

Does screening for physical and psychosocial symptoms vary between medical oncology treatment centres?

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Abstract

Objective: Our aim is to examine whether provider screening for physical and emotional symptoms, as reported by medical oncology outpatients, varies across medical oncology treatment centres.

Methods: A cross-sectional sample of 716 patients attending the outpatient medical oncology department of six public cancer treatment centres across five Australian states participated. Four patient-report survey items explored how often patients were specifically asked by clinical staff at the treatment centre about their (i) emotional distress (anxiety, distress and depression), (ii) pain, (iii) fatigue and (iv) other physical symptoms (e.g. nausea and constipation). Asking at less than half of all appointments was classified as infrequent screening.

Results: No significant associations were found between treatment centre and symptom screening for emotional distress ($p=0.65$), pain ($p=0.21$), fatigue ($p=0.95$) and other physical symptoms ($p=0.40$). The proportion of patients who were regularly screened versus infrequently screened was significantly higher for physical symptoms than emotional symptoms ($p<0.001$): 36% infrequently screened for emotional distress (range: 33–45%), 15% infrequently screened for pain (range: 9–21%), 16% infrequently screened for fatigue (range: 15–19%) and 11% infrequently screened for other physical symptoms (range: 5–17%).

Conclusions: No significant variation in symptom screening was found across treatment centres. While the majority of patients received recommended care, treatment centres must continue to improve symptom screening rates, particularly for emotional distress. However, screening is only the first step and must be accompanied by the offer of help and provision of help to relieve patient suffering.
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Background

Patient-centred care is one the six central aims of quality of health care outlined by the Institute of Medicine that should be pursued to facilitate improvements in quality of care [1]. Assessing the quality of patient-centred cancer care is essential to identifying barriers to the delivery of care and advocating for service improvement.

What aspects of patient-centred care should we evaluate?

The Institute of Medicine [1] recommendations related to relieving patients' physical discomfort and providing emotional support are able to be translated into measurable indicators of care, as best practice has been articulated in the literature. According to clinical practice guidelines, patients' physical and emotional issues should be recognised and regularly monitored through symptom screening at all stages of the cancer journey to enable timely intervention [2–6]. For example, pain should be assessed at each encounter with the health service and before, during and after procedures. Fatigue should be 'routinely' assessed

from point of diagnosis onward, including after completion of primary treatment. Distress should be assessed at 'regular intervals' and 'at times of change'. Symptom assessment may involve specifically asking patients about their symptoms during day-to-day encounters or routine systematic screening of patients via a pen-and-paper or electronic survey with the results fed back to providers to act upon during consultations [7]. Asking patients about their symptoms is important as it cannot be assumed that providers are always aware of their patients' needs [8,9] or that patients will actively inform clinicians when they are experiencing symptoms [10].

How should we evaluate delivery of physical and emotional symptom screening?

Various quality indicators [11–13] have been proposed to measure the delivery of patient-centred care. These measures vary in their content (i.e. dimensions of care, process and outcomes assessed) and mode of assessment (e.g. medical record abstraction and patient survey). International oncology groups have proposed a series of measurable indicators, appraised by searching medical records, to explore

the quality of supportive care delivered in outpatient cancer centres. The indicators are intended to be examined across time and compared with other treatment centres as a strategy for improving care delivery [12–14]. Indicators relevant to physical and emotional symptom screening include documentation of the patient being assessed for the presence of pain and emotional distress within the 1 month after the initial visit. While use of medical record audit is appealing as it allows data to be drawn from a representative sample, it is not known whether management of symptoms is accurately documented.

Other methods of measuring quality of symptom screening (such as the existence of policies, clinician survey and patient survey) also have advantages and disadvantages that may affect measurement accuracy. For example, while assessing whether a hospital has guidelines for symptom screening can be undertaken at little cost, adherence to guidelines does not always occur [15]. Assessment of providers' perceptions of care delivery may be subject to social desirability reporting and discordant with those of their patients [16–18]. Patient self-report surveys may be a costly and time-consuming approach. However, given the personal nature of patient-centred care, the patient is in the best position to report whether they received the intended care and whether it helped to relieve suffering or improved quality of life [1,19]. It may be that patient perceptions are potentially a more sensitive measure of patient-centred care delivery [20,21]. Such reasoning has led to the growth of patient experience surveys [22,23]. However, to our knowledge, no patient experience surveys have systematically explored variation in symptom screening across cancer treatment centres.

