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## PAPER FOUR

Medical oncology patients: are they offered help and does it provide relief?

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Medical oncology patients: are they offered help and does it provide relief?

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#### **ABSTRACT**

**Context:** Identifying modifiable gaps in the symptom management pathway, as perceived by patients, is the first step to relieving patient suffering.

**Objectives:** To describe the proportion of patients experiencing treatable cancer-related symptoms who reported i) a health care provider at the treatment centre offered assistance for their symptom, ii) they accepted the assistance offered, and iii) the assistance relieved suffering. Variation in symptom management among treatment centres was also examined.

**Methods:** A survey of 528 medical oncology outpatients recruited from six treatment centres. Eight items explored management of prevalent, burdensome and treatable cancer-related symptoms: pain, fatigue, other physical side effects, and emotional distress. Participants were asked about symptom management provided at the clinic from where they were recruited. Questions referred to the last occasion the patient experienced the symptom.

Results: Fewer patients were offered help to relieve fatigue (44%) and emotional distress (57%), than pain (90%) and other physical side effects (84%). In most cases, help was not offered as clinic staff were not aware of the patient's symptom. While the vast majority of patients accepted the help that was offered, more patients accepted help for physical symptoms (pain, 97%; fatigue, 95%; other side effects, 98%) than emotional symptoms (87%). When care was provided, most patients experienced at least a little relief from pain (99%), fatigue (94%) and emotional distress (96%). Symptom management did not vary significantly by treatment centre (p=0.073).

**Conclusion:** Quality improvement initiatives must focus primarily on improving providers' awareness of their patients' symptoms, and ensuring that patients are subsequently offered help.

## Introduction

Most cancer patients will experience one or more side effects as a result of their cancer and treatments including fatigue (up to 91%)<sup>1</sup>, pain (up to 59%)<sup>2,3</sup>, distress or anxiety (up to 45%)<sup>4,5</sup> or depression (up to 49%)<sup>6</sup> Appropriate symptom management is a fundamental component of quality cancer care <sup>7</sup>, and is essential for optimising quality of life<sup>8</sup>.

## **Deficits in the symptom management pathway**

Despite the availability of guideline recommendations regarding symptom management<sup>9-12</sup>, physical and emotional symptoms are often under-recognised<sup>13-15</sup> and under-treated<sup>16-17,18</sup>. The reasons for the evidence-practice gap are three-fold. Less than optimal symptom management may be a consequence of i) patients not being offered help, ii) patients not accepting the help that is offered, or iii) the help offered is of little benefit. First, concordance studies indicate that providers may not accurately detect or may underestimate the severity of common physical symptoms, such as pain or fatigue<sup>13,14</sup>, or emotional distress<sup>15,19</sup>. Second, awareness of cancer-related symptoms by clinic staff may not necessarily lead to appropriate or sufficient treatment <sup>16,20</sup>. Less than half of patients receive any advice or support for fatigue<sup>17,21</sup>, and psychosocial needs remain unmet in up to25% of all patients<sup>18,22</sup>. Third, when patients are referred to treatment, patient uptake of services and adherence to treatment if often suboptimal<sup>23,24</sup>. <sup>24,25</sup>.

## Does the current literature identify gaps in the symptom management pathway?

Little empirical data is available quantifying patients' perceptions of where in the symptom management pathway gaps occur. This may, in part be due to a lack of appropriate tools to identify these evidence-practice gaps. Existing symptom assessment tools<sup>26</sup> quantify symptom severity but do not assess the adequacy of clinical actions taken address such symptoms. While several tools have been developed to assess patient-reported barriers to symptom management, these items primarily focus on patient-related barriers, for example, patient's fear of addiction to pain medication<sup>25</sup>. Other studies exploring patients' symptom experience have examined medical records<sup>3,27-29</sup>, and/or assessed

quality of life and unmet needs via a patient-report survey<sup>2</sup>. While these approaches have helped to quantify evidence-practice gaps, they have limitations. First, documentation of the presence of symptoms and their treatment in administrative records may be incomplete or inaccurate<sup>27</sup>. Issues identified in quality of life and unmet needs surveys are not solely attributable to the quality of symptom care received, as factors including stage of disease and type of cancer are known contribute to the outcome<sup>22</sup>.

