



An Evaluation of the Information Sources of Cancer Patients' Relatives. A Prospective Survey

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Abstract

Patients followed up with a cancer diagnosis must be well-informed about cancer to be able to cope with it. Besides, informing the relatives of the cancer patients who are also experiencing the same process about the diagnosis and follow-up period of cancer is highly important. In the current study, it was aimed to evaluate the information sources about cancer which are referred to by relatives of cancer patients. Three hundred ninety-one cancer patient relatives were included in medical oncology clinic between May 1 and June 30, 2015. A questionnaire was applied to the participants, comprising 12 questions to elicit demographic information and 11 questions about the information sources to which they referred. The study included 183 female and 208 male participants with a mean age of 47.9 ± 13.6 years. While the oncologists were the primary information sources referred to by 87%, the Internet was the second most preferred information source by 72%. The websites most frequently referred were the official websites (70%), the websites of oncology associations (53%), and social networks and forums (32%). The primary factors affecting the Internet preference were age, education level, income level, and place of residence. The Internet was the second most referred information source about cancer by family caregivers following oncologists. Therefore, it is of crucial importance that physicians inform patients and their relatives comprehensively as well as guiding them to correct and reliable information sources.

Keywords Cancer · Family caregiver · Alternative information sources · Internet

Introduction

Cancer is the second leading cause of mortality and morbidity worldwide following cardiovascular diseases. Starting from the time of diagnosis, patients' relatives accompany the patient in the treatment and rehabilitation process. Thus, cancer has a profound effect not only on the patient, but also on their families.

The knowledge acquisition process of the patients and their relatives starts at the time of cancer diagnosis. One of the most important steps in dealing with cancer is to have sufficient information about the disease, available treatment options and their side effects, the course of the disease, and available supportive care. Providing sufficient information to the patients and their relatives increases the strength to combat with the disease, improves compliance with the disease process, and increases success rate of the treatment [1, 4, 9].

Patients and their relatives are mostly informed by the physicians and other healthcare personnel in the medical centers where the diagnosis is made and the treatment procedures are carried out [6, 8, 11]. They refer to alternative sources for the issues which they could not get enough information because of time insufficiency or reluctance to ask questions to the physicians. Today, as a consequence of widespread information technology, patients and their relatives stopped being passive information receivers and they become individuals who actively research and learn. There are many alternative information sources currently available such as the Internet, television, newspapers, journals, other patients, and patient relatives

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[3]. The availability of various information sources creates source richness; however, it also carries the risk of information pollution.

Sources of information for cancer patients have been previously evaluated by numerous studies. However, studies conducted on family caregivers are limited. We therefore evaluated the information source preferences of cancer patients' relatives. We also look for possible factors associated with information seeking, sharing this information, and sufficiency of information sources from family caregivers' perspective.

Materials and Methods

Study Center and Participants

The study was conducted in Dokuz Eylul University Faculty of Medicine (DEUFM) Medical Oncology Clinic, between May 1 and June 30, 2015. DEUFM is a tertiary care facility which is located in Izmir, with a population of 4.2 million, being the third largest city of Turkey. This center manages all types of cancer except hematologic malignancies, and it serves about 10,000 cancer patients per year. The study was initiated after the approval of local medical ethics committee. We included relatives of cancer patients, whose patients were diagnosed with cancer, and treatment/follow-up is ongoing in DEUFM Medical Oncology Clinic. The family member who is the main caregiver for the patient was selected and approached during a follow-up visit or treatment session. Participants were informed in detail about the study and written informed consent was obtained. Participants who agreed to be included in the study were asked to complete and return the survey forms within the clinic.

