

# Using The Internet For Health-Related Information From Perspectives Of The Patients With Chronic Diseases and Their Relatives

Kronik Hastalığı Olan Hasta ve Yakınlarınınım Perspektifinden Sağlığa İlişkin Bilgi İçin İnternet Kullanımı

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# Abstract

**Objective:** This study investigated the experiences and characteristics of chronic disease patients and their relatives in terms of internet usage for access to health-related information.

**Material-Method:** A total of 196 patients and 171 relatives were included in this study. The study data were collected through literature-based questionnaires developed by the researchers.

**Results:** In this study, 68.8% of the patients and 71.9% of the relatives used the internet for access to health-related information. The difference between participants who used the internet for health-related information was determined in terms of variables including age, type, and numbers of chronic diseases. Additionally, their frequency of internet usage, search topics, and online resources to access health-related information was significantly different (p<0.05). More than half of the participants (patients: 65.4%; relatives: 56.9%) stated they did not share the obtained information with health care providers, and no internet source was recommended by health professionals.

**Conclusions:** The results of the study indicate that although characteristics of seeking health-related information on the internet differed among patients and relatives, their experiences and opinions were nearly similar. Thus, health care professionals should consider the internet usage status of the patients and relatives to access health-related information and lead them to use reliable and up to date internet resources. They should also guide the creation of online content for chronic disease patients. Moreover, supporting approaches for patients seeking health-related information on the internet can be addressed comprehensively in field-specific studies, in-service training, and conferences.

Keywords: Access to Information, Chronic Disease, Internet.

# Introduction

The internet is commonly used all over the world as a powerful communication and information resource. The use of the internet to obtain health-related information has

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# Özet

**Amaç:** Bu çalışmada, kronik hastalığı olan hastaların ve yakınlarının sağlığa ilişkin bilgiye ulaşmada internet kullanımına ile ilgili deneyimleri ve özellikleri incelenmiştir.

**Materyal-Metot:** Çalışmaya toplam 196 hasta ve 171 hasta yakını dahil edilmiştir. Çalışmanın verileri literatür doğrultusunda araştırmacılar tarafından geliştirilen soru formları aracılığıyla toplanmıştır.

**Bulgular:** Bu çalışmada hastaların %68,8'i, yakınlarının ise %71,9'u sağlığa ilişkin bilgiye erişmek için interneti kullanmıştır. İnterneti sağlığa ilişkin bilgi edinmek için kullanan katılımcılar arasında yaş, kronik hastalık sayısı ve tipi gibi değişkenler açısından fark olduğu belirlenmiştir. Ayrıca, bu katılımcıların sağlıkla ilgili bilgiye erişmek için internet kullanım sıklıkları, arama konuları ve kullandıkları çevrimiçi kaynaklar anlamlı derecede farklılık göstermiştir (p<0,05). Katılımcıların yarısından fazlası (hastalar: %65,4; yakınları: %56,9) elde ettikleri bilgileri sağlık hizmeti sağlayıcılarıyla paylaşmadıklarını ve sağlık profesyonelleri tarafından hiçbir internet kaynağının tavsiye edilmediğini belirtmişlerdir.

**Sonuç:** Çalışmanın sonuçları, hastaların ve yakınlarının internette sağlığa ilişkin bilgi arama özellikleri arasında farklılık olmasına rağmen, deneyimlerinin ve görüşlerinin neredeyse benzer olduğunu göstermektedir. Bu nedenle, sağlık profesyonelleri, sağlıkla ilgili bilgiye erişmek için hastaların ve yakınlarının internet kullanım durumunu göz önünde bulundurmalı ve onları güvenilir ve güncel internet kaynaklarını kullanımaları için yönlendirmelidirler. Ayrıca, sağlık profesyonelleri kronik hastalığı olan hastalar için çevrim içi içerik oluşturulması konusunda rehberlik etmelidirler. Bunlara ek olarak, internette sağlığa ilişkin bilgi almak isteyen hastalar için destekleyici yaklaşımlar, alana özel çalışmalarda, hizmet içi eğitimlerde ve konferanslarda kapsamlı bir şekilde ele alınabilir.

Anahtar kelimeler: Bilgiye Erişim, Kronik Hastalık, İnternet.

become increasingly common. Nowadays, wireless network connections and mobile devices have easy access to the internet and make a significant contribution to providing health-related information. Some aspects such as improving

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the quality of life of individuals, the reducing health care costs, embracement of health policies which support individual disease management, the participation of patients in their health care decisions and the needs of comprehensive information about their own health status have increased the use of the internet for health-related information (1-5).

