

ORIGINAL ARTICLE

Tendency of cancer patients and their relatives to use internet for health-related searches: Turkish Oncology Group (TOG) Study

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Summary

Purpose: This study aimed to reveal the habits of using internet by cancer patients and their relatives to access health-related information and services in Turkey.

Methods: An 18-item questionnaire survey was applied in cancer patients and their relatives.

Results: A total of 1106 patients (male, 37.3%, and female, 62.7%) and their relatives were included in the study. The responders had been using internet to obtain health information about oncological diseases, once a month (34.2%), 1-2 times a week (27.4%) or 2-3 times a month (21.9%). After diagnosis of cancer was made, participants more frequently (64.4%) investigated health-related issues, while 64.9% of them considered internet as an important search tool, and 16.7% of them had thought to give up cancer therapy under the influence of internet information. Some (33.1%) participants had used herbal

medicine, and 16.7% of them had learnt these herbal products from internet. Still 12.7% of them had not questioned the accuracy of internet information, while 26.9% of them indicated that they had not shared the internet information about cancer with their physicians, and 13 % of them searched information in internet without asking their physicians.

Conclusion: Cancer patients and their relatives showed a higher tendency to use health-related internet information which may mislead them, and can result in treatment incompliance. Health professionals should offer evidence-based information to the patients and their relatives through internet.

Key words: cancer, cancer patients, herbal treatment, internet use

Introduction

Internet has developed day by day at an enormous pace, and has become an indispensable part of our lives. Internet has provided a chance to access information rapidly, and with equal opportunities. Internet users were around 2 bil-

lion people in 2010 worldwide, and this number reached 3.3 billion in November 2015, and 17.9% of the users were from European countries [1]. In Turkey 43 million people are internet users [2]. Access to information was made easy using inter-

net and its opportunities. However, this increase really challenges control mechanisms, and lots of misinformation are surfing on the internet.

Internet provides rapid share of information, and it is used in many fields, most importantly in health issues. An increasingly rapid rise in the internet usage in order to access to medical information and services has been observed. In the USA, 85% of adults are using internet, and approximately 80% of them prefer internet to access to medical knowledge [3]. Four or five percent of all internet usage are estimated to be related to health issues [4,5]. In Turkey health-related searches have increased from 22.4% in 2005 up to 66.3% in 2015 [2]. Because of the increased usage of internet for health-related issues, concerns about uncontrolled, inaccurate medical, or even fake information are gradually increasing.

Increase in the prevalence of health-related searches on internet is also seen in cancer patients. In a study on newly diagnosed 441 cancer patients, it has been detected that patients had obtained health-related internet information either directly (56.7%) or by way of family members or friends (24.3%). This study has demonstrated increased incidence of health-related internet searches among cancer patients [5].

In an era where using internet for health-related issues increases around the globe, in this study we aimed to reveal the habits of cancer patients and their relatives concerning access to medical information and services on the internet.

Methods

An 18-item questionnaire form was prepared. The questions of this survey are given in Table 1. This questionnaire survey was distributed to patients diagnosed with cancer between April 2015 and October 2015, and their relatives. The questionnaire forms were filled in by the study participants freely in a hospital environment without any intervention by any health personnel. Data obtained from 11 participating centers were entered in SPSS 20.0 program and frequency analysis was performed.

Results

A total of 555 (50.2%) patients and 551 (49.8%) patient relatives participated in the study. The study population (N=1106) consisted of 413 (37.3%) male and 693 (62.7%) female participants. Age distribution of study participants is shown in Table 2.

