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**A survey of patients' experience of pain and other symptoms while receiving care from palliative care services**

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## A survey of patients' experience of pain and other symptoms while receiving care from palliative care services

### Abstract

**Context** In Australia, patients at the end of life with complex symptoms and needs are often referred to palliative care services (PCSs), but little is known about the symptoms of patients receiving palliative care in different settings.

**Objective** To explore patients' levels of pain and other symptoms while receiving care from PCSs.

**Method** PCSs registered through Australia's national Palliative Care Outcomes Collaboration (PCOC) were invited to participate in a survey between 2008 and 2011. Patients (or if unable, a proxy) were invited to complete the Palliative Care Outcome Scale.

**Results** Questionnaires were completed for 1800 patients. One-quarter of participants reported severe pain, 20% reported severe 'other symptoms', 20% reported severe patient anxiety, 45% reported severe family anxiety, 66% experienced depressed feelings and 19% reported severe problems with self-worth. Participants receiving care in major cities reported higher levels of depressed feelings than participants in inner regional areas. Participants receiving care in community and combined service settings reported higher levels of need for information, more concerns about wasted time, and lower levels of family anxiety and depressed feelings when compared to inpatients. Participants in community settings had lower levels of concern about practical matters than inpatients.

**Conclusions** Patients receiving care from Australian PCSs have physical and psychosocial concerns that are often complex and rated as 'severe'. Our findings highlight the importance of routine, comprehensive assessment of patients' concerns and the need for Specialist Palliative Care clinicians to be vigilant in addressing pain and other symptoms in a timely, systematic and holistic manner, whatever the care setting.

### Keywords

symptoms, other, pain, experience, patients, services, survey, palliative, care, receiving, while

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# **A survey of patients' experience of pain and other symptoms while receiving care from palliative care services**

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**Key Words:** palliative care; pain; symptoms; psychological outcomes; social outcomes.

**Word count:** 3085

## **ABSTRACT**

**Context:** In Australia, patients at the end of life with complex symptoms and needs are often referred to palliative care services (PCSs) but little is known about the symptoms of patients receiving palliative care in different settings. **Objective:** To explore patients' levels of pain and other symptoms while receiving care from PCSs. **Method:** PCSs registered through Australia's national Palliative Care Outcomes Collaboration (PCOC) were invited to participate in a survey between 2008 and 2011. Patients (or if unable, a proxy) were invited to complete the Patient Outcome Scale. **Results:** Questionnaires were completed for 1800 patients. One quarter of participants reported severe pain, 20% reported severe "other symptoms", 20% reported severe patient anxiety, 45% reported severe family anxiety, 66% experienced depressed feelings, and 19% reported severe problems with self-worth. Participants receiving care in major cities reported higher levels of depressed feelings than participants in inner regional areas. Participants receiving care in community and combined service settings reported higher levels of need for information, more concerns about wasted time and lower levels of family anxiety and depressed feelings when compared to inpatients. Participants in community settings had lower levels of concern about practical matters than inpatients. **Conclusion:** Patients receiving care from Australian PCSs have physical and psychosocial concerns that are often complex and rated as "severe". Our findings highlight the importance of routine, comprehensive assessment of patients' concerns and the need for Specialist Palliative Care clinicians to be vigilant in addressing pain and other symptoms in a timely, systematic and holistic manner, whatever the care setting.

## **INTRODUCTION**

In the last two decades the expectations of patients and families for high quality, end of life care has increased due to the availability of specialised palliative care and a heightened awareness of the rights of the dying and expectations for a 'good death'.<sup>[1]</sup> While research suggests improved outcomes for patients receiving palliative care at the end of life,<sup>[2 3]</sup> little is known about the problems of patients accessing palliative care services (PCSs).

Palliative care in Australia is generally provided in hospitals, in-patient hospices or the community/ambulatory setting. Care is provided by diverse teams which can include (but are not limited to) doctors, nurses, allied health professionals, pastoral care professionals and volunteers.<sup>[4 5]</sup> PCSs are funded by Australian federal and state governments, private and not-for-profit organisations, patient co-payments, retail insurers and from a combination of these sources.<sup>[5-7]</sup> Settings of care and distribution of services may vary according to the history, funding source, geography, patient population and health professional demographics.<sup>[5-7]</sup> While the ability of PCSs to care for patients with complex symptoms may differ according to the location of the service and health professional expertise, it is unclear if the severity of patients' concerns differs according to the location of the service or setting of care.