## Is there variation in symptom management across treatment centres?

It is increasingly recognised that in order to improve the quality of patient care, changes to the health care system are required<sup>7</sup>. While a number of studies have focused on patient and cancer-related predictors of symptom experience(eg <sup>30,31</sup>), fewer have explored how the organisation of care within the treatment centre may impact on patient's symptom experience<sup>32-36</sup>. There is evidence to suggest that organisations with superior symptom management may have a lower staff to patient ratios, employ policies and procedures for symptom management, or have greater clinician-patient continuity of care<sup>32-35</sup>. However, to our knowledge, no previous studies have explored organisational variation in symptom assessment, treatment, and outcome from the patient's perspective. Understanding whether or not patient experiences of symptom management vary across cancer treatment centres may help to pinpoint potential systems-level factors that can promote or obstruct quality symptom management. Identification of treatment centre characteristics associated with better care could be used by health services to improve care delivery.

## Aims and rationale

To improve our understanding of the delivery of care at modifiable points in the symptom management pathway it is important to explore the provision of symptom management care from the patient's perspective. Therefore, this study aims to describe the proportion of medical oncology outpatients experiencing cancer-related symptoms (pain; fatigue; other general physical side effects; or emotional distress) who reported that they: 1) were offered assistance for their symptoms by a health care provider at the treatment centre; 2) accepted the assistance that was offered to them; 3)

experienced a degree of symptom relief from the accepted treatment; and 4) to explore variation in symptom management between treatment centres.

## **METHODS:**

## Sample:

*Treatment centres:* Six large publically-funded medical oncology clinics, representing five of seven Australian states and territories, participated. All clinics provided treatment to at least 400 new medical oncology cancer patients per year. Four clinics were situated in major cities and two in inner regional areas, approximately reflecting the distribution of clinics across the participating Australian states (23% located in regional areas).

**Participants:** Eligible patients had a confirmed cancer diagnosis of any tumour type, were attending the outpatient medical oncology clinic for their second or subsequent appointment, aged 18 years or older, able to read and understand English, and judged by clinic staff to be able to give informed consent and complete the survey.

Procedures: Eligible patients were approached by research staff while waiting for their clinic appointment and invited to participate in the study. Age and gender of non-consenters was collected. Consenting patients completed a baseline survey assessing patient and clinical characteristics. A second survey assessing symptom management was mailed to consenting patients four weeks later. Patients completed symptom management items in a location outside of the treatment centre to reduce the likelihood of social desirability reporting. Non-responders received a reminder survey after two weeks, and a second reminder after a further four weeks. Ethics approval was obtained from the University of Newcastle Human Research Ethics Committee and each participating health service.

## Measures

Symptom management

Development of the measure: Symptoms were included in the measure if existing research suggests they were: 1) prevalent in medical oncology patients; 2) burdensome to patients if not treated; and 3) treatable or modifiable<sup>37</sup>. Corresponding items were drafted and iteratively reviewed by the research team, and then distributed to a sample of consumer advocates for additional qualitative feedback on item comprehension and relevance. Items were then piloted with 188 patients and revised again to improve their quality and acceptability. The final revised items were completed by the sample reported in this paper.

Symptom management items: Items explored the management of four distinct symptom groups: (i) pain, (ii) fatigue, (iii) additional physical side effects (e.g., nausea, constipation, fever, infection), from here on known as "other physical side-effects", and (iv) emotional distress (e.g., anxiety, distress, or depression). For each symptom group, participants responded to two questions about symptom management at the clinic from where they were recruited. As shown in Table 1, participants were asked whether assistance was offered for their symptom, and if not, whether clinic staff were aware of the symptom. Examples of assistance were provided for each symptom. Next, participants who were offered assistance were asked whether the assistance provided relief.