Questionnaire

A questionnaire consisting of 23 questions in two sections was administered to family caregivers. In the first section, demographic information was queried (i.e., age, gender, relationship with the patient, educational level, monthly income, place of residence, tumor type, disease duration, and stage of the disease). In the second section, patient relatives were questioned about the sources which they received information about cancer; their opinions about the sufficiency and reliability of these information sources; and their opinions of their own level of knowledge. Participants' expectations from the information sources, sufficiency of the time spent by the physicians to inform them, and level of sharing the information they obtained from alternative sources with physicians were also questioned. The questionnaire was validated with a pilot study including 15 patients. Data obtained from this group was not included in the final analysis, but it was used for determination of the problems which may be encountered

during the application process and modifications were made accordingly.

Statistical Analysis

We used the “Statistical Package for Social Science (SPSS) 20.0” program for the analyses. While performing the analyses, we showed continuous numeric variables with normal distribution as mean \pm standard deviation (SD), and those without normal distribution as median, minimum, and maximum values. We stated the normal data as proportions (%). In the comparisons of the numeric data, we applied the Kruskal-Wallis H, Mann-Whitney *U*-, and chi-square tests in the dependent and independent samples. We accepted values of $p < 0.05$ in the comparison results between the groups as statistically significant.

Results

Demographic Features of the Survey Participants

The study included 391 patient relatives. The demographic features of the study participants are presented in Table 1. Of all the participants, 183 (47%) were female and 208 (53%) were male. The mean age was 47.9 ± 13.6 years. Education level of the participants were 7 (2%) literate, 98 (25%) primary school, 130 (33%) high school g, and 156 (40%) university. When the relationship of the participants to the patients was analyzed, 165 (42%) were spouses, 168 (43%) were sons or daughters. Of all the participants 252 (65%) were living with the patient and 139 (36%) were living apart from the patient. The mean cohabitation time of the participants with the patient was 27.9 ± 13.4 years.

Demographic Features of the Patients Cared by the Participants

Of the patients whose relatives were included, 103 (26%) had colorectal cancer, 94 (24%) had lung cancer, 86 (22%) had breast cancer, 58 (15%) had pancreas/stomach/liver cancer, and 50 (13%) had other type of cancers (Table 2). Regarding disease stage of the patients, participants stated that 199 (51%) patients had local/limited diseases and 171 (44%) patients had metastatic diseases. Twenty-one (5%) participants gave no response about the stage of the disease. A family history of cancer was reported by 162 (41%) participants, while 227 (58%) reported no family history of cancer (Table 2).

Frequency of Referral to Information Sources

Of all the participants, 161 (41%) were referring to any information source several times a month, 126 (32%)

Table 1 Demographic features of the patient relatives

	<i>n</i> (%)**
Age - years (mean ± SD)	47.9 ± 13.6
Gender	
Female	183 (47%)
Male	208 (53%)
Educational background	
Literate	7 (2%)
Primary school	98 (25%)
High school	130 (33%)
University	156 (40%)
Monthly income*	
< 500 TL (\$185)	12 (3%)
501–1000 TL (\$186–\$370)	96 (25%)
1001–3000 TL (\$371–\$1111)	186 (48%)
> 3000 TL (\$1111)	97 (25%)
Relationship to the patient	
Spouse	165 (42%)
Son/daughter	168 (43%)
Sibling	21 (5%)
Mother/father	17 (4%)
Friend	17 (4%)
Grandchild	3 (1%)
Residence	
Metropolitan	206 (53%)
City center	29 (7%)
County town	116 (30%)
Village-small town	40 (11%)
Living together with patient	
Yes	252 (65%)
No	139 (35%)

SD standard deviation

*1 Turkish Lira (TL) = \$ 0.37 USD (according to the conversion rate on May 2015)

**Sum may not be equal to 100% because of rounding error

several times a week, 65 (17%) several times a year, and 30 (8%) every day. Nine (2%) participants did not respond to this question. Disease duration less than 1 year was significantly associated with more frequent referral to any information source ($p < 0.001$) (Graphic 1). Stage of the disease stated by participants was not associated with frequency of information seeking.

