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# How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? data from a survey of five oncologists

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How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? Data from five oncologists.

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## Précis

This study found that medical oncologists' perceptions did not accurately reflect their patients reported physical and psychosocial problems. However, better knowledge of and rapport with the patient and a less pressured workload were associated with significant increases in the oncologists' awareness of their patients' reported levels of perceived needs and depression.

## **Abstract**

**Background:** Modern cancer treatments can cure or prolong patients' lives. However, the associated physical and psychosocial problems can detrimentally affect patients' compliance with treatment and, ultimately, their outcomes. Therefore, oncologists need to recognize the problems experienced by their patients and, where possible, help resolve these problems.

**Methods:** We conducted a cross-sectional survey of physical symptoms, anxiety, depression, and perceived needs among 204 consenting patients attending an outpatient medical oncology department. Immediately following consultations with consenting patients, medical oncologists and registrars also completed a survey, indicating their perception of each patient's level of these problems. These two data sets were then compared.

**Results:** Five oncologists' perceptions of patients' levels of the major physical symptoms (fatigue, nausea, vomiting, and hair loss) demonstrated the highest levels of awareness, with sensitivity rates up to 80%. Although sensitivity was below 50% for all other physical symptoms, specificity was over 78% for all symptoms except fatigue. Only 17% of patients classified as clinically anxious and 6% of those classified as clinically depressed were perceived as such by their oncologist. However, the oncologists perceived much higher levels of perceived needs than patients reported, resulting in high sensitivity but low specificity rates. Oncologists' knowledge of and rapport with their patients and the pressure of their workload were associated with their awareness of their patients' reported problems.

**Conclusions:** Medical oncologists' perceptions may not accurately reflect their patients' reported physical and psychosocial experiences. Further research should develop interventions to assist oncologists in detecting such problems, especially psychosocial ones.

**Keywords:** neoplasms, medical oncologists, patients, anxiety, depression, perceived needs, symptoms, detection.

## **Introduction**

Cancer is a major cause of mortality and morbidity throughout the world: approximately 9 million new cases are diagnosed and 5 million people die from it annually<sup>1</sup>. Most patients now undergo a combination of effective but, nonetheless, traumatic treatments, including surgical removal of the cancer, radiotherapy, chemotherapy, and hormone therapies<sup>2</sup>. While these treatments have the potential to cure some cancers and to prolong the lives of patients suffering others, they are associated with a wide range of physical and psychosocial problems.

Chemotherapy, for example, is associated with physical symptoms as diverse as fatigue, nausea, vomiting, alopecia, appetite loss, diarrhoea, constipation, difficulty sleeping, pain, fluctuations in weight, and amenorrhoea<sup>3-6</sup>. In addition, studies suggest that up to 91% of patients receiving chemotherapy experience elevated levels of anxiety and that up to 61% experience depression<sup>5; 7; 8</sup>. Furthermore, many aspects of patients' quality of life are also diminished: their physical and work activities are reduced, their social activities are disrupted, family and other relationships frequently deteriorate, their level of sexual activity decreases, and they often find themselves under increasing financial burdens<sup>9; 10</sup>.

While both cancer specialists and patients may accept such problems as an inevitable part of the disease and treatment<sup>11; 12</sup>, they can have a substantial impact on patients' compliance and outcomes: it has been estimated that up to one third of patients will abandon chemotherapy prematurely as a result of these physical and psychosocial symptoms, despite the potentially life-threatening consequences of such an action<sup>13</sup>. Therefore, it is important for cancer specialists to be aware of the prevalence of such problems among their patients and to do their best to prevent them, where possible, or to treat them when they occur.

There is little evidence about how well informed medical oncologists are about the physical and psychosocial experiences of their patients. The few studies located which have explored this

area have found rather unsatisfactory levels of awareness<sup>14-16</sup>. However, these studies have tended to ask the oncologists to rate the problems in different terms to those used by the patients, making direct comparisons difficult<sup>14-16</sup>.

As detection represents the first step to overcoming these physical and psychosocial barriers to treatment, it was considered appropriate to conduct a study to assess the accuracy of medical oncologists' perceptions of their patients' physical and psychosocial experiences. Therefore, this study aimed to assess medical oncologists' awareness of their patients' reported levels of physical symptoms, anxiety, depression, and perceived needs. To maximize their awareness, the oncologists were given detailed information about how their responses would be related to those of their patients.

It was hypothesized that higher levels of awareness would exist regarding patients' levels of physical symptoms than their levels of anxiety, depression, and perceived needs. A secondary hypothesis was that higher levels of awareness would result when the oncologists felt less pressured by their workload and for patients they knew well and with whom they had a good rapport.

## **Methods**

### **Setting**

This study was conducted in the outpatient clinic of an academic medical oncology department, which sees 150 to 180 outpatients each week. Approximately half of these patients are currently receiving treatment, including about 15 new patients per week, and the other half are attending for follow-up visits, having completed their course of treatment.