The study participants were mostly living in

Table 1. Items of the questionnaire

1. In what province are you living?
2. Where do you live? (City center/ County / Village-town)
3. Your educational level? (Primary education / Lycée/ University)
4. How do you connect to internet? (by means of a cell phone/Computer/Tablet)
5. What sources of information do you resort to when you want to get information about oncological issues? (I consult my physician / I enter into internet / I ask my intimates)
6. How often do you search for health information on internet? (2-3 times a month / once a month / 3 or more than 3 times a week / 1-2 times a week)
7. Have you more frequently visited health-related internet sources after you or your relative received the diagnosis of cancer? (Yes / It didn't change/ Decreased)
8. Do you investigate the background of the physician who planned your treatment? (Yes, I do / No, I don't)
9. Do you investigate the cancer treatment prescribed for you or your patient from internet sources? (Yes I do / No, I don't)
10. How important are internet sources for your choice of the hospital, and physician? (Very important / Important / Unimportant)
11. Have you ever give up or thought to discontinue your cancer therapy because of health-related internet information? (Yes I had / I thought to give up the treatment, but then I didn't change my treatment / No, I didn't give up my treatment, internet information didn't effect my decision about the treatment)
12. During your or your patient's treatment, have you ever used/or are still using herbal medicine? (I have never used / Yes, I have used)
13. If you are using a herbal product, where did you get information about this product? (Internet / Family members or friends / other patients)
14. How much do you trust the internet information about cancer? (All of them / Some of them / None of them)
15. Do you investigate the accuracy of the internet source of information about cancer? (Always/ Sometimes / Never)
16. Do you investigate the background of provider of the internet information, and his/her experience about the subject? (Always / Sometimes / Never)
17. How often do you share the internet information about cancer with your attending physician? (Always / Sometimes / Never)
18. Do you apply internet information about cancer without asking your physician? (Yes / Sometimes / Never)

Table 2. Age distribution of questionnaire survey participants

Years	N (%)
20 – 29	115 (10.4)
30 – 39	241 (21.8)
40 – 49	285 (25.8)
50 – 59	262 (23.7)
60 – 69	174 (15.7)
≥ 70	29 (2.6)

Table 3. Distribution of questionnaire survey participants among geographic regions of Turkey

Geographic regions	%
Marmara Region	34.9
Aegean Region	22.4
Central Anatolia Region	16.7
Mediterranean Region	9.7
Black Sea Region	7.6
Eastern Anatolia Region	7.8
Southeastern Anatolia region	0.9

Table 4. Distribution of the devices used by patients, and their relatives for connection to internet

Device	N (%)
Cell phone + Computer + Tablet	294 (26.5)
Cell phone + Computer	266 (24)
Cell phone	240 (21.7)
Cell phone + Tablet	35 (3.1)
Computer	237 (21.4)
Computer + Tablet	15 (1.3)
Tablet	19 (2)

Istanbul (22.4%) followed by Mugla (19.4%), and Ankara (14.2%). Their distribution among 7 geographic regions of Turkey is given in Table 3. They were living in the City center (62.3%), county (29.7%), villages or towns (8%). The study participants had primary education (22.2%), high school education (33.1%) or were university graduates (44.8%).

The type of the device used by the participants for the connection to internet indicated mostly cell phone (75.3%), followed by computer (73.2%). Detailed distribution of the devices used by patients and their relatives for connection to internet is given in Table 4.

The study participants indicated that when they wanted to acquire information about an oncological disease they consulted only a physician (43.3%), both physician and internet sources (35%), only internet (11.4%), and a physician, internet and a relative (7.1%), while 54.3% of the participants used internet to obtain information about an oncology issue.

The study participants linked to internet with the intention to get health information 2-3 times (N=242; 21.9%) or once (N=378; 34.2%) a month, ≥ 3 (N=183; 16.5%) or 1-2 (N=303; 27.4%) times or once a week (43.9%).

After diagnosis of cancer was made the frequency of internet searches by patients and their

relatives increased (N=712; 64.4%), did not change (N=338; 30.6%) or decreased (N=56; 5.1%).

Nearly half of the patients (N=518; 46.8%) indicated that they had looked up for internet information about the physician who planned their cancer treatment, while 53.2% (N=588) of them said that they had not made such a search. Cancer treatment prescribed by the attending physician was inquired by (N=483; 43.7%) of the patients on internet, while 56.3% (N=623) of them did not make such an investigation. The importance of internet concerning the selection of hospital and the physician was questioned and graded as very important (N=208; 18.8%), important (N=510; 46.1%), and not important (N=388; 35.1%).

Because of the internet information on cancer therapy 19 (1.7%) of the patients gave up their treatment, while 16.7% of them thought to discontinue their treatment, but finally they didn't. Internet information did not influence the treatment option of 81.6% (N=902) of the patients who didn't give up their treatment.

The patients and their relatives were inquired about the use of herbal products during their treatment period, and 66.9% (N=741) of them had not used these products, while 33% (N=365) of them did use them. Herbal product users learnt about these medicinal products from internet (16.7%), from family members or their social circle (80%), and from other cancer patients (3.2%).