Information Sources About Cancer Preferred by Family Caregivers

Oncologists were the leading information source for the participants (341 participants, 87%). This was followed by the Internet (72%), other cancer patients and their relatives (30%),

Table 2 Features of the patients

	<i>n</i> (%)*
Cancer type	
Colorectal	103 (26%)
Breast	86 (22%)
Lung	94 (24%)
Stomach/pancreas/liver	58 (15%)
Prostate	13 (3%)
Ovary	25 (6%)
Bladder	7 (2%)
Malignant melanoma	5 (1%)
Stage	
Local (limited)	199 (60%)
Metastatic (spread)	171 (44%)
Unknown	21 (5%)
Family history	
Present	162 (41%)
Absent	227 (58%)

*Sum may not be equal to 100% because of rounding error

physicians from other specialties (27%), television (25%), and newspapers/journals (17%) (Graphic 2).

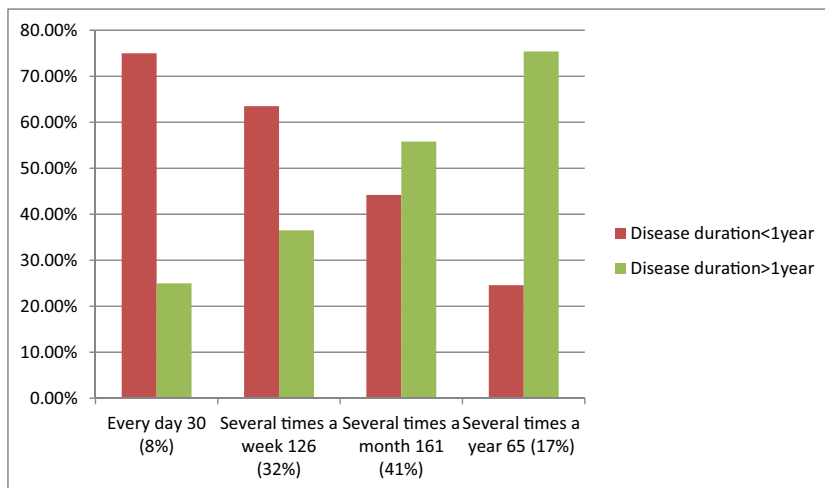
Three hundred (77%) participants stated that they have Internet access at home, while 91 (23%) do not have. Home Internet access availability was 90% among the ones who uses Internet as an information source; it was 42% among non-users ($p < 0.001$). The most preferred websites about cancer were official websites (70%), followed by the websites of oncology associations (53%), social networks and forums (32%), and alternative treatment websites (28%) (Graphic 3).

Factors Associated with Information Source Preference

Factors associated with referral to oncologists as the primary information source were having an education level of high school or higher ($p < 0.001$), cohabitation with the patient ($p = 0.009$) and having a family history of cancer ($p = 0.043$). None of the patients' characteristics were significantly associated with referral to oncologists as information source.

Internet use as an information source was significantly more in those under the age of 65 ($p < 0.001$), with an educational level of high school or above ($p < 0.001$), with a monthly income of 1000TL (370\$) or above ($p < 0.001$). Cohabiting with the patient ($p = 0.007$), living in cities ($p = 0.008$), and a disease duration of less than 1 year ($p = 0.001$) was also associated with preference of Internet use as information source (Table 3). The type of the cancer was not associated with Internet use as an information source.

Graphic 1. Frequencies of reference to information sources of the patient relatives



Sharing the Information Obtained from Other Sources with Physicians

While 82 (21%) participants reported that they frequently share the information they obtained from other sources with their physicians, 178 (46%) were occasionally and 125 (32%) were rarely sharing the information. Six (2%) participants did not respond to this question. While 217 (56%) participants stated that sharing information with the physician had a positive effect on the physician-patient relative relationship, 127 (33%) stated that there was no such effect and 26 (7%) stated a negative effect. In participants with higher education level (i.e., high school and above), sharing the information with physicians was found to have less positive effect on physician-caregiver relationship ($p = 0.024$). No other variables was found to have significant effect on physician-patient relative relationship.

