4%), home care (3%), palliative care providers (3%) and grief services (2%) (Table 44a). Results for this question by region are presented in Table 44b.

Table 44a: Q33 Which of the following care services do you access to provide care or support?

| | % of respondents (n=100) |
|---|-----------------------------|
| Cancer Council WA | 63.0 |
| Service groups – eg. Rotary, Lions | 19.0 |
| Church groups | 54.0 |
| Indigenous groups | 29.0 |
| Other | |
| HACC | 4.0 |
| Home care | 3.0 |
| Grief services | 2.0 |
| Palliative care providers | 3.0 |
| Miscellaneous (i.e. meals on wheels, outreach services) | 5.0 |
| Don't know | 9.0 |

**Multiple response question*

Table 44b: Q33 Which of the following care services do you access to provide care or support?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|---|------------|-------------------|-----------|---------|---------|---------------|-----------|
| n | 10 | 10 | 6 | 17 | 6 | 24 | 27 |
| Cancer Council WA | 50.0 | 90.0 | 50.0 | 52.9 | 100.0 | 58.3 | 63.0 |
| Service groups – eg. Rotary, Lions | 10.0 | 50.0 | 0.0 | 11.8 | 0.0 | 12.5 | 29.6 |
| Church groups | 50.0 | 50.0 | 50.0 | 52.9 | 50.0 | 66.7 | 48.1 |
| Indigenous groups | 0.0 | 20.0 | 83.3 | 47.1 | 66.7 | 12.5 | 25.9 |
| Other | | | | | | | |
| HACC | 0.0 | 10.0 | 0.0 | 0.0 | 16.7 | 0.0 | 7.4 |
| Home care | 0.0 | 20.0 | 0.0 | 5.9 | 0.0 | 0.0 | 0.0 |
| Grief services | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 4.2 | 3.7 |
| Palliative care providers | 10.0 | 0.0 | 0.0 | 11.8 | 0.0 | 0.0 | 0.0 |
| Miscellaneous (i.e. meals on wheels, outreach services) | 10.0 | 10.0 | 0.0 | 0.0 | 16.7 | 0.0 | 7.4 |
| Don't know | 10.0 | 0.0 | 0.0 | 11.8 | 0.0 | 4.2 | 18.5 |

**Multiple response question*

Eighty eight percent of respondents reported that in the event of a staff member struggling with issues relating to caring for palliative care patients, their health service provided access to a staff support service (Table 45a). When analysed by region, majority of all regions reported access to a staff support service (Table 45b).

Table 45a: Q34 In the event that staff were struggling with issues relating to caring for palliative care patients does your health service provide access to a staff support service?

| | n | % |
|--------------|------------|--------------|
| Yes | 123 | 88.5 |
| No | 14 | 10.1 |
| Don't know | 2 | 1.4 |
| Total | 139 | 100.0 |

Table 45b: Q34 In the event that staff were struggling with issues relating to caring for palliative care patients does your health service provide access to a staff support service

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 81.3 | 91.7 | 85.7 | 76.9 | 90.9 | 87.1 | 100.0 |
| No | 12.5 | 8.3 | 14.3 | 19.2 | 9.1 | 12.9 | 0.0 |
| Don't know | 6.3 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Just over one half of all respondents reported that before the time of the survey they had not heard of the 1300 palliative care outreach medical advisory number (56%). The Great Southern region had the highest proportion of respondents reporting that they had heard of this number (67%), the Goldfields were the least likely to have heard of the number (25%) (Table 46b).

Table 46a: Q35 Before today had you heard of the 1300 palliative care outreach medical advisory number

| | n | % |
|--------------|------------|--------------|
| Yes | 60 | 43.2 |
| No | 78 | 56.1 |
| Don't know | 1 | 0.7 |
| Total | 139 | 100.0 |

Table 46b: Q35 Before today had you heard of the 1300 palliative care outreach medical advisory number

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 25.0 | 66.7 | 28.6 | 46.2 | 27.3 | 58.1 | 36.1 |
| No | 75.0 | 33.3 | 71.4 | 50.0 | 72.7 | 41.9 | 63.9 |
| Don't know | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Just over one third of respondents (35%) had used this service in the past 12 months, with 17% using it five or more times (Table 47a). The results for this question analysed by region are shown in Table 47b.

Table 47a: Q35b If yes, how many times approximately in the last 12 months has your service used it?

| | n | % |
|--------------|-----------|--------------|
| 0 | 28 | 46.7 |
| 1 | 3 | 5.0 |
| 2 | 5 | 8.3 |
| 3 | 2 | 3.3 |
| 4 | 1 | 1.7 |
| 5 or more | 10 | 16.7 |
| Don't know | 11 | 18.3 |
| Total | 60 | 100.0 |

Table 47b: Q35b If yes, how many times approximately in the last 12 months has your service used it?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 10 | 10 | 6 | 17 | 6 | 24 | 27 |
| | % | | | | | | |
| 0 | 25.0 | 50.0 | 50.0 | 58.3 | 66.7 | 33.3 | 53.8 |
| 1 | 25.0 | 0.0 | 0.0 | 0.0 | 0.0 | 5.6 | 7.7 |
| 2 | 0.0 | 12.5 | 0.0 | 16.7 | 0.0 | 5.6 | 7.7 |
| 3 | 0.0 | 12.5 | 0.0 | 0.0 | 0.0 | 0.0 | 7.7 |
| 4 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 5.6 | 0.0 |
| 5 or more | 0.0 | 25.0 | 0.0 | 8.3 | 33.3 | 27.8 | 7.7 |
| Don't know | 50.0 | 0.0 | 50.0 | 16.7 | 0.0 | 22.2 | 15.4 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Approximately one half (50%) of respondents had heard of the Silver Chain Hospice Care Services' Rural Telephone Nurse Advisory Service number before the time of the survey, respondents from the Great Southern region were most likely to have heard of the of the number (67%), followed by the South West (61%), Goldfields (56%), Wheatbelt (47%), Midwest (46%), Pilbara (36%) and the Kimberley (14%) (Table 48b).