## **Subjects and Procedure**

Patients were recruited during two ten-day periods four months apart. During each data collection phase, consecutive, eligible, adult patients attending the outpatient medical oncology department for a second or subsequent treatment visit or for a follow-up visit were asked to participate in the study. Patients were considered ineligible for the study if they had insufficient English language skills to understand the survey or if their oncologist considered them too sick or distressed to participate. First visit patients were not approached as they had not yet received any treatment and were more likely to be emotionally distressed. Patients attending more than once during the study periods were surveyed only once.

Eligible patients were approached by a research assistant who explained the study and sought their consent to participate: patients were informed that this would involve completing a 15 minute survey on a touchscreen computer, regarding their current physical and psychosocial experiences, while waiting to see their oncologist; their oncologist completing a similar survey, detailing their perceptions of the patient's physical and psychosocial well-being; and their oncologist providing the research team with some information about the patient's diagnosis and treatment regime, from their medical records.

Consenting patients then completed the computer survey. If called to see their oncologist while completing the survey, patients could stop the survey, have their consultation and then return to where they stopped the survey. If patients did not return to complete the survey after their consultation, the computer recorded all the remaining questions as missing after a 24 hour period had elapsed.

The medical oncologists and registrars working in the outpatient medical oncology department during the study periods were asked to complete a brief deskpad survey for each eligible patient seen during the study periods. The completed deskpad surveys were returned to the research assistant at the end of each clinic for data entry.

### **The Patient Survey**

The 15-minute survey included questions grouped into the following 5 domains:

1. **Demographic characteristics** - including gender, age, marital status, educational level, and employment status.
2. **Cancer descriptors** - including the site of the primary cancer, the length of time since the original diagnosis, and the method of administration of the treatment.
3. **Physical symptoms** - including if & on how many days in the preceding week patients had experienced a range of 12 physical symptoms associated with systemic therapy. The symptoms included were determined in consultation with the participating oncologists to represent all the likely physical side effects of the drugs commonly used in the department. The actual symptoms are listed in Tables 2 and 4. For each symptom reported, patients were asked to what extent its severity had inhibited their usual daily activities: not at all, a little or a lot. This section was asked only of current treatment patients.
4. **Anxiety and depression levels** - were assessed using the Hospital Anxiety and Depression Scale (HADS), which contains 7 questions each about anxiety and depression, giving a score between 0 and 21 for each variable and classifying patients' anxiety and depression levels as low (0 - 7), borderline (8 - 10) or clinical (11 - 21)<sup>17</sup>. This instrument, which was developed with a general medical outpatient population, has been validated with cancer patients<sup>18-20</sup>.
5. **Perceived needs** - were assessed using the psychometrically-tested short form Cancer Needs Questionnaire (CNQ), which contains 29 items to measure patients' perceived needs within

five domains: psychological, health information, provider care and support, physical and daily living, and interpersonal communication needs<sup>21</sup>. The factors demonstrate good internal reliability with Cronbach alpha coefficients of 0.94, 0.96, 0.84, 0.89 and 0.75 respectively<sup>21</sup>. The CNQ also has good construct validity with factors loadings of 0.5 or, usually, greater<sup>21</sup>. For each item, patients indicate on a five-point scale whether that need is not an issue for them or whether they are experiencing no need for help or a low, moderate or high need for help with that item. The exact items which load on each factor are listed in Appendix 1.

In addition, information about each consenting patient's stage of disease at diagnosis, their current drugs, and treatment regimen was obtained from their medical records. Non-consenting patients were asked their age, gender and cancer site.

### **The Medical Oncologists' Survey**

The deskpad survey, which was developed in consultation with the oncologists, was in pen and paper format and was completed immediately following each consultation with an eligible patient. For each patient, the oncologists indicated their perception of the patient's level of:

1. **Physical symptoms** - whether they believed that the patient had not experienced each of the 12 potential symptoms at all, had experienced it mildly or had experienced it severely during the last week.
2. **Anxiety and depression** - whether they believed that the patient was currently experiencing a low, borderline or clinical level of both anxiety and depression.
3. **Perceived needs** - whether they believed that the patient currently had no need for help on each of the five factors included in the CNQ, a low need for help or a moderate-high level of need for help in that area.

Detailed definitions of each response option and how they would be compared to patients' responses were given on an explanatory cover sheet and "don't know" options were included for each question. These instructions and the actual oncologists' survey are included in Appendix 2.

The oncologists were also asked for other information which was considered likely to have an effect on their perceptions of their patients' experiences: how well they felt they knew the patient, how they rated their rapport with the patient and how pressured they felt by their workload at the time of the consultation.

## **Analyses**

### ***Overall prevalence of physical and psychosocial problems***

The prevalence of each physical and psychosocial problem was calculated from both the patients' reports and from the oncologists' perceptions and two-tailed z tests were conducted to assess whether significant differences existed between the two estimates for each problem.

