



OPEN ACCESS

# Palliative care is effective: but hospital symptom outcomes superior

Kathy Eagar,<sup>1,2</sup> Sabina Petranella Clapham,<sup>1,2</sup>  
Samuel Frederic Allingham<sup>1,2</sup>

<sup>1</sup>Australian Health Services Research Institute, University of Wollongong, Wollongong, New South Wales, Australia

<sup>2</sup>Palliative Care Outcomes Collaboration, University of Wollongong, NSW, Australia

## Correspondence to

Dr Kathy Eagar, Australian Health Services Research Institute, University of Wollongong, Wollongong, NSW 2522, Australia; keagar@uow.edu.au

Received 22 March 2018

Revised 25 July 2018

Accepted 8 August 2018

Published Online First

31 August 2018

## ABSTRACT

**Objectives** To explore differences in severe symptom outcomes for palliative care patients receiving hospital care compared with those receiving care at home.

**Methods** Change in symptom distress from the start of an episode of palliative care to just prior to death was measured for 25 679 patients who died under the care of a hospital or home-based palliative care team between January 2015 and December 2016. Logistic regression models controlled for differences between hospital and home and enabled a comparison of the number of severe symptoms just prior to death.

**Results** All symptoms improved and over 85% of all patients had no severe symptoms prior to death. Pain control illustrates this with 7.4% of patients reporting severe pain distress at episode start and 2.5% just prior to death. When comparing all symptom outcomes by place of death, hospital patients are 3.7 times more likely than home patients to have no severe symptoms.

**Conclusion** Symptom outcomes are better for hospital patients. Patients at home have less improvement overall and some symptoms get worse. Reasons for the difference in outcomes by hospital and home are multifactorial and must be considered in relation to the patient's right to choose their place of care.

of care. In 2016, the PCOC data collection represented 12.4% of all deaths in Australia (including unpredictable deaths) and more than 80% of all patients seen annually by specialist palliative care services. An important role of PCOC is to report on this repository of prospectively collected information. Previously, PCOC researchers have found that palliative care services achieve statistically significant improvements in pain and other symptoms<sup>2</sup> and have described symptom prevalence at the time dying is diagnosed.<sup>3</sup> In those previous studies, the palliative care phase<sup>2,3</sup> was the unit of counting with the outcome being the change from the beginning to the end of each phase.

Data presented here examine, for the first time, the change in symptom scores from the beginning of a palliative care episode to just prior to death. Episodes are defined by setting—either in a hospital/hospice or at home—and consist of one or more phases. The aim is to compare symptom outcomes for people receiving care in a hospital palliative care unit or hospice (henceforth referred to as a hospital episode) to those of people receiving care at home (a home episode).

## METHODS

Over the last decade, palliative care services across Australia have embedded the PCOC clinical assessment framework as part of routine care in both hospital and home settings.<sup>4</sup> PCOC holds outcome data representing more than 45 000 people receiving palliative care each year.<sup>5,6</sup> Physical symptom outcomes are measured using the Symptom Assessment Scale (SAS).<sup>7</sup> SAS measures symptom distress for each palliative care phase.<sup>8</sup> For this analysis, the first phase SAS scores are compared with final phase SAS scores collected just prior to death. The SAS is used by patients to rate distress relating to seven physical symptoms (difficulty

Across the healthcare spectrum, patients and their families need evidence in order to make informed choices about their care needs. Palliative care is no exception, and Australia is in a unique position internationally to provide such evidence.

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national programme for palliative care services to routinely measure and benchmark patient outcomes.<sup>1</sup> PCOC holds information on the outcomes of more than 250 000 Australians who have received palliative care over the last decade and the PCOC clinical assessment model is now firmly embedded into clinical practice at point



© Author(s) (or their employer(s)) 2020. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

**To cite:** Eagar K, Clapham SP, Allingham SF. *BMJ Supportive & Palliative Care* 2020;**10**:186–190.

sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain). It is an 11-point numeric rating scale ranging from 0 (no distress) to 10 (worst distress possible).<sup>1 7</sup> In this study, only severe SAS scores, categorised as 8–10, are used. Data are collected directly from patients wherever possible, but if this is not possible, clinical assessment ratings are based on family/carers and clinical judgement. Proxy assessments are accepted as a fair substitute for patient responses when the patient is unable to contribute their own view.<sup>9 10</sup> Patient psychological/spiritual distress as well as family/carer distress are included in the PCOC assessment protocol but are not reported here.

Symptoms distress outcomes are defined in this analysis as the change in the number of severe symptoms from the start to the end of an episode of care. In hospital, an episode of care is the continuous period of time from admission to death. In the community, it is the continuous time between first assessment and death. Patient episodes that end in transfer between settings are excluded, as are patients receiving advisory services from hospital consultation liaison teams.