Table 1: Example of participant survey pain management items

Q1	<u>Last time</u> you had cancer-related <u>pain</u> , were you offered assistance at this clinic to treat your pain?	<ol> <li>2.</li> </ol>	Never had cancer-related pain (participant did not receive Q2)  Yes, I was offered assistance for my pain (participant received Q2)
	(Examples of assistance could include medication, relaxation training, referral to pain specialist)	3.	Clinic staff were <u>not aware</u> of my pain (participant did not receive Q2)
	Please circle one number only	4.	Clinic staff were <u>aware</u> of my pain but did not offer assistance (participant did not receive Q2)
		5.	Clinic staff were <u>aware</u> of my pain but did not offer assistance because nothing could be done to help (participant did not receive Q2)
		1.	No relief
Q2	Did the pain treatment or assistance offered	2.	A little or some relief
	relieve your pain?	3.	A lot or complete relief
	Please circle one number only	4.	I did not accept or take the treatment or assistance I was offered

Demographic and clinical items: To describe the sample, information was collected about participants' age, sex, country of birth, marital status, education, cancer type, cancer stage at diagnosis, remission status, time since diagnosis, and treatments received.

## Statistical analysis:

To examine the representativeness of the sample, the age and gender of eligible responders and non-responders were compared using chi-square analyses. Frequency data were used to describe the management of each symptom set including: the proportion of patients who experienced the symptom, who were offered help, accepted help, and experienced relief. As only 15% of patients experienced all four symptoms we did not compare between symptoms. Participants with missing data were excluded from the analysis of the symptom. To calculate *overall symptom management* the number of patients who experienced at least a little relief was divided by the total number of patients who experienced the symptom. Participants who did not experience the symptom were excluded from this analysis. To explore variation in *overall symptom management* across treatment centres a logistic regression was performed. To reduce the number of potential tests, all four symptoms were combined into one variable comprised of four symptom categories: pain, fatigue, other side effects and emotional distress. To account for repeated measurements taken from individual participants, the logistic regression was adjusted for clustering within individual participants.

## **Results**

## Sample

A total of 1619 patients were approached between September 2012 to May 2014. Of these, 282 patients were ineligible due to: it being their first clinic visit (n=103), not being able to read or speak English (n=80), previously approached about the study, or were not visiting for a medical oncology appointment (n=38), unable to consent or complete survey independently (n=16), too sick (n=15), cancer diagnosis not confirmed (n=4), or other unspecified (n=26). Of the 1337 eligible patients,

1137 (85%) consented to participate, and 944 (71%) returned a baseline survey. Of those who consented, 716 (63%) returned a follow-up survey: 188 participants completed the pilot items which were subsequently revised to improve their quality, and 528 completed the final revised items that are presented in this manuscript. Compared to 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). The demographic and clinical characteristics of the 528 participants are presented in Table 2.

## The care pathway for cancer-related symptoms

Figure 1 represents three key points along the symptom management pathway: i) whether the patient was offered assistance for their symptom, ii) whether they accepted the assistance offered, and iii) whether they experienced relief from their suffering as a result of assistance.

**Did providers offer help?** Fewer patients were offered help to relieve fatigue (44%;95% CI: 39, 49%) and emotional distress (57%;95% CI: 51, 63%), compared with pain (90%; 95% CI: 86, 93%) and other physical side effects (84%;95% CI 80,88%). The most common reasons that help to manage pain and emotional distress was not offered was because patients perceived that clinic staff were not aware they were experiencing these symptoms. In contrast, of those patients reporting fatigue who were not offered assistance, the majority (n=123, 57%) reported that clinic staff were aware of this symptom but did not offer help.

**Did patients accept help offered?** Overall, the majority of patients accepted the help that was offered to relieve symptoms. A notably greater proportion of patients accepted help for pain (97%; 95% CI: 95,99%), fatigue (95%; 95%CI: 92, 98%), and other side effects (98%; 95%CI: 96-100%) when compared to the proportion who accepted help for emotional distress (87%; 95% CI: 82,92%).

Did patients experience relief from their suffering? Most patients who accepted offers of assistance experienced at least some relief from pain (99%; 95% CI: 98,100%), fatigue (94%; 95% CI: 90,98%), other physical side effects (98%, 95% CI:97,100%) and emotional distress (96%, 95% CI: 93,99%). Pain was the symptom where the greatest proportion of patients experienced relief after accepting offers of assistance (62% reported 'a lot or complete relief'). The assistance offered to manage fatigue and emotional distress appeared to provide relief to the lowest proportion of patients, with just 36% (95% CI: 29,44%) and 38% (95% CI: 29,46%) of patients reporting 'a lot or complete relief', respectively (Figure 1).