Table 48a: Q36 Before today had you heard of Silver Chain Hospice Care Services' Rural Telephone Nurse Advisory Service number?

| | n | % |
|--------------|------------|--------------|
| Yes | 70 | 50.4 |
| No | 68 | 48.9 |
| Don't know | 1 | 0.7 |
| Total | 139 | 100.0 |

Table 48b: Q36 Before today had you heard of Silver Chain Hospice Care Services' Rural Telephone Nurse Advisory Service number?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 56.3 | 66.7 | 14.3 | 46.2 | 36.4 | 61.3 | 47.2 |
| No | 43.8 | 33.3 | 85.7 | 50.0 | 63.6 | 38.7 | 52.8 |
| Don't know | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Approximately 30% of respondents who had heard of the number had used the service in the last twelve months, 9% of respondents used it once, 7% twice, 3% three times, 1% four times and 7% more than five times in the last twelve months (Table 49a). Table 49b shows the results for this question analysed by region.

Table 49a: Q36b If yes, how many times approximately in the last 12 months has your service used it?

| | n | % |
|--------------|-----------|--------------|
| 0 | 42 | 60.0 |
| 1 | 6 | 8.6 |
| 2 | 5 | 7.1 |
| 3 | 2 | 2.9 |
| 4 | 1 | 1.4 |
| 5 or more | 5 | 7.1 |
| Don't know | 9 | 12.9 |
| Total | 70 | 100.0 |

Table 49b: Q36b If yes, how many times approximately in the last 12 months has your service used it?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 9 | 8 | 1 | 12 | 4 | 19 | 17 |
| | % | | | | | | |
| 0 | 44.4 | 75.0 | 0.0 | 58.3 | 50.0 | 52.6 | 76.5 |
| 1 | 22.2 | 12.5 | 0.0 | 8.3 | 0.0 | 10.5 | 0.0 |
| 2 | 11.1 | 12.5 | 0.0 | 8.3 | 0.0 | 5.3 | 5.9 |
| 3 | 11.1 | 0.0 | 0.0 | 8.3 | 0.0 | 0.0 | 0.0 |
| 4 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 5.3 | 0.0 |
| 5 or more | 11.1 | 0.0 | 0.0 | 0.0 | 25.0 | 15.8 | 0.0 |
| Don't know | 0.0 | 0.0 | 100.0 | 16.7 | 25.0 | 10.5 | 17.6 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Overall, just over one half of respondents reported having special local issues relating to palliative care (56%) (Table 50a). The South West region reported the greatest proportion of special local issues (74%), compared with the Midwest who reported the least (46%) (Table 50b). Table 51 shows the brief descriptions of what the local issues are and Table 52 presents respondents responses to “what are the most important changes to improve palliative care in your local health area?”

Table 50a: Q37 Do you have any special local issues relating to palliative care?

| | n | % |
|--------------|------------|--------------|
| Yes | 78 | 56.1 |
| No | 61 | 43.9 |
| Total | 139 | 100.0 |

Table 50b: Q37 Do you have any special local issues relating to palliative care?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| | % | | | | | | |
| Yes | 50.0 | 50.0 | 71.4 | 46.2 | 63.6 | 74.2 | 47.2 |
| No | 50.0 | 50.0 | 28.6 | 53.8 | 36.4 | 25.8 | 52.8 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Table 51: Q37a If yes please describe briefly