The patient cohort includes all people who died receiving the care of a hospital or home-based palliative care service between 1 January 2015 and 31 December 2016 and who had both an assessment at episode start and another just prior to death. A requirement of inclusion in the study is that patients have data completion for both study time points.

Logistic regression was used to investigate the number of symptoms causing severe distress just prior to death, controlling for the initial number of severely distressing symptoms, setting of care (hospital/home), age group, sex and life-limiting illness (cancer/non-cancer). Having no severe symptoms just prior to death was the measure of interest.

All data analysis was undertaken using SAS software (SAS Institute, Cary, North Carolina, USA).

## RESULTS

A total of 40 004 patients in the PCOC database died between January 2015 and December 2016. In total, 25 679 (64%) met the criteria for inclusion in this study and 14 365 (36%) did not. Episodes not meeting inclusion criteria had clinical assessment data at episode start but not at episode end. They fell into two categories. There were 1620 (4.0%) consultation liaison episodes. There were also 12 745 (31.8%) other episodes with symptoms measured only once at the start of the episode. These episodes were typically late referrals. The median episode length was 3 days (2 days for hospital patients and 8 days for home patients) and 79% were in the deteriorating or terminal phase at their first (and only) assessment.

Table 1 shows the profile of the included patients. Hospital was the most common place of death, accounting for 76.6% of patients, with cancer being the main reason people were receiving palliative care

**Table 1** Cohort characteristics

N	25 679
Female (%)	46.4
Malignant diagnosis (%)	81.5
Setting of care/place of death (%)	
Hospital palliative care unit/hospice	75.1
Home	20.4
Residential aged care facility	4.0
Community—not specified	0.5
Age (years)	
Mean	73.6
SD	13.7
Range	0–109

(80%). In the overall PCOC data set, the distribution of episodes in hospital and home is roughly equal, but is skewed towards hospitals in this analysis as people are more likely to be admitted to hospital to die. This is consistent with PCOC data (not reported here) on the number of home palliative care episodes that end with the patient being transferred to hospital.

The median time between last assessment and death was 1 day in hospital and 2 days at home (table 2). Although there were some differences by place of death, the final phase was most likely to be the terminal phase (85.3%). The median time between the first and last assessment was 6 days for hospital/hospice and 21 days for home (table 2).

Table 3 summarises the results of the logistic regression, modelling the number of severe symptoms just prior to death. When the other variables in the model are held constant, patients in the hospital are

**Table 2** Final palliative care phase type and length of phase prior to death

	Entire cohort (N=25 679)	Hospital (PCU/ hospice) (N=19 292)	Community (home/racf/ other) (N=6387)
Phase type (%)			
Stable	2.4	1.1	6.4
Unstable	0.9	0.6	2.0
Deteriorating	11.3	9.0	18.4
Terminal	85.3	89.4	73.1
Time between first and last assessment (days) <sup>1</sup>			
Median	8	6	21
IQR	3–21	2–15	7–54
Time between last assessment and death (days)			
Median	1	1	2
IQR	1–3	1–3	1–5

**Table 3** Summary of logistic regression results

	OR	95% CI
Severe symptoms at start		
None	5.232	(4.907 to 5.578)
One or more	1	
Setting of care/place of death		
Hospital palliative care unit / hospice	3.772	(3.534 to 4.027)
Home / residential aged care facility	1	
Age		
<55	1	
56–65	1.511	(1.349 to 1.693)
66–75	2.283	(2.054 to 2.537)
76–85	3.367	(3.033 to 3.739)
86+	3.916	(3.493 to 4.390)
Sex		
Female	0.958	(0.899 to 1.020)
Male	1	
Life-limiting illness		
Cancer	4.256	(3.980 to 4.550)
Non-cancer	1	

3.7 times as likely than those at home to have no severely distressing symptoms just prior to death. Similarly, patients with cancer are 4.3 times as likely than those with non-cancer diagnosis to have no severely distressing symptoms just prior to death.