## Was there variation in overall symptom management across treatment centre?

As shown in Table 3, there was no significant variation among treatment centres for overall symptom management ( $\chi^2(5)=10.07$ , p=0.073). This finding was further attenuated after adjusting for age, gender and cancer type ( $\chi^2(5)=9.47$ , p=0.0918). Despite this lack of overall variation, patients from treatment centre A had 1.6 greater odds of greater symptom relief than the reference treatment centre C. The pseudo R squared for the contribution of treatment centre was less than 1% ( $R^2=0.0088$ ) indicating that treatment centre did not account for much of the variation in overall symptom management. Fewer patients experienced relief from their fatigue (n=150; 39%; 95% CI: 34, 44%; range 26-48%) or emotional distress (n= 120; 48%; 95% CI: 41,54%; range 36%-57%) compared to patients who had experienced pain (n=247; 87%; 95% CI: 83,91%; range 75-94%) or other physical side effects (n=299; 81%;95% CI: 77,85%; range 72-89%).

Table 2: Patient demographics and cancer-related characteristics

		ample I=528
	n	(%)
Gender		
Male	229	(43)
Female	299	(57)
Age at diagnosis (years)		
Mean (SD)	61.97	(SD=11.8)
18-34	13	(3)
35-44	28	(6)
45-54	90	(18)
55-64	155	(31)
65-74	157	(31)
75 or more	59	(12)
Marital status		
Married or in a relationship	341	(67)
Single, divorced, widowed	168	(33)
Education		
Primary school	28	(6)
High school	216	(43)
Trade or university	250	(49)
Other	13	(3)
Australian born		
Yes	366	(72)
No	144	(28)
Cancer type		
Breast	155	(31)
Colorectal	92	(18)
Upper gastrointestinal	44	(9)
Lung	43	(9)
Prostate	30	(6)
Urogenital	29	(6)
Haematological	18	(4)
Gynaecological	14	(3)
Other	87	(17)
Stage at diagnosis		
Early	288	(60)
Advanced	151	(31)
Unknown	41	(9)
Remission status		
In remission	125	(25)
Not in remission	210	(42)
Unknown	160	(32)
Months post-diagnosis		
Less than 6 months	142	(28)
6-12 months	106	(21)
13-24 months	82	(16)
More than 24 months	179	(35)
Treatment ever received*		
Surgery	360	(71)
Chemotherapy	407	(80)
Radiotherapy	258	(54)
Hormone treatment	115	(24)
Biological therapies	58	(12)

<sup>\*</sup>Totals do not add up to 100% as patients may have received more than one treatment

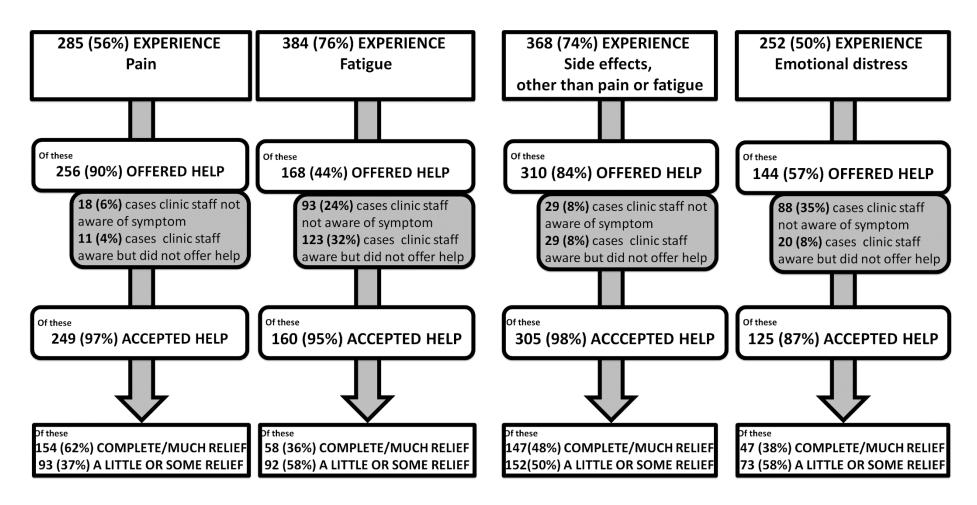


Figure 1: The care pathway for cancer-related symptom

Table 3: Overall symptom relief by treatment centre.