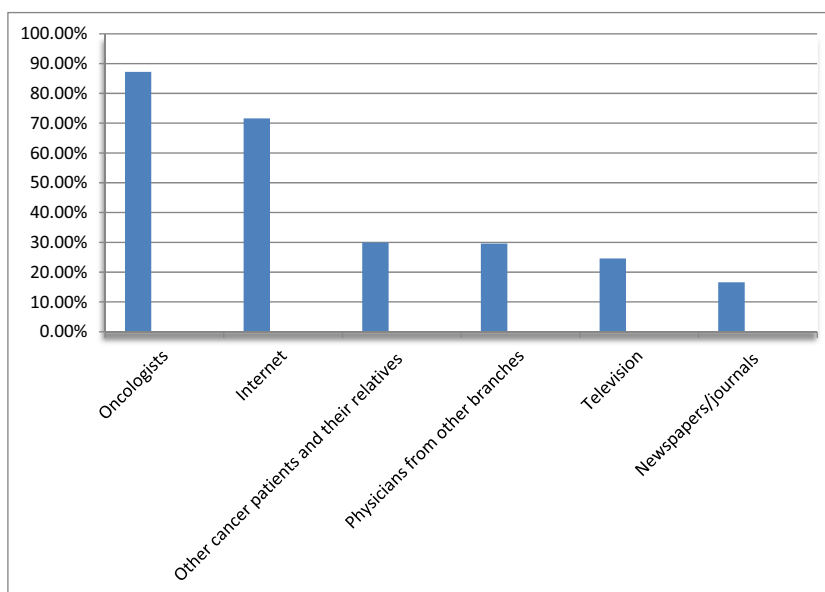
Sufficiency of the Time Spent by Physicians to Inform Patients and Their Relatives

When participants asked to evaluate the time spent by physicians to inform patients and relatives, 158 (40%) participants scored it as sufficient, 145 (37%) as partially sufficient, and 80 (21%) as insufficient. Eight (2%) participants did not respond to this question. With a disease duration of more than 1 year, the number of the participants who reported the time spent by physicians to give information as ‘insufficient’ was significantly higher ($p = 0.006$).

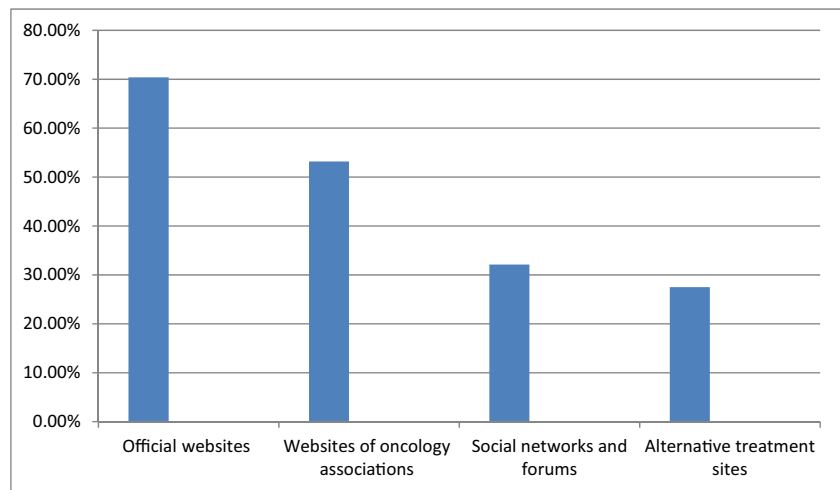
Expectations of Participants from Information Sources

When the expectations of patient relatives were evaluated, the greatest expectation from the information source was

Graphic 2 Information sources about cancer referred to by the patient relatives



Graphic 3 Websites preferred by those who use the Internet as an information source



to obtain information about treatment choices and side effects (mean 3.95 points) and the lowest expectation was to obtain information about alternative treatment options (mean 3.23 points). The scoring of the expectations of patient relatives from all information sources are presented in Table 4.

