Access To Online Information By Adult Saudi Cancer Patients

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Abstract

Background: The proportion of Saudi cancer patients who utilize online information resources is unknown; therefore, we designed this project to characterize Internet utilization by this group.

Patients and Methods: Saudi cancer patients who met defined eligibility criteria responded to a questionnaire to examine Internet utilization, barriers to access, and information needs.

Results: Of the 150 patients included, only 19 (13%) used the Internet to receive online information. From patients' perspective, inability to use computer (57%), limited English language proficiency (55%), and not knowing about online resources (44%) were the most frequent barriers. A multivariate analysis showed that owning a personal computer was the only variable that distinguished Internet users from non-users.

Conclusion: This study provides the only available data concerning access to Internet information by cancer patients in Saudi Arabia. The study showed that the access rate is unacceptably low due to several barriers. Prompted by the study results, pragmatic recommendations are provided.

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INTRODUCTION

It is estimated that about 800 million persons are online worldwide, of which 1.5 million are from Saudi Arabia [1]. Patients with cancer and their caregivers frequently seek out information about the disease, management, therapeutic options, and prognosis [2,3,4,5]. Since the proportion of Saudi cancer patients who utilize online information resources is unknown; this study was designed to characterize Internet use by this group and to identify various barriers that hinder utilization.

PATIENTS AND METHODS

Adult Saudi cancer patients who report to the outpatient facility of the oncology department at our hospital, were the potential participants. Participant must have a histologically confirmed diagnosis of cancer, and must have been informed about his/her diagnosis and management plan. Illiteracy or physical but not mental disability could not preclude participation.

Four Saudi research assistants invited eligible participants to complete a questionnaire that was designed based on literature review [6, 7]. Independent back-translation and comparison of the source with the Arabic translated text were performed to ascertain clarity and un-ambiguity. The Cronbach's alpha method was also used to estimate internal consistency reliability [8].

The study was approved by the Institutional Review Board and all participants signed informed consent.

STATISTICAL METHODS

The sample size of eligible participants for the initial phase of the study was determined according to definite assumptions. Because of a presumed drive to seek information, it was projected that access to Internet resources in this group would be higher than the 1% reported in the KSA [9] or the 5% reported recently according to the Global Reach statistics [1]. Therefore, it is postulated that

cancer patients might show a 10% Internet access rate. It is also assumed that the acceptable margin of error for that estimate is 5% and 95% is the confidence level that can be tolerated. Over approximately two-month period, approximately 3000 outpatient visits are expected. While nearly 1000 of these visits are made by patients with repeated encounters, it will become possible to draw the study sample from 2000 patients over two months. Based on these numbers, a sample size of 130 participants was required [10, 11]. To allow for a possible 15% wrong inclusion, withdrawal, data errors, etc. it was decided to include 150 patients.

Differences between groups, e.g., information resource users vs. nonusers, were compared using X^2, Fisher exact test, t test, or non-parametric procedures where appropriate. Variables with significant levels pf $P \leq 0.1$ on univariate analysis were considered for entry into a binary multivariate logistic regression model to examine correlation with a dependent binary variable: Internet users vs. nonusers. SPSS software (Version 11.0; SPSS Inc., Chicago, IL, USA), was used to perform all analyses. All P values were two-sided.

RESULTS

In a pilot phase, the internal consistency reliability for all questionnaires' items revealed a satisfactory alpha value of 0.96. Moreover, the alpha values for some chosen items ranged between 0.95 and 1.0 indicating high internal consistency reliability.

Of all potentially eligible participants approached, 26 patients were excluded for the following reasons: 19 patients (11 females and 8 males) lacked the minimal information about their disease and/or prognosis; four females refused participation; two (one male and one female) had poor performance status; and one patient refused signing the consent form. The study included 150 eligible respondents.

There were 73 (49%) and 77 (51%) males and females, respectively. The median and the 95% confidence interval (CI) for age were 42 years (CI, 38 and 43 year). The median age for males and females was equal at 42 years.

Table 1 shows the characteristics of the participants. Surveying patients about how they received the information about their illness revealed that 140 (93%), 54 (36%), 42 (28%), 33 (22%), 32 (21%), and 25 (17%) obtained such information from the medical team, other patients, mentioned newspapers, family members, nursing staff, and television or radio, respectively. On the other hand, only 19

(13%) of patients used the Internet to receive online information.