There are an estimated 179 PCSs in Australia, 115 of which are currently participating in the Palliative Care Outcomes Collaboration (PCOC)—representing more than 85% of all people referred to services. PCOC, funded by the Australian Government's National Palliative Care Program, aims to improve the quality of services, promote capacity building within the PCS workforce and support rigorous evaluation of care outcomes.<sup>[4 5 8 9]</sup> Services are eligible to participate in PCOC if they provide palliative care to patients with a life-limiting illness through members of a multidisciplinary team and are able to systematically capture patient outcomes data at point-of-care.<sup>[8]</sup>

PCOC facilitated a quality improvement activity aimed at improving patient care through the administration of a health related quality of life survey. Individual participating services conducted quality improvement activities in response to the concerns raised in the survey. This paper provides a snapshot of the symptom burden experienced by patients' receiving care from PCSs in Australia. The aim is to explore the frequency and severity of symptoms and health related quality of life experienced by patients being cared for by PCSs and the association between care setting, geographical location, and reported symptoms and concerns.

## **METHODS**

### **Study Design**

A cross-sectional survey of patients from PCSs participating in PCOC was conducted annually for four years between 2008 and 2011.<sup>[8]</sup>

PCOC invited services to participate in the study to evaluate patients' experiences of symptoms and measures of health related quality of life while receiving palliative care.

### **Ethics Approval**

Ethics approval was received from the University of Wollongong Human Research Ethics Committee, proposal number HE06/045. Where required by individual PCSs, additional site specific approval was obtained. Patient participation was voluntary with informed consent implied when the questionnaire was completed.

### **Sample**

Palliative care services participating in PCOC were invited to take part in the study each year. Service participation was voluntary with sites agreeing to undertake assessments using the Palliative Outcome Scale Version 2 (POS2),[10] A target of 20 assessments was set for each service to receive an individual, anonymised feedback report for quality improvement purposes. However, all data were included in this study, irrespective of the number of assessments completed by each service.

Patient eligibility criteria included: fluency in English, 18 years of age or older, capacity to provide informed consent, and received care from the PCS for a minimum of three days.

### **Instrument**

The POS2 is a user friendly instrument which measures patients' health related quality of life during the previous three days.[11-13] After a review of the literature this instrument was selected for the survey because it measures essential and important outcomes in palliative care, is simple to use and places minimal additional reporting burden on patients. PCSs considered the items useful in providing clinical care and informing quality improvement activities. Primarily patient rated, it takes less than ten minutes to complete.[10 11] It is validated in advanced cancer and chronic disease patient populations and is used widely, both clinically and in research.[11 13] The questionnaire includes eight items about the patient's physical symptoms, psychological needs and the level of information and support provided at the end of life, and two items about practical matters.[10] Three different Likert rating scales are used throughout the instrument. For all items, '0' always corresponds to the patient having no problems or concerns and '4' corresponds to the highest level of severity or concern.[10 14]

Demographic information such as date of birth, gender and who completed the survey (patient, proxy) was collected on fields added to the survey form. The geographical location of the services and setting of care were classified by the research team using PCOC data. Geographical location was classified as: a major city; inner regional; outer regional; remote; or very remote according to the Australian Statistical Geography Standard (ASGS) Remoteness Structure, 2006.[15]

## **Procedure**

Patients who agreed to participate were given the POS2 questionnaire with written and verbal instructions from their clinician on how to complete it. If the patient consented but was unable to complete the questionnaire, their significant other would complete the patient's survey (Significant other proxy).[12] In the absence of a 'significant other' proxy, the clinician completed the staff-rated version (health professional proxy).[11] Once completed, the survey was returned to the service to inform patient care and to meet with site-specific quality assurance processes. De-identified surveys were then forwarded to PCOC for analysis.

## **Analyses**

Frequencies and percentages were calculated for the categorical variables. Means and standard deviations (*sd*) were calculated for continuous data.

For POS2 questions 1 to 8, the five point Likert scales (where 0=no problem and 4=highest level of concern) were collapsed and recoded to create a three point rating scale where symptoms were absent (0), mild/moderate (1, 2) and severe/overwhelming (3, 4). The original response scales for questions 9 and 10 were retained for the analysis.[10]

Separate multiple linear regressions (using robust standard error estimation to account for state level clustering in the data) were used to determine the significant factors associated with POS2 item scores (pain, other symptoms, patient anxiety, family anxiety, information needs, shared feelings, depressed feelings and self-worth). Age of the patient and the number of years the PCS participated in the study were treated as covariates in all models. As univariate analyses showed no association between sex and POS2 items, sex was excluded from the models.

Analyses were conducted using SPSS v18 (SPSS, Chicago, IL, USA, 2013) and Stata v12 (StataCorp, Collage Station, Texas USA, 2011).

