


Original Research Article

# Patient-reported outcome measurement of symptom distress is feasible in most clinical scenarios in palliative care: an observational study involving routinely collected data

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## Abstract

**Background:** Implementation of routinely collected patient-reported outcome measures (PROMs) ensures patients' priorities are at the forefront of care planning and helps to standardize approaches to quality improvement. In palliative care, barriers to PROMs are widely known but what are not understood are the clinical and care settings in which patients are more likely to report and when proxy reporting is needed.

**Objective:** To examine the incidence of patient-reported symptom distress compared to the incidence of proxy reporting in palliative care and influencing factors.

**Methods:** A national observational study using routinely collected PROMs data with influencing factors investigated by logistic regression modelling. Participants were patients with an advanced life-limiting illness receiving palliative care in an inpatient or a community healthcare setting in Australia.

**Results:** Sixteen thousand one hundred and fifty-eight reports of symptom distress were collected from 1117 patients seen by 21 palliative care services. The majority of respondents were diagnosed with cancer (76%), were older ( $\geq 65$  years, 72%) and had nominated English as their first language (88%). The majority of symptom distress reports were completed by patients (61%). The odds of a patient providing a self-report were greater when they were receiving community versus inpatient palliative care (odds ratio (OR): 3.0; 95% confidence interval (CI): 2.25–4.01), for patients diagnosed with malignant versus non-malignant disease (OR 1.7; 95% CI: 1.26–2.31), and for those who required an urgent change in their care plan versus those whose symptoms and problems were adequately managed (OR: 1.38; 95% CI: 1.04–1.83).

**Conclusion:** Three factors are associated with an increased likelihood of patient versus proxy reporting in palliative care: healthcare setting, diagnosis, and the acuity and urgency of the patient's clinical needs. PROMs are feasible in most clinical scenarios in palliative care, including when an urgent clinical response is required.

**Key words:** palliative care, patient-reported outcome measures, symptom assessment, caregivers, proxy

## Introduction

Patient-reported outcome measures (PROMs) have become increasingly important in health care. Their value for quality improvement and their role in informing daily clinical care and in driving decision-making are particular advantages [1, 2]. Despite these well-recognized benefits, the national implementation of outcome measurement as part of routine care often remains elusive [3]. This gap potentially compromises the quality of health care and the health outcomes for populations and patients worldwide.

In palliative care, barriers related to the widespread use of PROMs have been identified. Commonly described barriers include the characteristics of palliative patients, staff beliefs, institutional barriers, and the psychometric and clinimetric properties of the measures available for use in palliative care [4]. It is not uncommon for patients requiring palliative care to be described as a vulnerable group who are unable to complete PROMs [4], with their decline in cognitive or physical functioning [5] and performance status [6] associated with an increased likelihood of proxy reporting.

These types of challenges to PROMs in palliative care have meant that clinicians may complete outcome measures on behalf of patients in their care, instead of asking patients. Whilst proxy reports are mostly accurate in relation to symptom distress [7, 8], clinicians tend to underestimate symptoms [6, 9] and unpaid carers [8, 10] have been found to overestimate symptoms in comparison to patient reports.

A number of demographic factors have been observed to influence the congruence between patient and proxy reports of symptom distress [7]. Unfortunately, setting of care is a rarely examined factor, meaning the influence of healthcare setting on patient versus proxy reports is largely unknown.

Whilst the available literature is useful in identifying challenges and discrepancies in PROMs, many studies have relatively small sample sizes and have been conducted with a particular focus on one patient or proxy group.

In Australia, the Palliative Care Outcomes Collaboration (PCOC) is a national palliative care initiative that focuses on patient- (and proxy-) reported outcomes. The collection and use of nationally standardized routine clinical assessment data are core to the PCOC model, which has been shown to be feasible and useful in improving outcomes and quality for patients receiving palliative care [11, 12].

The objective of our national study was to utilize the PCOC initiative and national data collection to identify and examine the incidence of patient-reported symptom distress in palliative care patients and to examine factors associated with patient versus proxy reporting for the purposes of identifying clinical scenarios in which patient reports of symptom distress are feasible. Informed by the literature, we hypothesized that both demographic (i.e. sex, age and preferred language) and clinical factors (i.e. diagnosis, the acuity and urgency of the patient's clinical need, and performance status) would influence patient versus proxy reporting in palliative care. We also aimed to explore whether healthcare setting influenced patient-proxy reporting.

## Methods

### Study design

A national observational study involving analysis of routinely collected patient-reported and proxy-reported symptom distress data.

