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ORIGINAL ARTICLE

Internet use by cancer survivors: current use and future wishes

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Abstract
Objective The objective of this study was to evaluate the extent of internet access and use and patient characteristics associated with internet use. We also aimed to study when and at which sites cancer patients search for information, the self-reported effect on health care use, and patients' wishes with respect to future internet possibilities.
Materials and methods We drew a sample of 390 patients diagnosed with breast (n=128), prostate (n=96), or gynecological (n=89) cancer or lymphoma (n=77) in four different hospitals in the period 2002–2004, who were 65 years or younger at diagnosis. These patients were sent a questionnaire that contained 45 questions about demographics and three broad applications of internet use: content, communication, community.
Results Of the 261 (75%) patients who responded, 60% used Internet by themselves, 9% via others, whereas 31% did not use the Internet. High education, young age, and high socio-economic status were all independently positively associated with internet use. Of the patients with complaints but pre-diagnosis, 41% searched the Internet for information about cancer daily to several times a week. After diagnosis, during treatment, and at follow-up, this was, respectively, 71%, 56%, and 4%. Although patients preferred to get reliable information from the Web site of their oncologist (88%), hospital (70%) or Dutch Cancer Society (76%), Web sites that are completely financed and created by pharmaceutical industries were mentioned most as source of information. Patients who used the Internet to find information about cancer felt themselves to be better informed about their disease (72%); only 3% thought that consulting the Internet increased the frequency of visiting their doctor, whereas 20% felt that information from the Internet influenced the treatment decision made by their doctor. Most patients who use the Internet would like to be able to access their own medical file (79%) or test results (81%) if possible.
Conclusion Many cancer patients use the Internet to find reliable information about their disease and treatment. Patient information centers from hospitals should be strongly encouraged to improve disease and treatment information facilities on their hospital Web site, especially since most patients view their oncologist still as the most important source of information.

Keywords Internet · Breast cancer · Prostate cancer · Lymphoma · Gynecological cancer

Internet is increasingly recognized as an important source of information. Several publications have reported the prevalence of internet use as a source of cancer information, recently reporting that 30–50% of patients use the Internet to search for information on their own health [1–6]. The percentage of internet users who search for health information has been stable in America over the past years [7]. Patients become better informed about their disease [3], are able to cope better [5], or e-mail with their doctor [8] or search for a second opinion on the web, and several studies have reported about the changing relation between doctors and patients [3, 5, 9]. However, the possibilities of Internet are changing rapidly, leading to an ongoing need to evaluate patients' use, opinions, and future wishes.

In the Netherlands, the percentage of persons with access to a personal computer increased from 60% in 1998 to 73%

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in 2004 and 88% in 2006, whereas the percentage of persons with internet access increased from 16% in 1998 to 64% in 2004 and 85% in 2006 [10]. Internet access is very much related to age. In 2006, 90% of persons under 55 years had internet access compared to 73% of those 55–65 years and 50% of those 65–75 years [10].

The main goal of our comprehensive cancer center is to facilitate good quality health care for cancer patients in Southeast Netherlands close to their homes. As we recognize the increasing role of the Internet as a source of information and also as a communication tool, we wanted to evaluate the current use of Internet by cancer survivors in our area. We therefore evaluated the extent of internet access, use, and patient characteristics that can be associated with internet use. As it is not known when and where cancer patients search for information, we investigated in which phase of their disease cancer patients are searching for information, what kind of information patients are searching for, and which Web sites they visit. Last, we asked about the self-reported effect of internet information searches on health care use and patients' wishes with respect to future internet possibilities. The results of this study are of importance in improving quality of care for cancer survivors by optimally using the (future) possibilities of the Internet.

Materials and methods

Participants

A population-based, cross-sectional survey on internet use was conducted through the Eindhoven Cancer Registry (ECR). The ECR records data on all patients newly diagnosed with cancer in the southern part of the Netherlands, an area with 2.3 million inhabitants, 17 hospital locations, and two large radiotherapy institutes. In May 2005, we drew a random sample of 390 patients diagnosed with breast (n=128), prostate (n=96), or gynecological (n=89) cancer or lymphoma (n=77) in four different hospitals in the period 2002–2004, who were 65 years or younger at diagnosis. To exclude all deceased patients, our sample was linked with the database of the Central Bureau for Genealogy, which collects data on all deceased Dutch citizens through the civil municipal registries. Hereafter, 120 breast cancer patients, 90 prostate cancer patients, 83 patients with a gynecological cancer, and 56 patients with a lymphoma were sent an information letter together with a questionnaire by their oncologist. By replying, the patients explicitly agreed to participate and consented to the linkage of the filled questionnaire with their disease history as registered in the ECR. Returned questionnaires only contained a study number which guaranteed anonymity.

Measures

The ECR routinely collects data on tumor characteristics like date of diagnosis, subsite, histology, stage (Tumor–Node–Metastasis clinical classification), primary treatment, and patient characteristics including gender and date of birth. An indicator of socioeconomic status was developed by Statistics Netherlands based on individual fiscal data from the year 2000 on the economic value of the home and household income, and provided at aggregated level for each postal code (average of 17 households) [11]. Socioeconomic status was categorized according to tertiles ranging from 1 (low) to 3 (high).