Figure 1

Table 1: Characteristics of the 150 Participants

Characteristics	Patients No. (%)*
Dwelling	
Urban region	99 (66)
Rural region	51 (34)
Educational level	
Illiterate	16 (11)
Primary or secondary school	32 (21)
High school or some high school	42 (28)
College or some college	53 (35)
Higher education	7 (5)
Arabic language proficiency	
Speak only	14 (9)
Read or write only	8 (5)
Read and write (average)	23 (15)
Read and write (good)	105 (70)
English language proficiency	
Speak only	14 (9)
Read or write only	23 (15)
Read and write (average)	49 (33)
Read and write (good)	8 (5)
Not at all	56 (37)
Occupation	
Homemaker	43 (29)
Student	29 (19)
Teacher	24 (16)
Governmental employee	21 (14)
Self-employed	15 (10)
Other	2 (1)
Non-employed	16 (11)

*Percentages were rounded

Table 2 depicts the results of patients' responses to questions about access to computers and to the Internet information, perception of the quality of the Internet information, and the trust in such information. Despite the fact that 74% of patients have computers and 49% stated possible access to the Internet, only 13% actually used the Internet to seek health-related information. A large proportion of patients thought that the information retrieved is of excellent or good quality (50%), besides being trustable (35%).

Figure 2

Table 2: Access to and Appraisal of Internet Information by the 150 Patients

Questionnaire Items	Patients No. (%)*
Owned a computer	
Yes	111 (74)
No	39 (26)
Possible Internet access	
Yes	74 (49)
No	76 (51)
Possible Internet access from	
Home	69 (46)
Work	14 (9)
Other	9 (6)
Using Internet to seek health-related information	
Patients	19 (13)
Proxy or indirect users (relative/friend)	52 (35)
Quality of Internet health-related information	
Excellent	14 (9)
Good	61 (41)
Poor	4 (3)
Not applicable or don't know	71 (47)
Do you feel that you can trust Internet health-related information?	
Yes	53 (35)
No	8 (5)
Not applicable or don't know	89 (60)

*Percentages were rounded

In the subsequent section of the questionnaire, patients were asked about what information they would seek if there were a computer and an Internet access. Most patients would search for information concerning nutrition (74%) and their specific disease (69%), its treatment (69%) and its outcome (71%). Fifty-nine percent of patients also indicated that they would seek information about complimentary and alternative medicine (CAM).

In response to a question intended to explore respondents' perception about the criteria that would influence accessing a particular Web site, 93 (62%) and 87 (58%) of patients were influenced by the ease of use of a particular Web site and the currency of the content, respectively. On the other hand, sponsorship or qualifications of authors would only influence approximately one-third of the participants.

Table 3 depicts the barriers that preclude accessing Internet health-related resources from patients' perspective. The Table shows that inability to use computer and English language illiteracy were the most frequently quoted barriers. In addition, a large number of patients stated that they were not aware about the availability of online health-related resources.

Figure 3

Table 3: Barriers that Preclude Accessing Internet Health-Related Resources from Patients' Perspective (150 Patients)

Barriers	Patients No. (%)*
Inability to use computer	85 (57)
Inability to read and/or write in English language	83 (55)
Not knowing about the existence of online health-related resources	66 (44)
Lack of time	60 (40)
No adequate female healthcare workers to help/teach females patients	54 (36)
Nobody to help/teach	53 (35)
Non-availability of computers	47 (31)
Inability to read and/or write in Arabic language	46 (31)
The cost of required hardware	43 (29)
The cost of Internet access	41 (27)
Mistrusting Internet information	38 (25)
Non-availability of Internet access	38 (25)
Living in rural areas	34 (23)

*Percentages were rounded

Table 4 shows the characteristics of Internet users compared with that for non-users. Variables that found significantly different between the two groups in the univariate analyses were entered into a binary backward stepwise logistic regression multivariate analysis to identify variables that independently characterize users. The model identified owning a personal computer as the only variable that distinguished Internet users (Wald's statistics = 5.65, odds ratio 4.46 [95% CI 1.30 to 15.29], P = 0.017).