### ***Assessing oncologists' awareness regarding individual patients***

The responses provided by each patient were compared with those given by their medical oncologist. Three forms of analyses are reported as indicators of the oncologists' degree of awareness of their patients' responses: sensitivity, specificity, and overall disagreement level.

In these analyses, sensitivity represents the proportion of patients reporting each physical or psychosocial problem who were perceived to be experiencing it by their medical oncologist and specificity represents the proportion of patients reporting having not experienced each problem who were perceived to be free from it by their oncologist. They were calculated using 2 by 2 tables comparing each patient reporting having experienced, or not experienced, each problem with their oncologist's perceptions of their experiences.

Respondents for whom the oncologists reporting not knowing their status on any given problem were excluded from these analyses for that problem. Unfortunately, the high rates of “don’t know” responses for three of the physical symptoms, hot flushes, metallic taste in the mouth and pain in the injected limb, made such diagnostic analyses unfeasible for these problems.

In these analyses, the overall disagreement level represents the proportion of patients whose responses were in different categories to those of their oncologist. It was calculated using 3 by 3 tables of the basic results from the patient and oncologist surveys, using the response options described above.

### ***Exploring Potential Predictors of Improved Awareness***

Continuity-adjusted chi square analyses were conducted to assess whether three potential predictor variables relating to the doctor-patient relationship were related to the level of the oncologists’ awareness: how well the oncologist felt they knew the patient (first visit or not very well versus fairly or very well), how they would rate their rapport with the patient (excellent or good versus fair, poor or terrible), and how pressured they felt by their workload at the time of the consultation (not at all or not very versus fairly or very). A number of patient characteristics (gender, age, primary cancer site, stage of disease at diagnosis, and reason for the current visit) were also explored as potential predictors of the level of awareness. Where the chi square analyses indicated a significant degree of association, odds ratios were conducted to assess the magnitude of the associations.

### **Ethics**

This study was approved by the University of Newcastle’s Human Research Ethics Committee.

## **Results**

### **Participants' Characteristics**

During the study period, 288 treatment and follow-up patients attended the medical oncology department. Of these, 230 (80%) were considered eligible to participate in the study. Patients were considered ineligible if they were too sick (18%) or if they could not speak sufficient English to understand the survey (2%). Of the 230 eligible patients, 12 (5%) saw the oncologist too quickly to be asked to participate in the study. Of the 218 patients approached, 204 (94%) consented and 196 (90%) completed the survey. This represents a response rate of 68% of all patients attending during the study periods.

For patients not completing the whole survey, any fully-completed sections (physical symptoms, anxiety, depression or perceived needs) were included in the analyses but partially-completed sections were excluded. Therefore, the denominators vary slightly between the different results sections reported.

Table 1 summarizes the demographic, disease, and treatment characteristics of the study participants. Non-consenters tended to be older than the consenting patients but were otherwise similar.

### **INSERT TABLE 1 HERE**

Among the study participants: there were more women than men; ages ranged between 20 and 86 years, with a mean of 57 years; colorectal and breast cancers represented the two most common primary sites, accounting for almost 60% of all participants; just over half the patients were diagnosed with stage 3 or 4 cancers; just over a third had been diagnosed during the

previous 6 months; just over half were attending for a treatment, as opposed to a follow-up, visit; the vast majority of patients received their treatment intravenously; less than half had received any treatment during the previous two weeks; and fluorouracil, cyclophosphamide, methotrexate, and leucovorin were the four most commonly prescribed drugs.

### **Medical Oncologists' Characteristics**

The three medical oncologists and two registrars working in the medical oncology outpatient clinic during the study periods all consented to participate in this study. The medical oncologists were all male, aged between 41 and 46 years, had between seven and 21 years experience in the medical oncology field, including seven to 14 years experience in the current medical oncology department, and spent between 26 and 30 hours with patients each week. The registrars were also both male. One was aged 28 years, had 6 months experience in the medical oncology field, all spent in the current department, and spent approximately 12 hours with patients each week. The other was aged 30 years, had three years experience in the medical oncology field, two of which had been spent in the current department, and spent approximately 30 hours with patients each week.

### **Prevalence of Physical Symptoms**

Table 2 summarizes the prevalence of each physical symptom, according to the patients' report and the medical oncologists' perceptions indicating where significant differences were found. It also indicates the proportion of patients for whom the oncologists indicated not knowing their status on each symptom.

**INSERT TABLE 2 HERE**

As shown, patients' reported levels of most physical symptoms were higher than the levels perceived by their medical oncologists, with hair loss, vomiting, and skin rashes being the only

physical symptoms perceived, by the oncologists, to be more prevalent than they were reported by patients. However, only three symptoms showed significant differences between patients' reports and oncologists' perceptions: having a metallic taste in the mouth, hot flushes and fatigue. The first two of these symptoms were also, along with pain in the injected limb, ones for which the oncologists reported the lowest levels of awareness. This is of concern as two of these symptoms, hot flushes and metallic taste, were reported by approximately one third of patients but perceived by the oncologists for less than one tenth of patients.

