

Changes in Daily Activities of Cancer Patients after Diagnosis: How Do Canadian and Iranian Patients Perceive the Change?

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Abstract

Background: Being diagnosed with cancer has major impacts on a patient's life. This study was conducted to explore how specific daily activities of patients change as a result of cancer diagnosis or its treatment and how these patients feel about such changes.

Methods: This was a cross-sectional descriptive study. Cancer patients referred to our clinics and by completing a questionnaire, they reported their daily activities and how they changed after diagnosis. A total of 201 patients in Canada and 167 patients in Iran completed the questionnaire. The research setting was the outpatient cancer clinics of the Jewish General Hospital in Montreal, Canada (February to April 2008) and Imam Reza Hospital and Ghaem Hospital in Mashhad, Iran (March to August 2008).

Results: More than 40 percent of the patients reported changes after the diagnosis in at least 8 out of 22 daily activities listed in the questionnaire. While a negative perception towards the changes was more common, some patients also perceived some changes as positive. More than half of the participants (56.9%) who were employed at the time of diagnosis experienced changes in the amount or type of their paid work after being diagnosed with cancer.

Conclusion: The impact of a cancer diagnosis and treatment on a patient's daily activities is drastic. There is a need to provide support and interventions to help patients maintain daily activities they need and/or like. Further studies are needed to better understand the nature of such interventions.

Keywords: Activities of daily living; Neoplasms; Early detection of cancer

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Introduction

It is estimated that more than 24 million people live worldwide who have been diagnosed with cancer in the last five years [1]. It is estimated that the burden of cancer will triple by 2030 [2]. A cancer diagnosis is considered one of the most traumatic events an individual can face [3]. Physical and psychological problems caused by cancer and its treatment are potential obstacles to normal functioning. For example, it has been shown that fatigue, a frequent symptom experienced by people with cancer, can impair the physical functioning and quality of life of patients [3-7].

Cost of treatment, cost of possible disability and cost to the family are some financial concerns that

cancer patients may have, even in countries with socialized medicine such as Canada [8, 9]. Changes in social functioning such as participation in public life after a cancer diagnosis are also reported [10]. A large amount of medical literature is dedicated to negative physical and psychological impacts of cancer on patients' and their families' lives. On the other hand, several studies suggest that people with such a stressful disease may experience some positive changes, including benefits in the areas of life perspective, relationships with others and self-perception in comparison with the pre-cancer period [10-12].

Being capable of normal daily activities is one of the determinants of quality of life of cancer

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patients [13]. A wide range of previous studies can be found with a focus on the impact of cancer on patients' day-to-day lives. Some investigators have developed assessment tools to evaluate the amount of physical or social activities patients engage in after the diagnosis of their disease [14, 15]. Measures of daily activities have even been suggested as potential predictors of treatment outcome in cancer patients [16].

Klauer et al. (1998) studied positive and negative changes in cancer patients' lives after diagnosis, but they focused on changes in general domains like physical well-being, leisure-time activities and intellectual functioning rather than specific social or individual activities [10]. To the best of our knowledge, there is no published study that evaluates how specific daily activities of patients change after a cancer diagnosis and how the patients perceive such changes.

It is known that cultural differences are an important factor in the psychological impacts of cancer [17, 18].

Social attitudes towards cancer and compliance with treatment are deeply affected by cultural beliefs and norms [19]. Furthermore, one can expect to see differences in the amount and type of activities of daily living across cultures.

This study's main objective was to describe to what extent cancer patients maintain individual and social activities they need and/or want after being diagnosed with the disease in two different cultural settings: Iran and Canada. A secondary objective was to determine the extent to which these changes are related to performance status. The study also aimed to provide a better understanding of how patients feel about changes in their specific daily activities after cancer diagnosis.

Materials and Methods

This was a cross-sectional descriptive study using self-report to assess current daily activities, changes in daily activities since diagnosis and patient's perception as to whether each change was a change for better or for worse. The Research Ethics Committee of the Jewish General Hospital in Montreal, Canada and that of Mashhad University of Medical Sciences, Iran approved the study. Performance status was studied because we hypothesized that those with a lower performance status would have a greater change in daily activities, and knowing whether it was the same or different for the participants in Canada versus Iran would be helpful in interpretation of any differences.