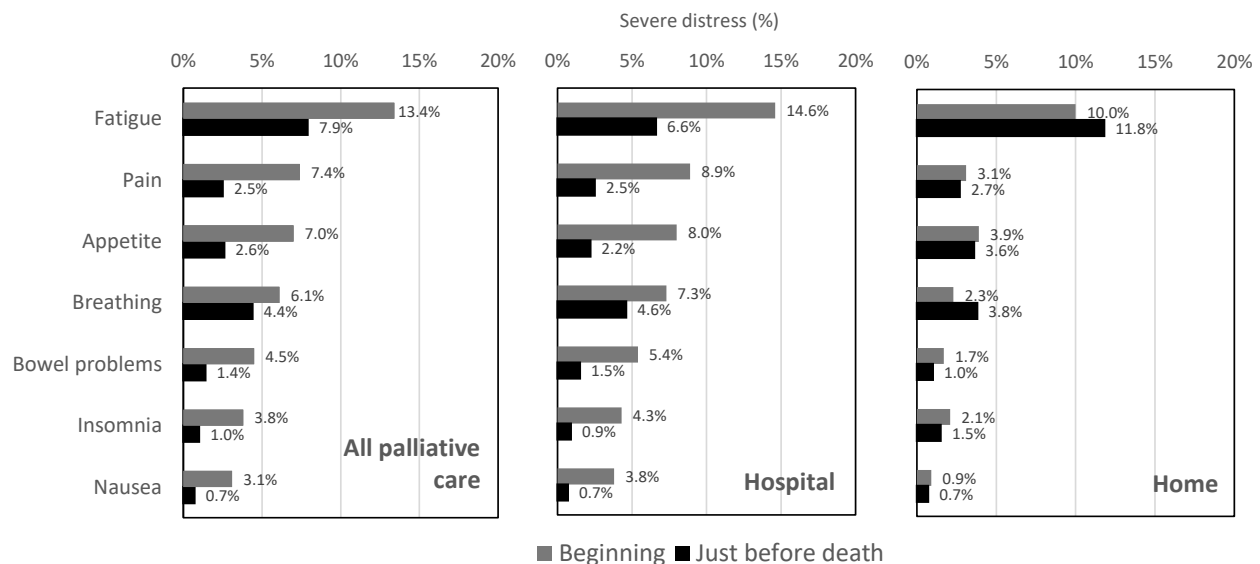
One quarter of all palliative care patients (26.0%) reported having severe distress from at least one symptom at the start of their palliative care episode. This decreased to 13.9% just prior to death. **Figure 1** shows the percentage of patients reporting severe

distress for each of the seven symptoms captured in the SAS tool. People in their final days and hours experience less pain and other problems than earlier in their illness. Fatigue is the most common symptom causing distress and is more common than pain. Breathing problems at end of life are also more common than pain. In total, 7.4% of patients reported severe distress from pain at episode start and only 2.5% in the last few days of life. Distress from fatigue and lack of appetite is not surprising as a loss of energy and appetite is common as death approaches while most pain can be effectively managed. Other problems such as distress from bowel problems (constipation, diarrhoea, pain), difficulty sleeping and nausea are experienced less often and these also typically improve as death approaches.

## DISCUSSION

Severe pain and symptom outcomes are better for hospital patients. Patients at home have less improvement overall and some symptoms get worse. Pain and symptom control are fundamental to palliative care. Pain and symptom control are key reasons for a palliative care referral, and they are also core domains that patients and families use to judge the care that they receive. Our key findings are twofold. First, higher levels of severe symptom distress reported at the start of palliative care reduce significantly. Second, those who die at home experience less improvement overall and distress from fatigue and breathing problems get worse. The reasons for the increase in these symptoms may be due to environmental or individual factors or both.

Reasons for the differences in symptom outcomes between hospital and home are multifactorial. This cohort includes patients who choose their place of care



**Figure 1** Severe symptoms at episode start and just prior to death.

and their place of death as well as those who do not. Some elect home palliative care and a home death and some elect to be admitted to hospital at end of life. Other patients effectively have little choice because they are admitted to palliative care for terminal care due to factors such as late identification of needs and late referral to palliative care.

When physical symptoms exceed the intensity of care that can be delivered in the community, people are frequently admitted to hospital for symptom management. National PCOC data confirm this with 74% patients being admitted to hospital in the unstable or deteriorating phase,<sup>5</sup> an indication of higher symptom needs. In consequence, symptoms at the start of a hospital episode are more severe (figure 1) and therefore there is more room for improvement compared with home-based care.

Care at home requires families and healthcare professionals (including a family physician) to provide adequate support.<sup>11 12</sup> For some patients, this might not be achievable on any sustainable basis. Not all community palliative care can offer a rapid response service on a 24 hours 7 days basis and access to medical resources is often limited relative to availability in hospitals.

A person's wishes and choices regarding end-of-life care also impact their outcomes. Not everyone wants to go to hospital in their final stages of life and many people would prefer to be at home.<sup>13 14</sup> Another consideration is that some people elect little or no pain relief and others elect to stay at home even if pain and symptom control might be better if they were in hospital.