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- Distance - the pats system does not allow for an escort, that is a family member, when they have to travel to Perth for diagnosis and treatment. For some of these people it is the first time they have been to Perth
 - It would be good if we had someone to come in and help us develop a care plan for clients
 - Our isolation, it's hard for patients to get to health services. It takes people hours just to get to a hospital
 - Very stretched out - we are very far away from support services and help. Once a gentleman died and we couldn't reach help. We called for help on a Thursday and over the weekend he died and we only heard from the hospital on Tuesday
 - The distance from anywhere else. There is a lack of staff, also a lack of all resources. We just don't have the staff to provide the service
 - Lack of resources and staffing, people that want to die at home don't have that choice because there aren't the resources, they have to go to the hospital because there just aren't the resources to allow people to die at home
 - Maintain both staff and skills with low patient numbers
 - Distance, difficulty in getting equipment, special care items like pressure mattress and lamb's wool underlays takes forever to get here and then the cost to get them
 - Lack of resources in this small community
 - Just the distance, we are very isolated, our palliative care patients are elderly. The problem is transporting them, they want to have their family there and there needs to be accommodation for them
 - It was really full on when I had to provide this service, I had to do a blood transfusion and organise that all here, it was a couple of weeks of a real mental struggle. I didn't have anyone here to debrief to, it would be nice to have someone
 - There is not a plan or resources for people to die at home, we had one palliative bed and the indigenous people didn't want to be in that bed because it is the dying bed
 - Supply - if they need a proper bed, some have to use their home mattress, getting a wheelchair, just simple palliative care equipment. Transport - need to be transported and people don't have the money and pats won't pay
 - We don't get paid for providing this service
 - Around here, it tends to be mostly indigenous care, we provide holistic care, there are a lot of communication difficulties and cultural difficulties, their perception of death is very different. Also the arrangements for funerals are very difficult
 - I'm a sole nurse in an isolated area, palliative care is definitely the most difficult thing that I have to do, it's a one-to-one basis here and it's very, very difficult
 - Lack of registered nurses to provide home care
 - Transport - no public transport for patients and families, if necessary we have to use an ambulance which we then have to fund
 - Our isolation - being isolated makes it hard for us to go and help patients out where they live. Also we are only open 5 days a week and some people do require care which is after hours but we can't provide that service
 - The main issues I think is education and training - some of the patient's carers can be quite technical with types of infusion pumps etc and staff need to have proper education and training
 - The whole networking - need to have policy and process in place, we need to be advised of the situation with the patient. To be linked into the specialist on going care plan
 - We have no hostel or aged care facility. We work with our resources of two nurses and one aboriginal health worker
 - A lack of trained staff across the board
 - I don't think that the palliative care service into the community is as available as it should be and as available as it was before it was taken over by the hospital. I feel that people aren't getting the support that they should be getting
 - Identified need in this community but it hasn't been financed well, the coordinator gets little support, her time is shared between palliative care and her duties as a clinical nurse
 - Because we are isolated it is difficult to give palliative care in their own homes
 - When palliative care patients are sent to Perth sometimes we don't get feedback or get it later than we should
 - We have so many Indigenous patients so there are lots of cultural issues - we have to be aware of the cultural differences and sometimes it can be hard. We need more indigenous health support services that can help and assist us
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- Travel for palliative care patients to Perth for treatment is an issue if they are not an in-patient. This is an issue because the hospital cannot provide the transport
 - Getting services into a client's home when they live remotely. Ability to die at home when they live remotely is difficult. To access emergency symptom control you have to drive to the hospital - excellent care in town but nearly impossible out
 - I would like to have a special room that is required for palliative care, there needs to be a more 'palliative friendly' room, one of our double rooms should be made into this
 - GP training - because my GPs don't have a background with palliative care, they don't know much about how to deal with it. They need more training and education to enlighten them
 - Hard with lack of staff
 - It is hard to network because we are so isolated and far away
 - We couldn't provide intensive home nursing, staff levels and retaining staff, can't release staff for these jobs, not enough permanent staff
 - Indigenous, cultural issues e.g. when someone dies at home that house must be vacated for some considerable time, if that house has had several families living there then they must all leave, in small communities this causes major problems
 - Our population is an aging one and it would be nice to have more support for people here, but because of lack of resources and staff we can't really help them as much as they need it, we need to have access to support services even if they can't
 - Oncologists are reluctant to send patients to their community
 - We're a big area, there is nothing formal here, it's very ad hoc
 - Ability and funding and the staff to provide after hours care