### Participants and setting

Purposive sampling was used to identify eligible services that participate in PCOC and are representative of the type of inpatient and

community palliative care service provision in Australia and their population catchment. This was important given that the Indigenous population constitutes approximately 3% of the population, some services have lower proportion of patients with non-malignant disease and there is variation in service models across the nation. To address this, 21 services were invited to participate.

### Sample size

An analysis of throughput of patients was completed to estimate the number of palliative care assessments required. The G\*power calculator [13] was used to obtain an estimate of the sample size required to detect a difference in patient reports of at least 10% points when comparing two groups. At power of 0.9 and level of significance of 0.05, a total sample size of 385 patients was identified as sufficient. To achieve the associated 95% confidence interval (CI) to be no wider than 10% points, the sample size was increased to 500 patients.

A minimum of 20 consecutive patients for each service was established to ensure meaningful results at a service level, as the primary purpose of PCOC is to drive improvements in outcomes and quality. This approach allowed for the possibility that 3–4 services might not complete the data submission and approximately 30% of data could be missing from patients that were either in a deteriorating or terminal palliative care phase. However, this approach also meant that for research purposes, we were likely to have a larger data set available for analysis. This was deemed appropriate given the purpose of PCOC.

### Measures

Patient and proxy symptom distress reports were captured through the use of the PCOC Symptom Assessment Scale (SAS), which is a valid and reliable patient-reported measure able to be used by patients in a variety of palliative care settings as part of routine clinical care [14]. The scale assesses eight symptom dimensions: pain, insomnia, nausea, bowel problems, appetite problems, breathing problems and fatigue. An 'other' item may be added to the measure. Perceived distress is evaluated on a 0–10 numerical scale with zero representing absent distress, 1 being mild distress and 10 being the worst possible (supplementary file). In the Australian population, a moderate degree of internal consistency has been observed (Cronbach's  $\alpha$  of 0.62 ( $P < 0.001$ )). Test-retest reliability ranges from  $r = 0.84$  for nausea and breathing to  $r = 0.94$  for pain [15].

The urgency and acuity of patient need were derived through the use of the Palliative Care Phase (Phase) (See Figure 1). The Palliative Care Phase refers to a measure with moderate inter-rater reliability [16], which captures clinically relevant categories of palliative care, informed by the acuity and urgency of the patient's need [16, 17]. Performance status was also measured at the point of care via the Australia-modified Karnofsky Performance Status (AKPS) scale, which is an 11-point scale validated to measure the patient's performance across the dimensions of activity, work and self-care. A higher score equates to a better level of function (100 normal abilities to 0 death) [18].

Diagnosis was captured at the point of clinical care and then collapsed into cancer versus non-malignant disease for analysis. Language and country of birth were captured using standardized questions published by the Australian Bureau of Statistics [19, 20].

### Data collection

PCOC's data set captures demographic, setting and clinical assessment information for palliative care patients. For patients in hospital,

Phase	Start	End
<b>Stable</b>	<p>Patient problems and symptoms are <b>adequately controlled</b> by established plan of care <b>and</b></p> <ul style="list-style-type: none"> <li>• Further interventions to maintain symptom control and quality of life have been planned <b>and</b></li> <li>• Family/carer situation is relatively stable and no new issues are apparent.</li> </ul>	<p>The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.</p>
<b>Unstable</b>	<p>An urgent change in the plan of care or emergency treatment is required <b>because</b></p> <ul style="list-style-type: none"> <li>• Patient experiences a new problem that was not anticipated in the existing plan of care, <b>and/or</b></li> <li>• Patient experiences a rapid increase in the severity of a current problem; <b>and/or</b></li> <li>• Family/carers circumstances change suddenly impacting on patient care.</li> </ul>	<ul style="list-style-type: none"> <li>• The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) <b>and/or</b></li> <li>• Death is likely within days (i.e. patient is now terminal).</li> </ul>
<b>Deteriorating</b>	<p>The care plan is addressing anticipated needs but requires periodic review <b>because</b></p> <ul style="list-style-type: none"> <li>• Patients overall functional status is declining <b>and/or</b></li> <li>• Patient experiences a gradual worsening of existing problem <b>and/or</b></li> <li>• Patient experiences a new but anticipated problem <b>and/or</b></li> <li>• Family/carers experience gradual worsening distress that impacts on the patient care.</li> </ul>	<ul style="list-style-type: none"> <li>• Patient condition plateaus (i.e. patient is now stable) <b>or</b></li> <li>• An urgent change in the care plan or emergency treatment <b>and/or</b></li> <li>• Family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) <b>or</b></li> <li>• Death is likely within days (i.e. patient is now terminal).</li> </ul>
<b>Terminal</b>	<p>Death is likely within days.</p>	<ul style="list-style-type: none"> <li>• Patient dies <b>or</b></li> <li>• Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).</li> </ul>