### **Prevalence of Psychosocial Problems**

Table 3 summarizes the prevalence of each psychosocial problem, according to the patients' report and the medical oncologists' perceptions indicating where significant differences were found. It also indicates the proportion of patients for whom the oncologists indicated not knowing their status on each problem.

**INSERT TABLE 3 HERE**

As shown, patients' scores on the HADS indicated similar rates of clinical anxiety and depression to those perceived by the oncologists. When combining patients with borderline and clinical levels, the oncologists perceived higher levels than patients' scores indicated. Perceived needs were the only outcome measures where the oncologists' perceptions indicated consistently significantly higher levels of each problem than did the patients' reports.

### **Awareness About Patients' Levels of Physical Symptoms**

Table 4 provides a summary of the sensitivity, specificity, and overall level of disagreement regarding the oncologists' perceptions of their patients' levels of each physical symptom.

**INSERT TABLE 4 HERE**

As shown, the oncologists' perceptions of patients' experiences of hair loss were reasonable, with both sensitivity and specificity around 80%. However, the sensitivity of the oncologists' perceptions of patients' experiences of other physical symptoms was lower. On the other hand, specificity rates were generally above 85%, indicating that few patients reporting not having experienced a given symptom were perceived to be suffering from it.

Vomiting and skin rashes were the physical symptoms with the lowest overall level of disagreement between oncologists' perceptions and patients' reported experiences, with less than 20% disagreement. Fatigue was the physical symptom showing the highest overall level of disagreement with over half of all patients' reports disagreeing with their oncologists' perceptions.

### **Awareness About Patients' Levels of Anxiety and Depression**

Table 5 includes a summary of the sensitivity, specificity, and overall level of disagreement regarding the medical oncologists' perceptions of their patients' levels of anxiety and depression. As shown, only 17% of clinically anxious and 6% of clinically depressed patients were perceived as such by their oncologist. Therefore, although the oncologists estimated about the right overall prevalence of clinical anxiety and depression, as shown in Table 3, they did not accurately identify the individuals affected.

### **INSERT TABLE 5 HERE**

The sensitivity of the oncologists' perceptions of anxiety levels increased when patients with borderline levels were added to those with clinical levels: more than half the patients with elevated anxiety levels were perceived as such by their oncologist. However, this improvement

in sensitivity was at the expense of specificity, which almost halved. Similar results were achieved when considering the oncologists' perceptions of patients with borderline, as well as clinical, levels of depression. However, both the improvement in sensitivity and the decrease in specificity were smaller in this case.

### **Awareness About Patients' Levels of Perceived Needs**

Table 5 also includes a summary of the sensitivity, specificity, and overall level of disagreement regarding the medical oncologists' perceptions of their patients' levels of need within each of the five domains of the CNQ.

The higher rates of needs perceived by the oncologists than those reported by the patients resulted in higher sensitivity rates than for the other outcome measures but also in lower specificity rates. The overall level of disagreement ranged from 51% to 66% across the domains of the CNQ.

### **Predictors of Improved Levels of Awareness**

Table 6 summarizes the associations found between the doctor-patient relationship variables and improved levels of oncologists' awareness of their patients' reported levels of perceived needs and depression.

#### **INSERT TABLE 6 HERE**

As expected, oncologists' were two to five times more likely to be aware of the perceived needs and/or depression levels of patients they perceived they knew better; two to four times more likely for patients with whom they felt a high level of rapport; and two to nine times more likely when they felt less pressured by their workload.

However, none of these relationship variables was significantly associated with the oncologists' awareness of patients' levels of anxiety, or any of the physical symptoms. In addition, no significant associations were found between any of the patient characteristics explored as potential predictors and oncologists' awareness of any of the outcome measures.

## **Discussion**

This study aimed to assess medical oncologists' awareness of their patients' reported levels of physical symptoms, anxiety, depression, and perceived needs. As hypothesized, the level of awareness tended to be higher for physical symptoms than for psychosocial problems. Also as hypothesized, higher levels of awareness were observed when oncologists felt less pressured by their workloads and for patients they knew well and with whom they had a good rapport. However, before discussing these results further, it is considered worthwhile to discuss the strengths and limitations of the current study.

### **Strengths and Limitations**

A major strength of this study is that it represents one of the first explorations of oncologists' awareness of their patients' reported levels of physical and psychosocial problems. Therefore, it provides some much needed insight into an area of doctor-patient communication which would appear to be in need of some improvement. This information represents a first step towards achieving such improvements.

The high participation rates (89% of eligible patients and 100% of oncologists) obtained in this study aid the generalizability of our results. However, due to financial constraints, data could be

collected from only three oncologists and two registrars in one medical oncology department. Therefore, the results may have been different if additional departments and oncologists had been included. Certainly, there was much variation between individual oncologists with regards to the accuracy of their perceptions of their patients' levels of each outcome measure. Therefore, the data presented here should be considered preliminary. Nonetheless, the results do indicate much room for improvement and scope for intervention in this area of doctor-patient communication.