## **RESULTS**

### **Patient characteristics**

Questionnaires were completed for 1800 patients. Participants' mean age was 69 years (*sd* 12.8) and ranged from 19 to 100 years. The majority of patients (61%) were treated in major cities. Almost one-quarter of patients were cared for in an inpatient setting (24%), 32% in community-based services and 44% in combined model services where the exact setting of care (i.e. community or inpatient) was unknown (Table 1). Almost half of participants (48%) reported completing the survey themselves. The remainder were completed by a significant other ( $n=659$ , 40%) or a health professional proxy ( $n=187$ , 11%).

**Table 1: Patient characteristics**

<b>Patients (N=1800)</b>	<b>n</b>	<b>(%)</b>
<b>State</b>		
Queensland	566	(31)
New South Wales	389	(22)
Tasmania	286	(16)
South Australia	218	(12)
Victoria	190	(10)
Western Australia	100	(6)
Australian Capital Territory	51	(3)
<b>Geographical Location<sup>a</sup>*</b>		
Major cities	1104	(61)
Inner regional	347	(19)
Outer regional	246	(14)
Across locations	103	(6)
<b>Setting of Care</b>		
Unspecified <sup>b</sup>	798	(44)
Community	568	(32)
Inpatient	434	(24)
<b>Sex*</b>		
Male	969	(54)
Female	790	(46)
<b>Who completed the survey*</b>		
Patient	793	(48)
Significant other	659	(40)
Health professional	187	(11)
<b>Age mean, (sd)(n=1546)*</b>	<b>69</b>	<b>12.7</b>

Scores may not equal to 100% due to rounding

<sup>a</sup>Using the Australian Statistical Geography Standard (ASGS) Remoteness Structure, 2006

<sup>b</sup>These PCSs provide both inpatient and community models of care. For patients treated in combined services, the setting of care was unspecified

\*Total n may not equal 1800 due to missing data

### Services characteristics

A total of 49 PCSs participated. Half of the services (51%) were from major cities compared to 58% of all services participating in routine data collection through PCOC for the period, and which received a PCOC report for July to December 2011. Fewer inpatient services participated in the study than are represented in the overall PCOC sample (30% vs 54%). Three services were classified as "Across locations" for geographical location as they served both a major city and regional area or across an inner and outer regional area (Table 2). Twenty-five services (51%) participated in the study for only one year; 17 (35%) participated for two years; and seven (14%) participated for three years. Patient and service characteristics were similar in all four years of the study. A median of 22 (IQ range: 13, 51) questionnaires were completed per service.

**Table 2: Characteristics of the 49 service which participated in the study between 2008 and 2011 compared to all Palliative Care Outcomes Collaboration (PCOC) services which received a report for July to December 2011**

Services	Geographical location	Major cities	<i>Inpatient</i>	<i>Community</i>	<i>Combined</i>	<i>Total</i>
			<i>n %</i>	<i>n %</i>	<i>n %</i>	<i>n %</i>
			12 (80)	3 (18)	10 (60)	25 (51)



included in the study	of service	Inner regional	2 (13)	10 (60)	3 (18)	15 (31)
		Outer regional	1 (7)	2 (13)	3 (18)	6 (12)
		Across locations	0 (0)	2 (13)	1 (6)	3 (6)
		<b>Total</b>	<b>15 (30)</b>	<b>17 (35)</b>	<b>17 (35)</b>	<b>49 (100)</b>
All PCOC services July-December 2011	Geographical location of service	Major cities	38 (70)	8 (35)	14 (56)	60 (58)
		Inner regional	14 (26)	6 (26)	9 (36)	29 (28)
		Outer regional	2 (4)	8 (35)	2 (8)	12 (12)
		Remote	0 (0)	1 (4)	0 (0)	1 (1)
		<b>Total</b>	<b>54 (53)</b>	<b>23 (22)</b>	<b>25 (24)</b>	<b>102 (100)</b>

Scores may not equal to 100% due to rounding

### Symptoms and health-related quality of life

The majority of participants reported some level of problems or concerns for six out of the eight symptom and psychosocial wellbeing items in the questionnaire. Most participants reported pain (83%, where 25% had severe or overwhelming pain) and 80% reported experiencing other symptoms (17% had severe or overwhelming other symptoms).

In the psychosocial domain, patient anxiety was reported by 78% of participants, with 22% reporting severe or overwhelming anxiety. Family anxiety was reported by 89% of participants, with 45% reporting severe or overwhelming concerns. Approximately two thirds reported depressed feelings and three quarters (77%) reported problems with self-worth (Table 2).

