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Case studies: palliative care in Vital Signs 2014: The State of Safety and Quality in Australian Health Care

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Abstract

Palliative care is a vital component of Australia's healthcare services, and is provided to those living with a life-threatening illness, whether they are adults, adolescents or children. The aim of palliative care is to improve a person's quality of life by managing the symptoms of their illness and providing emotional, spiritual and social support for the person and their family or carers. Unlike other areas in health care, palliative care focuses on addressing the patient's needs rather than the underlying medical diagnosis (see the box on the right).

Keywords

PCOC, quality, safety, state, 2014, signs, vital, care, health, australian, studies, case, palliative

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Palliative Care

Introduction

Palliative care is a vital component of Australia's healthcare services, and is provided to those living with a life-threatening illness, whether they are adults, adolescents or children. The aim of palliative care is to improve a person's quality of life by managing the symptoms of their illness and providing emotional, spiritual and social support for the person and their family or carers. Unlike other areas in health care, palliative care focuses on addressing the patient's needs rather than the underlying medical diagnosis (see the box on the right).¹¹⁸

49%

Increase in the number of palliative care-related hospital stays between 2001 and 2010

What is palliative care?

According to WHO, palliative care is: *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. Palliative care:*

- *provides relief from pain and other distressing symptoms*
- *affirms life and regards dying as a normal process*
- *intends neither to hasten or postpone death*
- *integrates the psychological and spiritual aspects of patient care*
- *offers a support system to help patients live as actively as possible until death*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
- *will enhance quality of life, and may also positively influence the course of illness*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*¹¹⁹

Palliative care is traditionally seen as a service for patients with cancer, and cancer remains the most common reason for referring patients to palliative care, accounting for approximately 83 per cent of people receiving care.¹²⁰ However, people with non-cancer illnesses such as cardiovascular disease, renal failure, motor neurone disease, liver failure and dementia are now increasingly being referred to palliative care.^{120, 121}

Palliative care can be provided in the home, in community-based settings (such as residential aged care centres), in hospices and in specialist and generalist hospital wards. Regardless of where it is delivered, palliative care is generally provided by multidisciplinary teams. Members of these teams can include counsellors, dieticians, GPs, nurses, occupational therapists, pastoral care workers, pharmacists, physiotherapists, social workers and specialist palliative care doctors.

These specialist teams also support and provide advice to healthcare providers working in other parts of the health system whose patients require assistance with daily living and/or other support to enhance their quality of life and their emotional and/or spiritual wellbeing.

Palliative care aims to improve a person's quality of life by managing the symptoms of their illness and providing emotional, spiritual and social support for the person and their family and carers

Palliative care, like every area of health care, involves a coordinated approach to improving the quality of care that patients and their families receive. One of the most effective ways to achieve this is by systematically collecting and comparing data on patient outcomes. This provides opportunities to identify best practice, and opportunities for palliative care services to learn from each other. The Palliative Care Outcomes Collaboration (PCOC) is a national program funded by the Australian Government that has adopted nationally validated clinical assessment tools to systematically measure patient outcomes and benchmark service performance across Australia.¹²²

More than 100 palliative care services nationally submit data on patient outcomes to PCOC. These services receive a PCOC report twice a year summarising the patient outcomes they have achieved in the last six months. The report shows how their patient outcomes compare with those of other palliative care services and with national benchmarks (see the box on the right).

Benchmarks

Benchmarking is the process of establishing what is best practice, and benchmarks are standards of performance produced as a result of that process. In palliative care, national benchmarks relate to patient outcomes; all palliative care services are measured against a set of nationally agreed benchmarks. At the service level, benchmarking allows services to identify patient outcomes that could be improved and should be the focus of initiatives to improve quality. At the state and national levels, benchmarking allows the healthcare industry to identify successful quality improvement initiatives or models of care.

Why is it important?

Australians are living longer than ever before. In addition to this longer life expectancy, patterns of morbidity and mortality are changing, and there is an increase in the relative proportion of people living with, and dying from, chronic illnesses.