Why explore variation between cancer treatment centres?

Seminal work by Wennberg [24] identified unwarranted organisational variations in the delivery of a range of healthcare services that could not be explained by scientific knowledge. Variations were attributed to the 'idiosyncrasies' of individual clinicians and institutions and availability of local hospital resources. Just as major variations in the technical aspects of medical practice continue to be identified across hospitals [25], so too may hospital-level variations occur in the delivery of patient-centred care. Understanding whether such hospital-level variations exist may help to pinpoint characteristics about the structure and process of care delivery at which we can intervene. For example, organisations that are more successful in recognising patient symptoms may have lower staff-to-patient ratios, implement policies and procedures for symptom management or have available psychological services. The appeal of being able to change aspects of the treatment centre environment is that (1) the environment can simultaneously impact many patients and (2) patient outcomes may be

affected without additional burden being placed on the patient via patient-focused interventions, such as patient prompt lists to promote question asking [26].

Limited examination of variation across centres in patients' perceptions of care for emotional and physical symptoms

A review of system-level variation in the delivery of patient-centred cancer care shows mixed outcomes. Shin *et al.* [27] identified significant variation in pain management across 34 inpatient palliative care centres. Regional variation in the delivery of care has been reported, including patient evaluation of pain management [22], physician communication, nursing care and coordination of care [23]. Similarly, in a study of three cancer treatment centres, variation in satisfaction with nursing care was identified [28]. Conversely, while Stolzmann *et al.* [29] found variation in overall care satisfaction across 128 medical centres, this was largely the result of differences between patient-level rather than hospital-level factors. Furthermore, while Kleeberg *et al.* [30] found that handling of symptoms and performance of medical staff varied across cancer outpatient settings, analysis revealed that high-performing and low-performing hospitals differed by patient characteristics. Carey *et al.* [31] did not find any variation in patient anxiety, depression or quality of care perceptions across four radiation oncology settings after adjusting for patient and disease characteristics. To our knowledge, only one study has explored variation in screening of patient physical and emotional symptoms across cancer treatment centres [32]. This study employed medical record audit across 11 medical oncology practices in the USA and found that assessment of pain and distress significantly varied by practice site (14–88% and 3–45% not screened within 1 month of initial visit, respectively) even after controlling for patient's age, gender and cancer type. The difference was attributed to clinic accreditation requirements and formalised screening processes.

Study aim

Given the potential limitations of medical record completeness for assessing aspects of patient-centred care, the primary aim of this study was to examine whether provider screening for physical and emotional symptoms, as reported by patients, varies across cancer treatment centres. Secondly, in a previous single-centre study using patient self-report data, we established that fewer patients report being asked about their emotional symptoms compared with physical symptoms (Zucca *et al.* under editorial review). Therefore, we also aimed to examine whether these findings remain consistent in a multicentre sample.

Methods

Sample

Medical oncology treatment centres

Participants were recruited from six major medical oncology treatment centres across five states. Centres were eligible if they provided care for at least 400 new cancer patients per year.

Patients

Eligible patients within each of the centres had a confirmed cancer diagnosis of any cancer type, were attending an outpatient medical oncology unit for their second or subsequent appointment, were aged 18 years or older, were able to read English and were judged to be able to give informed consent.

Procedures

Clinic staff identified potentially eligible patients from the clinic list. Potentially eligible patients were consecutively approached by trained research staff while waiting for their appointment in the clinic waiting room. Consenting patients completed a pen-and-paper baseline survey assessing patient, disease and treatment characteristics. To examine sample representativeness, the age and gender of nonconsenters were obtained. A second survey assessing symptom management was mailed to consenting patients 4 weeks later. Nonresponders received a reminder survey after 3 weeks, and a second reminder survey after a further 3 weeks. Ethics approval was obtained from the University of Newcastle Human Research Ethics Committee and the ethics committee of the participating health services.