The responders to the questionnaire items indicated that they trusted all (N=94; 8.5%) or part (N=812; 73.4%) of the internet information on cancer, while 200 (18.1%) participants did not trust these information at all. The patients indicated that they had always (N=511; 46.2%) or sometimes (N=454; 41%) investigated the accuracy of internet source of cancer information, while 141 (12.7%) did not. The study participants said that they had always (N=376; 34%) or sometimes (N=442; 40%) searched for the background and relevant experience of the provider of the internet information, while 228 (26%) responders had not ever tried to make such an inquiry.

The study participants reported that they had shared internet information about their cancer with their physicians every time (32.9%; N=364), sometimes (40.1%; N=444) or not at all (26.9%; N=289). The patients indicated that they had always (N=48; 4.3%) or sometimes (N=96; 8.7%) applied internet information without asking their physicians, while the majority of them (N=962; 87%) had not apply internet information without asking their physicians.

Discussion

Use of internet is increasing day by day so as to attain health information and related services. Individuals mainly use internet to get information about diseases. Among a total of 1289 patients who participated in a USA study, 65% had internet access, and as reported by investigators 74% (48.1% of the total) of them consulted to internet to get health-related information. Still in the USA, the National Center for Health Statistics organized a questionnaire survey among 7192 adults aged between 18-64 years which revealed that 51% of the adults were using internet to get health information [6]. Tekin et al. detected that 94.9% of 586 internet users who presented to the outpatient clinics had said that they had preferred internet to obtain health-related information [7]. Bass et al. investigated 441 newly diagnosed cancer patients, and detected that patients had obtained health-related internet information either directly (56.7%) or by way of family members or friends (24.3%) [5]. The most comprehensive study performed with 8001 participants concerning health-related use of internet in Turkey disclosed that 78.7% of the participants linked to a website when they needed information on health issues [8]. In a study by Yirmibesoglu et al. 35.9% of 256 cancer patients and their relatives used internet to get information about their diseases [9]. However in our study, 54.3% cancer patients and their relatives had used internet to obtain information about oncology. In an article by Eysenbach et al. on the influence of internet on cancer patients, the authors indicated that approximately 2.3 million cancer patients in the world surfed on internet, and also emphasized higher rates of internet use among cancer patients [10]. Various studies have demonstrated higher rates of internet use among cancer patients.

The patients and their relatives reported that cell phone was by far the most used means of connection with internet (75.3%). Based on the data released by Turkish Statistical Institute (TUIK), the use of smart phones which can be used to enter into internet has increased from 53.7 % in 2004, up to 96.7% in 2015 [2]. Easier and faster access into internet by means of mobile internet naturally has increased the rates of internet use. In a study performed in Turkey, the means of connection to internet were computer (93.9%), cell phone (49%), and tablet (21.4%) [8]. In our study, cell phones, computers and tablets were used by 75.3, 73.2, and 30.9% of the study participants, respectively.

Cancer patients can ask their physician, a relative or another patient who had suffered from this disease before or else the patient can surf on the internet searching information about the disease. Use of internet enables patients to access into a wide spectrum of information about their diseases and their treatment modalities rapidly and easily. As a result of information gathered by the patients, they can ask new questions to their physicians; besides, internet contributes to self-development of physicians and encourages them to keep track of new information. To this end, 54.3% of the patients and their relatives indicated internet as a source of their cancer-related information. In a study performed by Baskale et al. the authors detected that cancer patients gathered information about their disease from their physicians (82.5%), while 70.8% acquired this information from the internet [11]. In another study performed in Turkey, the study participants indicated that they linked to internet (78.7%) or 66.2% of them consulted their physicians for health-related information [8]. In a study performed by Tekin et al. the study participants indicated that they had used internet to gain information about their disease (66.2%), treatment methods (45.3%) or for preliminary information before they consulted their physicians [7]. Internet users prefer internet for various reasons. They use internet to obtain information about some diseases and their treatments, and the drugs they are using, and as an aid in their search for the hospital, the physician, and novel alternative treatment methods. Besides, the patients access to internet so as to understand the causes and progression of their disease, to search for support groups, and get in contact with them [12]. In our study nearly half of the patients and their relatives searched on the internet the cancer therapy and the physician who prescribed it.