 - Lack of resources for our patients because of their isolation. They don't get appropriate access to allied health services because we just don't have them here, lack of knowledge that the local GP has in regards to palliative care
 - Some GPs are reluctant to refer patients to palliative services early in their treatment
 - 80-90% of our patients are indigenous, the cross-cultural considerations are significant, most of the palliative care guidelines are not built for a traditional indigenous culture so supporting and training staff around that is challenging
 - Having better facilities if we have more than one in patient. Having have right sort of environment for palliative clients from the community volunteers. To be able to provide professional support e.g. trained staff
 - Geographical isolation - because we are so remote and isolated patients have to travel really far to the nearest major centre and this can be a major issue and also they have problems with transport and it takes a long time
 - When aged care turns into palliative care, some of our aged care clients are really palliative care but can only be admitted as a medical patients. There really is a lack of organised palliative care especially as most of our clients are Indigenous
 - Lack of staff support - we are a one man station and its hard to get staff support, when the staff are having a tough time they have a number to call its called prime but that's not good enough, its nice to talk to someone about issues in person
 - Geographical distances - it is hard to provide in home care and it can be very difficult
 - Because we cover a large area and our clients can be an hour away
 - Difficulty in getting staff here that have relevant expertise. After hours care and 24 hour care in the homes of patients
 - Transportation when recumbent aged care residents have to go to main hospital for review. Volunteer service, problem when can't be carried in a car, ambulance emergency only
 - Nursing staff shortage we really need more nurses, it' also hard because we provide after hours care in the home but its not formally done, so they just choose to do it so the only way to help the nurses is to have more staff, more nurses
 - No training in the hospital so sometimes hard to get support e.g. to know drugs of choice
 - Well the main thing is our isolation - because of this we don't have good networking and communication. I mean we do liaise but it would help us if there was a network for all palliative care to fall under one umbrella
 - We're just finding it hard to get education, have had a couple of education sessions in the past few months, we would like more education here, it needs to be more accessible so more people will attend
 - The GPs are not trained in palliative care support and management, it is very frustrating as they don't know what to do in most cases in organising medication and pain control
 - No visiting specialist so would like help when pain is difficult to control
 - It is a fact that palliative care patients here are classed as a number on the wards and there is no extra funding available for them yet they are high maintenance patients
 - Would be nice to have a dedicated unit in the hospital, a qualified doctor for palliative care
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- Would like to be provided with additional resources to provide funding. Palliative resources come from the hospital then that depletes the hospital supplies. We need the use of a car
 - Distance - by the time we get equipment to the client they have died, it takes too long to get equipment to and from places, some of the equipment is old and needs to be updated. Lack of education for staff, the staff turn over is very high
 - After hours and weekends are a problems for us, we can't get the patient's own GP, locums are reluctant to provide medication that we think is suitable Lack of knowledge of the GP, they need more palliative care training
 - Currently we don't have appropriate and efficient palliative care coordination from the hospital but clients are well supported in the community
 - Need increased funds and to increase hours local palliative care nurse can provide with her services
 - No coordinator for the service which makes things hard – it's hard to get access to the different support services. Also we have problems referring patients to palliative care specialists because the hospital refuses to take them
 - Would like a 4 bed unit when the new hospital is built with the funding to pay coordination of the hospice. Like more funding for community palliative care
 - In our local situation where the palliative care beds are located in position is very inappropriate, they are in a noisy corridor with a lot of through traffic to theatre and they have no access to the chapel. The environment is too noisy
 - Need to have regional palliative care for the whole wheat belt, it needs a coordinator. I can't go over my boundary by one yard, I do some phone call support but that's it. There are areas that are not serviced
 - Limited transport options for patients to get to specialists in Perth. There are no buses or options that patients can use when they need to go to Perth for specialist care. That really needs to be improved
 - Lack of funding for palliative services, also it is difficult to find qualified staff who are experienced in palliative care. The salaries of the staff here are very low in comparison to other remote areas
 - Governance structure with <town> palliative care service, here is not good governance of the money, roles not clearly defined
 - Lack of chaplaincy services, no paid volunteers coordination
 - Increase support service for us, nurses, carers and the GPs. Increase beds
 - Aboriginal health, more staffing, budget for Aboriginal health
 - I think it's a big need for such a small service, we certainly need clinically trained palliative care nurses to offer service and support
 - Treatment for the client, the distance the patients have to travel for care
 - We require more funding to improve the palliative care services here
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Table 52: Q38 What would be the most important change to improve palliative care in your local health area