	Treatment centre						Total	
Symptom	A n %	B n %	C n %	D n %	E n %	F n %	N %	
Pain	30 (75%)	50 (88%)	58 (89%)	31 (86%)	31 (94%)	47 (89%)	247 (87%)	
Fatigue	21 (35%)	37 (46%)	38 (44%)	13 (26%)	12 (26%)	29 (48%)	150 (39%)	
Side effects other than pain or fatigue	48 (75%)	70 (89%)	69 (84%)	28 (72%)	33 (79%)	51 (82%)	299 (81%)	
Emotional distress	18 (41%)	24 (44%)	35(57%)	17(53%)	9 (36%)	17 (49%)	120 (47%)	
Crude OR(95%CI)	1.62(1.04-2.52)	1.04(0.67-1.60)	reference	1.59(0.98-2.59)	1.49(0.90-2.48)	0.97(0.60-1.55)		
P value	0.032	0.874		0.062	0.120	0.897	0.073	

OR = odds ratio; CI= confidence interval

#### **Discussion**

This study explored perceptions of the quality of symptom care received among a sample of medical oncology outpatients. Our results suggest that clinical staff are less prepared to detect and offer assistance for emotional distress and fatigue than for pain and other physical side effects. This study highlights key points in the care pathway that will assist treatment centres in developing and targeting appropriate quality improvement initiatives to facilitate relief of patients' physical side effects and emotional distress.

## Did providers offer help?

Encouragingly, patients were offered help for their pain in nine out of ten instances, perhaps reflecting the effect of decades of dedicated literature that has led improved oncology care guidelines<sup>9</sup>. However, the 10% of patients who were not offered pain assistance remains a concern, and suggests that treatment centres can continue to improve their ability to detect and provide assistance to patients. In contrast, there appears to be a much larger task at hand to achieve optimal symptom management of fatigue and emotional distress. Our results indicate that only half of all patients experiencing fatigue or emotional distress were offered help. This finding is consistent with the literature that suggests providers may not consider addressing psychosocial issues to be a key duty<sup>38</sup>. Similarly, fatigue may be perceived as a less important symptom and more challenging to treat, and therefore may remain undiscussed and untreated<sup>39</sup>.

Perceived lack of staff awareness of the patient's pain, emotional distress, and other physical side effects was a primary reason patients reported they were not offered help. Thus, improving symptom care must primarily focus on providers' awareness of their patients' symptoms. Furthermore, awareness of emotional symptoms was poorer than physical symptoms. This may be a consequence of providers misjudging the presence or severity of patient emotional symptoms<sup>19</sup>, and/or patients' reluctance to raise emotional concerns without prompting<sup>40</sup>. Indeed when patients' perceived clinicians were aware of their distress only 8% reported not being offered help, unlike 32% of patients

with fatigue who were not offered help. These results suggest that clinicians may be quite willing to provide help for emotional distress once it has been identified.

Potential initiatives to improve provider awareness may include routine and systematic screening of patient symptoms via a pen-and paper or electronic survey, however only modest evidence for efficacy has been demonstrated to date<sup>23,41</sup>. Incorporating a prompt or tick-box for providers to complete within medical records could be another potential option to improve symptom screening<sup>36</sup>. Similarly, patient-focused initiatives, such as provision of education and question prompt lists to encourage more active participation in medical consultations, could also be considered as they have achieved some success in improving the frequency of patient question-asking<sup>42</sup>.

Deficits in the management of fatigue could not primarily be explained by provider awareness alone. In most cases, help was not offered despite patients perceiving that their providers were aware of the symptom. However, it is possible that management of patient fatigue was more prevalent than we have concluded. Patients may have incorrectly reported they did not receive care, despite providers offering education and advice about effective self-care strategies. For example, three patients who responded that no help was offered wrote that nothing could be done except bed rest, or sleep or to take time off work. These responses may represent advice or assistance offered by providers to manage fatigue that have not been recognised by patients as such. Despite the possibility that the provision of care for fatigue was underestimated, our results highlight that fatigue management remains in need of improvement. As a minimum standard, quality improvement activities to improve the management of fatigue should seek to ensure fatigue management guidelines are implemented with all cancer patients. Guidelines indicate that before treatment all patients should be prepared to anticipate the high likelihood of experiencing the debilitating symptom fatigue<sup>10</sup>. Furthermore, after symptom onset, patients should receive education and counselling for self-care strategies, management of concurrent symptoms, and recommendations for use of evidence-based strategies including physical therapy, and cognitive behavioural therapy<sup>10</sup>.