In Canada, participants were recruited from the outpatient cancer clinic of the Jewish General Hospital in Montreal from February to April 2008. All patients with a confirmed diagnosis of cancer, 18 years or older who wished and consented to participate in the study completed the questionnaires including those who were not under active treatment and came for a follow-up visit. Those who were unable to communicate in English or French and those whose physical or mental impairment was likely to make their participation burdensome or unreliable were excluded. In Canada, a unit coordinator or a volunteer who knew the patient well enough to determine eligibility made that assessment. In Iran, patients were recruited at the outpatient radiation oncology clinics of Imam Reza Hospital and Ghaem Hospital in the city of Mashhad from March to August 2008. The same inclusion and exclusion criteria were applied as in Canada except for the language: patients who were unable to communicate in Persian were excluded from the study. In Iran, a doctor or a nurse who was involved in the patients' care assessed the eligibility.

Those deemed eligible were given an information sheet describing the study, the rights of the participants and the contact details of the researchers along with the study questionnaire to complete. It was indicated in the information sheet that completing the questionnaire was considered as the patient's consent to participate. There was no written consent form.

In Montreal, the willing participants completed the study questionnaire on their own. Because of the expected high number of uneducated patients in Mashhad and our desire to be as inclusive as possible and also not to embarrass anyone, in Mashhad all the questions were read aloud by a clinical staff member for all the participants regardless of their level of education.

A questionnaire entitled "Daily Activities Questionnaire" was designed and used to collect data. The first section of the questionnaire concerned demographic information, disease-related data, performance status and employment information. The Eastern Cooperative Oncology Group (ECOG) performance status score was used to measure performance status, with scores ranging from 0 to 4, with 0 indicating "fully active, able to carry on all pre-disease performance without restriction" and 4 meaning "completely disabled, cannot carry on any self-care, and totally confined to bed or chair" [20]. This was determined by patients themselves as it has been shown that ECOG scores determined by patients and physicians are similar [21].

The second section of the questionnaire had a table with a list of 22 specific daily activities (such as exercise, reading, speaking on the phone, visiting with friends, etc.). For each activity, participants were asked to indicate: how much time they currently spend on; if they are doing it more than, the same amount as, or less than before cancer diagnosis; and how they feel about any changes (positive, negative, or unimportant). Participants were asked to add any activities not specified in the list and provide similar information about them. The table was followed by four questions asking the participants: which of the activities is most relaxing for them; what activities if any they would like to do but cannot because of the disease or treatment; if they wake up during the night; and if they do wake up, what they do at night. A final open-ended question provided an opportunity for the participants to explain anything else they want about changes in their daily activities.

The questionnaire was originally designed in English by JSH and then discussed and revised by SRC. The questionnaire was presented to a panel of health professionals and graduate students in Canada and their input was used to develop the final version. This version was translated into French and Persian. The Persian version was adapted to be used in Iran. Two changes were made to the Persian version to accommodate cultural differences. The English and French versions ask the participants about their type of cancer while in the Persian translation this part was not included because of the high possibility that some patients were not told that they have cancer and we did not want to risk informing them of it through the questionnaire. Furthermore, because it is rare for people in Iran to have pets at home, "caring for pets" was not included in the list of daily activities of the Persian version.

Statistical analysis was done using SPSS 15. During analysis, if a patient left a question regarding change since diagnosis blank, we assumed that there had been no change for that activity. Otherwise missing data were left as missing. Spearman's rank correlation was used to determine the correlation between time since diagnosis and changes in activities. For other correlations, Chi-square test was used.

Results

Over the recruitment period, 201 patients in Montreal and 167 patients in Mashhad entered the study. Table 1 presents patient characteristics. The percentage of female participants was higher than males in both cities (70.6% vs. 29.4% in Montreal;

68.9% vs. 31.1% in Mashhad). A larger percentage of Canadians were divorced (18 vs. 0.8). Canadian participants had higher education levels ($p < 0.001$), with most having a college or university education while in Iran most had completed only primary school or were uneducated. Breast cancer was the most common malignancy in both settings (120 patients out of 368; 32.6%). The average time since the diagnosis of Canadian patients was more than twice of that of Iranian patients (in Montreal: 36.4 months, range: 0-285; in Mashhad 15.8 months, range: 0-120). Out of 123 patients who were employed before diagnosis, 70 (56.9%) changed the amount or type of their work after being diagnosed with cancer (in Montreal: 30/70, 42.9%; in Mashhad: 40/53, 75.5%). The ECOG performance status scores were similar in the two countries, with a median of 1 (an ECOG score of 1 means that the patient has restrictions in physically strenuous activities, but is able to carry out work of a light or sedentary nature).