Another potential limitation of this study is the reliance on patients' self-report of their physical and psychosocial problems. Previous research has suggested that self-report may be unreliable due to its reliance on patients' memories and the possibility of social desirability bias<sup>22; 23</sup>.

However, research has also indicated that symptoms of treatment are more accurately reported by patients themselves than by their physicians<sup>15; 24</sup>. Furthermore, psychometrically-evaluated scales were employed for the assessment of patients' levels of anxiety, depression, and perceived needs and patients were asked about their physical symptoms in the preceding week only.

Although psychometrically tested in other settings<sup>18-20; 25</sup>, the validity and reliability of patients' responses to the HADS and CNQ questions using a touchscreen computer survey is unknown. Therefore, psychometric assessment of this computerized survey method is recommended as a topic for future research. However, the touchscreen computer methodology does provide many advantages and opportunities for intervention. If completed during patients' waiting time (average 1 - 2 hours), summaries of patients' responses, highlighting areas of concern can be fed back to their oncologists prior to each consultation. Previous research has demonstrated the acceptability of this survey delivery method to patients: 90% reported a willingness to complete

such a survey each time they attend for treatment and 96% were happy for their oncologist to receive a summary of their results<sup>26</sup>.

It is also possible that removing the necessity for oncologists to ask patients about their symptoms and other needs could result in more consultation time being available for the exploration and solution of any problems identified. As detection represents the first step towards solving any of these problems, it is hypothesized that the regular provision of this information to oncologists would result in a reduction in the levels of anxiety, depression, physical symptoms, and perceived needs experienced by their patients. The research team are currently planning a randomized controlled trial to test this hypothesis.

### **Comparisons to Previous Research**

The prevalence of most of the physical and psychosocial problems explored were comparable to those found in previous studies<sup>3; 4; 6; 8; 20; 27-30</sup>. However, the levels of perceived needs reported by patients in this study were much lower than those previously reported<sup>25</sup>. It is possible that the quality of care provided to cancer patients has improved since the previous study was conducted in the early 1990s. However, the extreme improvements required to produce such large reductions in perceived needs make it unlikely that this is sufficient explanation of these findings. The previous study administered the survey as a pen and paper, take-home survey, in contrast to the computerized, in-clinic delivery method employed in the current study<sup>25</sup>.

Therefore, it is possible that either the computerized delivery, the hospital setting or both have impacted on patients' responses in this study. The previous study also included patients receiving radiotherapy, whose needs may be different to those of patients receiving chemotherapy and hormone therapy<sup>25</sup>. Therefore, as discussed earlier, psychometric testing of this new method of survey delivery is recommended.

The less than optimal levels of awareness of patients' reported problems were also consistent with previous research<sup>14-16</sup>.

### **The Level of Oncologists' Awareness of Patients' Problems**

Overall, this study found less than optimal levels of awareness of patients' reported levels of physical and psychosocial problems. The oncologists also reported a lack of awareness regarding patients' experiences of some physical symptoms. Patients reported higher levels of most physical symptoms, anxiety, and depression but lower levels of perceived needs than were perceived by the oncologists. There are a few possible explanations of these findings.

First, it has been suggested that both patients and oncologists perceive these types of problems, particularly the physical ones, as an inevitable part of their disease and treatment<sup>11; 12</sup>. Therefore, patients may feel their symptoms and other problems are not sufficiently serious to warrant discussion with their oncologist.

Second, time could be a factor. The patient survey took, on average, 14 minutes to complete: approximately the same amount of time as the average patient's consultation with their oncologist. Whereas the survey concentrated on assessing patients' physical and psychosocial problems, oncologists, in their consultations, must also assess the current treatment's effect on the cancer and on the patient's immune system, examine the patient, decide whether the patient is well enough to receive their next scheduled treatment, decide whether to maintain or change the patient's treatment regimen, explain these and other issues to the patient, and answer any questions the patient may have. Therefore, it is not surprising that the oncologists elicited less information than the computer regarding patients' physical and psychosocial problems.

Third, the higher level of awareness about physical symptoms, especially those more commonly associated with chemotherapy, suggests that the oncologists are more practised at considering these issues. The oncologists may feel more able to help their patients with these physical symptoms than with their psychosocial problems: they can prescribe anti-emetics for nausea and vomiting and provide information about wigs for hair loss. However, simply acknowledging the patient has a psychosocial problem and referring them to, and encouraging them to use, appropriate support services may be the only intervention required by the oncologist.

### **Predictors of Improved Awareness**

Oncologists' knowledge of and rapport with their patients and the pressure of their workload were found to be significantly associated with their levels of awareness of their patients' reported levels of perceived needs and depression but not of anxiety or the physical symptoms. Although not achieving statistical significance, there were general trends in the predicted direction for the majority of outcome measures. Such associations are intuitively easy to understand and provide a rationale for providing cancer patients with continuous care from a single oncologist, wherever possible.