**Table 3: Severity of health-related quality of life concerns measured by the POS2 questions**

POS2 Item	Absent (Scored 0)		Mild/ Moderate (Scored 1/2)		Severe/ Overwhelming (Scored 3/4)		Mean score/ (sd)
	n	(%)	n	(%)	n	(%)	
1. Pain	306	(17)	1025	(58)	438	(25)	2.7 (1.1)
2. Other symptoms <sup>1</sup>	353	(20)	1118	(63)	298	(17)	2.5 (1.0)
3. Patient anxiety	388	(22)	991	(56)	388	(22)	2.5 (1.2)
4. Family anxiety	201	(12)	770	(44)	779	(45)	3.1 (1.3)
5. Information	1224	(71)	275	(16)	224	(13)	1.7 (1.3)
6. Shared feelings	996	(57)	581	(33)	182	(10)	1.8 (1.1)
7. Depressed feelings	565	(33)	963	(55)	215	(12)	2.2 (1.1)
8. Self-worth	397	(23)	999	(58)	320	(19)	2.4 (1.2)

<sup>1</sup> Other symptoms defined as 'e.g. nausea, coughing or constipation'[10]

Scores may not equal to 100% due to rounding

Total n may not equal 1800 due to missing data

Questions about wasted time and whether practical matters had been addressed were less of a concern for most participants. Most participants (88%, n=1496) reported no time had been wasted and 9% (n=152) reported up to half a day wasted. Practical matters were a concern for less than one

third of participants: 26% ( $n=447$ ) reported still working on matters and 4% ( $n=59$ ) that matters had not been addressed.

Multivariate linear regression models (adjusting for age of the patient, the number of years the PCS participated in the study and state), indicated that geographical location was associated only with the level of depressed feelings (Figure 1). Participants receiving care in a service located in a major city reported a higher level of depressed feelings than patients receiving care in inner regional locations ( $\beta=0.29$ ; 95% *CI*: 0.01-0.57;  $p=0.042$ ), Appendix 1.1.

*FIGURE 1 TO GO HERE*

Setting of care was associated with a number of the POS2 items (Figure 2). Participants receiving care from community and unspecified settings of care reported a higher level of need for information (Community  $\beta=0.27$ ; 95% *CI*: 0.06-0.49;  $p=0.011$ , Unspecified  $\beta=0.25$ ; 95% *CI*: 0.05-0.46;  $p=0.016$ ) and experienced more concerns about wasted time compared to those receiving care in inpatient settings (Community  $\beta=0.08$ ; 95% *CI*: 0.02-0.14;  $p=0.008$ , Unspecified  $\beta=0.07$ ; 95% *CI*: 0.01-0.13;  $p=0.023$ ). However, participants in inpatient settings reported higher levels of problems with family anxiety (Community  $\beta=-0.22$ ; 95% *CI*: -0.42- -0.02;  $p=0.034$ , Unspecified  $\beta=-0.22$ ; 95% *CI*: -0.44- -0.02;  $p=0.028$ ) and depressed feelings (Community  $\beta=-0.22$ ; 95% *CI*: -0.37- -0.06;  $p=0.006$ , Unspecified  $\beta=-0.21$ ; 95% *CI*: -0.37- -0.05;  $p=0.011$ ) than participants receiving care from community and unspecified service settings. For practical matters, only participants in inpatient settings reported a higher level of problems than patients receiving care in a community setting ( $\beta=-0.21$ ; 95% *CI*: -0.37- -0.05;  $p=0.011$ ). (Appendix 1.2)

*FIGURE 2 TO GO HERE*

On multivariate analysis, mean scores on nine out of the ten POS2 items varied according to who completed the instrument (Figure 3). Significant other and health professional proxies scored higher levels of problems than did the patient respondents for pain (Significant other  $\beta=0.29$ ; 95% *CI*: 0.16-0.41;  $p<0.001$ , Health professional  $\beta=0.31$ ; 95% *CI*: 0.12-0.50;  $p=0.001$ ), patient anxiety (Significant other  $\beta=0.52$ ; 95% *CI*: 0.40-0.65;  $p<0.001$ , Health professional  $\beta=0.32$ ; 95% *CI*: 0.13-0.51;  $p=0.001$ ), family anxiety (Significant other  $\beta=0.84$ ; 95% *CI*: 0.70-0.98;  $p<0.001$ , Health professional  $\beta=0.52$ ; 95% *CI*: 0.31-0.74;  $p<0.001$ ), shared feelings (Significant other  $\beta=0.19$ ; 95% *CI*: 0.06-0.31;  $p=0.003$ , Health professional  $\beta=0.34$ ; 95% *CI*: 0.15-0.54;  $p=0.001$ ), depressed feelings (Significant other  $\beta=0.47$ ; 95% *CI*: 0.34-0.59;  $p<0.001$ , Health professional  $\beta=0.45$ ; 95% *CI*: 0.26-0.65;  $p=0.001$ ) and self-worth (Significant other  $\beta=0.42$ ; 95% *CI*: 0.29-0.55;  $p<0.001$ , Health professional  $\beta=0.55$ ; 95% *CI*: 0.34-0.75;  $p<0.001$ ). For other symptoms ( $\beta=0.24$ ; 95% *CI*: 0.12-0.36;  $p<0.001$ ), information needed ( $\beta=0.15$ ; 95% *CI*: 0.00-0.30;  $p=0.044$ ), and practical matters ( $\beta=0.15$ ; 95% *CI*: 0.03-0.29;  $p=0.019$ ), only significant others reported a statistically higher level of concerns than the patient. Furthermore,