In total, 148 patients (40.2%) (74 or 36.8% in Montreal; 74 or 44.3% in Mashhad) reported changes in at least 8 listed activities after diagnosis with cancer. The mean number of activities that changed in Canadian and Iranian patients was 6.2 and 7.1, respectively (median in Montreal = 6; median in Mashhad = 7). Seventy-two patients (19.6%) (56 or 27.9% in Montreal; 16 or 9.6% in Mashhad) reported no changes in their daily activities. In both settings, the longer the time since diagnosis, the larger the number of daily activities that changed ($p < 0.001$). Table 2 presents the number of changed activities by country and sex. Table 3 presents the number of changed activities by ECOG score. In Canadian patients, changes in the following activities were more common after diagnosis: sleeping or taking a nap during the day, doing house chores, exercise and doing sports, going out for a walk and watching TV. In Iranian patients, the five activities in which changes were most frequent were: sleeping or taking a nap during the day, watching TV, sitting doing nothing, visiting with family and doing house chores.

In both countries, more of the changes in activities were perceived as being negative than as either positive or unimportant. Patients in Mashhad reported a mean of 3.5 (median: 3; range: 0 to 20) changed activities in which they perceived the change as negative while the mean of the number of activities with positive and unimportant changes were 1.9 (median: 1; range: 0 to 14) and 1.8 (median: 1; range: 0 to 20), respectively. In Montreal, the mean number of negative, positive and unimportant

Table 1. Patient characteristics

	Canada (n=201)	Iran (n=167)
	Number (%)	Number (%)
Age average	56.0	47.4
Sex		
Male	59 (29.4)	52 (31.1)
Female	142 (70.6)	115 (68.9)
Marital Status		
Single	18 (8.9)	24 (14.4)
Married	130 (64.7)	133 (79.6)
Divorced	37 (18.4)	1 (0.8)
Widowed	16 (8.0)	9 (5.4)
Education†		
University or college graduate	121 (60.2)	17 (10.2)
High school graduate	59 (29.4)	19 (11.4)
Primary school or uneducated	21 (10.4)	131 (78.4)
Type of Cancer		
Breast	75 (37.3)	45 (26.9)
Colorectal	22 (10.9)	9 (5.4)
Gastric	4 (2.0)	14 (8.4)
Esophageal	0 (0.0)	13 (7.8)
Lung	4 (2.0)	6 (3.6)
Brain	0 (0.0)	13 (7.8)
Lymphomas	21 (10.4)	2 (1.2)
Malignant Melanoma	10 (5.0)	0 (0.0)
Other cancers	53 (26.4)	56 (33.5)
Unknown or unstated	12 (6.0)	9 (5.4)
Time since Diagnosis	36.4 months	15.8 months
ECOG‡ Performance Status	Mean = 1.2 Median = 1	Mean = 1.3 Median = 1

† In Montreal, college education is free and approximately 15.9 % of the population has a college degree [22].

‡ ECOG = The Eastern Cooperative Oncology Group [20]

Table 2. The mean of number of changed activities by type of change, city and sex

	Direction of change		
	Doing more	Doing less	Total
Montreal			
Male	2.6	2.7	5.3
Female	2.8	3.7	6.5
Total	2.8	3.4	6.2
Mashhad			
Male	3.0	5.0	8.0
Female	2.5	4.2	6.7
Total	2.7	4.4	7.1
All Patients			
Male	2.8	3.7	6.5
Female	2.7	3.9	6.6
Total	2.8	3.8	6.6

changes was 2.5 (median: 0; range: 0 to 17), 1.8 (median: 0; range: 0 to 11) and 1.0 (median: 0; range: 0 to 20), respectively.