### **Implications for Future Research**

The detection of a problem, whether physical or psychosocial, represents the first step towards the adequate treatment of that problem. The failure to adequately detect and treat the physical and psychosocial problems discussed in this paper could result in many patients experiencing potentially unnecessary physical or emotional discomfort, which may even lead to them discontinuing such potentially life-saving, or life-prolonging, treatment<sup>13</sup>.

The less than optimal levels of awareness found in this study indicate a need for further research to develop and evaluate interventions aimed at improving medical oncologists' detection and treatment of these problems among their patients. It may be prudent to consider including more training in the detection and appropriate treatment of these problems in medical oncologists' specialist training. Alternatively, such information could be routinely collected from patients and summarized for the oncologists prior to their consultations. The touchscreen computers employed in this study offer an easy and acceptable method of collecting and disseminating such information<sup>26</sup>.

The data presented here is preliminary and we would recommend that additional data be gathered to allow comparisons between oncology departments and between oncologists. Such comparisons could help in identifying other potential solutions to the issues raised in this paper.

## **Conclusions**

The data presented here suggest that medical oncologists' perceptions do not accurately reflect their patients' reported levels of anxiety, depression, perceived needs, or many physical symptoms. Therefore, further research is recommended to explore ways of improving oncologists' detection and treatment of their patients' physical and psychosocial problems.

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**Table 1:** The characteristics of study participants.

Characteristic	Participants* (N=204)
<i>Gender (patient reported)</i>	
Female	61.6
Male	38.4
<i>Age (patient reported)</i>	
< 50 years	28.4
50 - 59 years	22.7
60 - 69 years	30.8
70+ years	18.1
<i>Primary cancer site (patient reported)</i>	
Colorectal	29.4
Breast	27.5
Head/neck	6.2
Stomach	6.6
Lung	2.8
Other	27.5
<i>Stage of disease at diagnosis (extracted from records)</i>	
Stage 1 or 2	46.1
Stage 3 or 4	52.9

**Table 1** (continued)

Characteristic	Participants* (N=204)
<i>Length of time since initial diagnosis (patient reported)</i>	
Up to 6 months	38.4
More than 6 months	61.6
<i>Reason for today's visit (patient reported)</i>	
Treatment	59.7
Follow-up	40.3
<i>Main method of drug administration† (patient reported)</i>	
Intravenous	92.9
Oral	7.1
<i>Last treatment session at clinic† (patient reported)</i>	
In the last 7 days	23.0
1 - 2 weeks ago	17.5
2 - 3 weeks ago	43.7
More than 3 weeks ago	15.9

\*Totals may not add to 100% due to missing data.

† The proportions shown here are only of patients currently receiving treatment (N=122).

**Table 2: The prevalence of physical symptoms: patient report versus medical oncologists' perceptions.**

Outcome Measure	N	Prevalence (%)		% patients where oncologists "don't know" status
		patient report	oncologists' perceptions	
Fatigue	122	66.4	52.5 <sup>a</sup>	1.6
Nausea	122	40.2	36.1	0.8
Hot flushes	62	38.7	9.7 <sup>b</sup>	53.2
Hair loss	122	32.8	40.2	0.0
Metallic taste in the mouth	121	32.2	9.9 <sup>c</sup>	35.5
Sore mouth	122	32.0	22.1	0.8
Appetite loss	122	30.3	19.7	1.6
Diarrhoea	122	23.0	18.9	4.1
Constipation	122	22.0	14.6	4.1
Vomiting	122	11.5	17.2	0.8
Skin rash	122	9.8	10.7	1.6
Pain in the injected limb	85	3.5	2.4	37.7

a p<0.05 on z test of the difference between patient report and oncologists' perceptions.

b p<0.0005 on z test of the difference between patient report and oncologists' perceptions.

c p<0.0001 on z test of the difference between patient report and oncologists' perceptions.

**Table 3:** The prevalence of elevated anxiety, depression, and perceived needs: patient report versus medical oncologists' perceptions.

Outcome Measure	N	Prevalence (%)		% patients where oncologists "don't know" status
		patient report	oncologists' perceptions	
<i>Anxiety &amp; Depression</i>				
Anxiety (clinical)	197	9.1	8.1	0.5
Depression (clinical)	198	9.1	7.6	4.6
Anxiety (borderline/clinical)	197	26.9	51.3 <sup>b</sup>	0.5
Depression (borderline/clinical)	198	20.2	29.3 <sup>a</sup>	4.6
<i>Perceived Needs</i>				
Physical and daily living	202	22.8	60.9 <sup>b</sup>	1.5
Psychological	200	18.5	63.5 <sup>b</sup>	2.5
Health information	193	11.9	70.0 <sup>b</sup>	3.1
Provider care & support	199	5.5	48.7 <sup>b</sup>	8.0
Interpersonal communication	198	1.0	56.1 <sup>b</sup>	12.6

a p<0.05 on z test of the difference between patient report and oncologists' perceptions.

b p<0.0001 on z test of the difference between patient report and oncologists' perceptions.