## Did patients accept help offered?

The vast majority of patients who were offered help accepted the help. This suggests that developing strategies to increase patient uptake of offers of support should not be the primary focus of our efforts to improve symptom relief for patients. Consistent with current literature, help for emotional symptoms was not always accepted<sup>40</sup> as patients may prefer to self-manage distress, find the offered assistance unacceptable, or difficult to access<sup>23,40</sup>. Alternatively, providers' acknowledgement of the patient's distress may be considered helpful in and of itself without referral to counselling or use of medications<sup>40</sup>. The offer of emotional validation and support may allow the patient to feel cared for and strengthen the patient-provider relationship, a key ingredient in patient satisfaction<sup>43</sup>.

## Did patients experience relief from their suffering?

Our results suggest that if help is offered, and it is accepted, then the patient will experience at least some relief. This is particularly true for people who accepted help for pain, as most experienced complete relief. In contrast, most people who accepted help for fatigue or emotional distress experienced only some, rather than complete relief. While a lot or complete symptom relief should be the goal of symptom management, this is not always possible. Systematic reviews indicate psychosocial interventions have only small to moderate impact on emotional functioning<sup>44</sup>. Similarly, fatigue interventions have small to moderate reductions on patient fatigue levels<sup>45,46</sup>.

## Is there variation in symptom management across treatment centres?

There was no significant variation in symptom management of pain, fatigue, side effects and distress across treatment centres. While previous literature suggests that clinical outcomes such as survival vary across treatment centres<sup>47</sup>, this study is one of a small number to explore variation in patient satisfaction and quality of patient-centred care<sup>33-36</sup> among hospitals. These previous studies show mixed results. For example, Shin and colleagues<sup>35</sup> found significant variation in pain control among palliative care centers and Jacobsen and colleagues<sup>36</sup> found significant variation in pain and distress assessment among medical oncology sites. On the other hand, Carey and colleagues<sup>33</sup> did not find any variation in patient anxiety or depression between treatment centres. Our findings may reflect either 1)

that treatment centre factors do not play a role in symptom management, or 2) the centres selected for this sample are too homogenous and do not allow the identification of potential modifiable systems-level factors. Perhaps inclusion of private hospitals in the sample would have resulted in greater treatment centre variation.

## Strengths and limitations

This study described symptom management within six Australian public treatment centres, thus the generalizability of results to international treatment centres should be made with caution. While we under-sampled younger patients and males, these patient characteristics were not significantly related to symptom relief (post-hoc; age: p=0.071; gender: p= 0.872), suggesting we are unlikely to have incorrectly estimated symptom management.

We chose to explore the functioning of the medical oncology unit rather than exploring the actions of individual health professionals. While our data does not allow feedback to be provided to specific health professional groups, it reflects care delivery within organisational units of multi-disciplinary teams. Given the difficulties with changing behaviour of individual health care providers<sup>48</sup>, looking towards system-oriented initiatives may best support providers to deliver care.

Our results do not assess whether patients received assistance for the symptoms elsewhere. For example, they might have received care from their primary care practitioner, surgeon or radiation therapist. However, given that lack of co-ordinated care is a key area for improvement, it is essential that staff within the medical oncology clinic ensure patients' symptoms are being actively managed. Furthermore, while we explored symptom uptake, we did not explore patients' treatment adherence, which may have also had an impact on symptom relief<sup>24,25</sup>.

Finally, only four prevalent burdensome and treatable symptom groups were assessed. Future studies could explore the management of a greater variety of symptoms.

## Conclusion

Treatment centres have a responsibility to help patients by delivering optimal evidence-based cancer care and reducing the burden of cancer-related symptoms. Our results highlight that quality improvement initiatives must initially focus on improving providers' awareness of their patients' symptoms. Our results also highlight that awareness may not always lead to the subsequent offer of help. We must ensure that patients in need are offered help consistent with evidence based guidelines.