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- Increase staffing so we could provide more after hours services
 - Very small area, the rest are transient
 - Advice line would be the most helpful, because it is so infrequent that we need the help. Regional coordinator would help us to keep up to date with things like standards, instead of having to access the tertiary centres all the time
 - We need to be able to link with the patient's GP or specialist in Perth and be advised of the situation of the patient and what their on going care plan is - because we don't have many palliative care patients we don't know how to manage
 - A big influx of money to provide 24 hour care in some situations when clients and their families wish to die at home. If we had regional and rural access to treatment clinics for chemotherapy and dialysis for long term patients would be great
 - Advertising the service
 - Temporary residents only, remote area nurse - very limited resources, need at least 10 days notice if there is to be a palliative patient
 - Education for staff on how to care for palliative patients, updates on current issues and management
 - More staff training and updates
 - More community support, community nursing for terminal care, having the 1300 number to call has been valuable
 - Given the services we already have I don't think we need anything else, our community is young so we don't really require anything here, plus we already have other places to send people to if need be but we hardly ever do that
 - Probably education for the staff and training basics about how to care for palliative care patients, we could also benefit from a formal booking system for palliative care clients as this would put things in more order
 - No home and community care available. Patients tend to relocate to other areas, links are in place via other places if ever required
 - Better access to a support person for advice
 - I think having a palliative care team, we need people with specific training and the ability to be on call to come anytime
 - Accessibility - patient transport to regional centres. Increase the video linkup that already exists
 - The resources - we just need the funding to actually employ people, also being able to have the extra staff when you need them
 - To have a car to go out and provide palliative care. Communication system as mobile phones are not much good here sometimes
 - Consultant for me to access things for me so I'm not running around trying to find what we need, where we can get it and how we can get it here or to organise things for when someone comes home to died
 - Finances are certainly always a huge issue, there isn't enough funding for palliative care, then comes human resources - lack of staff, then comes education and knowledge to execute palliative care to the highest standard possible
 - Access to telephone advice and counselling for families, patients and carers
 - More education for the staff, more knowing of who to contact and what to do, also more up-to-date resources
 - We just aren't doing enough, that is, we don't have enough patients to make any judgement, our clients are very different and come from very different families. I'm not unhappy with how the services are progressing
 - It's really just having medical staff to support you through it, my local doctor wasn't here, I only had direction from Perth, I needed more medical back-up
 - Money and people! Access to resources, after hours resources as well. Access to people who can give clinical advice
 - Having access to appropriate house care for patients 24 / 7
 - I think they should have a booklet with palliative care pathways and up to date information about who to contact in our area for support services, for example if I need to find a social worker in our area it would be nice to know how to contact
 - Get the palli-care coordinator establish, then put into place policies and training for the staff
 - Probably more staff education, most of our staff are not trained in palliative care
 - Recognition that there is a need for palliative care in rural areas, some access to temporary funding when the need occurs, a referral person apart from the cancer nurse
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- I suppose some training would be useful, again, the hospital looks after everyone from birth to death, because the majority of the demographic are young people, we mainly specialise in child care and maternal care
 - Communication with consultants earlier, ongoing care issues for chronic illnesses, early communication with clients, before crisis or before they are too sick to make decisions
 - We have no respite care, no medical facilities here, need to be able to have patients to stay over night
 - I'm happy with the services provided, I'm happy with the direction, I'm happy with the support that I get
 - Try to meet their needs as they present, work with them and their families, if they don't want to stay in hospital, allow them to stay at home providing they aren't too far away
 - More staff training for necessary skills when required, update of current methods and treatments
 - To have a local doctor
 - Increased access to nursing services, there is only one of me and I do everything and it's just too hard, we need more nurses to do the job, also we need more up to date training to be available in palliative care
 - We need more access to the different support services, that would really help us and the service that we can provide to our patients, for example we have one man who was in palliative care and he wanted to see a counsellor in his last days
 - More education for staff regarding new ways in palliative care
 - Not enough staff, well it's hard to say because we don't have any palliative care patients so I don't really think there is anything
 - We think we are doing it really well with what we have but access to more equipment would be good things like morphine pumps and mattresses etc. we could really do with more equipment
 - To have coordinated network, clinical pathways
 - I think we need more education about medications and pain control management, I think that's our biggest issue
 - More resources for people to be able to stay at home in the last stages of their life, all the old people have to leave town
 - To have access to after hours staffing support
 - Better communication between medical practitioners and us, they really need more training in palliative care
 - Palliative care would improve with the help of the rural cancer nurse coordinator once she has established her service
 - Only one doctor, from overseas, different cultural background, has trouble with issues relating to death
 - Because the service is delivered from an acute hospital service, they don't understand the needs of patients, it would improve if a designated person could go out into the community as and when they are required
 - More support for coordinators role, better communication with the stakeholders
 - Education of the staff in management of palliative care patients like in the issue of pain relief
 - To have a standardised plan for people to use
 - Sometimes a problem with delays e.g. seeing a minister of religion
 - More aboriginal staff to provide more support for the patients
 - Building structure that houses palliative care needs to be renovated to give it a pleasant site and possibly a garden with fresh flowers and window views
 - Probably better communication between the delivering services, it would probably be quite good to have meetings with the people in our region
 - More staff, nurses and carers, access is hard as it is remote, anything that improves access would help
 - More funding to provide more staff to remote areas
 - Having access to information on a staff level, the hotline number is a good idea but we've never heard of that before, we need to have more access to guidelines and information, for example, pain relief to help us give the best quality care
 - GP training - GPs should be trained to learn more about palliative care and how to use it properly
 - Feedback from metropolitan hospitals on our clients medical needs, it is lacking when they are referred back to us
 - More staff
 - Networking between the three palliative care services
 - A designated nurse for palliative care
 - Home visits and family support by provision of more staff and more funding
 - Letting patients have their terminal rights
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- We need a clinical nurse coordinator to come out and give education to the staff for specific patients, that would really help the staff and the patients. The staff really need someone to come in regularly and support them and teach them
 - We really need to have someone who can coordinate palliative care, we need to be able to get a team together
 - A bit more access to palliative care training for staff
 - A support group for palliative care patients in the region
 - Lack of medical knowledge with pain management in the local community, the people that access our facilities. The nurses are great when it comes to palliative care but the doctors need to be educated
 - I think the GPs knowledge of symptoms related to palliative care is the most important thing that needs to be addressed, in particular pain management, need to give appropriate dosing and prescribe the right medications
 - Maybe more quality staff
 - Increased funding so the carers could give more care to patients and family, both physical and mental and emotional
 - Improved doctor nursing communication, some doctors withhold some patient information and seeing a patient in the first instance when they are unstable and in a phase of deterioration does not help best practice
 - Access to clinical knowledge and support
 - Access to equipment that is required, we need more beds and wheelchairs, we definitely have a need for more equipment and resources
 - Addressing the guidelines so that they can be more specific to the needs of an indigenous culture
 - Protocol, clinical nurse specialist, we have no allocated funding for palliation, department of health fund palliative to silver chain but they don't provide palliative care in the <town> community, but they get the funds, but we provide the care
 - More liaison with the cancer care nurse or like a coordinator as you mentioned in the survey
 - To up facilities for palliative care especially for the local indigenous population
 - Well we have found that doctors are not really diagnosing patients when it comes to palliative care them seem to not want to get involved
 - Support for the staff and educating them, the staff go through a really hard time dealing with palliative care and support is really important for them, calling some number isn't good enough there should someone they can talk to in person
 - Improvement and flexibility with funding requirements - we currently only get funded for 7 hrs of palliative care per week and that is insufficient time if we have several palliative patients requiring care
 - 24 hour care to the homes of patients
 - The transportation of residents for review and treatment modification in the public sector, need for transport vehicle that is non urgent when patients must lie down
 - Having a regional coordinator
 - I would like to utilize the existing palliative care service but expand them to have more staff and we need to have regional meeting to enhance our communication. We also need to have some staff education programs about palliative care
 - A support system providing help by phone, issue then of confidentiality. More training for staff
 - All palliative care needs to come under one organisation instead of being split up into three different towns because it makes networking hard
 - More staff - we don't have a palliative care person available because we are far out and it is very hard to find replacements when a staff member is sick or on leave, it is hard because not everyone is trained in palliative care
 - Probably easier access, the hotline is good but it would be better if we could get someone to come in and look at the patient
 - Better informed GPs on palliative care matters
 - Regional coordinator for palliative care, palliative care team, palliative care person, equipment
 - Access to counselling services for the families
 - To have more funding made available for these services
-