Many people living with chronic and life-threatening conditions need palliative care to help manage their symptoms and to support themselves and their families and carers for the duration of the illness and towards death. There has been an increase in referrals to palliative care services in recent years; the number of palliative care-related hospital stays increased by 49 per cent between 2001 and 2010. Of all the patients who died in hospital in 2010/11, more than one-third (37 per cent) received palliative care.¹²¹

While palliative care has traditionally been seen as a service for people with cancer, people with non-cancer illnesses are now increasingly being referred to palliative care

Palliative care services support the person and their families and carers in living with a life-threatening illness and in preparing for death. When possible, it aims to support a person's preferences regarding the care they feel will best meet their needs and the place of their death. Because palliative care patients often move between hospital, home and other facilities, careful coordination is important to ensure that care remains patient-centred.

The supportive and educative role of palliative care contributes to people staying in their homes and helps with planning hospital admissions. Palliative care provided in the home can reduce unnecessary emergency department visits and hospital admissions. It can also reduce the number of unnecessary diagnostic tests that are ordered, while ensuring that the patient is prescribed the most effective medicines for pain and symptom relief.

Findings

The information presented in this case study comes from data submitted to PCOC by participating palliative care services in the three-year period from January 2011 to December 2013. The information collected by PCOC includes patient characteristics, descriptions of the place of care and clinical assessments (see the box on the right).

In the most recent patient outcome report for July to December 2013, of all the palliative care services operating in Australia, 100 were benchmarked nationally. This excludes a number of services that participate in PCOC but are too small to be benchmarked. Of the 100 services, 54 provided PCOC with information about care provided in the hospital, 28 provided information on care provided in the home and 18 provided information across both settings.

Clinical assessment in palliative care

The PCOC clinical assessment covers:

- the stage of the patient's illness (palliative care phase)
- the patient's ability to manage activities of daily living (function)
- distress and problems associated with pain and other common physical symptoms
- the patient's psychological or spiritual problems
- family or carer problems associated with the patient's illness.

One of PCOC's national benchmarks is a measure of service responsiveness: how long patients wait to be contacted after being referred to palliative care. Over the three-year period, the time taken for palliative care services to contact people referred to them improved slightly. For care provided in hospital (see Figure 29, item a), the proportion of patients who were contacted on the

day of or the day after being referred increased from 90 per cent to 92 per cent. A similar improvement was seen in care provided in the home, with an increase from 52 per cent to 55 per cent (see Figure 30, item a) in those who were contacted soon after being referred. Despite this improvement, these findings highlight that patients living at home wait longer to receive palliative care services than patients who are in a hospital.

Another patient outcome measure in palliative care relates to periods when patients become clinically unstable. An unstable phase starts when a patient requires an urgent change in their plan of care, or emergency treatment is required because:

- the patient experiences a new problem that their existing plan of care did not anticipate
- the patient experiences a rapid increase in the severity of a current problem
- the circumstances of a carer or family member change suddenly, affecting the patient's care.

The unstable phase ends when the new plan of care is in place and has been reviewed, and no further changes are required. While this does not necessarily mean that the change in symptoms and/or the crisis have been fully resolved, it does indicate that a clear plan of care is in place. It is important to establish the new plan of care and assess its effectiveness as soon as possible.

A patient is considered to have an acceptable outcome if they spend no more than three days in the unstable phase. There has been a considerable improvement in achieving this benchmark over the three-year period. For care provided in hospital, the proportion of patients spending no more than three days in the unstable phase increased from 62 per cent to 80 per cent (see Figure 29, item b), while in patients receiving care at home the proportion increased from 53 per cent to 70 per cent (see Figure 30, item b). Again, the results for patients cared for at home were not as good as those for patients cared for in hospital.

Palliative care services focus on managing the needs of patients and their family members and carers. For patients, this includes managing pain, other physical symptoms, and psychological and spiritual needs. The PCOC national benchmarks for each of these domains relate to the proportion of patients who experienced no distress or only mild distress at the end of a phase of palliative care. A palliative care phase ends when the patient's plan of care changes or when they are discharged from the palliative care service. Patients may begin their palliative care phase with no or mild distress from pain and stay that way, or they may start with moderate or severe distress but have no distress or only mild distress at the end of their phase. For both of these situations, there have been improvements over the three years for patients receiving care in hospitals and at home (see Figure 29, items c and d, and Figure 30, items c and d).