**Figure 1** Palliative care phase definitions [16, 21].

clinical assessments using the PCOC SAS, Phase and AKPS are routinely undertaken daily and at phase change. For patients at home, the assessments are collected at each encounter (e.g. each visit) and at phase change. Data are collected using paper forms that are stored with the patient's medical record or captured directly at point-of-care using an electronic medical record (e.g. hand-held device).

At each assessment, clinicians record who rated the patient's level of distress on the PCOC SAS (SAS rated by). A 'patient-report' is defined as an occasion where the patient reported on their own symptom distress. In this study, any report not classified as a patient report was treated as a report by a proxy, i.e. an occasion when an unpaid caregiver (e.g. family) or a palliative care clinician (e.g.

physician, nurse and allied health) assessed and reported on the symptom distress on behalf of the patient with no input from the patient [21]. Data on patients' socio-demographic characteristics and diagnosis are collected once at the commencement of each episode of care.

## Analysis

Descriptive statistics were used to describe participants' demographic characteristics (sex, country of birth, diagnosis and age), clinical characteristics (diagnoses and clinical assessments including the PCOC SAS, Phase and AKPS) and setting of care. This was followed by the calculation of counts and percentages of the variables of interest by patient versus proxy reporting. Logistic generalized linear modelling was used to evaluate associations between SAS rated by patient or proxy (the dependent variable) and demographic, clinical and healthcare setting variables.

Descriptive analyses were conducted using SAS 9.4 (the SAS Institute, Cary, NC, USA) for analysis. The model was developed using proc genmod [22] to accommodate the nested structure of the PCOC data set, accounting for patients having many assessments throughout their care and being treated by different palliative care services. Pre-established standards to define what was acceptable for the extent of missing items were used, with items with values of >4% deemed to be insufficient [23]. The regression analysis controlled for sex, country of birth, preferred language, Indigenous status, diagnosis, age, setting of care and phase. Records with missing data items were excluded from the logistic regression. No imputation of missing data occurred.

## Results

All 21 services approached to participate in this study agreed to participate. A total of 16 158 symptom distress (PCOC SAS) assessments were collected for 1117 patients. Limited missing values were found for all items (i.e.  $\leq 4\%$ ).

The majority of patients in this study had a cancer diagnosis (76%,  $n = 846$ ), were  $\geq 65$  years (72%,  $n = 802$ ) and nominated English as their preferred language (89%). A sizeable proportion of the patients were born outside of Australia (44%) (Table 1). A representative sample of the Australian palliative care population was achieved except in relation to place of birth. There was a slightly higher proportion of patients born in a country other than Australia in the sample analysed; however, approximately the same proportion preferred English as their first language (Table 1).

When comparing incidences of patient versus proxy reports, overall, 61% of symptom distress was reported by patients versus 39% reported by a proxy (Table 2). The proportion of patient reports varied by diagnosis, setting of care, performance status and palliative care phase (Table 2). Patient reports were more common for those with a malignant diagnosis (63%). Patient reports were substantially more common in the community setting (71%), compared to the proportion of patient reports completed in an inpatient setting (38%). The incidence of patient reports decreased with declining performance status and at the start of the terminal phase of care. Age-related trends were evident but were somewhat inconsistent (Table 2).

The logistic generalized linear model (Table 3) showed that diagnosis and setting of care were most strongly associated with patient reporting. Patients in the community were 3 times as likely to

**Table 1** Characteristics of the patients involved in the study (N = 1117) compared to the entire PCOC cohort for the comparable time period (N = 5294)