**Table 4:** Medical oncologists' awareness of their patients' reported levels of physical symptoms.

Outcome Measure	N	Sensitivity#	Specificity†	% overall
		(%)	(%)	disagreement*
Hair loss	122	80.0	79.3	27.9
Fatigue	120	58.2	56.1	51.7
Nausea	121	57.1	77.8	35.5
Vomiting	121	57.1	87.9	16.5
Diarrhoea	117	52.0	89.1	23.1
Sore mouth	121	46.2	89.0	26.4
Constipation	118	40.7	92.3	22.9
Appetite loss	120	35.1	86.7	31.7
Skin rash	120	16.7	89.8	17.5

# The proportion of patients reporting experiencing each problem perceived as such by their oncologist.

† The proportion of patients reporting not experiencing each problem perceived as such by their oncologist.

\* The proportion of patients whose responses were in different categories to those of their oncologist.

**Table 5: Medical oncologists' awareness of their patients' reported levels of anxiety, depression, and perceived needs.**

<b>Outcome Measure</b>	<b>N</b>	<b>Sensitivity# (%)</b>	<b>Specificity† (%)</b>	<b>% overall disagreement*</b>
<i>Anxiety &amp; Depression</i>				
Anxiety (clinical only)	196	16.7	92.7	52.6
Depression (clinical only)	189	5.9	91.9	39.7
Anxiety (borderline/clinical)	196	56.6	50.3	52.6
Depression (borderline/clinical)	189	39.5	71.5	39.7
<i>Perceived Needs</i>				
Health information	187	95.7	31.1	66.3
Provider care & support	183	80.0	48.6	51.4
Psychological	195	78.4	38.0	59.0
Physical and daily living	199	69.6	40.5	57.8
Interpersonal communication	173	50.0	35.7	64.2

# The proportion of patients reporting experiencing each problem perceived as such by their oncologist.

† The proportion of patients reporting not experiencing each problem perceived as such by their oncologist.

\* The proportion of patients whose responses were in different categories to those of their oncologist.

**Table 6: Outcome measures whose level of awareness was associated with oncologists' knowledge of the patient, their rapport with the patient or the pressure of their workload.**

Predictor Variables	% of patients whose oncologist correctly perceived their level of .....									
	... psychological needs		... provider care needs		... health information needs		... interpersonal communication needs		... depression	
	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)
<i>How well know patient?</i>		(n=197)		(n=196)		(n=191)		(n=196)		
fairly/very well	45.5	2.4 (1.2-4.8)	51.1	2.6 (1.3-5.2)	38.1	2.6 (1.2-5.6)	39.4	5.2 (2.1-13.0)		not significant
not very well/ not at all	25.9	ref group	28.3	ref group	19.2	ref group	11.1	ref group		
<i>How is rapport with patient?</i>				(n=197)		(n=191)		(n=196)		(n=196)
excellent/good		not significant	52.9	1.9 (1.1-3.4)	40.6	2.1 (1.1-3.9)	44.7	3.9 (2.0-7.5)	68.6	2.5 (1.4-4.4)
fair/poor/terrible			36.6	ref group	24.4	ref group	17.2	ref group	46.8	ref group
<i>How pressured by workload?</i>		(n=199)		(n=198)		(n=192)		(n=197)		(n=196)
not at all/not very pressured	54.2	2.5 (1.4-4.5)	62.5	3.1 (1.7-5.7)	52.9	4.1 (2.2-7.8)	60.6	8.6 (4.4-17.1)	71.4	2.5 (1.3-4.6)
fairly/very pressured	32.3	ref group	34.9	ref group	21.3	ref group	15.1	ref group	50.4	ref group

Each odds ratio indicates the increased likelihood of awareness in that sub-group compared to the "reference group".

## Appendix 1: The CNQ Items

Factor	What is your current level of need for help with....
Health Information	<ul style="list-style-type: none"> <li>• being given a full explanation for EVERY test and treatment procedure you go through?</li> <li>• being fully informed about all of the benefits and side-effects of treatment or surgery BEFORE you agree to have it?</li> <li>• being fully informed about the odds of treatment success?</li> <li>• being fully informed about your test results AS SOON AS POSSIBLE?</li> <li>• being fully informed about the POSSIBLE effects of the cancer on the length of your life?</li> <li>• being fully informed about cancer remission?</li> <li>• being fully informed about things you can do to help yourself get well?</li> </ul>
Psychological	<ul style="list-style-type: none"> <li>• dealing with fears about the cancer spreading or returning?</li> <li>• coping with fears about the pain and suffering you might experience?</li> <li>• coping with anxiety about having treatment or surgery?</li> <li>• coping with fears about further physical disability or deterioration?</li> <li>• accepting the changes in your appearance and self-image?</li> <li>• coping with worry that the cancer is beyond your control?</li> <li>• coping with an uncertain future?</li> <li>• working through your feelings about death and dying?</li> <li>• learning to feel in control of your situation?</li> </ul>