Australians are living longer, and with this comes an increase in the relative proportion of people who are living with, and dying from, chronic illnesses

This means that more people are stable, with no or mild distress during their palliative care phase, and more people with moderate or severe distress see that distress reduced during their palliative care phase. The decline shown in Figure 30, item d, between January and June 2012 is attributed to a change in measurement, as this period includes additional information collected at discharge.

Similar patterns of improvement exist for the same measures of distress caused by nausea, breathing problems and bowel problems (as measured by the Symptom Assessment Scale¹²³) – as well as for family or carer and psychological or spiritual problems (as measured by the Palliative Care Problem Severity Score¹²⁴) – for palliative care provided in hospital and at home (see Figure 31).

Implications

The availability and quality of Australian palliative care has improved considerably in the last decade. Benchmarking is one of the most effective strategies for promoting better patient outcomes.¹²⁵ By embedding a common clinical language and introducing national benchmarks for patient outcomes, PCOC demonstrates significant improvements in patient outcomes across Australia. This is confirmed by an analysis of patient outcomes for services participating in PCOC between January 2009 and December 2011, which demonstrated statistically significant improvements in patient outcomes.¹²⁶

From a national perspective, there is a concern that patients receiving palliative care in hospitals are generally achieving better outcomes (see Figures 29 and 31) than patients receiving palliative care at home (see Figures 30 and 32). A major concern is the difference in time that patients are unstable. In the most recently reported period (the last six months of 2013), there was a 10 per cent difference in the proportion of patients who were unstable for no more than three days in hospitals (80 per cent) compared to those receiving care in the home (70 per cent) (see Figure 29, item b and Figure 30, item b). There are also differences in pain and symptom outcomes – as well as how long patients wait after being referred to palliative care.

Better understanding the reasons behind the differences in patient outcomes is an essential step towards closing the gap in outcomes between care provided in hospital and care provided at home. It is also a key part of ensuring that patients and their families can make informed choices about the care they receive at the end of their life.

What we do not know

In Australia, there is no single source of information that covers all aspects of palliative care. Although PCOC covers palliative care services at home and in hospital, there is still a small number of specialist palliative care services that do not collect or submit information. Other than PCOC, sources of information about palliative care concentrate on care provided in hospitals and residential aged care facilities,¹²¹ but provide limited information about the quality of care provided or about patient outcomes.

Furthermore, palliative care provided to children is currently outside the scope of PCOC. Although this accounts for only a small proportion of palliative care provided nationally, it is another important aspect of palliative care where only limited information is available.

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- Sabina Clapham, University of Wollongong.

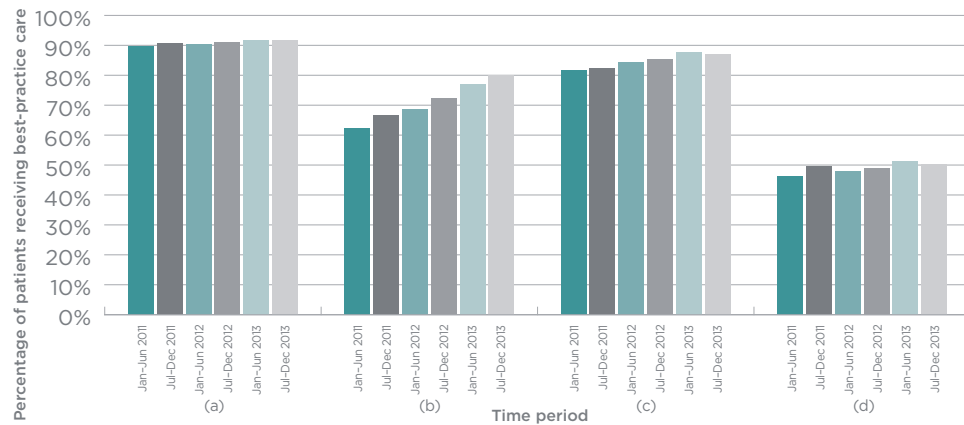
It is concerning that patients receiving palliative care in hospitals are generally achieving better outcomes than patients receiving palliative care at home