Around 30% of respondents reported that in their clinical opinion, there were patients that their service provided care to who had needs that should normally require referral to a specialist palliative care service, however for some reason a referral was not made (Table 53a). Forty percent of respondents from the Pilbara reported the largest proportion of patients who had needs that would normally require referral to a specialist palliative care service though a referral was not made. This compared with 19% of respondents from the Goldfields who had the smallest proportion (Table 53b). Table 54 presents reason why a referral was not made and Table 55 shows final comments from respondents.

Table 53a: Q39 In your clinical opinion are there patients that your service has provided care to who have needs that should normally require referral to a specialist palliative care service though for some reason a referral is not made?

| | n | % |
|--------------|------------|--------------|
| Yes | 40 | 28.8 |
| No | 99 | 71.2 |
| Total | 139 | 100.0 |

Table 53b: Q39 In your clinical opinion are there patients that your service has provided care to who have needs that should normally require referral to a specialist palliative care service though for some reason a referral is not made?

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 12 | 7 | 26 | 11 | 31 | 36 |
| Yes | 18.8 | 33.3 | 42.9 | 19.2 | 45.5 | 41.9 | 19.4 |
| No | 81.3 | 66.7 | 57.1 | 80.8 | 54.5 | 58.1 | 80.6 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Table 54: Q40 Why wasn't a referral made?

- Managed them locally
 - Encouragement for the GPs to use specialist practitioners, they are reluctant to use the phone specialist line (1300 number)
 - With Indigenous patients, the distance is too far for them to travel and they don't wish to leave their homes
 - Patient not in a good condition to travel to the service
 - Our medicos are too stubborn to do it, they know better, they are improving. They are worried that they might kill the patient and they might go to jail
 - Ownership by the doctor
 - We work in conjunction with GP service, it often seems that palliative care isn't something they give priority to
 - Our GP didn't make a referral, he has been our GP for a long time and it's his way or the high way
 - The GP didn't want to refer he wanted to care personally
 - Lack of awareness of doctor
 - GPs don't see it as a specialty area
 - Delay in referrals, left a bit too late, hospice sounds like final stages
 - The client refused to have any extra service
 - The doctor thinks they can manage locally
 - Doctor refused to allow referral
 - A reluctance to refer on and a reluctance to listen to advice, the overseas trained doctors like to own the problem and don't like advice from us
 - As most of our patients are Indigenous, they want to die in their community, there is no specialist facilities available for care in the community, care needs to be worked on an individual basis as to what the family and the patient want
 - The doctor just won't refer, no reason
 - The GP not wanting to access the specialised care they think they know it all
 - Mostly it is in relation to a change in medication for patient that we think the patient should have made by the GP and the GP at times does not listen and prescribe that change of medication
 - The GP wants to deal with it themselves and they don't deal with it effectively, pain control mainly and nausea
 - In a case of sudden death, when a patient suddenly dies, there hasn't been a referral process as it has been too late
 - Well when we refer the patients to hospitals they won't take them, its because they have a certain amount of private beds and public beds and they just won't take our patients
 - There are some health providers in town that don't realise that their patient is outside their area of skills and expertise, that they really should refer the patient to palliative care
 - Patient choice, want to stay in rural area
 - The patient does not want to go to Perth, they don't want to leave home, GP has not realised the benefits that patient would get by travelling to a specialist palliative service
 - Sometimes the health specialists don't realise that the patient actually requires specialist care so then a referral is not made
-

Table 55: Do you have any final comments?

-
- Need to have a better awareness on Indigenous expectation and protocol, there needs to be a formal procedure in place so any one can pick it up and know what to do. It is hard to train the staff because they are mostly agency staff
 - There are many times we have actually made referrals but the patients have not attended them this is probably because of the distance to get there and also some of them would sacrifice expert care to stay in their community
 - It's a very difficult area to deal with, there is a lack of staff and support, there is also a real lack of infrastructure
 - I think they need to look at the rural sector harder because it is a big section
 - Well as I said we really need some kind of booklet or even just a laminated sheet listing all the different care and support services that are available, so if we do need access to palliative care we know that these are the services available
 - Our Indigenous clients don't accept care regularly, they want to be in their own environment. If there is a particular clinical issue where we need to be able to manage the patient, we need to be able to contact metropolitan specialists
 - As with the cancer network it would be good to have a similar network set up that provided knowledge and all training on a regular basis
 - I just want to say that the support we get from the regional palliative care service is just brilliant they really have a great relationship with us and are great to have, I think GPs could have a better understanding about the use of morphine
 - Have a high turn over of staff, mostly agency staff so that makes it hard for training and for people to build up local knowledge, need to have better awareness of indigenous expectations in time of a family death
 - Tyranny of distance, no resources readily available
 - It was good and interesting and we are glad that someone is looking into palliative care in rural and remote areas
 - Foreign trained doctors need specific information and support relating to palliative care choices and options
 - I'd love Silver Chain to get the palliative care service back, because we are community oriented, we understand the difference between the needs of clients, we are out and about all the time, we can see the patients when they need to be seen
 - What we need is to be kept up to date with the latest in pain relief
 - There is a bit of a problem with dealing with different doctors in our region in getting their individual perceptions on what medications need to be used with palliative care patients for pain relief
 - There needs to be a lot more done to provide community services and access as alternative to hospital, more funding for this, people want to be able to die at home
 - We do have a palliative bed, standard of general hospital nursing not up to intensive palliative nursing, we are a long way from a regional centre so cant come home to die or be close to family at end of life
 - We've seen all the advertisements about talking to your GP if you require palliative care services, but where are the doctors going to refer the patients? There is nowhere, I'm hoping that this information collected actually does something
 - Basically we can get what we need when we need it
 - We had a patient who died with vomiting and it could have been resolved quickly if we had the specialists and medication but we didn't so the person had to keep vomiting until he died, things like that can be resolved by the GP
 - Difficult in an aged care setting to always cope, it is dealing with dieing all the time and the staff have not been trained for palliative care, we need to up skill, we also need to debrief with the caring staff after a death
 - We have access to a palliative coordinator across our region who is a very good nurse
 - It's an issue that has to be dealt with properly, acute issues have a heavier weighting and the long term ones get overlooked
 - A lot of the patients that we have are Malay, they have a very different way of dealing with palliative care, for example, they prefer to die at home so they will discharge themselves from hospital to return to their homes to die
 - I think the HACC system who assess the people for palliative care don't look ahead and do something about the lack of facilities which is getting worse, there is a lack of planning in this state, they keep the older aboriginal population alive
 - We do need some education and support for staff in the rural communities. Most places are a one man band and there really isn't any support
 - Needs adequate regional coordination
-