The advantages of obtaining health-related information from the internet include providing patients with a better understanding of their medical condition, providing social support, facilitating their participation in health-care decisions, empowering self-efficacy in disease management, and improving the treatment outcomes (1, 6-8). The internet can also positively affect the interaction between the patient and the health care providers and steer toward patient-centered interaction in patients who actively use health information (7).

Despite all these advantages, individuals who use the internet to acquire information about their health problems or of their loved ones' may experience some difficulties. While accessing the desired information on the internet is as simple as touching a few keys, reaching accurate, up to date and evidence-based information is a challenge. Individuals may feel anxious about the information which they trust, and they may encounter unwanted effects due to incorrect information and advice from the internet. This situation may adversely affect their treatment outcomes (7, 9, 10).

Chronic disease patients and their relatives may seek more information due to complex and long-term treatments, to deal with the signs and symptoms of the disease, adapt to lifestyle changes, and to support self-care and activities of daily living (11–18).

Previous research investigating seeking behavior on the internet for health-related information focused mainly on patients (2, 3, 7, 11, 14-18). Few of the current studies examined the use of the internet by patient's relatives for health-related information and compared the characteristics of patients and relatives about internet usage. Determining opinions and experiences of chronic disease patients and their relatives on access to health-related information is crucial for health care providers because they have key responsibilities to assess and give information through correct sources to their patients. In this study, we investigated the characteristics of internet usage for access to health-related information and experiences on the issue from the perspectives of chronic disease patients and their relatives. We hypothesized that this study could provide insight for health-care providers for chronic disease patients about the frequency of internet use to seek health-related information among patients and their relatives, the reason for their internet preference for healthrelated information, the preferred online resources, and type of information accessed.

### **Material and Methods**

#### **Study Design and Participants**

This cross-sectional descriptive study was conducted in medical departments (internal medicine, neurology, cardiology, endocrinology, gastroenterology, nephrology, thoracic medicine, medical oncology, and hematology clinics) of Baskent University Hospital located in Ankara, Turkey.

The study population consisted of chronic disease patients and their relatives applying to these medical departments. The inclusion criteria were an age of 18 years and more, no problem in communication, being literate, having at least one chronic disease and/or being the patient's relatives, able to use the internet, and willingness to participate in this study. The sample size of the study was calculated by power analysis. The power was calculated based on these results since the t-test was used to investigate the difference between the use of the internet to access health-related information, and age. Based on the analysis, 80% power, 5% margin of error, and 0.5 effect size were achieved when attending to 96 people who used the internet for health-related information and 48 people who did not use the internet. At the time of this survey, 419 people were interviewed; however, 12 patients and their 11 relatives refused to participate in the study, and 15 patients and their 11 relatives could not use the internet. Eventually, 136 patients and their 123 relatives who met the inclusion criteria and who used the internet to access health-related information, and 63 patients and their 48 relatives not using it comprised the study sample. Overall, 370 individuals (199 patients and 171 relatives) participated in the study (Figure 1). Each individual who met the inclusion criteria was included in the study regardless of being a patient or the relative. For this reason, the sample size of the patient and the relatives was different. The study sample constituted patients with cancer, cardiovascular diseases (hypertension, heart failure, hyperlipidemia, coronary artery disease, and arrhythmia), hypo/hyperthyroidism, diabetes mellitus, chronic renal failure, chronic stomach and intestinal diseases, rheumatoid arthritis, systemic lupus erythematosus, liver failure, chronic obstructive pulmonary disease, and anemia and/or their relatives.

419 patients and relatives applied to medical departments (internal medicine, neurology, cardiology, endocrinology, gastroenterology, nephrology, thoracic medicine, medical oncology and hematology clinics)				
The inclusio	n criteria:			
18 years a	nd more			
No problem in c	ommunication			
Being li	terate			
Having at least one chronic disea	ase and/or being their relatives			
To be able to	use internet			
To volunteer to partie	cipate in this study			
Patients	Relatives			
Refuse: 12	Refuse: 11			
Not internet user: 15	Not internet user: 11			
199 Patients	171 Relatives			
User the internet for health	User the internet for health			
information: 136	information: 123			
Not user: 63 Not user: 48				
370 individuals (199 patients and 171 relatives) participated				

Figure 1. The study samples

### **Data Collection Procedure**

The data were collected using questionnaires developed by the researchers based on literature (5, 6, 14, 15, 18-20). The patients and the relatives had separate questionnaires, although the questionnaires included similar questions. The questionnaires were divided into two sections. The first sections included questions related to the patient's and his/her relative's descriptive characteristics such as age, gender, educational status, marital status, patient's chronic diseases, and the number of chronic diseases. The second section had questions related to using internet characteristics and their opinions on using the internet to access health-related information such as skill, frequency, reasons for using the internet, whether the respondent used the internet to access health-related information or not and reasons for not using, preferred internet resources, whether they found information obtained from the internet is useful or not, and finally, the approach of health care professionals to their internet using experiences, etc.