1/3

Proportion of patients who died in hospital in 2010/11 who received palliative care

Figure 29

Responsiveness indicators and pain outcome indicators for palliative care provided in hospital, 2011–2013



(a) Patients contacted on day of, or day after referral (%)

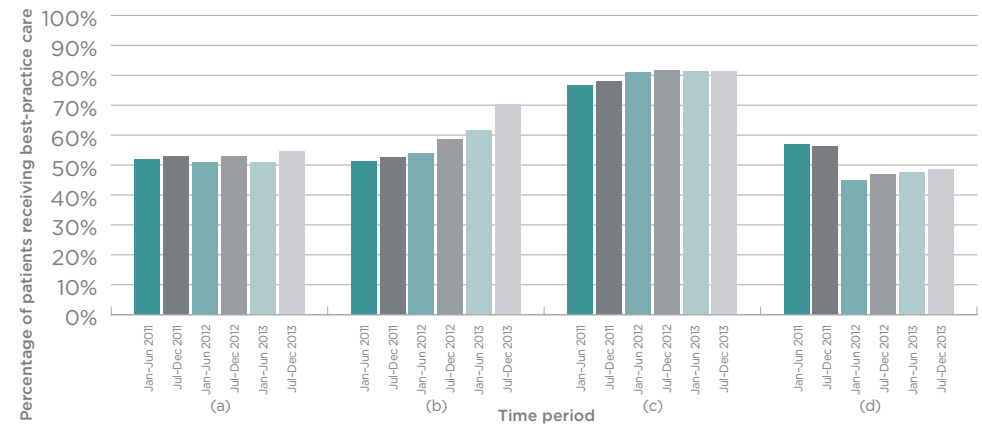
(b) Patients in unstable phase for 3 days or less (%)

(c) Patients with mild or no pain at phase start with mild or no pain at phase end (%)

(d) Patients with moderate or severe pain at phase start with mild or no pain at phase end (%)

Figure 30

Responsiveness indicators and pain outcome indicators for palliative care provided at home, 2011–2013



(a) Patients contacted on day of, or day after referral (%)

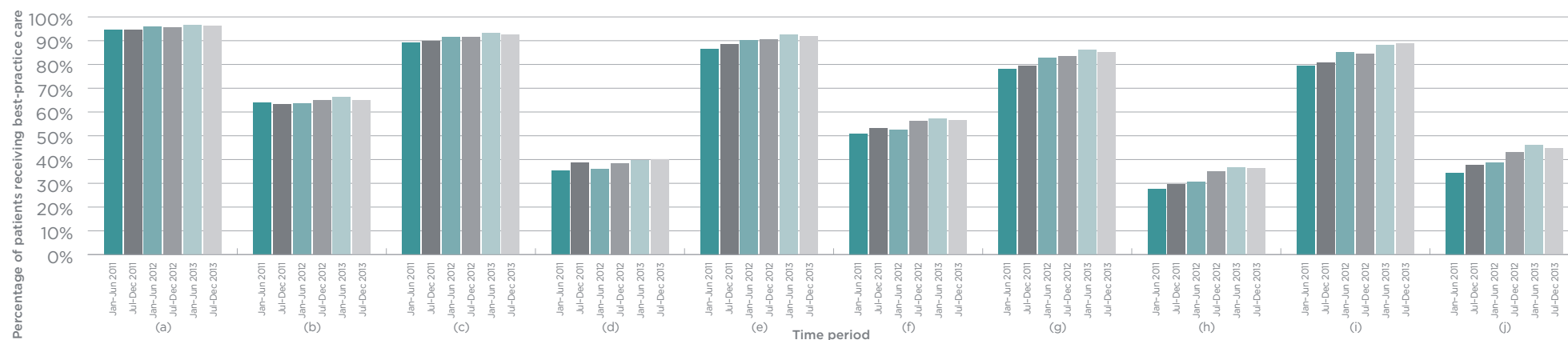
(b) Patients in unstable phase for 3 days or less (%)

(c) Patients with mild or no pain at phase start with mild or no pain at phase end (%)