Table 3 Factors associated with the preference of Internet as an information source

Internet use	Present <i>n</i> (%)**	Absent <i>n</i> (%)**	<i>p</i> value
Income level*			
< 1000 TL (\$370)	60 (56%)	48 (44%)	<i>p</i> < 0.001
> 1000 TL (\$370)	220 (78%)	63 (22%)	
Educational level			
Primary school	44 (42%)	61 (58%)	<i>p</i> < 0.001
High school	95 (73%)	35 (27%)	
University	141 (90%)	15 (10%)	
Duration of disease			
< 1 year	150 (80%)	38 (21%)	<i>p</i> < 0.001
> 1 year	126 (64%)	70 (36%)	
Age			
< 65 years	262 (77%)	80 (23%)	<i>p</i> < 0.001
> 65 years	16 (34%)	31 (66%)	
Residence			
Metropolitan	157 (76%)	49 (24%)	<i>p</i> = 0.008
City center	17 (59%)	12 (41%)	
County town	85 (73%)	31 (27%)	
Village/small town	21 (53%)	19 (48%)	
Cohabitation with patient			
Yes	169 (67%)	111 (80%)	<i>p</i> = 0.007
No	83 (33%)	28 (20%)	

*1 Turkish Lira (TL) = \$ 0.37 USD (according to the conversion rate on May 2015)

**Sum may not be equal to 100% because of rounding error

Discussion

The characteristics of information seeking and sources of information among cancer patients have been previously evaluated by numerous studies. However, studies conducted on family caregivers were limited. In this study, we mainly evaluated the information source preference of cancer patient relatives, and some other characteristics of information seeking. As expected, oncologists were the primary information source for patient relatives. The Internet was found to be the second most preferred information source.

We presented the demographic features of the family caregivers in Table 1. In our study, Majority of the caregivers were spouses and sons/daughters. Number of male caregivers was slightly more than females (i.e., 208 vs 183). We did not question patients’ gender in our survey, so we are not able to comment on this issue. However, in the last 3 decades, increasing trend in the number of male family caregivers was demonstrated previously [16].

Eighty-seven percent of the participants stated that they refer to their oncologist for information. Previous studies also showed oncologist as the most referred information source

Table 4 Expectations of patient relatives from all information resources

Expectations	Mean score *
General information about cancer	3.88
Progression of the cancer	3.93
Treatment choices and side effects	3.95
Support access to treatment facilities	3.59
Alternative treatment options	3.23
Access to other treatment centers	3.31
Recent advances in treatment	3.79

*Participants were asked to score their expectations from all of the information sources in a Likert-scale [1 = the lowest expectation – 5 = the highest expectation]

with a rate of 96% for patients, and 95% for family caregivers [10]. While characteristics of the caregivers (i.e., higher educational level, living with the patient, and family history of cancer) were associated with referral to oncologist, none of the patient characteristics (type of cancer, duration of cancer) was. In the current study, the second most referred information source by patient relatives was the Internet. Seventy-two percent of the participants stated that they use Internet to find information about cancer. Reported rate of Internet use among family caregivers varies between 8 and 57% in previous studies [3, 5, 10, 15]. This variability among studies can be explained by the years in which the studies were conducted. In parallel with increased accessibility, Internet use has increased over time. While home Internet availability rate in Turkey was 50% in 2013 [17], it was 77% in our population in 2015. According to the report of Turkey National Statistical Institution (TUIK), 60% percent of Internet users were obtaining information about health from Internet [17]. In our study among the participants who have Internet access at home, 90% were using Internet to get information about cancer. We found a higher rate of Internet use for health purposes compared to TUIK report. However, unlike our study, the previous one was conducted in the whole population (i.e., including the healthy ones). Obviously, Internet use for health-related purposes is more common in caregivers of sick population compared to healthy population.