In order to assess the internal validity of the questionnaires, expert opinions from two nursing faculty were taken. After making the necessary recommended changes, the final versions of the questionnaires were prepared. In order to assess the comprehensibility of the questionnaires, a pre-application was performed with five patients and five relatives who were not included in the sampling.

The data collection forms were provided to the patients and the relatives in the department waiting rooms by the first two co-authors by face to face interview method. The data collection process lasted approximately 15–20 minutes.

#### **Data Analysis**

The data were recorded using the statistical package for social science (IBM SPSS 23.0) program and analyzed using descriptive statistics for the numeric data, frequencies for categorical data, independent sample t-test, and chi-square test. Independent variables of this study included descriptive characteristics of participants, and the dependent variable was the use of the internet to access health-related information. These variables were generally compared with the chi-square test. Only, t-test was used to determine whether there was a difference between age and number of chronic disease use of the internet to access health-related information. The statistical significance value was accepted as p<0.05.

#### **Ethical Considerations**

The study was approved by the Baskent University of Medical and Health Sciences Research and Ethical Committee (project no: KA12/181). The written permission from the hospital was obtained to perform the study, and verbal informed consent was obtained from all participants. Before the questionnaires were applied, the participants were explained about the purpose of the study, voluntary nature of study participation, the choice of the patients to not write their name on the form, the data would be analyzed only from the answers, and that their privacy would be protected.

### Results

The mean age of the participant patients and the relatives was  $45.6\pm13.4$  and  $42.1\pm12.5$ , respectively. More than half of the patients and the relatives were female, married, and had associate/bachelor's degrees, and their incomes were equal to expenditure (Table 1).

In the study, cardiovascular diseases (36.2%-48%) and cancer (32.7%-43.3%) were the most frequently mentioned chronic diseases. The mean number of chronic diseases stated by the patients and the relatives were  $1.8\pm0.1$  and  $1.98\pm1.1$ , respectively. A total of 68.8% of chronic disease patients and 71.9% of the relatives reported that they used the internet for health-related information (Table 1).

Table 1. Descriptive characteristics of the participants

Descriptive characteristics	Patients (N:199)	Relatives (N:171)
Age (±SD)	45.59±13.45	$42.06 \pm 12.53$
Gender	N (%)	N (%)
Female	124 (62.3)	113 (66.1)
Male	75 (37.7)	58 (33.9)
Marital status		
Married	137 (68.8)	109 (63.7)
Single	62 (31.2)	62 (36.3)
Education status		
Primary/high school	57 (28.6)	54 (31.6)
Associate / Bachelor's degree	142 (71.4)	117 (68.4)
Income Level		
Less than expenditure	31 (15.6)	20 (11.7)
Equal to expenditure	116 (58.3)	108 (63.2)
More than expenditure	52 (26.1)	43 (25.1)
Chronic disease*		
Cardiovascular disease	72 (36.2)	82 (48)
Cancer	65 (32.7)	74 (43.3)
Diabetes mellitus	36 (18.1)	44 (25.7)
Hypothyroidism / Hyperthyroidism	53 (26.6)	20 (11.7)
Chronic kidney disease	28 (14.1)	16 (9.4)
Total number of chronic disease ( $\pm$ SD)	1.8±0.9	$1.98 \pm 1.1$
Internet using status for health related information		
Yes	136 (68.8)	123 (71.9)
No	63 (31.2)	48 (28.1)

\*Multiple variables were chosen. Frequencies were determined based on "n"

A statistical difference was observed in the patients' age and their internet use status for health-related information (p<0.05), while there was no such significant difference between using the internet for health-related information and other sociodemographic characteristics (Table 2).

On examining cardiovascular diseases of patient participants or their relatives and their status of using health-related information on the internet, a statistically significant difference was observed between cardiovascular disease in patients and relatives of diabetics and the use of health-related information on the internet (p<0.05). The mean number of chronic diseases of patients who did not use the internet to search for healthrelated information was higher, and this difference was found to be statistically significant (p<0.001). Further, no significant difference was found between the patients and their relatives who participated in the study and used the internet to obtain health-related information (p>0.05) (Table 2).