	Study cohort (%) (N = 1117)	PCOC cohort (%) (N = 5294)
Sex		
Male	52.9	51.8
Female	47.1	48.2
Country of birth		
Australia	55.8	62.0
Other	44.2	38.0
Preferred language		
English	88.8	90.5
Other	11.2	9.5
Indigenous status		
Aboriginal and/or Torres Strait Islander	1.5	1.5
Neither Aboriginal nor Torres Strait Islander	98.5	98.5
Life-limiting illness		
Cancer diagnosis	76.4	78.1
Non-cancer diagnosis	23.6	21.9
Age		
0–34	1.5	1.1
35–44	3.1	2.2
45–54	7.7	6.9
55–64	15.5	16.5
65–74	25.0	25.9
75–84	26.4	27.1
85–94	18.2	18.2
95+	2.6	2.1

self-report as those in hospital (odds ratio (OR): 3.00; 95% CI: 2.25–4.01). Cancer patients were 1.7 times as likely to self-report as those with non-malignant disease (OR: 1.71; 95% CI: 1.26–2.31). Patients in an unstable phase were 1.38 times as likely to self-report than those in a stable phase (OR: 1.38; 95% CI: 1.04–1.83). Decreasing performance status was also related to decreasing odds of self-reports. Sex and preferred language were not associated with patient reporting in this study.

## Discussion

### Statement of principal findings

This study is one of the first to examine patient versus proxy reporting of symptom distress using nation-wide routinely collected PROM data. We have identified three factors associated with an increased likelihood of patient versus proxy reporting in palliative care: healthcare setting, diagnosis, and the acuity and urgency of the patient's clinical need. The implications of these findings for clinical practice means that PROMs are feasible in most clinical scenarios in palliative care, although proxy reporting is required in some scenarios, especially in inpatient settings. Importantly, PROMs are feasible across a range of clinically significant phases throughout a patient's trajectory, although patient reporting is less likely to occur as a patient's performance deteriorates, when a patient enters a phase of deterioration or when they begin to actively die.

**Table 2** Characteristics of those reporting: All assessments by patient and proxy reports

	Assessments (N)	Rated by (%)	
		Patient	Proxy
Type of assessments completed	16 158	60.8	39.2
Sex			
Male	8111	60.9	39.1
Female	7957	61.2	38.8
Country of birth			
Australia	8770	62.2	37.8
Not Australia	7122	59.4	40.6
Preferred language			
English	14 065	61.7	38.3
Not English	1814	54.9	45.1
Diagnosis			
Cancer diagnosis	12 654	62.5	37.5
Non-malignant diagnosis	3396	44.1	55.9
Age			
0–34	462	58.0	42.0
35–44	485	65.8	34.2
45–54	1318	66.5	33.5
55–64	2818	61.4	38.6
65–74	3765	64.0	36.0
75–84	4332	61.0	39.0
85–94	2699	53.9	46.1
95+	189	55.6	44.4
Setting			
Inpatient	5101	38.3	61.7
Community	11 057	71.1	28.9
Palliative care phase type			
Stable	7816	70.1	29.9
Unstable	692	65.3	34.7
Deteriorating	6271	58.5	41.5
Terminal	1368	15.4	84.6
AKPS			
10	868	7.3	92.7
20–40	6270	45.2	54.8
50–60	6502	75.1	24.9
70+	2093	86.6	13.4

**Interpretation within the context of the wider literature**

A major and novel finding from our study is that the acuity and urgency of patient need is associated with an increased likelihood of patient’s reporting their level of distress. This finding was surprising. We thought that patients whose symptoms were being adequately managed (i.e. patients in a stable phase) would be more likely to self-report compared to those who required urgent attention (i.e. unstable phase). However, patients assessed to be in an unstable phase were 38% more likely to self-report than those in the stable phase. This finding is contrary to the often-held belief in health care that palliative care patients are too unwell to use PROMs and that PROMs may be overly burdensome for patients to complete [4]. Our study helps debunk the myth that patients may not wish to self-report.

A second novel finding from our study is the difference in patient versus proxy reporting in inpatient and community settings, with a higher proportion of patients self-reporting in community settings. Many previous studies have been restricted by a focus on

**Table 3** ORs and 95% CIs for factors associated with patient reports of symptom distress (versus proxy report)

	ORs	95% CIs	
		Lower	Upper
Sex			
Male	1		
Female	1.033	0.816	1.308
Preferred language			
Other	1		
English	0.957	0.583	1.571
Diagnosis			
Non-cancer	1		
Cancer	1.707	1.264	2.306
Age group			
0–34	0.488	0.176	1.351
35–44	0.796	0.288	2.198
45–54	0.962	0.386	2.401
55–64	0.750	0.336	1.670
65–74	0.880	0.400	1.934
75–84	0.785	0.358	1.724
85–94	0.700	0.321	1.527
95+	1		
Setting of care			
Inpatient	1		
Community	3.004	2.253	4.006
Phase			
Stable	1		
Unstable	1.377	1.038	1.825
Deteriorating	0.730	0.614	0.868
Terminal	0.320	0.229	0.447
AKPS			
10	0.052	0.034	0.080
20–40	0.262	0.196	0.351
50–60	0.639	0.507	0.804
70+	1		

one particular healthcare setting, thus precluding comparisons across settings. Reasons for this observed difference are likely to be multifactorial. Community patients have higher functional and performance statuses compared to inpatients [24] and patient report is associated with higher AKPS scores (i.e. higher performance status across the dimensions of activity, work and self-care). In contrast, inpatients in the Australian context tend to have poorer functional status and performance and are more likely to end their episode of palliative care in death (i.e. 54% of patients die in inpatient settings compared to 25% of patients receiving care in the community) [24].