-
- Define point of palliative care, we are an aged care facility, some people consider this is end of life stage
 - As an aged care centre all patients are residents and in these answers all questions are relating to terminal care
 - GPs have not interest in palliative care and just don't believe in it, they don't want to talk about it, they need to be educated because they come from all different cultural backgrounds and they bring their beliefs with them
 - The residents deserved the same supports as the metro region has, further training of GP in palliative care, end of life issue, GP can't cope with medicating a dying person, they are afraid of hastening a death even though the patient is dying
 - No longer have a team of trained volunteers that was set up by Silver Chain, not maintained since the hospital took over. Equipment not maintained or added to since then, palliative care has lost its voice
 - Don't want to see any more project officers appointed, I'd like to see funds going direct to patient care, funding for rural transport, people want to be able to be looked after at home, more use of technology e.g. webcam and computers
 - We have really improved service, having the hospice operate under private contract and attached to the hospital has been very good
 - I feel that the GPs in this area too often make a late diagnosis of a patient as a palliative care patient and as such they keep them in acute beds too long so that often when I get a patient referred it is too late
 - <hospital> has helped us with equipment such as pressure mattress, it would blow our budget if we have to buy one ourselves, they give us a lot of support and we refer to them a lot
 - Supporting staff, we don't get a lot of support, staff dealing with home deaths and family situations can get quite burnt out and I think we need support for that, sometimes the worker get forgotten
-

4. Discussion

Provision of services and patient care/outcome

Overall, community palliative care was the most common type of service provided by organisations. This was the case in the Goldfields, Great Southern, Midwest, Pilbara and Wheatbelt regions. Hospitals were the most common service in the Kimberley and long term care was the most common in the South West. Most organisations cared for between one and five palliative care patients in the past 12 months. Approximately three quarters of patients had a cancer diagnosis and approximately one half had a non-cancer diagnosis, (cardiovascular disease was common in all regions apart from the Kimberley and South West where respiratory failure was the highest non-cancer diagnosis). Hospitals/health centres were the most common place in all regions where palliative care deaths occurred and the most common problem with certification of death was access to a doctor for signing. Most of the palliative care referrals came from local or regional centres, with medical referrals the most common type (these were also the most common type of referrals from tertiary sites such as Perth).

The Kimberley region cared for the greatest proportion of Indigenous palliative care patients and babies, children and adolescents, they also had the greatest proportion of palliative care deaths in their health service in the past twelve months. They encountered the least amount of problems with certification of deaths and the lowest proportion of bed shortages for their palliative care patients. The Kimberley also reported the greatest proportion of formal allocation process for palliative care.

The Pilbara region cared for the lowest proportion of babies, children and adolescents, encountered the least amount of palliative care deaths in their organisations however reported the greatest proportion of problems with the certification of deaths. The South West cared for the least amount of Indigenous palliative care patients and encountered the greatest bed shortage for their palliative care patients, this region also had the lowest proportion of a formal allocation process for people to palliative care.

Delivering palliative care

The Great Southern region was most likely to have a multidisciplinary team that met to discuss the provision of palliative care services for patients, and had the greatest proportion of referral processes to another service if there was a bereaved family member with problems (palliative care unit/team was the most common service family members were referred to and GP and counselling services were the most common referral for bereaved families to consult with). This region had the greatest proportion of staff trained in palliative care (overall the most common types of training include; in-service training, PEPA and palliative care courses) and were the most likely to provide after hours palliative care support (all regions reported high proportions of staff being paid to deliver this service).

The South West had the greatest proportion of awareness of the 2005 “Standards for providing quality care for all Australians” (overall, over half of all respondents who were aware of these standards reported that their organisation had implemented them). They also had the highest proportion of planned bereavement processes to support families following the death of a patient (overall this was mostly provided for as long as needed apart from in the Kimberley region).

Midwest respondents were least likely to report having a multidisciplinary team that met to discuss the provision of palliative care services in their region. The Pilbara was the least likely to have staff trained in palliative care and least likely to have a referral process in place for bereaved family members. The Kimberley had the lowest proportion of respondents reporting after hours palliative care support and the Wheatbelt region were the least likely to be aware of the 2005 “Standards for providing quality care for all Australians”.

Overall, doctors and nurses were the most likely health professional to comprise multidisciplinary teams. Physiotherapists and chaplains/religious leaders as well as doctors and nurses were the most common health professionals organisations accessed to provide care to patients and their families. Majority of respondents strongly agreed

or agreed that there was a need for a clinical nurse consultant to coordinate palliative care access in their region.

All regions apart from the Pilbara reported a person responsible for the coordination of palliative care services in their health region (in all regions this person was mainly a nurse). In the goldfields a small proportion of respondents reported that the coordination was their sole responsibility, whereas around half the respondents from the Great Southern region reported it was their sole responsibility.

Assessment and care planning

A majority of respondents strongly agreed/agreed that standardised palliative referral systems, protocols, care plans and clinical pathways would improve care. The Midwest region showed the highest level of agreement and the Great Southern Region showed the lowest level of agreement.

Approximately one half of organisations collected specific information on their palliative care patients and a majority of these organisations retained the information as a hospital record. The Kimberley region collected the greatest proportion of information, however the South West region retained the most for hospital records. The Pilbara was shown to collect the lowest proportion of specific information on their palliative care patients and lowest proportion of retaining information for hospital records.