In the sample, 40.4% of patients and 51.2% of their relatives specified that they used the internet several times a week to acquire health-related information. A statistically significant difference was observed between patients and their relatives and in the frequency of using the internet for health-related information (p<0.05). Besides, in pairwise comparisons between groups, a significant difference was observed between "several times a week" and "several times a month" ( $X^2$ =6.001, p=0.014) and "every day" and "several times a month" ( $X^2$ =6.383, p=0.012). According to the abovementioned evaluations, the search for health-related information on the internet was more frequent among relatives than the patients (Table 3).

health-related information, 59.6% of the patients expressed that obtaining information from the internet was easier and faster and, 46.3% of their relatives reported that they deemed that information on the internet was current. Here, the preferred reasons for participants were found statistically different (p<0.001) (Table 3).

In the study, the most common search word on health-related topics on the internet of participants was "disease" (80.9%–94.3%), "current treatments" (59.6%–66.7%) and "medicines" (54.4%–52%), and the difference between patients and their relatives on these topics was significant. According to these, relatives obtained more information from the internet about the diseases of patients they had cared for (p=0.001), disease-related experimental treatments (p=0.04), and associations/ communities (p<0.000) (Table 3).

When looking at internet resources for information as per Table 3, some differences were observed among the participants. While "personal websites of the doctors (56.6%)", "websites of the hospitals" (41.9%), and "official health sites" (39.7%) were the most common internet resources were preferred by patients, for patient's relatives, the most preferred sources, were "websites of academic institutions" (51.2%), "the

When inquired about the reasons to prefer the internet for

Table 2. U	Jsing internet status	for health-related	information of the	patients and th	neir relatives in	n terms of descri	ptive characteristics
	0						

			internet status for he	t status for health-related information				
Descriptive characteristics		Patients (n=199) n(%)			Relatives (n=171) n(%)			
	_	Yes	No	Chi-Square test	Yes	No	Chi-Square test	
Age	Mean±SD	43.9±12.4	49.2±14.9	t=-2.422 <b>p=0.017*</b>	41.1±11.9	44.5±13.7	t=-1.626 p=0.106*	
Gender	Female	90 (72.6)	34 (27.4)	X <sup>2</sup> =2.142	79 (69.9)	34 (30.1)	X <sup>2</sup> =0.672 p=0.412	
	Male	47 (62.7)	28 (37.3)	p=0.143	44 (75.9)	14 (24.1)		
Manifal status	Married	94 (68.6)	43 (31.4)	X <sup>2</sup> =0.011	77 (70.6)	32 (29.4)	X <sup>2</sup> =0.247	
Marital status	Single	43 (69.4)	19 (30.6)	p=0.917	46 (74.2)	16 (25.8)	p=0.619	
Education status	Primary / high school	36 (63.2)	21 (36.8)	X <sup>2</sup> =1.204	35 (64.8)	19 (35.2)	X <sup>2</sup> =1.979 p=0.160	
	Associate / Bachelor's degree	101 (71.1)	41 (28.9)	p=0.272	88 (75.2)	29 (24.8)		
	Less than expenditure	22 (71)	9 (29)		16 (80)	4 (20)		
Income status	Equal to expenditure	73 (62.9)	43 (37.1)	X <sup>2</sup> =5.404 p=0.067	78 (72.2)	30 (27.8)	X <sup>2</sup> =1.079 p=0.583	
	More than expenditure	42 (80.8)	10 (19.2)		29 (67.4)	14 (32.6)		
Type of chronic dise	ease							
Cardiovascular	Present	43 (59.7)	29 (40.3)	X <sup>2</sup> =4.377	55 (67.1)	27 (32.9)	X <sup>2</sup> =1.841	
disease	Not present	94 (74)	33 (26)	p=0.036	68 (76.4)	21 (23.6)	p=0.175	
Canaan	Present	40 (61.5)	25 (38.5)	X <sup>2</sup> =2.402	55 (74.3)	19 (25.7)	X <sup>2</sup> =1.841	
Cancer	Not present	97 (72.4)	37 (27.6)	p=0.121	68 (70.1)	29 (29.9)	p=0.175	
D'1 / III/	Present	21 (58.3)	15 (41.7)	X <sup>2</sup> =2.264	26 (59.1)	18 (40.9)	X <sup>2</sup> =4.837	
Diabetes mennus	Not present	116 (71.2)	47 (28.8)	p=0.132	97 (76.4)	30 (23.6)	p=0.028	
Total number of chro (Mean±SD)	onic disease	1.6±0.8	2.1±1.1	t=-3.340 <b>p=0.001</b>	1.9±1.1	2.2±1.2	t=-1.681 p=0.095*	