with the exception of pain, self-worth and shared feelings, significant others scored statistically higher than health professional compared to patient assessment for all POS2 items (Appendix 1.3).

FIGURE 3 TO GO HERE

## **DISCUSSION**

This cross-sectional survey of 1800 patients found that people receiving care from PCSs frequently experience high levels of pain, other symptoms and psychosocial concerns, regardless of the geographical location or setting of care. Our findings highlight the importance of routine, comprehensive assessment of patients' concerns and the need for timely, holistic interventions to address identified problems. These findings are consistent with previous international research which identifies the high prevalence of pain and other symptoms in palliative care for people diagnosed with cancer.[16]

Our study, however, goes further by exploring the severity of symptoms using a self-report measure in the clinical setting and whether patients in different services or geographical settings have a greater symptom burden. Depression was the only factor found to be associated with the geographical location of the service, with patients in major cities reporting higher levels of depressed feelings than patients in inner regional locations. Further research is warranted to explore whether disease characteristics are associated with symptom complexity and psychosocial concerns and whether these disease characteristics differ between the geographical locations of PCSs.

Setting of care was associated with a number of psychosocial items. Participants in inpatient units reported higher levels of depressed feelings, family anxiety and concerns with practical matters than participants in community settings but had fewer concerns about receiving adequate information. These differences may reflect a higher level of complexity of cases in the inpatient setting where patients are more likely to be an acute admission. In such a setting, it is not unusual for patients to be given bad news, be receiving complex treatments or be in the terminal phase of their illness. Hence, the higher levels of anxiety and issues with practical matters may relate to the adjustment this group of patients are experiencing. However, unlike the study of largely (95%) cancer patients receiving palliative care by Potter et al., our study found no association between care setting and levels of pain or other symptoms. [16]

While self-reported measures are the gold standard for determining the severity of patients' symptoms and concerns,[17-18] it is usual for proxies (significant other or clinician) to assess patients' symptoms and quality of life when the patient is unable to complete their symptom assessment independently.[18-20] When comparing proxy rating of symptoms to patients' self-reporting, significant others tend to over-rate [20-22] and health professionals under-rate the patients' experience.[16-19-23] Consequently, PCSs in our study were encouraged to support patients to assess and report their own levels of need. When a proxy completed the POS2 (regardless of

whether a health professional or significant other), scores were higher for six of the ten items (including pain) than when the patient completed the measure. This suggests that proxies were more likely to complete the survey when the patient was sicker and had a higher symptom burden, and were, thus, unable to do so themselves. The high proportion of questionnaires completed by proxies in our study reflects the acuity of patients cared for by the PCSs.

There are a number of limitations which may affect the generalisability of our findings. At the service level, PCSs registered in the PCOC program self-selected to participate in the study, which may have resulted in a bias towards services that value quality improvement. Furthermore, our study sample was over-represented by metropolitan services when compared to all services involved in PCOC and under-represented by inpatient services.

At the patient level, patient residential postcode was not collected which may have provided a clearer picture of service access, including those patients who travelled to major cities for care.[4] For participants from combined inpatient/community model services, it is unclear from which part of the service (i.e. inpatient or community) patients were receiving care. Furthermore, we do not know how long each patient was cared for by the PCS prior to participating in the study or what their diagnosis was. Inclusion criteria reflected the POS2 recommendation that the patient be cared for by the service for a minimum of three days prior to completing the instrument.[10] However, a severe level of pain and other symptoms after three days in a PCS is of concern for any diagnosis. Another potential limitation was the high level of missing age data (i.e. n=254). However, there were no differences between participants who provided their age and those who did not for geographical location, setting of care or who completed the POS2. Hence, the missing data are not likely to unduly affect our findings.

In this study, individual POS2 results were provided to the PCS to help inform clinical management. Hence, patients and significant other proxies may have understated their level of concerns. Services involved in PCOC routinely collect patient clinical data for reporting and quality improvement, and point-of-care data reflect our findings.[9] Data about participants' symptoms were also not collected on admission to the service. Consequently, we were unable to assess changes from initial presentation to the POS2 assessment. However, this was not the aim of the current study and we have reported changes in pain and symptoms in PCSs involved in the PCOC program elsewhere.[24] While the POS2 is short and easy to use, an important limitation is that '*Other symptoms*' are not defined and, as such, it does not identify the specific symptoms the patients experienced.