Younger age, higher income level, higher education level, living in cities, having Internet access at home, and shorter duration of the disease were significantly associated with referring to the Internet as an information source among family caregivers. Regarding age and education level, our findings were in accordance with previous cancer studies [8, 11]. A higher rate of Internet use as an information source was an expected result due to higher rates of Internet use at younger ages and higher educational levels. Similarly, Internet use as an information source was higher in participants with a higher income, which was shown in previous studies [7, 13]. Participants who live in cities refer to Internet more than the ones who live in rural areas. Considering these findings, ease of access to Internet service, more frequent exposure to newer technologies, using Internet in daily life, and having a comfort level to spent time with Internet favors Internet use as an information source for cancer.

In the current study, the preference of television or newspaper/journal as an information source was less among family caregivers (25 and 17% respectively). In 2007, Nick et al. reported this rate in family caregivers as 28 and 30% respectively [10]. Regarding patients, television and newspaper/journal referral was 82 and 86% respectively in 2000 [3], and 7 and 15% respectively in 2007 [10]. Referring to television or newspaper/journal as an information source for cancer gradually decreased over time. The fall in the use of television and/or newspaper/journal is in correlation with the increased use of

the Internet over time. Considering that the Internet is a more interactive information source, the ease of access to the desired information and the gradual spread of the Internet sub-structure are possible reasons for this trend.

In the current study, the disease duration was found to be the most important factor affecting the frequency of referral to information sources by patient relatives. Disease duration of 1 year or less was associated with more frequent referral or information sources. Possible explanations for this maybe the higher interest in obtaining information about the diagnosis, side effects, and the course of the disease in the earlier phases of cancer, and the decline in the interest and searching activities with the increased level of knowledge over time.

Among family caregivers, we found that 21% frequently, 46% occasionally, and 32% rarely shares information they obtained from all other sources with their physicians. In previous studies, this was questioned among cancer patients regarding information obtained from Internet, and sharing information with physicians was reported to vary between 30 and 45% [12, 15]. In the current study, 56% of the participants stated a positive effect of sharing information on caregiver-physician relationship. Previously, positive effect was reported as 23% [2]. The higher rate of positive response in our study may be the result of the sufficiency of time spent by physicians to inform the patient relatives. Sharing the information obtained from alternative sources was found to have less positive effect on physician-caregiver relationship in participants with a higher education level. Probably, less-educated people are relatively easier to satisfy compared to educated ones.

In our study, greatest expectations from information sources were learning about treatment options and side effects followed by progression of cancer. Similarly, in a study about the use of Internet in breast cancer patients, the subjects of the most concern were the side effects and prognosis [12]. In the current study, expectations of getting information about alternative treatment options were the lowest. In accordance with our results, the quest for information by cancer patients about alternative treatment options was also low in previous studies [12, 14]. This results suggest that patients' relatives are more interested in proven or scientifically supported information about diagnosis, treatment, and prognosis of their patients.

Our study has some restrictions. First, order of preference for information sources was not questioned. The same limitation is also valid in respect of the websites referred. Second, this study was conducted in a single oncology center and was not including hematological cancer patients. Our study has notable strength arising from reasonable number of participants included. Research on family caregivers was limited, so our study adds considerable information to the literature.

With the current widespread use of information technologies, the Internet gains an important place in daily life. It has become a source that is frequently referred to obtain

information about health, particularly regarding protection from diseases, diagnosis of the diseases, treatment options, and side effects. Therefore, it is to be expected that both patients and their relatives frequently refer to the Internet to obtain information about cancer.

In summary, Internet was seen to be the second most preferred source of information following oncologists for family caregivers whose patients are followed up or treated for cancer. Therefore, it is critical that physicians not only comprehensively inform patients and their relatives but also guide them to correct and reliable information sources.

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Compliance with Ethical Standards

Disclaimer The authors declare that the submitted work is their own and that copyright has not been breached in seeking its publication. They confirm that the article is an original work, has not been published before, and is not being considered for publication elsewhere in its final form, in either printed or electronic media.

Conflict of Interest The authors declare that they have no conflict of interest.

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