The frequency of internet use to get health-related information by the patients and their relatives was also questioned in our study. Most of them (64.4%) stated that they had used internet every week after diagnosis of cancer was made. In another study performed in Turkey the authors reported that the patients and their relatives had searched the internet more often 2-3 times a month for getting health information [8]. Helft et al. investigated the use of mass media by cancer patients for health information and their expectations based on the internet information, and reported increased level of interest of 71% of these patients about the information presented to them

after their diagnosis was established [13].

During their search for health information on internet, the patients and their relatives also inquire their physicians' background and the treatment provided. Nearly half (46.8%) of the patients and their relatives who participated in our study indicated that they had investigated the physician who planned their treatment, and 43.7% of them also searched their cancer treatment on the internet. Also, in our study we detected that for the selection of the hospital and the physician, internet had been used very frequently (64.9%). In a study performed in Turkey, more than half of the study participants had pointed out to the important role of internet in the selection of the hospital, and the physician [8]. However, in a study conducted by Tekin et al. the investigators noticed that internet was used at a rate of 30.9% for the selection of the hospital and the physician, and determined that information gathered from health sites was very effective in 30.4% of the participants in making health-related decisions [7].

Information retrieved from internet can adversely impact the treatment of the patient or even alter the treatment applied altogether. In our study, the rates of withdrawal or modification of the treatment were very low. Indeed, 1.7% of our patients discontinued their treatment, while 16.7% of them thought to give up their treatment but finally they did not. In a study performed on cancer patients, 60.3% of the participants indicated that internet information had effected their individual decision-making. In the same study, information obtained from internet had been used more frequently to confirm recommended treatment modalities, while a small group of patients benefited from internet information to switch to a similar or an additional treatment [14]. Helft et al. reported that 10% of their patients stated that internet information was effective on their decision-making [13]. In a study by Pautler et al., the corresponding rate was 8% [15] while in a study performed in Turkey 41.6% of the participants indicated that they had discontinued their drug therapy under the influence of internet information [8].

Another serious aspect of the internet use for health-related information and services is drugs sold on internet. Drugs sold on internet without any official auditing which are used unconsciously as herbal medicinal products are threatening public health. Herbal products have been reportedly used by 3-25% of cancer patients [16]. Cancer patients and their relatives had a tendency to use

herbal products. Indeed 33% of them were using herbal products, and 16.7% had learnt about these products from the internet. In a study by Isikhan et al. on 704 cancer patients, 39.2% of their patients were reportedly using herbal products [17]. In another study, use of herbal products was determined in 53% of breast cancer patients, and 46.8% herbal product users had gained information about these products from social and visual media [18]. Internet information can lead to use of deleterious herbal products and applications.

Internet has been used increasingly to get health-related information, however the most important hazard is its adverse impact on health state of the visitors because of misinformation and erroneous applications. Latthe et al. reported that internet information may not be a reliable source all the times [19] while Ebel et al. investigated internet use by cancer patients and emphasized that physicians should direct their patients to reliable web sites [20].

The great majority of patients and their relatives who participated in our study trusted the internet information, and only a small percentage (18.1%) indicated their mistrust. Most of the patients and their relatives who participated in our study investigated the accuracy of the information source, background and the experience level of the providers of this internet information.

Despite higher levels of internet use by the patients and their relatives, only a few of them share this information with their physicians. Tekin et al. noticed that 60% of their study participants did not share internet information with their physicians [7]. Murray et al. determined that 50% of the patients who acquired health information from internet did not share this information with their physicians [21]. In our study responders mostly shared health-related internet information with their physicians and most of the cancer patients and their relatives shared the internet information they had learnt with their physicians while the majority of them (87%) did not apply them without asking their physicians.

Conclusion

Nowadays, internet is an indispensable source of information and communication. It is used increasingly on every field, as well as to acquire health information and services. Our study has demonstrated that higher number of cancer patients and their relatives are using internet to this end. Considering important health problems such as cancer, access into accurate information

has an utmost importance for human health. Erroneous information on internet results in treatment incompliance and serious health problems. To this end health professionals and organizations should offer evidence-based, high-quality,

and reliable information to the patients and their relatives through internet.

Conflict of interests

The authors declare no conflict of interests.

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