Links support to deliver services

Medical centres were the most common organisation contacted if there was a clinical problem with a patient and general practitioners the most commonly contacted position. The Kimberley had the greatest proportion of formal links in place with metropolitan specialist palliative care providers (Great Southern region had the lowest proportion), and links in place with palliative care provides in their local area (Pilbara had the lowest proportion) (most common provider in local regions were the palliative

care units and contact was made only occasionally). Overall the most common care services accessed to provide care and support was the Cancer Council WA.

The Great Southern region was the most likely to have heard of the 1300 palliative care outreach medical advisory number (Goldfields least likely) and the Silver Chain Hospice Care Services' Rural Telephone Nurse Advisory Service number (Kimberley least likely). Overall, approximately one half of respondents had made use of the 1300 palliative care outreach medical advisory number in the past twelve months and less than half had used the Silver Chain Hospice Care Services' Rural Telephone Nurse Advisory Service number in the past twelve months.

Majority of respondents in all regions reported that in the event that staff were struggling with issues relating to caring for a palliative care patient, there was access to a staff support service. In addition, only around a third of respondents reported that there were patients that their service provided care to, who had needs that should normally require referral to a specialist but for some reason a referral was not made.

The South West region reported having the most special local issues relating to palliative care whereas the Midwest region reported the least.

Appendices

Appendix 1: Q2 How many palliative care patients did your organisation care for in the past 12 months

| | n | % |
|--------------|------------|--------------|
| 0 | 21 | 15.1 |
| 1 | 13 | 9.4 |
| 2 | 15 | 10.8 |
| 3 | 11 | 7.9 |
| 4 | 4 | 2.9 |
| 5 | 11 | 7.9 |
| 6 | 7 | 5.0 |
| 7 | 4 | 2.9 |
| 8 | 1 | 0.7 |
| 9 | 1 | .07 |
| 10 | 8 | 5.8 |
| 12 | 5 | 3.6 |
| 13 | 3 | 2.2 |
| 15 | 1 | 0.7 |
| 16 | 1 | 0.7 |
| 17 | 1 | 0.7 |
| 20 | 3 | 2.2 |
| 21 | 3 | 2.2 |
| 22 | 1 | 0.7 |
| 23 | 2 | 1.4 |
| 25 | 1 | 0.7 |
| 30 | 3 | 2.2 |
| 34 | 1 | 0.7 |
| 42 | 1 | 0.7 |
| 43 | 1 | 0.7 |
| 44 | 1 | 0.7 |
| 60 | 2 | 1.4 |
| 64 | 1 | 0.7 |
| 67 | 1 | 0.7 |
| 80 | 1 | 0.7 |
| 102 | 1 | 0.7 |
| 134 | 1 | 0.7 |
| 146 | 1 | 0.7 |
| 150 | 1 | 0.7 |
| 160 | 1 | 0.7 |
| Don't know | 5 | 3.6 |
| Total | 139 | 100.0 |

Appendix 2: Q2 How many palliative care patients did your organisation care for in the past 12 months

| | Goldfields | Great Southern | Kimberley | Midwest | Pilbara | South West | Wheatbelt |
|--------------|--------------|----------------|--------------|--------------|--------------|--------------|--------------|
| n | 16 | 10 | 6 | 26 | 11 | 29 | 36 |
| | % | | | | | | |
| 0 | 31.3 | 0.0 | 0.0 | 26.9 | 36.4 | 6.5 | 8.3 |
| 1 | 12.5 | 0.0 | 28.6 | 11.5 | 18.2 | 6.5 | 5.6 |
| 2 | 6.3 | 25.0 | 0.0 | 7.7 | 9.1 | 0.0 | 22.2 |
| 3 | 0.0 | 8.3 | 0.0 | 3.8 | 9.1 | 12.9 | 11.1 |
| 4 | 18.8 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 2.8 |
| 5 | 0.0 | 0.0 | 28.6 | 3.8 | 9.1 | 6.5 | 13.9 |
| 6 | 6.3 | 8.3 | 14.3 | 7.7 | 0.0 | 0.0 | 5.6 |
| 7 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 8.3 |
| 8 | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 0.0 |
| 9 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 2.8 |
| 10 | 0.0 | 8.3 | 14.3 | 7.7 | 0.0 | 6.5 | 5.6 |
| 12 | 0.0 | 8.3 | 0.0 | 0.0 | 9.1 | 3.2 | 5.6 |
| 13 | 0.0 | 0.0 | 0.0 | 7.2 | 0.0 | 3.2 | 0.0 |
| 15 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| 16 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| 17 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| 20 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 9.7 | 0.0 |
| 21 | 12.5 | 0.0 | 0.0 | 0.0 | 9.1 | 0.0 | 0.0 |
| 22 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| 23 | 6.3 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| 25 | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 | 0.0 |
| 30 | 0.0 | 16.7 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| 34 | 0.0 | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 |
| 42 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| 43 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| 44 | 6.3 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| 60 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 6.5 | 0.0 |
| 64 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 2.8 |
| 67 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 2.8 |
| 80 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 2.8 |
| 102 | 0.0 | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 |
| 134 | 0.0 | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 |
| 146 | 0.0 | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 |
| 150 | 0.0 | 0.0 | 0.0 | 0.0 | 3.8 | 0.0 | 0.0 |
| 160 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 3.2 | 0.0 |
| Don't know | 0.0 | 16.7 | 14.3 | 0.0 | 0.0 | 6.5 | 0.0 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |