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Are Touchscreen Computer Surveys Acceptable to Medical Oncology Patients?

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Abstract

The acceptability of a touchscreen computer survey to assess levels of physical side effects, anxiety, depression, and perceived needs among cancer patients receiving chemotherapy and hormone therapy was assessed. Despite an overall lack of previous experience with computers, this touchscreen computer survey was highly acceptable to patients. In addition, 96% of patients were happy for their oncologist to receive a summary of their results and 89% indicated that they would be happy to complete such a survey at each visit to the hospital. Therefore, touchscreen computers represent an acceptable and efficient method of assessing the levels of physical side effects, anxiety, depression, and perceived needs experienced by these patients. The use of such routine patient surveys has the potential to improve the breadth and quality of care provided by oncologists to their patients.

Introduction

There is a reasonable body of evidence that people undergoing chemotherapy to treat cancer may experience a range of physical and emotional side effects. Physical side effects include problems as diverse as fatigue (21 - 96% of patients), nausea (37 - 95%), vomiting (26 - 65%), hair loss (32 - 100%), appetite loss (39 - 59%), diarrhoea (21 - 38%), constipation (28 - 31%), difficulty sleeping (45 - 57%), pain (23 - 38%), fluctuations in weight (31 - 86%), and amenorrhoea (4 - 15%) {1,2,17,20,21,22,23,25,38}. Studies suggest that up to 91% of patients receiving chemotherapy experience elevated levels of anxiety and that up to 61% experience depression {2,5,8,17,18,23,24,25,38}. In addition, 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 {1,2,8,17,20,30}.

There is some evidence that patients who experience more of these physical and psychosocial side effects are less likely to comply with their treatment regimes {35}. Non-compliance in this area can be life-threatening. Therefore, it is important for oncologists to be aware of and, where possible, to address as many of these side effects as possible. There is little evidence about how well informed medical oncologists are about their patients' side effects. One study found that less than half the patients with depression were identified by staff in a Medical Oncology Clinic {47}. Therefore, it would appear that a significant first step to improving this aspect of patient care could be to improve oncologists' awareness of their patients' levels of physical and psychosocial side effects.

In an ideal world, oncologists would have sufficient time to discuss all these potential problems with their patients and to explore possible solutions. However, the mean consultation length (excluding first visits) during the current study was 15 minutes. During this consultation, the oncologist must assess whether the treatment is having the desired effect on the cancer, whether it is causing any major problems, whether the patient is well enough to receive the next scheduled treatment or whether the patient should be given a different treatment. Achieving these aims may result in little time being available to explore the psychosocial impact and the less life-threatening physical side effects of the treatment.

However, medical oncology patients tend to spend a reasonable amount of time waiting. Therefore, a possible solution to this problem could be for patients to complete a survey about their physical side effects and psychosocial needs while waiting to see their oncologist. This information, in a standardised format, could then be given to the oncologist at the beginning of the consultation. The oncologist could scan the list for any problem areas to be addressed during the consultation. Having such information in a computerised database would allow oncologists to monitor changes in each patient's needs. Therefore, asking patients to complete regular computer-based surveys represents a novel solution to this problem. To maximise user-friendliness, touchscreen computers can be used, where respondents answer questions by simply pressing the appropriate box on the screen of the computer. Computerised surveys also have the advantage of ensuring that patients are asked all the appropriate questions in the correct order. Some other advantages of this form of survey technology are that the questions asked of patients can be revised relatively simply, no paper is required for printing the surveys, no data entry is required, there is minimal chance of errors in the data, and no storage space is required for the surveys.

Computerised surveys have been found acceptable in a variety of settings, including psychiatric clinics, drug addiction centres, antenatal clinics, and general practice{40,41,42,43,44,45,46}. However, people with cancer tend to fall into the older age groups and, therefore, are less likely to have had any experience with computers and more likely to be "computerphobic" than members of the general population. Therefore, it was felt necessary to test the acceptability of such an intervention to the patients before embarking on a randomised controlled trial. Consequently, this study aimed to assess the acceptability to medical oncology patients of a touchscreen computer survey to assess their levels of physical side effects, anxiety, depression, and perceived needs.