The five activities most frequently reported as relaxing were completely different in the two cities. In Montreal, they were reading (19.4%), watching

TV (18.4%), going out for a walk (10.4%), listening to the radio/music (10.0%) and exercise and doing sports (7.0%). In Mashhad, the top five most relaxing activities were individual religious/spiritual activities

Table 3. The mean of number of changed activities by city and performance status score

ECOG† Score	City	
	Montreal	Mashhad
0: able to carry on all activities without restriction	3.1	5.5
1: have restrictions in physically strenuous activities but able to carry out work of a light or sedentary nature	7.8	6.8
2: capable of self-care but unable to carry out work activities, up and about more than 50% of waking hours.	8.2	8.7
3: capable of only limited self-care, confined to bed or chair more than 50% of waking hours.	7.4	8.7

† ECOG = The Eastern Cooperative Oncology Group [20]

(27.5%), visiting with family (19.8%), sleeping (14.4%), visiting with friends (8.4%) and taking a trip (7.8%). Most patients (249 or 67.7%), (149 or 74.1% in Montreal; 100 or 59.9% in Mashhad) indicated that there are activities they would like to do but cannot because of the disease or treatment.

In comparison to male patients, female patients more often had an increase in time spent speaking on the phone after the diagnosis ($p=0.002$). In contrast, more men (47.6%) than women (27.6%) increased the time they spent watching TV ($p=0.003$). People with higher ECOG scores (lower performance status) had more changes towards doing these activities less than before the diagnosis: exercise and doing sports ($p=0.006$), going out for a walk ($p<0.001$), speaking on the phone ($p<0.001$), doing house chores ($p<0.001$), shopping ($p<0.001$), group religious activities ($p=0.003$), visiting with friends ($p=0.002$), visiting with family ($p=0.008$), community activities ($p=0.012$) and taking a trip ($p=0.022$). These participants had more changes towards watching TV ($p=0.001$), sitting doing nothing ($p<0.001$) and sleeping or taking a nap during the day ($p<0.001$).

Discussion

The results of this study show that being diagnosed with and being treated for cancer has a major impact on the day-to-day life of patients. Most frequently, changes in specific daily activities of cancer patients after diagnosis are perceived as negative; however, patients experience positive changes as well. While physical impairments caused by illness and treatment are important causes of change in patients' activities, it is interesting to see that patients with good performance status scores also experienced changes in their activities.

Interruption in employment is a serious consequence of being diagnosed with and treated for a disease like cancer. It has not only economic consequences for the patient and patient's family, but also negatively affects their psychological status and quality of life [23]. Our study shows that many patients in both countries (56.9%) had to change the amount or type of their paid work after being diagnosed with cancer. This percentage is higher in Iran (75.5% vs. 42.9%) perhaps because many cancers are diagnosed in advanced stages [24].

In comparing the results from Iran and Canada, it should be considered that the two populations have not been matched to enable an unbiased comparison. In addition, the method of data collection was slightly different: patients in Canada answered the questionnaire on their own while the questions were read aloud by a researcher for Iranian participants (therefore allowing uneducated people to participate in the study). This might partially explain (together with the difference in educational levels of the populations themselves) the considerable difference in education levels of participants in the two countries. We should also be aware of our limitations in generalizing the results of this study that is done in only two cities to the whole population of Canada and Iran. Lack of the open communication about the diagnosis in Iran [24] could have been potentially confusing for Iranian patients regarding what we meant when we talked about the time of diagnosis and the changes that happened afterwards. However, our interviewer in Iran had access to patients' charts and reminded them of the date of diagnosis even if they were not told at the time that they had cancer.

Due to our method of recruitment, we are unable to comment on the number of patients who refused to participate in the study. While there is no

reason to believe that those patients who were eligible but did not participate would have answered the questions differently, this can potentially be a limitation for generalization of the study results.

Conclusion

This descriptive study increases our understanding of how cancer and its treatment affect the daily activities of cancer patients and how this impact is perceived by them in two different cultural settings: Iran and Canada. Further studies, including those using qualitative methodologies, can capture more aspects of the impact of cancer and its treatment on daily activities of cancer patients and lead us to find ways of helping patients to do what they want to do. These needs can be different from one culture to another. Development of interventions and providing support for patients to maintain their daily routines, to reverse or decrease the changes that are perceived as negative and to empower patients to keep those changes that they experience as positive can certainly improve their quality of life.

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Conflict of Interest

The authors have no conflict of interest in this article.

Authors' Contribution

Javad Shahidi and S. Robin Cohen designed the study and the questionnaire, analyzed the data and wrote the paper. Ali Taghizadeh-Kermani, Mohammad Reza Ghavamnasiri, Fahimeh Khoshroo, and Leila Pourali contributed to patient's recruitment, data entry, literature review and writing-up process. Mahmood Reza Gohari contributed to the statistical

design of the study as well as statistical analysis. All authors read and approved the final manuscript.

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