Measures

Physical and emotional symptom screening items

A four-item survey was developed to explore patient's perceptions of provider screening behaviour. Symptoms that met the following criteria were prioritised: (1) the issue is prevalent for medical oncology patients and demonstrated gaps in care delivery; (2) failure to deliver care will result in significant patient burden; (3) the issue is treatable or modifiable; and (4) the issue is important to patients. Corresponding items were drafted, iteratively reviewed by the research team and distributed to a sample of consumer advocates for qualitative feedback on item comprehension and relevance.

Four distinct symptom groups were selected as priority areas: (i) pain, (ii) fatigue, (iii) additional physical symptoms (e.g. nausea and constipation), from here on known as 'other physical symptoms', and (iv) emotional distress (anxiety, distress or depression). For each symptom group, patients responded to one question asking how often a doctor or healthcare worker at the hospital or clinic

from where they were recruited specifically asked if they were experiencing the symptom (i.e. pain, fatigue, other physical symptoms and emotional distress) from their cancer or its treatment. Patients were asked to recollect across all appointments, since they first attended the clinic or hospital for their cancer care. Patients were instructed to select one option from the following six: (1) every appointment, (2) most appointments, (3) about half of my appointments, (4) less than half of my appointments, (5) never asked but I told the healthcare worker about this symptom and (6) never. Threshold scores were established using recommendations from clinical practice guidelines that emphasise screening at regular intervals and at times of change [2–4,6]. Patients who responded that they were asked at either 'every appointment' or 'most appointments' or 'about half of their appointments' were categorised as having been regularly *screened*. Asking 'at less than half of all appointments' was judged as too infrequent. Therefore, those who responded 'asked at less than half of appointments' or 'never' were classified as *infrequently screened*. Patients who responded 'never asked, but told the health care worker about the symptom' were categorised as *patient-volunteered information*.

Demographic and clinical items

These items included age, sex, country of birth, marital status, education, cancer type, current remission status, time since diagnosis and number and reason for clinic visit, which were assessed at baseline.

Statistical analysis

To examine sample representativeness, participant demographics were compared with those of eligible nonparticipants using chi-square analyses. Eligible nonparticipants were composed of those who did not consent to the study and those who consented but did not complete a follow-up survey. For each of the four symptom groups, the proportion of patients (1) regularly screened by clinic staff or having volunteered information and (2) infrequently screened by clinic staff was calculated for each centre. To examine the association between screening and treatment centre, chi-square analyses were conducted for each of the four symptom groups. Finally, Cochran's *Q*-test was used to examine differences in symptom screening across the four symptoms comparing screened or volunteered information with infrequently screened. To explore the difference in screening across symptoms, Cochran's *Q*-test was conducted on the mean screening rate.

Post hoc power calculations were undertaken. Our sample was composed of six treatment centres with sample sizes ranging from 84 to 244 patients per centre. Assuming a conservative 40% referent proportion, this number was sufficient to detect differences in the proportion of patients screened between at least two centres of at least 15%

Table 1. Patient demographics and cancer-related characteristics

	Sample, N = 716	
	n	(%)
Gender	N = 716	
Male	306	(43)
Female	410	(57)
Age at diagnosis (years)	N = 689	
Mean (SD)	61.8 years	(SD = 11.8)
18–34	16	(2)
35–44	42	(6)
45–54	128	(18)
55–64	210	(29)
65–74	207	(28)
75 or more	86	(12)
Marital status	N = 695	
Married, in a relationship	461	(66)
Single, divorced, widowed	236	(34)
Education	N = 693	
Primary school	41	(6)
High school	293	(42)
Trade, university	337	(49)
Other	22	(3)
Australian born	N = 697	
Yes	521	(75)
No	176	(25)
Cancer type	N = 684	
Breast	223	(33)
Colorectal	131	(19)
Lung	61	(9)
Upper gastrointestinal	58	(8)
Prostate	39	(6)
Other urogenital	39	(6)
Other	133	(19)
Remission status	N = 582	
In remission	134	(23)
Not in remission	292	(50)
Unknown	160	(27)
Months post-diagnosis	N = 695	
Less than 6 months	184	(26)
6–12 months	145	(21)
13–24 months	117	(17)
More than 24 months	249	(36)
Treatment ever received ^a		
Surgery	500	(72)
Chemotherapy	572	(83)
Radiotherapy	363	(56)
Hormone treatment	158	(24)
Biological therapies	84	(13)
Number of visits	N = 676	
Mean (SD)	19.7 visits	(SD = 18.5)
Less than 10 visits	226	(33)
10–19 visits	180	(27)
20–29 visits	103	(15)
30 or more visits	167	(25)
Reason for visit	N = 685	
Discuss treatment options	73	(11)
Receive treatment or check-up	370	(54)
Post-treatment follow-up	217	(32)
Other	25	(4)