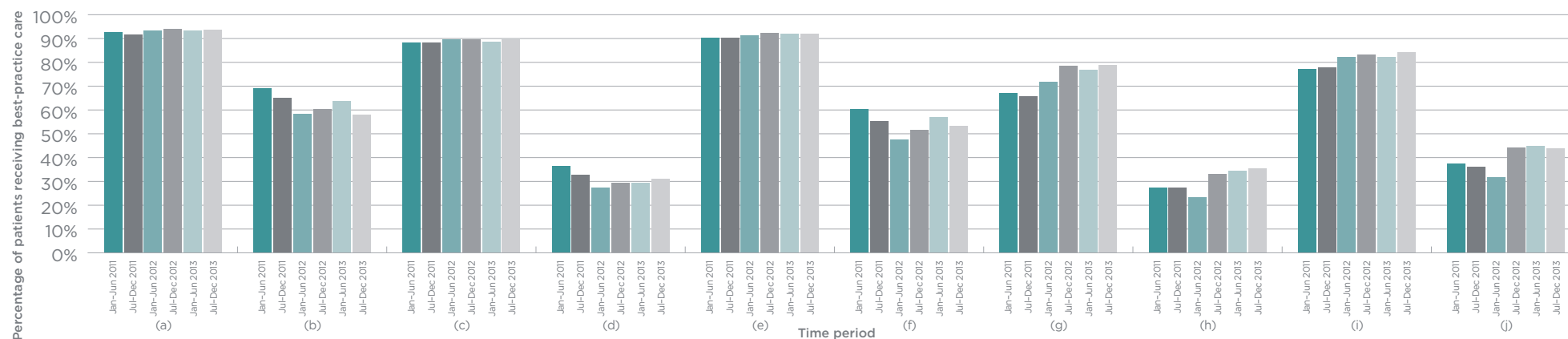
(d) Patients with moderate or severe pain at phase start with mild or no pain at phase end (%)

Figure 31

Symptom outcome indicators for palliative care provided in hospital, 2011–2013



- (a) Patients with mild or no nausea at phase start with mild or no nausea at phase end (%)
- (b) Patients with moderate or severe nausea at phase start with mild or no nausea at phase end (%)
- (c) Patients with mild or no breathing problems at phase start with mild or no breathing problems at phase end (%)
- (d) Patients with moderate or severe breathing problems at phase start with mild or no breathing problems at phase end (%)
- (e) Patients with mild or no bowel problems at phase start with mild or no bowel problems at phase end (%)
- (f) Patients with moderate or severe bowel problems at phase start with mild or no bowel problems at phase end (%)
- (g) Patients with mild or no family/carer problems at phase start with mild or no family/carer problems at phase end (%)
- (h) Patients with moderate or severe family/carer problems at phase start with mild or no family/carer problems at phase end (%)
- (i) Patients with mild or no psychological/spiritual problems at phase start with mild or no psychological/spiritual problems at phase end (%)
- (j) Patients with moderate or severe psychological/spiritual problems at phase start with mild or no psychological/spiritual problems at phase end (%)

Figure 32**Symptom outcome indicators for palliative care provided at home, 2011–2013**

- (a) Patients with mild or no nausea at phase start with mild or no nausea at phase end (%)
- (b) Patients with moderate or severe nausea at phase start with mild or no nausea at phase end (%)
- (c) Patients with mild or no breathing problems at phase start with mild or no breathing problems at phase end (%)
- (d) Patients with moderate or severe breathing problems at phase start with mild or no breathing problems at phase end (%)
- (e) Patients with mild or no bowel problems at phase start with mild or no bowel problems at phase end (%)
- (f) Patients with moderate or severe bowel problems at phase start with mild or no bowel problems at phase end (%)
- (g) Patients with mild or no family/carer problems at phase start with mild or no family/carer problems at phase end (%)
- (h) Patients with moderate or severe family/carer problems at phase start with mild or no family/carer problems at phase end (%)
- (i) Patients with mild or no psychological/spiritual problems at phase start with mild or no psychological/spiritual problems at phase end (%)
- (j) Patients with moderate or severe psychological/spiritual problems at phase start with mild or no psychological/spiritual problems at phase end (%)