\*Independent sample t test was used.

websites of the doctors" (48%), "official health sites" (41.5%) and "websites of the hospitals" (41.5%). Further, "websites of unknown origin" was used as the fourth search word by patients (35.3%) and the fifth by relatives (34.1%). A statistical difference was observed between the preferences for these information resources by participants. According to their relatives, patients used more of "the online newspapers" ( $X^2$ =3.925, p=0.048) and "websites of health insurance" ( $X^2$ =6.793, p=0.009) and, the relatives used more of "websites of academic institutions" ( $X^2$ =7.338, p=0.007) as a source of information (Table 3).

In this study, we also evaluated the experiences of chronic disease patients and their relatives concerning the health

information they obtained from the internet in the last month. More than half of the participants (61.0%-60.2%) reported that they could easily access the information they were seeking. Further, 52.9% of the patients and 64.2% of the relatives stated that they felt more comfortable when asking questions to the medical staff. Nearly all the participants (98.5%-96.7%) pointed out that an internet source was not recommended by medical staff previously, and 65.4% of the patients and 56.9% of their relatives did not share with health care providers the information obtained from the internet. A statistically significant difference was observed between these experiences of participants (p>0.05) (Table 4).

Table 3. Comparison of	patients' and their relatives	internet using status for health-relate	d information and internet using characteristics
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Internet using status for health-related information and internet using characteristics		Patients (n=136) n (%)	Relatives (n=123) n (%)	Chi-Square test
Status of using	Yes	136 (68.8)	123 (71.9)	
internet to get health- related information	No	63 (31.2)	48 (28.1)	X <sup>2</sup> =0.564, p=0.453
The frequency of	Every day	10 (7.4)	17 (13.8)	
using the internet	Several times a week	55 (40.4)	63 (51.2)	W <sup>2</sup> 0 220 . 0 025
for health-related	Several times a month	39 (28.7)	20 (16.3)	$X^2 = 9.320, p = 0.025$
information	Several times a year	32 (23.5)	23 (18.7)	
	Getting information is easy/fast	81 (59.6)	46 (37.4)	X <sup>2</sup> =12.692, <b>p&lt;0.001</b>
Reasons for	Provides prior knowledge	52 (38.2)	52 (42.3)	X <sup>2</sup> =.439, p=0.508
for health-related	Provides an opportunity to compare information obtained from different sources	26 (19.1)	30 (24.4)	X <sup>2</sup> =1.06, p=0.303
	The information is the latest	22 (16.2)	57 (46.3)	X <sup>2</sup> =27.724, <b>p&lt;0.001</b>
	Disease	110 (80.9)	116 (94.3)	X <sup>2</sup> =10.473, <b>p=0.001</b>
	Recent treatments	81 (59.6)	82 (66.7)	X <sup>2</sup> =1.399, p=0.237
Health-related topics	Medicine	74 (54.4)	64 (52)	X <sup>2</sup> =0.147, p=0.702
searching on the	Complementary methods	45 (33.1)	46 (37.4)	X <sup>2</sup> =0.526, p=0.468
internet*	Stress management	20 (14.7)	15 (12.2)	X <sup>2</sup> =0.348, p=0.555
	Treatment methods on trial	17 (12.5)	27 (22)	X <sup>2</sup> =4.091, <b>p=0.043</b>
	Patient organizations	8 (5.9)	25 (20.3)	X <sup>2</sup> =12.118, <b>p&lt;0.001</b>
	Individual web sites of doctors	77 (56.6)	59 (48)	X <sup>2</sup> =1.938, p=0.164
	Websites of the hospitals	57 (41.9)	51 (41.5)	X <sup>2</sup> =0.005, p=0.942
	Official web sites related to health	54 (39.7)	51 (41.5)	X <sup>2</sup> =0.83, p=0.774
	Unknown websites	48 (35.3)	42 (34.1)	X <sup>2</sup> =0.038, p=0.846
_	Websites of academic institutions	47 (34.6)	63 (51.2)	X <sup>2</sup> =7.338, <b>p=0.007</b>
Internet resources for health-related	Forums related with health	46 (33.8)	41 (33.3)	X <sup>2</sup> =0.007, p=0.934
information*	Online medical journals	39 (28.7)	39 (31.7)	X <sup>2</sup> =0.282, p=0.595
	Online newspapers	25 (18.4)	12 (9.8)	X <sup>2</sup> =3.925, <b>p=0.048</b>
	Websites of special foundations related with chronic disease	24 (17.6)	18 (14.6)	X <sup>2</sup> =0.432, p=0.511
	Websites of health insurance companies	10 (7.4)	1 (0.8)	X <sup>2</sup> =6.793, <b>p=0.009</b>
	Websites of drug companies	8 (5.9)	12 (9.8)	X <sup>2</sup> =1.36, p =0.244