Method

Patients' Recruitment and Procedure

All adult patients attending the Medical Oncology Department of a large teaching hospital for a second or subsequent treatment visit or for a follow-up visit, during two two-week study periods, were asked to participate in this study investigating the physical and psychosocial side effects of chemotherapy. First visit patients were not considered eligible for the study as they would not yet have experienced the impact of the chemotherapy. Consenting patients were asked to complete a survey on a touchscreen computer while waiting to see their oncologist. The survey took an average of 15 minutes to complete. A research assistant was present to explain the study to and to obtain consent from patients and to help them use the computer, if necessary. The computer was on a desk, with a chair provided to allow patients to be seated while

completing the survey. On completion of the computer survey, patients were asked to complete a brief pen and paper survey indicating their reaction to the computer survey.

The Touchscreen Computer Survey

The survey included questions in five main domains:

1. Demographic characteristics - including gender, age, marital status, educational level, employment status, and distance travelled to the Medical Oncology Department.

2. Cancer descriptors - including site of cancer, time since diagnosis, method of administration of the chemotherapy, and current and previous treatment modes.

3. Side effects - including if & on how many days, in the week preceding data collection, patients had experienced a range of physical side effects associated with chemotherapy. For each side effect reported, patients were asked to what extent the side effect had prevented them from engaging in their usual daily activities. This section was not asked of follow-up 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){33}. This instrument has been validated with cancer patients{34,48,49}.

5. Perceived needs - were assessed using the short form Cancer Needs Questionnaire (CNQ29), 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. This instrument is adapted from the full length CNQ, which has been fully psychometrically tested{37}.

The Acceptability Survey

This pen and paper survey asked for patients' opinions of such issues as the ease of completing the survey, the length of the survey, their willingness to complete the survey whenever visiting the hospital, and the truthfulness of their answers. The survey also asked about the amount of experience each patient had had with computers.

Results

Patients' Participation Rates and Characteristics

During the study period, 315 repeat visit and follow-up patients attended the Medical Oncology Department. Of these, 264 patients (83.8%) were considered eligible to participate in the study. Patients were considered ineligible if they were too sick (14.0%); they could not speak sufficient English to understand the survey (1.9%); or their computer data was corrupted (0.3%). Of the 264 eligible patients, 10 (3.8%) saw the doctor too quickly to be asked to participate in the study. Of the 254 patients approached, 241 (94.8%) consented and 233 (91.7%) completed the computer survey. This represents a response rate of 73.9% of all patients attending during the study period. On completion of the computer survey, patients were asked to complete the acceptability survey: 229 (98.3%) consented. The data presented in this paper is based on the responses of these 229 patients.

Table 1 summarises the characteristics of the patients participating in this study. Given the small number of non-consenters, no comparisons were made between the two groups.

INSERT TABLE 1 HERE

Acceptability of the Computer Survey

Table 2 summarises the responses to the acceptability survey. Despite their lack of experience with computers, most patients found the touchscreen computer survey highly acceptable and considered it an appropriate method of collecting this sort of data. Although 19% of patients reported needing help to complete the survey on this occasion, only 11% felt they would need help if they were to complete it again.

INSERT TABLE 2 HERE

Discussion

This study found that medical oncology patients were highly accepting of a 15 minute touchscreen computer survey to assess their levels of physical side effects, anxiety, depression, and perceived needs. This result is particularly reinforcing given the median age (62 years) and the general lack of computing experience of the patients surveyed.

The patients' willingness to have their oncologists receive copies of their survey results at each visit suggest that this would be an appropriate, as well as efficient, way for oncologists to obtain basic information about the impact of treatment on their patients' physical and

psychosocial well-being. Much information included in this survey may not otherwise come to the attention of the oncologists.