A third key finding from our study is clarification of the characteristics of patients for whom proxy reporting may be more likely. Two key characteristics associated with increased proxy reporting is low performance status and deteriorating or terminal phase. This is when the patient is no longer able to complete all care tasks independently (AKPS ≤40) and when they have increased care needs or are actively dying. This finding aligns with results from other studies that have identified an association between performance status and proxy reporting [6] and may be used to help guide improvements in practice in palliative care settings. For example, auditing of the use of PROMs by patients’ performance status and palliative care phase may help identify areas to target to increase the use of PROMs in practice. Our study also showed that older old adults (95+ years) can use PROMs.

Finally, we found that patients with a primary cancer diagnosis, compared to those with a non-malignant diagnosis, were 1.7 times as likely to self-report. In advanced disease, cognitive impairment may limit the patient’s ability to self-report [25]. Neurological disease accounts for 28% of all non-malignant diagnoses in the national PCOC population [24], helping to substantiate this finding. Those

with partial cognitive impairment may be able to self-report but patients who are unable to communicate verbally or using gestures will usually require reporting by proxy [26].

### Implications for policy, practice and research

Our findings suggest patient-reported symptom distress measurement is feasible in most palliative care scenarios, especially in community healthcare settings. Along with other routine clinical assessment measures, the PCOC SAS is successfully implemented as a routine measure of patient-reported symptom distress throughout Australia. Their national implementation offers information about the symptoms that are most important to patients. This information at scale can be used to drive and inform policy, ensuring that what matters to patients is prioritized. Our study demonstrates that patient-reported symptom distress measures can be used in urgent palliative care clinical scenarios, regardless of setting of care and regardless of age. Further research is required to identify the particular characteristics and specific reasons for the need for proxy reporting in patients with non-malignant diagnoses.

### Strengths and limitations

The embedding of PROMs into routine clinical care and quality improvement is core to PCOC. The integration of this national initiative into healthcare systems is likely to influence the feasibility of routinely collected PROMs, as well as the incidence of patient reporting. Although the PCOC model is currently being adopted in other national settings, including countries within the European and the Western Pacific regions, the findings may not be generalizable to all palliative care populations and countries. Nevertheless, our sample size is substantial and one of the larger applied health services' research studies completed on this topic within palliative care. A sampling bias may have been introduced through the use of purposive sampling of the services. This was countered by the variation between the participating services, and the sample analysed was very similar to the broader PCOC population.

Secondary diagnosis data were not collected in our study. This information would have allowed analysis of the effect of neurological disorders which may affect the capacity of patients to self-report. The role of the caregiver on patient reports was not investigated, nor was the validity of the choice to complete a proxy report over a patient report. These limitations provide an indication of areas for future research.

### Conclusions

In patients with advanced, life-limiting illness, patient reporting of symptom distress is feasible in most palliative care scenarios, including when an urgent clinical response is required. The urgency of the needs of patients should not limit opportunities to self-report, especially as these self-reports may be used as an early warning sign of the need for an urgent response. Proxy reporting is needed when patients are in the deteriorating and terminal phases. The reasons why patients in stable phases may have increased likelihood of proxy reports requires investigation, and further examination of the associations between diagnosis and PROMs may be useful.

### Supplementary material

Supplementary material is available at *International Journal for Quality in Health Care* online.

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### Data availability

PCOC is a mature and well-established national palliative care program. Researchers may apply for access to PCOC's routinely collected, de-identified and aggregated outcome data.

### Ethics

Ethical approval was granted by the University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical Human Research Ethics Committee (reference no. HE2006/045). This involved an amendment to the original PCOC ethics application to ensure approval of the analysis of patient and proxy data, which was not routinely submitted to PCOC although routinely documented by some services. As only routinely collected, de-identified, aggregated clinical data were used in this study, separate participant consent was not necessary.

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