Factor	What is your current level of need for help with....
Provider Care & Support	<ul style="list-style-type: none"> <li>• being allowed to have family and friends with you at hospital whenever you want?</li> <li>• having your rights for privacy more fully protected when you're at the clinic or hospital?</li> <li>• nurses attending promptly to your PHYSICAL needs in hospital?</li> <li>• NURSES acknowledging and showing sensitivity to your feelings and EMOTIONAL needs?</li> <li>• your CANCER SPECIALIST acknowledging and showing sensitivity to your feelings and EMOTIONAL needs?</li> </ul>
Physical and Daily Living	<ul style="list-style-type: none"> <li>• dealing with lack of energy and tiredness?</li> <li>• coping with disturbed sleep?</li> <li>• coping with keeping up with work around the home?</li> <li>• coping with frustration at not being able to do the things you used to do?</li> <li>• coping with fears about losing your independence?</li> <li>• coping with feeling bored and/or useless?</li> </ul>
Interpersonal Communication	<ul style="list-style-type: none"> <li>• coping with awkwardness in talking with others about the cancer?</li> <li>• coping with changes in other people's attitudes and behaviour towards you?</li> </ul>

## Appendix 2: The Medical Oncologists' Survey Instrument

Please use this desk-pad to complete a survey after each consultation. You will be asked to rate four things for each patient:

1. **Anxiety Level** - Please indicate whether you believe that each patient has a low, borderline or clinical level of anxiety. Anxiety is defined as "a subjectively unpleasant emotional response to perceived stress of threat".
2. **Depression Level** - Please indicate whether you believe that each patient has a low, borderline or clinical level of depression. Depression is characterised by feelings of sadness, a decrease in activity and a loss of interest or pleasure in most usual activities.
3. **Impact of Side Effects in the Week Prior to the Visit** - For each potential side effect, please indicate whether, to the best of your knowledge, the patient has:
  - a. **Not experienced** it in the last week.
  - b. **Experienced** it but it has **not significantly prevented** them from engaging in usual daily activities in the last week - **Mildly affected**.
  - c. **Experienced** it and it has **significantly prevented** them from engaging in their usual daily activities in the last week - **Severely affected**.
4. **Level of Perceived Needs** - For each of the five needs factors, please indicate whether, to the best of your knowledge, the patient currently has no need, a low level of need or a moderate-high level of need for help. Definitions and examples of each type of need are given below:
  - a. **Psychological Needs** - for help in dealing with anxieties and fears aroused by the diagnosis of cancer and the treatment of the disease.  
*eg: Need help to cope with worry that the cancer is beyond your control.*
  - b. **Physical Needs** - for help with coping with requirements of basic daily living.  
*eg: Need help to cope with keeping up with work around the home.*
  - c. **Provider Care Needs** - for help with physical and emotional needs while in the hospital or at the clinic.  
*eg: Need help with nurses attending promptly to your physical needs in hospital.*
  - d. **Information Needs** - for help with being fully informed about the disease, treatment options and prognosis.  
*eg: Need help with being fully informed about your test results as soon as possible.*
  - e. **Interpersonal Communication Needs** - for help with dealing with other people's reaction to the disease.  
*eg: Need help with coping with awkwardness in talking with others about the cancer.*

**Please give all completed surveys to the Research Assistant at the end of each clinic. Thank you for your help!**

## Medical Oncology Staff Survey

**ABOUT THE PATIENT** : Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Date Seen: \_\_\_\_\_ Length of today's consultation: \_\_\_\_\_ mins

Side Effects (For patients currently in treatment only)	In the last week, this patient has...			Don't know
	not had it	had it mildly	had it severely	
Nausea	1	2	3	4
Vomiting	1	2	3	4
Fatigue	1	2	3	4
Constipation	1	2	3	4
Diarrhoea	1	2	3	4
Sore mouth	1	2	3	4
Hair loss	1	2	3	4
Appetite loss	1	2	3	4
Skin rash	1	2	3	4
Metallic taste in mouth	1	2	3	4
Pain in the injected limb	1	2	3	4
Hot flushes ( <i>women only</i> )	1	2	3	4

Anxiety & Depression Levels	Low	Borderline	Clinical	Don't know
Anxiety level	1	2	3	4
Depression level	1	2	3	4

Perceived Needs	No need	Low need	Mod/high need	Don't know
Psychological needs	1	2	3	4
Physical needs	1	2	3	4
Provider care needs	1	2	3	4
Information needs	1	2	3	4
Interpersonal	1	2	3	4
Communication needs	1	2	3	4

### ABOUT YOURSELF

Name: \_\_\_\_\_ Date completed (*if not day of consultation*): \_\_\_\_\_

**1. How well do you know this patient?**

First time I've seen him/her 1  
 Not very well 2  
 Fairly well 3  
 Very well 4

**2. How would you rate your rapport with this patient?**

Excellent 1  
 Good 2  
 Fair 3

**3. How pressured do you feel by your workload today?**

Not at all pressured 1  
 Not very pressured 2  
 Fairly pressured 3  
 Very pressured 4