^aTotals do not add up to 100% as patients may have received more than one treatment.

for each of the proportions of interest with a significance threshold of 5% and power ranging from 72% (smallest two centres) to 98% (largest two centres).

Results

Medical oncology treatment centres

Treatment centres were located in five out of the six Australian states. All centres were publically funded. While all centres were situated in urban areas, four centres were situated in major cities and two in inner regional areas. This distribution of centres approximately reflected the distribution of treatment centres across the participating Australian states (23% located in regional areas).

Patients

Across the six centres, 1619 patients were approached between September 2012 and May 2014. A total of 282 patients were ineligible because it was their first clinic visit ($n=103$) or they were unable to read English ($n=80$), were previously approached about the study or were not visiting for a medical oncology appointment ($n=38$), were unable to complete survey independently ($n=16$), were too sick ($n=15$), had unconfirmed cancer diagnosis ($n=4$) or had other unspecified reasons ($n=26$). Of the 1337 eligible patients, 1137 (85%) consented to participate, and 944 (71%) returned a baseline survey. A total of 716 (63% response rate) returned a follow-up survey, 692 (97%) had complete data for one or more screening items, and 661 participants (92%) had complete data for all four screening items. Patient demographics and cancer-related characteristics are described in Table 1. Compared with all eligible participants, those who completed the follow-up survey were significantly less likely to be aged 18–34 years ($\chi^2(5)=11.55$, $p=0.04$) and male ($\chi^2(1)=6.579$, $p=0.01$).

Does symptom screening vary by cancer treatment centre?

Figure 1 presents the proportion of patients across each of the six treatment centres who were infrequently screened. Overall, 14.6% of patients were infrequently screened for pain (range: 9.1–21%), 15.9% of patients were infrequently screened for fatigue (range: 14.5–18.5%), 11.4% of patients were infrequently screened for other physical symptoms (range: 5.1–16.9%), and 35.3% of patients were infrequently screened for emotional distress (range: 30.4–44.8%). Univariate analysis revealed no significant association between treatment centre and *infrequent screening* for emotional pain ($\chi^2(5)=7.17$, $p=0.21$), fatigue ($\chi^2(5)=1.10$, $p=0.95$), other physical symptoms ($\chi^2(5)=5.12$, $p=0.40$) and distress ($\chi^2(5)=3.30$, $p=0.65$). Consequently, no further testing was conducted to adjust for potential confounding.

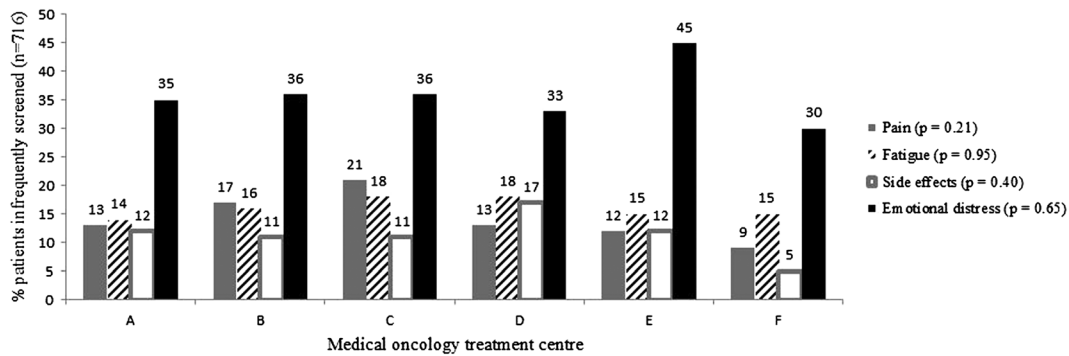


Figure 1. Proportion of patients infrequently screened for emotional distress and physical symptoms, by medical oncology treatment centre