Future research by this team aims to link patient socio-demographic, diagnosis and clinical assessment information which is collected and submitted regularly by participating PCSs as part of the PCOC program, with one-off and snapshot surveys. In the current study, this was not possible as surveys were submitted in a format that did not allow linkage with other data sources.

While this study involved a heterogeneous sample of people receiving palliative care, approximately 80% of patients in PCOC-enlisted services had a primary diagnosis of cancer during the study period.[25] It is assumed that our sample included a similar proportion of patients with a cancer diagnosis. Due to the recruitment process being coordinated at each site, the number of patients who may have refused to participate is unknown.

Never-the-less, our pragmatic study found that after three or more days of receiving palliative care, many patients still experience pain or other symptoms at a severe level and that outcomes vary according to care setting but not the geographical location of the service. Patients referred for palliative care have both physical and psychosocial concerns that are often complex, multifaceted and severe. Our findings highlight the importance of routine, comprehensive assessment of patients' concerns and the need for SPC clinicians to be vigilant in addressing pain and other symptoms in a timely and holistic manner.

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## **AUTHOR DISCLOSURE STATEMENT**

All authors declare no competing financial interests exist.

## **COMPETING INTEREST**

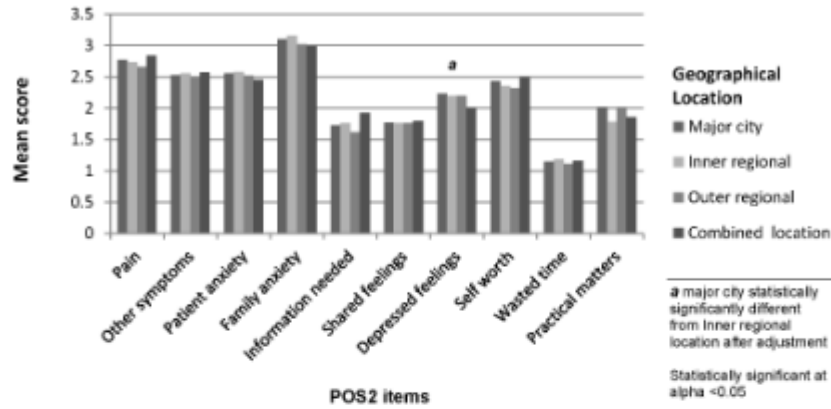
None declared.

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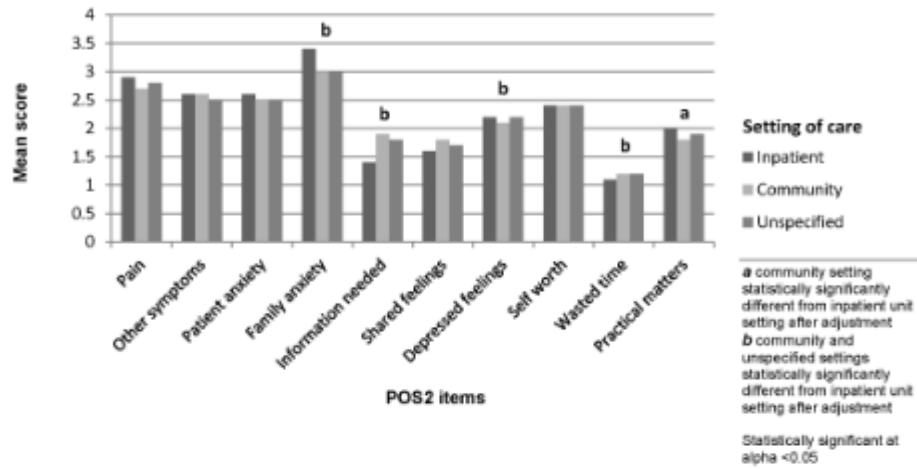
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**Figure 1: Mean POS2 item scores and association between scores and geographical location after adjustment for age, number of years the PCS participated in the survey and state**