## **Disclosures and Acknowledgments**

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## **Appendix A: Survey items**

Please answer the following items in relation to the cancer care you received at the hospital or clinic written on your cover letter.

These two items are about cancer-related pain

D4a	<u>Last time</u> you had cancer-related <u>pain</u> , were you offered assistance at this clinic to treat your pain?		Never had cancer-related pain (go to Question D5) Yes, I was offered assistance for my pain (continue to Question D4b)
	(Examples of assistance could include medication, relaxation training, referral to pain specialist)  Please circle one number only	8.	Clinic staff were <u>not aware</u> of my pain (go to Question D5)
		9.	Clinic staff were <u>aware</u> of my pain but did not offer assistance <i>(go to Question D5)</i>
		10.	Clinic staff were <u>aware</u> of my pain but did not offer assistance because nothing could be done to help (go to Question D5)
D4b	Did the pain treatment or assistance offered relieve your pain?	6.	No relief A little or some relief A lot or complete relief
	Please circle one number only	8.	I did not accept or take the treatment or assistance I was offered

These two items are about cancer-related tiredness or fatigue

D5a	Last time you had cancer-related tiredness or fatigue, were you offered assistance at this clinic to treat your tiredness or fatigue?  (Examples of assistance could include medication, exercise advice, counselling, education programs)  Please circle one number only	3.	Never had cancer-related fatigue (go to Question D6)  Yes, I was offered assistance for my fatigue (continue to Question D5b)  Clinic staff were not aware of my fatigue (go to Question D6)  Clinic staff were aware of my fatigue but did not offer assistance (go to Question D6)  Clinic staff were aware of my fatigue but did not offer assistance because nothing could be done to help (go to Question D6)
D5b	Did the treatment or assistance offered for your fatigue provide relief?  Please circle one number only	1. 2. 3. 4.	No relief A little or some relief A lot or complete relief I did not accept or take the treatment or assistance I was offered

Please answer the following items in relation to the cancer care you received at the hospital or clinic written on your cover letter.

These two items are about cancer-related physical side effects, other than pain or fatigue, such as nausea, constipation, fever or infection.

D6a <u>Last time</u> you had cancer-related <u>physical side</u> <u>effects, other than pain or fatigue</u>, were you offered assistance at this clinic to treat your

- 1. Never had physical side effects (go to Question D7)
- 2. Yes, I was offered assistance for my physical side effects (continue to Question D6b)

	physical side effects?  (Examples of assistance could include information about self-care, medications, tablets, etc.)	<ol> <li>Clinic staff were <u>not aware</u> of my physical side effects (go to Question D7)</li> </ol>
		4. Clinic staff were <u>aware</u> of my physical side effects but did not offer assistance (go to Question D7)
	Please circle one number only	<ol> <li>Clinic staff were <u>aware</u> of my physical side effects but did not offer assistance because but nothing could be done to help (go to Question D7)</li> </ol>
		1. No relief
D6b	Did the treatment or assistance offered for your physical side effects provide relief?	2. A little or some relief
		3. A lot or complete relief
	Please circle one number only	4. I did not accept or take the treatment or assistance I wa offered

These two items are about cancer-related distress, anxiety, and depression

D7a	<u>Last time</u> you had cancer-related <u>distress</u> ,	1.	Never had distress, anxiety, or depression (go to Question D8)
	anxiety, or depression, were you offered assistance at this clinic to treat your distress, anxiety, or depression?	2.	Yes, I was offered assistance for my distress (continue to Question D7b)
		3.	Clinic staff were <u>not</u> <u>aware</u> of my distress
	(Examples of assistance could include		(go to Question D8)
	counselling, medication, information about self-care etc.)	4.	Clinic staff were <u>aware</u> of my distress but did not offer assistance (go to Question D8)
	Please circle one number only	5.	Clinic staff were <u>aware</u> of my distress but did not offer assistance because nothing could be done to help

		(go to Question D8)
D7b	Did the treatment or assistance offered for your distress, anxiety, or depression provide relief?	 No relief A little or some relief A lot or complete relief I did not accept or take the treatment or assistance I was
	Please circle one number only	offered

Please answer the following items in relation to the cancer care you received at the hospital or clinic written on your cover letter.

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