Table 2. Frequency and percentage of patients by frequency of screening for each symptom

	N	Regularly screened or patient-volunteered information			Infrequently screened		
		At every appointment n (%)	At most appointments n (%)	At about half of appointments n (%)	Never asked but informed providers about symptom n (%)	At less than half of appointments n (%)	Never n (%)
Pain	678	327 (48.2)	156 (23.0)	61 (9.0)	35 (5.2)	50 (7.4)	49 (7.2)
Fatigue	681	269 (39.5)	183 (26.9)	64 (9.4)	57 (8.4)	69 (10.1)	39 (5.7)
Symptoms other than pain or fatigue	678	324 (47.8)	166 (24.5)	69 (10.2)	42 (6.2)	39 (5.8)	38 (5.6)
Anxiety, depression, distress	680	202 (29.7)	116 (17.1)	70 (10.3)	52 (7.7)	88 (12.9)	152 (22.4)

Cochran's $\chi^2(3) = 249.54, p < 0.0001$.

Were fewer patients screened for their emotional symptoms compared with physical symptoms?

Across all treatment centres combined, the proportion of patients who were infrequently screened versus regularly screened or patient-volunteered information was significantly different between the four symptom groups (Cochran's $\chi^2(3) = 249.54, p < 0.0001$) (Table 2). The majority of patients were screened at 'every appointment' or 'most appointments' for their pain (48% and 23%, respectively), fatigue (40% and 27%, respectively) and other physical symptoms (48% and 25%, respectively), compared with less than half being regularly screened for emotional distress (30% and 17%, respectively). A greater proportion of patients were never screened for emotional symptoms (22%) compared with physical symptoms (pain, 7%; fatigue, 5%; and symptoms, 6%).

Conclusions

Symptom screening did not vary by cancer treatment centre

We found no significant variation among treatment centres in rates of screening for physical and emotional symptoms. To our knowledge, only one study has explored variation in screening of patient physical and emotional symptoms across cancer treatment centres [32]. The prior study, conducted by Jacobsen *et al.* [32] in 11 hospitals in the USA

found significant variation in screening rates across centres. Findings indicated that between 14% and 88% and between 3% and 45% were not screened within 1 month of initial visit for emotional distress and pain, respectively. In contrast, our study found more narrow rates of screening for emotional distress (30–45% infrequently screened) and pain (9–21% infrequently screened), indicative of greater uniformity in practices across centres. There were substantial differences with respect to our study and that of Jacobsen and colleagues, which may account for the disparity in results.

Why our data differed from the Jacobsen *et al.* data [32]

Health system differences

It is possible that fundamental differences in health service delivery may explain the differences. The Australian treatment centres included in this analysis are all publically funded, despite accounting for almost half (45%) of all Australia medical oncology treatment centres. The USA healthcare system is primarily a private enterprise, reflected in the 11 USA practice sites that demonstrated variation [32]. It can be beneficial for private enterprise to strive to differentiate oneself from the crowd by applying innovations in products and processes [33]. This differs to a government-funded and administered healthcare system that seeks to standardise the delivery of care [34]. Our

findings may suggest that compared with a primarily privatised US health system, publically provided Australian cancer care is delivered with greater uniformity.

Use of medical record versus patient self-report

Methodological differences in our study compared with Jacobsen *et al.* [32] may also explain the differences in centre variation in provider screening. Our study administered patient self-report surveys whereas the Jacobsen *et al.* [32] study employed medical record audit undertaken by site-specific medical record abstractors. Despite growing interest in ensuring that patient physical and emotional symptoms are documented [12–35], it is unlikely that informal questioning of patients is documented on each occasion. It is possible that quality indicators assessed via medical record abstraction may reflect variation in documentation rather than actual delivery of care. Documentation of screening may systematically vary, potentially without any corresponding differences in care delivery. Consequently, patient self-report is considered the best method for measuring patient-centred care [1,19]. The Commission on Cancer has recently recommended that psychosocial distress screening should be offered, at a minimum, during a pivotal medical visit. Documentation of screening in the patient medical record is also required. These recommendations may mean that results of any future studies conducted in the USA may be subject to a reduction in variability in documentation.