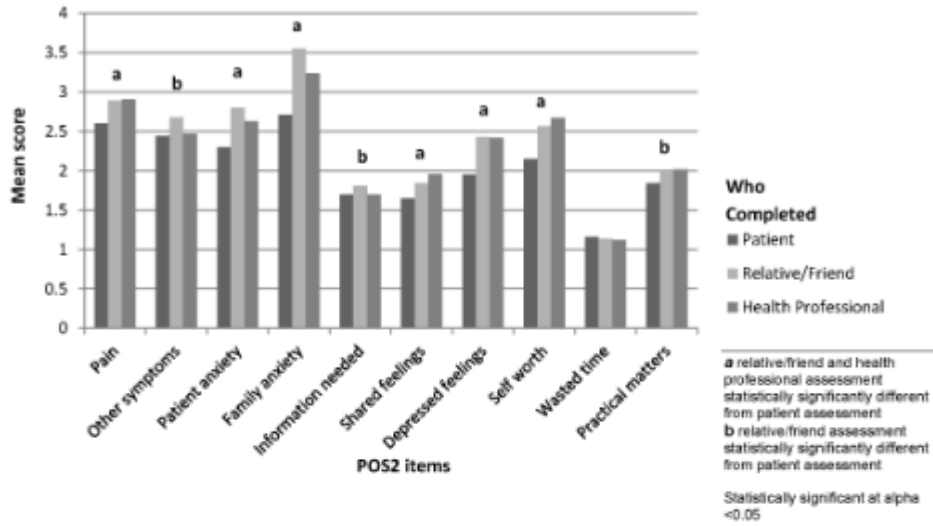


**Figure 2: Mean POS2 item scores and association between scores and setting of care after adjustment for age, number of years the PCS participated in the survey and state**





**Figure 3: Mean POS2 Item scores and association between scores and who completed the questionnaire after adjustment for age, number of years the PCS participated in the survey and state**



## Appendix 1

**Table 1.1 Association between POS2 items and geographical location to after adjustment for age and number of years the service participated.**

Item	$\beta$	95% confidence limits	p value
<b>Pain (n=1537)</b>			
Major Cities <sup>a</sup>			
Inner regional	-0.08	-0.35 to 0.19	0.561
Outer regional	-0.26	-0.56 to 0.03	0.079
Combined	-0.13	-0.40 to 0.13	0.326
<b>Other Symptoms (n=1534)</b>			
Major Cities <sup>a</sup>			
Inner regional	0.02	-0.25 to 0.30	0.866
Outer regional	-0.07	-0.36 to 0.22	0.618
Combined	0.01	-0.25 to 0.27	0.961
<b>Patient Anxiety (n=1537)</b>			
Major Cities <sup>a</sup>			
Inner regional	0.18	-0.10 to 0.46	0.208
Outer regional	0.10	-0.21 to 0.40	0.536
Combined	0.16	-0.11 to 0.44	0.250
<b>Family Anxiety (n=1518)</b>			
Major Cities <sup>a</sup>			
Inner regional	0.24	-0.05 to 0.54	0.108
Outer regional	0.15	-0.18 to 0.48	0.377
Combined	0.23	-0.08 to 0.53	0.147
<b>Information (n=1497)</b>			
Major Cities <sup>a</sup>			
Inner regional	-0.12	-0.48 to 0.23	0.488
Outer regional	-0.08	-0.45 to 0.29	0.668
Combined	-0.04	-0.37 to 0.28	0.797
<b>Shared feelings (n=1526)</b>			
Major Cities <sup>a</sup>			
Inner regional	-0.06	-0.31 to 0.19	0.653
Outer regional	-0.07	-0.35 to 0.21	0.634
Combined	-0.05	-0.31 to 0.21	0.708
<b>Depressed feelings (n=1514)</b>			
Major Cities <sup>a</sup>			
Inner regional	0.29*	0.01 to 0.57	0.042
Outer regional	0.24	-0.06 to 0.55	0.119
Combined	0.24	-0.04 to 0.51	0.096
<b>Self-worth (n=1491)</b>			
Major Cities <sup>a</sup>			
Inner regional	-0.11	-0.39 to 0.17	0.436
Outer regional	-0.22	-0.52 to 0.09	0.170
Combined	-0.15	-0.44 to 0.13	0.293
<b>Wasted time (n=1482)</b>			
Major Cities <sup>a</sup>			
Inner regional	-0.04	-0.14 to 0.06	0.474
Outer regional	-0.08	-0.19 to 0.04	0.185
Combined	0.01	-0.09 to 0.12	0.778
<b>Practical matters and personal affairs (n=1477)</b>			
Major Cities <sup>a</sup>			
Inner regional	0.16	-0.11 to 0.44	0.237
Outer regional	-0.07	-0.37 to 0.23	0.648
Combined	-0.08	-0.36 to 0.20	0.592

<sup>a</sup>Major cities is the reference category.

Age of the patient, the number of years the PCS participated in the study and state were treated as covariates.