The use of computerised feedback on these issues would ensure that all information was collected in a standardised way for all patients seen. If routinely collected, such data could be analysed to assess the likely physical and psychosocial impact of various treatment options. Such information could be useful to oncologists and their patients in helping them to choose between potential treatment options.

It is also possible that, by removing the necessity for oncologists to question patients about their side effects and other needs, it would actually 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 hypothesised that the regular provision of this information to oncologists would result in a reduction in the levels of anxiety, depression, physical side effects, and perceived needs experienced by their patients. The authors are currently planning a randomised controlled trial to test this hypothesis.

The potential benefits offered by the routine use of this form of technology are large and numerous. First, the computer can be programmed to provide the clinicians with immediate feedback about both individual patients and across groups of patients: traditional survey methods would require a significant amount of time to analyse and report back such information. Second, in areas with high non-English speaking populations, the computer could begin by asking patients which language they speak and, subsequently, present the survey in an appropriate language: traditional survey methods often make the inclusion of non-English speaking groups prohibitive due to the time and financial costs involved. Third, computers

installed with sound cards could provide verbal versions of the survey, allowing the inclusion of patients with literacy or visual difficulties who also tend to be routinely excluded from traditional surveys.

In conclusion, the authors believe that the introduction of routine touchscreen computer surveys assessing patients' levels of physical side effects, anxiety, depression, and perceived needs could significantly improve the quality of care offered to cancer patients receiving medical oncology. It is also considered likely that a similar strategy could be applied, and found useful, among other patient groups - especially those who spend extended periods of time waiting to see their physician.

References

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Table 1

The Characteristics of Study Participants

Characteristic	% participants (N=229)
Gender	
Male	40.9
Female	59.1
Age	
< 50 years	27.0
50 - 59 years	21.5
60 - 69 years	32.5
70+ years	19.0
Education level^a	
Less than Higher School Certificate	71.7
Higher School Certificate or higher	28.3
How much experience have you had with computers?	
None at all	59.4
A little	21.0
Quite a bit	15.3
Lots	4.4

(table continues)

Characteristic	% participants (N=229)
Primary cancer site	
Bowel/colon/rectum	29.1
Breast	26.2
Stomach	6.8
Head/neck	6.3
Lung	3.8
Bone	1.7
Prostate	0.8
Other	25.3
Length of time since initial diagnosis	
Up to 6 months	37.1
More than 6 months	62.9
Previous treatments received^b	
None	46.8
Surgery	43.0
Radiotherapy	26.2
Other chemotherapy	16.9
Hormone therapy	7.2
Other treatment	6.8

(table continues)

Characteristic	% participants (N=229)
Stage of disease at diagnosis ^c	
Stage 1	11.6
Stage 2	29.2
Stage 3	27.0
Stage 4	27.0
Reason for visit	
Treatment	48.9
Follow-up	51.1

^aThe Higher School Certificate represents the completion of High School and is undertaken at age 18 years. ^bTotals in this section do not add to 100% as patients could have multiple responses. ^cTotals in this section do not add to 100% due to missing data.

Table 2

Patients' Responses to the Acceptability Survey

Question	% agree/ strongly agree
	N=229
<hr/>	
The computer survey	
... was easy to complete.	96.5
... was enjoyable.	95.6
... was not stressful. ^a	93.4
... did not make me anxious. ^a	92.1
... did not take too long to do. ^a	92.1
... was not too personal. ^a	97.4
... is a good way for doctors to get this sort of information.	97.9
I answered all the questions truthfully.	99.1
I'd be happy for my doctor to receive a summary of my results to put in my medical records.	96.1
I'd be willing to complete the survey each time I visited the doctor.	89.5
I needed a lot of help to complete the survey.	19.2

(table continues)

Question	% agree/ strongly agree
	N=229
Now I've done the survey once, I'd be happy to do it on my own next time.	89.0
I would usually have time to do the survey while waiting to see the doctor.	98.7

^aThese items were phrased negatively in the patient survey but have been transposed for ease of presentation.