Figure 4

Table 4: Characteristics of Users of the Internet (19 Patients) compared with that for Nonusers (131 patients)

Characteristics	Patients No. (%)*		P value
	Nonusers	Users	
Sex			NS†
Males	65 (50)	8 (42)	
Females	66 (50)	11 (58)	
Dwelling			0.021
Urban region	82 (63)	17 (90)	
Rural region	49 (47)	2 (10)	
Educational level			NS
Illiterate/Primary or secondary school	44 (36)	4 (21)	
Higher education level	87 (66)	15 (79)	
Arabic language proficiency			NS
Speak only/read or write only	41 (31)	4 (21)	
Read and write (average/good)	90 (69)	15 (79)	
English language proficiency			NS
Speak/read or write only/nil	85 (65)	8 (42)	
Read and write (average/good)	46 (35)	11 (58)	
Owned a computer	92 (70)	19 (100)	0.006
Possible Internet access	61 (46)	13 (68)	NS
Proxy access	41 (31)	11 (58)	NS
Quality of Internet information (only for those who rated quality)			NS
Poor	4 (7)	0 (0)	
Good/excellent	58 (93)	17 (100)	
Trusting Internet information (only for those who gave opinion)	43 (84)	10 (100)	NS
Interested in joining Internet training	86 (67)	11 (58)	NS
Seeking information concerning			
Nutrition	92 (70)	19 (100)	0.004
General about cancer	75 (57)	13 (68)	NS
A specific disease	89 (68)	15 (79)	NS
Treatment	91 (70)	13 (68)	NS
Prognosis and cure rate	91 (70)	15 (79)	NS
Effect on quality of life	59 (45)	9 (47)	NS
Support groups	47 (36)	9 (47)	NS
Prevention and early detection	70 (53)	11 (58)	NS
Complimentary/alternative medicine	76 (58)	13 (68)	NS
Cancer hospitals and centers	59 (45)	11 (58)	NS
Cancer professionals	55 (42)	15 (79)	0.003
Cancer clinical trials	38 (29)	11 (58)	0.018

*Percentages were rounded
†NS denotes not significant

DISCUSSION

Seeking cancer information on the Internet is very common for patients, caregivers, cancer survivors, healthcare professionals, and the public. While it was predictable that the majority of patients received information about their illness from the medical staff (93%); it was rather interesting to find that other patients were the second most common source of such information (36%). In accord with the latter finding, participants in focus groups of patients in the UK found that practical and experiential information from other patients was highly valuable [12].

The low rate of using the internet for seeking online health information in the present study (13%) was that reported among cancer patients in developed countries [2,3,4,5].

Although only few respondents were online health information seekers, large proportions thought that the information is of excellent or good quality (50%) and 35% would trust such information. In a survey from the USA, respondents with greater trust in online health information sources were significantly less educated and less health information oriented [13].

Nutritional information was the most frequently stated information that participants would be keen to find. The survey also showed that most patients would search for information vis-à-vis their specific disease, treatment, and prognosis. It was not surprising that 60% of the surveyed patients would seek CAM information online. Cancer care professionals in the country should be aware of the significant desire for CAM information and consequently, they must protect information seekers from non-credible knowledge or scientifically unfounded fraud [14, 15].

Ease of use and currency of the information, were the most frequently stated criteria that would influence users to access a particular Web site. The low computer literary rate among our patients December explain their consideration for easy Internet access. While there are many informative guidelines that teach patients how to find and evaluate the quality of online information [16,17,18], unfortunately no such guidelines are available in Arabic language.

In the population of this study, despite that 74% and 49% of patients owned computers or have potential access to the Internet, respectively, it appears from patients' perspective – that computer and language illiteracy are the most important obstacles that would widen and deepen the technology gap. Comparing the 19 patients who actually used the Internet to find health information vs. those who did not, showed that owning a personal computer was the only variable that differentiated the two groups.

LIMITATIONS

The current series December have several limitations. The demographics and the number of the respondents in the present study December limit the generalization of the findings to other populations. However, the sample size in our series was determined using accurate statistical methods and valid assumptions. Furthermore, our facility is a referral center for cancer patients from a fast growing area of the country. Therefore, it is it is likely that the derived results would remain unchanged in another representative population.

Another limiting feature is related to the use of non-validated questionnaire. However, the results of the performed validation and reliability processes were assuring.

Finally, the study did not address the potential confounding effect of non-Internet information resources such as books,

magazines, radio, etc. However, baseline assessment of the information sources in this study showed that only few patients have actually used these educational tools.

RECOMMENDATIONS

The derived results of the current project served as impetus to formulate pragmatic recommendations to promote accessing Internet resources by cancer patients:

1. Healthcare authorities in the country should plan and implement a nationwide program to educate patients about computer and Internet use. The program should develop a strategy to overcome barriers to access.

2. There is a significant lack of adequate number of credible cancer information resources in Arabic language. It is the responsibility of the healthcare authority to secure resources to establish trustworthy Arabic language cancer information Web sites.

3. Healthcare professionals should be able to help patients by making specific Web site recommendations to potential users.

4. Healthcare providers should not underrate the wide prevalence of CAM interest in the country. We must protect public interest and guide patients about the credibility and quality of Internet CAM information.

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