## Appendix 1

**Table 1.2 Association between POS2 items and setting of care to after adjustment for age and number of years the service participated.**

Item		$\beta$	95% confidence limits	p value
<b>Pain (n=1537)</b>				
	Inpatient <sup>b</sup>			
	Community	-0.08	-0.24 to 0.09	0.361
	Unspecified	0.02	-0.14 to 0.18	0.797
<b>Other Symptoms (n=1534)</b>				
	Inpatient <sup>b</sup>			
	Community	0.00	-0.15 to 0.17	0.933
	Unspecified	-0.04	-0.20 to 0.11	0.573
<b>Patient Anxiety (n=1537)</b>				
	Inpatient <sup>b</sup>			
	Community	-0.13	-0.30 to 0.05	0.156
	Unspecified	-0.05	-0.22 to 0.12	0.557
<b>Family Anxiety (n=1518)</b>				
	Inpatient <sup>b</sup>			
	Community	-0.22*	-0.42 to -0.02	0.034
	Unspecified	-0.22*	-0.42 to -0.02	0.028
<b>Information (n=1497)</b>				
	Inpatient <sup>b</sup>			
	Community	0.27*	0.06 to 0.49	0.011
	Unspecified	0.25*	0.05 to 0.46	0.016
<b>Shared feelings (n=1526)</b>				
	Inpatient <sup>b</sup>			
	Community	0.03	-0.13 to 0.19	0.699
	Unspecified	-0.01	-0.17 to 0.15	0.905
<b>Depressed feelings (n=1514)</b>				
	Inpatient <sup>c</sup>			
	Community	-0.22*	-0.37 to -0.06	0.006
	Unspecified	-0.21*	-0.37 to -0.05	0.011
<b>Self-worth (n=1491)</b>				
	Inpatient <sup>b</sup>			
	Community	-0.04	-0.22 to 0.14	0.638
	Unspecified	0.01	-0.17 to 0.19	0.880
<b>Wasted time (n=1482)</b>				
	Inpatient <sup>b</sup>			
	Community	0.08*	0.02 to 0.14	0.008
	Unspecified	0.07*	0.01 to 0.13	0.023
<b>Practical matters and personal affairs (n=1477)</b>				
	Inpatient <sup>b</sup>			
	Community	-0.21*	-0.37 to -0.05	0.011
	Unspecified	-0.16	-0.33 to 0.00	0.053

<sup>b</sup>Inpatient is the reference category.

Age of the patient, the number of years the PCS participated in the study and state were treated as covariates.

## Appendix 1

**Table 1.3 Association between POS2 items and who completed the survey to after adjustment for age and number of years the service participated.**

Item		$\beta$	95% confidence limits	p value
<b>Pain (n=1412)</b>				
	Patient <sup>c</sup>			
	Family/carer	0.29**	0.16 to 0.41	<.001
	Health professional	0.31**	0.12 to 0.50	0.001
<b>Other Symptoms (n=1409)</b>				
	Patient <sup>c</sup>			
	Family/carer	0.24**	0.12 to 0.36	<.001
	Health professional	0.03	-0.15 to 0.22	0.710
<b>Patient Anxiety (n=1413)</b>				
	Patient <sup>c</sup>			
	Family/carer	0.52**	0.40 to 0.65	<.001
	Health professional	0.32**	0.13 to 0.51	0.001
<b>Family Anxiety (n=1396)</b>				
	Patient <sup>a</sup>			
	Family/carer	0.84**	0.70 to 0.98	<.001
	Health professional	0.52**	0.30 to 0.74	<.001
<b>Information (n=1378)</b>				
	Patient <sup>c</sup>			
	Family/carer	0.15*	0.00 to 0.30	0.044
	Health professional	0.18	-0.05 to 0.43	0.130
<b>Shared feelings (n=1404)</b>				
	Patient <sup>c</sup>			
	Family/carer	0.19*	0.06 to 0.31	0.003
	Health professional	0.34**	0.15 to 0.54	0.001
<b>Depressed feelings (n=1403)</b>				
	Patient <sup>c</sup>			
	Family/carer	0.47**	0.34 to 0.59	<.001
	Health professional	0.45**	0.26 to 0.65	<.001
<b>Self-worth (n=1383)</b>				
	Patient <sup>c</sup>			
	Family/carer	0.42**	0.29 to 0.55	<.001
	Health professional	0.54**	0.34 to 0.75	<.001
<b>Wasted time (n=1373)</b>				
	Patient <sup>c</sup>			
	Family/carer	-0.02	-0.07 to 0.03	0.509
	Health professional	-0.04	-0.11 to 0.04	0.366
<b>Practical matters and personal affairs (n=1374)</b>				
	Patient <sup>c</sup>			
	Family/carer	0.15*	0.03 to 0.29	0.019
	Health professional	0.18	-0.02 to 0.39	0.084

<sup>c</sup> Patient is the reference category.

Age of the patient, the number of years the PCS participated in the study and state were treated as covariates.