## CONCLUSION

Australian palliative care is leading the world in having a national system of routine patient outcome measurement and benchmarking using point-of-care assessment of symptoms. The PCOC data demonstrate that those receiving care in a hospital with designated palliative care services have better pain and symptom control than those receiving palliative care at home.<sup>6</sup> This current analysis lends further weight to this conclusion.

This study raises a number of issues for further exploration. This includes the need to undertake further work exploring the impact of proxy scores on symptom outcomes as final ratings just prior to death are more likely to be provided by proxies. This work is already in progress.

Although it is difficult in an observational study to attribute change to an intervention, the results presented here are consistent with PCOC data collected nationally for more than a decade, which show both significant improvement nationally year on year while at the same time finding consistently better symptom management in the hospital setting. Significant work is now in progress to better understand the effect of model of care and resources on outcomes in

both settings. This includes an exploration of service level features that lead to improvement, including the relationship between key service characteristics and outcomes.

While it is not possible to be definitive about the reasons for the difference in outcomes between hospital and home, a better understanding of this is crucial for policy and service development. Differences in patient outcomes need to be taken into account in formulating national palliative care policies and in service planning. At the clinical level, this information is critical to allow patients and families to make informed choices about the best place for their care.

**Acknowledgements** The Palliative Care Outcomes Collaboration is funded by the Australian Government Department of Health. The authors would like to thank the participating palliative care services and many clinicians and staff involved in assessing patients and compiling the information. Without their efforts towards improving patient outcomes, this research would not have been possible. The authors acknowledge this data set contains information on more than 25 000 people who died a predictable death with all this represents in human terms for each of those people and their families.

**Funding** This study was funded by Department of Health, Australian Government.

**Competing interests** None declared.

**Patient consent** Not required.

**Ethics approval** Ethical approval by the Human Research Ethics Committee, University of Wollongong / Illawarra Shoalhaven Local Health District, ID: 2006/045.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

## REFERENCES

- 1 Palliative Care Outcomes Collaboration (PCOC). <http://www.pcoc.org.au> (accessed Feb 2018).
- 2 Currow DC, Allingham S, Yates P, *et al*. Improving national hospice/palliative care service symptom outcomes systematically through point-of-care data collection, structured feedback and benchmarking. *Support Care Cancer* 2015;23:307–15.
- 3 Clark K, Connolly A, Clapham S, *et al*. Physical symptoms at the time of dying was diagnosed: a consecutive cohort study to describe the prevalence and intensity of problems experienced by imminently dying palliative care patients by diagnosis and place of care. *J Palliat Med* 2016;19:1288–95.
- 4 Clapham S. Palliative Care Outcomes Collaboration (PCOC) clinical manual. Australian Health Services Research Institute, University of Wollongong. 2014. <https://ahsri.uow.edu.au/pcoc/assessment-package/groups/public/@web/@chsd/@pcoc/documents/doc/uow129133.pdf> (accessed Feb 2018).
- 5 Palliative Care Outcomes Collaboration. Patient outcomes in palliative care national results for January–June 2017 detailed report. 2017. <https://ahsri.uow.edu.au/pcoc/reports/national/index.html> (accessed Feb 2018).

- 6 Palliative Care Outcomes Collaboration. Helicopter report—trends in outcomes 2009 to 2016. 2017. <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow207619.pdf> (accessed March 2018).
- 7 Aoun SM, Monterosso L, Kristjanson LJ, *et al.* Measuring symptom distress in palliative care: psychometric properties of the Symptom Assessment Scale (SAS). *J Palliat Med* 2011;14:315–21.
- 8 Masso M, Allingham SF, Banfield M, *et al.* Palliative care phase: inter-rater reliability and acceptability in a national study. *Palliat Med* 2015;29:22–30.
- 9 Miyashita M, Yasuda M, Baba R, *et al.* Inter-rater reliability of proxy simple symptom assessment scale between physician and nurse: a hospital-based palliative care team setting. *Eur J Cancer Care* 2010;19:124–30.
- 10 Kutner JS, Bryant LL, Beaty BL, *et al.* Symptom distress and quality-of-life assessment at the end of life: the role of proxy response. *J Pain Symptom Manage* 2006;32:300–10.
- 11 Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;332:515–21.
- 12 Burns CM, Abernethy AP, Dal Grande E, *et al.* Uncovering an invisible network of direct caregivers at the end of life: a population study. *Palliat Med* 2013;27:608–15.
- 13 Pollock K. Is home always the best and preferred place of death? *BMJ* 2015;351:h4855–3.
- 14 Gomes B, Calanzani N, Koffman J, *et al.* Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC Med* 2015;13:235.