Fewer patients were regularly asked about their emotional symptoms than physical symptoms

Fewer patients were regularly asked (at half of their appointments or more) about their emotional distress than their pain and other physical symptoms [32]. This finding was remarkably consistent across each of the six treatment centres, pointing towards homogeneity in care delivery despite very large distances of up to 4000 km between the individual centres. This remarkable lack of variation may be the result of educational training and certification of health providers by independent national bodies and uniform values and expectations built from a tradition of government involvement in the organisation and administration of health care.

Providers may give higher priority to physical symptoms of cancer care than emotional symptoms. It could be argued that a more conservative cut point ('ever' versus 'regularly' screened) should be applied to emotional symptom screening. Even when applying this cut point to the data via a post hoc analysis, emotional symptoms (22% never screened) continue to be less frequently screened than physical symptoms (Cochran's $\chi^2(3)=51.45$, $p < 0.0001$). While patients are concerned about physical symptoms and side effects of their cancer and treatment [36], unmet needs related to

psychological issues are consistently identified by patients across the cancer trajectory [37,38].

Strengths and limitations

As a consequence of ethics processes being prohibitively expensive, no private hospitals were included in the sample despite accounting for approximately 45% of all Australia medical oncology treatment centres [39]. Exploring screening across a larger number of medical oncology treatment centres representing both the public and private sectors would improve the representativeness of the sample and increase the likelihood of identifying between-centre variation. While this is the largest study of its type, generalisation of findings to all medical oncology clinics should be made with caution.

While patient self-report has been deemed an ideal measure of assessing patient-centred care [1], recall may limit accuracy [19]. Furthermore, we chose to look at the functioning of the medical oncology unit as a whole, rather than assess individual providers. This approach provided a more generalised perspective of care delivered at the treatment centre, which was considered appropriate given the focus on multidisciplinary care in Australia. Future studies could explore a greater variety of symptoms.

Follow-up surveys assessing symptom screening were administered 4 weeks after the baseline survey. Patients had adequate opportunity to have received care at that hospital on several occasions and to have been screened. However, administering items within a follow-up survey impacted on the response rate (63%), and our sample under-represented younger patients and men. Previously, we did not identify any associations between sex and age and physical and emotional symptom screening (Zucca *et al.* under editorial review), suggesting that we may not have incorrectly estimated symptom screening.

Implications and future research

This study adds to the limited international knowledge about variation in patient-centred care across treatment centres. Patients deserve to receive optimal care irrespective of whom they see and which treatment centre they attend [1]. Importantly, uniformity of care is not desirable when it delivers less than optimal care. Our findings indicate that treatment centres in this study have an opportunity to improve their rates of symptom screening, particularly for emotional distress.

Patient-focused interventions to encourage active participation in health care, such as those to encourage patient question asking, increase health literacy or empower patients to improve communication skills, have had modest success [26,40–43]. Giving responsibility to physically and emotionally vulnerable individuals to improve screening rates appears not only ineffective but also unreasonable. Responsibility for screening patients to establish their physical and psychosocial well-being surely rests with the

clinical staff of treatment centres. To achieve this desirable outcome, there may be a need to critically examine existing treatment centre policies, provider beliefs and interpersonal skills. A system-based approach, such as distress screening [44], will be required where common barriers such as forgetting to ask, lack of role definition about addressing psychosocial or information needs, referral pathways and perceived lack of time are overcome [45,46]. Before widespread adoption of any of these approaches occurs, there is a need to rigorously test whether such interventions have an impact on patient outcomes [44].

Finally, there is also a need to ensure that improving care delivery in treatment centres is guided by accurate and credible measurement. Without this, it will be difficult to persuade providers, administrators and healthcare systems to undertake quality improvement initiatives. Future research should triangulate quality indicators abstracted from medical records with equivalent patient self-report

data (and vice versa) [37]. Such an approach would help to ensure that our data are best positioned to inform care delivery.

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Conflict of interest

There are no known conflicts of interest for any of the authors.

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