\*Multiple variables were chosen. Frequencies were determined based on "n"

Experiences about internet use for health-related information	Patients (n=136) n (%)	Relatives (n=123) n (%)	Chi-Square test		
How do you rate your internet experience to gain health related information in	n the last month	?			
I found the information easily	83 (61.0)	74 (60.2)	X <sup>2</sup> =0.018, p=0.894		
I felt satisfied with the information obtained from the internet	63 (46.3)	58 (47.2)	X <sup>2</sup> =0.02, p=0.887		
I felt confused by the information I was found	37 (27.2)	24 (19.5)	X <sup>2</sup> =2.123, p=0.145		
I was concerned about the accuracy of the information obtained from the internet	27 (19.9)	33 (26.8)	X <sup>2</sup> =1.766, p=0.184		
I reached very little information about the issue which I want to learn	14 (10.3)	6 (4.9)	X <sup>2</sup> =2.659, p=0.103		
I had difficulties to understand information obtained from the internet	12 (8.8)	5 (4.1)	X <sup>2</sup> =2.385, p=0.123		
I spent so much time to find information which I wanted to learn.	5 (3.7)	7 (5.7)	X <sup>2</sup> =0.593, p=0.441		
What did you do after getting health related information from the internet in the last month?					
I feel confident to raise new questions about the disease and treatment process with health professionals	72 (52.9)	79 (64.2)	X <sup>2</sup> =3.384, p=0.066		
I noticed the seriousness of the problem and applied for a doctor	41 (30.1)	32 (26)	X <sup>2</sup> =0.544, p=0.461		
I did nothing	25 (18.4)	21 (17.1)	X <sup>2</sup> =0.076, p=0.783		
I tried to diagnose the health problem by myself.	15 (11.0)	12 (9.8)	X <sup>2</sup> =1.034, p=0.596		
I got support from others for my health problem	11(8.1)	10 (8.1)	X <sup>2</sup> =0.000, p=0.990		
I tried to treat the health problem by myself	4 (2.9)	4 (3.3)	X <sup>2</sup> =0.021, p=0.885		
Have you ever been recommended by a health professional about internet reso	ources?				
No	134 (98.5)	119 (96.7)	$V^{2}=0.026$ m=0.428		
Yes	2 (1.5)	4 (3.3)	A=-0.920, p=0.428		
Have you ever shared the health information obtained from the internet with a	health profess	ional?			
No	89 (65.4)	70 (56.9)	$V^2 - 1.083 n - 0.150$		
Yes	47 (34.6)	53 (43.1)	A =1.903, p=0.139		

Table 4. Comparison of patients' and their relatives' experiences about using internet for health-related information

\*Multiple variables were chosen. Frequencies were determined based on "n"

# Table 5. Opinions of participants about internet use for health-related information

	Patients (n=136) n (%)			Relatives (n=123) n (%)		
	Agree	Not sure	Disagree	Agree	Not sure	Disagree
I believe that the health information obtained from the internet is accurate and reliable	107	13	16	96	14	13
	(78.7)	(9.6)	(11.8)	(78)	(11.4)	(10.6)
I check the accuracy of the health information obtained from the internet	125	2	9	106	8	9
	(91.9)	(1.5)	(6.6)	(86.2)	(6.5)	(7.3)
I check the currency of the health information obtained from the internet	121	2	13	104	9	10
	(89)	(1.5)	(9.6)	(84.6)	(7.3)	(8.1)
I check who wrote the health information on the internet	122	3	11	112	3	8
	(89.7)	(2.2)	(8.1)	(91.1)	(2.4)	(6.5)
I compare the information obtained from the internet with other resources	113	2	21	103	4	16
	(83.1)	(1.5)	(15.4)	(83.7)	(3.3)	(13)
I believe that health information obtained from the internet is useful	116	11	9	111	7	5
	(85.3)	(8.1)	(6.6)	(90.2)	(5.7)	(4.1)
I try recommendations about health which I learn from the internet	90	20	26	79	22	22
	(66.2)	(14.7)	(19.1)	(64.2)	(17.9)	(17.9)
I try health recommendations which I learn from the internet after consultation of health professionals	111	6	19	104	8	11
	(81.6)	(4.4)	(14)	(84.6)	(6.5)	(8.9)
I share the health information which I learn from the internet with my relatives and other patients	107	9	20	97	7	19
	(78.7)	(6.6)	(14.7)	(78.9)	(5.7)	(15.4)
I suggest health recommendations which I obtain from the internet to	53	14	69	54	20	49
my relatives and other patients to apply	(39)	(10.3)	(50.7)	(43.9)	(16.3)	(39.8)
Since I fear from the reactions of health professionals I do not share information obtained from the internet with them	40	9	87	28	9	86
	(29.4)	(6.6)	(64)	(32.3)	(7.3)	(69.9)

	Patients (n=63) n (%)	Relatives (n=48) n (%)	Chi-Square test
The reasons for not using internet for health-related information*			
Information obtained from internet is unreliable	44 (69.8)	23 (47.9)	X <sup>2</sup> =5.473, <b>p=0.019</b>
It is time consuming to access an information on the internet	8 (12.7)	16 (33.3)	X <sup>2</sup> =6.845, <b>p=0.009</b>
Information obtained from internet induces stress affects mood negatively.	18 (28.6)	7 (14.6)	X <sup>2</sup> =3.055, p=0.08
The information given by doctor is enough	10 (15.9)	8 (16.7)	X <sup>2</sup> =0.013, p=0.911
Information resources except for internet*			
Health professionals	62 (98.4)	47 (97.9)	X <sup>2</sup> =0.038, p=0.846
Books	18 (28.6)	12 (25)	X <sup>2</sup> =0.176, p=0.675
Television	17 (27)	7 (14.6)	X <sup>2</sup> =2.472, p=0.116
Friends / Family members	8 (12.7)	12 (25)	X <sup>2</sup> =2.791, p=0.095

Table 6. The reasons for not using internet for health-related information and other resources used among the participants

\*Multiple variables were chosen. Frequencies were determined based on "n"

In Table 5, the opinions of patients with chronic disease and their relatives toward the use of health-related information are given. Participants in the study often believed that the information obtained from the internet was reliable, accurate (78.7%–78%), and useful (85.3%–90.2%). They checked the accuracy of the information (91.9%–86.2%), current status (89%–84.6%), and the author (89.7%–91.1%) of the information and compared with other written sources (83.1%–83.7%). They similarly applied the recommendations that they received from the internet about health (66.2%–64.2%) or by consulting a doctor, nurse, or health professional (81.6%–84.6%). However, they recommended these practices less frequently to their relatives or other patients (39%–43.9%). The opinions of participants did not show any significant difference (p>0.05).

The reasons for chronic diseases patients and their relatives not using the internet for health-related information were examined in the study. A total of 69.8% of the patients and 47.9% of their relatives did not use the internet because they thought the information was not reliable. The difference between items of "a lack of reliable information" ( $X^2$ =5.473, P=0.019) and "take the time to get the information" ( $X^2$ =6.845, p=0.009) from these reasons and groups was statistically significant. The majority of these individuals (98.4% –97.9%) similarly approached and preferred the medical staff for health-related information (p>0.05) (Table 6).

# Discussion

The rapid development of information technologies and increased access to online resources has enhanced the popularity of the internet in getting health-related information, similar to the other fields. In accordance with previous reports, our study results revealed that patients with chronic disease and their relatives frequently use the internet to get healthrelated information (21, 22).

In our study, younger patients used the internet for healthrelated information much frequently, which is comparable to the observations in previous reports (6, 11). This finding may be attributed to the facts that it is difficult to keep up the latest technological opportunities with increasing age; older individuals usually have poor skill of using the internet, they spend less time on the internet, prefer conventional resources rather than the internet, and their disease duration from the diagnosis is longer (11).

Earlier reports highlighted that individuals with higher education and income levels frequently used the internet to seek health-related information (6, 11, 23, 24). On the contrary, we observed that getting health-related information from the internet did not change because of the educational, marital, and income status of both of the patients and their relatives. One possible reason why educational status did not affect the search health information on the internet may be the increase in internet literacy and accessibility to online resources compared to the past. Another reason could be the difference in sample characteristics.

We found that the patients and relatives used the internet at a similar rate for health-related information. Till date, no earlier study has compared the internet using the behaviors of patients and their relatives. Therefore, it was not possible to make direct comparisons with other reports. On the other hand, similar socio-demographic characteristics, including age, gender, and educational, and income level, may be contributed to this finding.

In the current study, patients with any cardiovascular disease used the internet for health-related information much frequently than those with any other condition. Likewise, relatives of diabetes mellitus patients used the internet more frequently to seek health-related information. Supporting our finding, Jadhav et al. emphasized that cardiovascular diseases were among the most common chronic diseases all over the world (25). Therefore, patients with the cardiovascular disease require more information about lifestyle changes like diet and exercise and may use the internet more frequently.

One of the most striking findings in the current study was that with the increase in the number of chronic diseases, there was a decline in the frequency of internet usage to seek healthrelated information. Consistent with our findings, Ayers and Kronenfeld reported that individuals with more chronic disease used online resources less frequently (11). This may be because the burden of chronic diseases increases with age and negatively affects the internet using the ability of elderly people compared to younger individuals.

In the current study, while patients mostly preferred the internet to "getting easy/fast information", relatives mostly preferred to "get the current information". This finding suggests that while the relatives of the patients sought more current information obtained from the internet, the patients were more interested in easy access to the information.

In the present study, the most prevalent issues searched by both patients and their relatives on the internet were diseases, current treatment methods, and medicines. Earlier reports conducted in chronic disease patients also emphasized that disease and treatment modalities were the most frequent topics sought on the internet (16, 26).

On assessing the preferred online resources by patients and their relatives, the relatives of the patients used academic institutions' web sites more frequently, while the patients used the web sites of health insurance companies' and online journals more frequently. Our findings indicate that relatives of the patients used more reliable internet resources than patients.

We did not find related studies comparing patients and their relatives in terms of seeking health-related information on the internet. The patients' relatives frequently used online current and reliable information about the patients' disease, recent treatments, complementary methods, treatment methods on trial, and patient organizations. On cumulatively evaluating these findings, it can be said that relatives can support patients in decision making and care processes. Additionally, both of the patients and relatives in the current study mainly believed that health information obtained from the internet was accurate, reliable, as well as useful. Two-thirds of participants tried the advice they learned online. Although the internet contains several helpful information for individuals, it also poses a risk of misleading through irrelevant or wrong information. For most of the patients and their relatives, it may not be possible to verify the accuracy and validity of the information. Thus, they should examine the reliability of the information. In this context, the majority of the participants stated that they relied on their experiences and opinions about internet use for health-related information, although, it still poses a risk.

In our study, more than half of the patients and relatives reported that they did not share the information which they obtained from the internet with health professionals. This rate varied between 26.9% and 59% in previous reports (21, 22, 24). Nevertheless, the participants frequently had shared the health information and the advice they learned online with other patients or relatives. Although not specifically addressed in this study, patients and their relatives may feel worried about health professionals' negative attitudes toward acquiring information from the internet, or the health professionals may not ask their internet using status. In our study, individuals mentioned using unacknowledged internet resources at higher rates, and not sharing such information with health professionals may mislead the patients and their relatives and may have adverse outcomes.

In the present study, a large number of participants reported that health professionals did not recommend any online resources, in accordance with previous reports (26, 27). Surveys conducted with nurses also revealed that only a few of the nurses led the patients to reliable internet resources (28–30).

Most of the patients and relatives did not use the internet for health-related information reported that they did not prefer the internet as a resource because they found the information unreliable. Additionally, when we compared the patients and relatives in terms of this variable, patients were less frequent in preferring the internet than the relatives due to unreliable information on the internet. Other reasons reported by patients and their relatives for not using the internet to get health-related information included "using the internet was time-consuming", "caused stress", and "affected mood adversely". Also, there was a difference between the patients and the relatives in terms of the item of "using the internet were time-consuming" among participants, and the patients preferred this item more frequently.

For the patients and their relatives who did not use the internet for health-related information, health professionals were the most preferred information resource, concurrent with previous reports (13, 20).

# Conclusion

This study suggested a similar rate of seeking health-related information on the internet by the patients and relatives. However, reasons for their preference of internet and specific online resources indicated differences between the patients' and relatives' choices. Most of the patients and relatives did not share the information obtained from the internet, and health professionals also did not recommend reliable online resources.

Due to technological improvements, health care professionals will increasingly encounter patients and their relatives who seek health-related information on the internet. Thus, they should update themselves about current, scientific, and online sources of information that are coherent to patients. Additionally, they should also assess internet usage status of patients and their relatives for health-related information and lead them to reliable internet sources. Health professionals may guide in creating online content on specific issues related to their fields that patients can easily access. The importance of such a subject can be noted in meetings such as in-service training, conferences, etc. Also, more detailed, field-specific studies on this subject can be carried out.

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