There was no validated Dutch questionnaire available about internet use by cancer patients. We therefore developed a new questionnaire based on a literature study and four broad application areas as defined by Eysenbach [12]: content (information), communication (e-mail, instant messaging), community (chatrooms, mailing lists, bulletin board), and e-commerce (selling or buying products and services on the internet). As the latter application was not (yet) broadly available, we did not ask about patients' use of this application but their wishes in relation to e-commerce. In addition, we asked patients about other sources of information used, effect of Internet on health care use, and patients' wishes related to future internet use. We generated a list of 60 items that were then reviewed by an expert panel of three researchers and six cancer survivors. These reviewers examined the list for redundant or incomprehensible items and evaluated the content of the items according to the defined applications. This resulted in combinations of some items and elimination of others and reduced the final questionnaire to 45 questions about demographics and internet use.

Statistical analyses

All statistical analyses were performed using SAS (version 9.1 for Windows, SAS Institute, Cary NC, USA). Routinely collected data from the ECR on patient and tumor characteristics enabled us to compare nonrespondents with respondents using chi-square statistics or Fisher's exact test for categorical variables and t test for continuous variables. These tests were also used to compare other subgroups as presented in the tables. Multivariate logistic regression analyses were carried out in order to investigate the independent association between patient characteristics (age, comorbidity, marital status, education, and occupation) and tumor characteristics (stage, grade, treatment, time since diagnosis) with the use of internet (outcome). Variables that showed a statistically significant (p<0.05) univariate association with internet use were included in the multivariate model.

Results

Of the 349 cancer patients who were sent a questionnaire, 261 (75%) responded. There were no differences between respondents and nonrespondents when comparing gender, type of cancer, or age (Table 1). However, nonrespondents were more often classified into the lowest socio-economic class than respondents (34% vs. 19%, p=0.02). Of the 261 returned questionnaires, 7 patients did not complete the questions on the use of Internet, leaving information of 254 patients to be analyzed. Of these, 153 (60%) used Internet by themselves, 23 by others (9%) and 78 (31%) did not use the Internet (Table 2).

Men were more likely to use the Internet by themselves, compared to women, of whom a higher percentage had access via another or no access. No access or access via another was also higher among the elderly (60–69), women with breast cancer, participants with a lower education, those who had no work or were retired, and those with a low socio-economic status.

Multivariate logistic regression analyses revealed that education was most strongly associated with internet use (Table 3). Adjusted for the influence of gender, age, tumor, work situation, Socio-economic status SES and having children, survivors with a college/university degree had a 26 times higher chance of using Internet compared to those with primary school. Young age (<50 years vs. 60–69, OR=14.5) and high SES (vs. low, OR=5.7) were also both independently associated with internet use.

Table 1 Demographic and clinical characteristics of respondents and non-respondents

	Respondents (n=261)		Non-respondents (n=88)		p value
	n	%	n	%	
Gender, male	92	35	31	35	0.84
Age at time of survey, mean	56.7		55.7		0.41
<50 year	55	21	20	23	
50–59 year	86	33	32	36	
60–69 year	120	46	36	41	0.71
Months since diagnosis, mean	26.3		26.0		0.77
10–18 months	48	18	24	27	
19–24 months	69	26	19	22	
25–30 months	49	19	12	14	
31–42 months	95	36	33	38	0.25
Tumor					
Breast	93	36	27	31	
Prostate	68	26	22	25	
Gynecological[a]	57	22	26	30	
Lymphoma	43	16	13	15	0.52
Socio-economic status[b]					
Low	48	19	30	34	
Medium	115	45	28	32	
High	87	34	26	30	
Instituted	8	3	3	3	0.02

[a] Cancer of the uterus, cervix, ovary

[b] Missing data for four patients

According to the four broad application areas of Internet [12], cancer survivors with internet access most often used the Internet for its content, e.g., to find information about their health in general (71%) or cancer (84%) more specifically. Although half of all patients with internet access e-mailed with friends or family, only 2% had e-mail contact with their primary-care physician, and 8% reported e-mail contact with their cancer oncologist. Six percent of internet users had contact with patient support groups through the Internet. As sourcing for information was the most important application used by internet users, this paper focuses further on this application.

When asking patients about the importance of different sources of information about cancer, the medical oncologist was most frequently (91% of all respondents) reported as the most important source of information, followed by the oncology nurse (70%), family (68%) and friends (64%; data not shown). Compared to patients who used the Internet, patients who did not more often reported the general practitioner (71 vs. 58%, p=0.07) and pharmacist (35 vs. 13%, p=0.0006) to be an important source of information. Internet was reported to be an important source of information about cancer by 57% of internet users.

Of all internet users (n=153), 84% had ever searched the Internet for information about cancer. During pre-diagnosis, when a patient had complaints and/or was waiting for test results from the hospital, 41% of the patients searched the Internet for information about cancer daily to several times a week, whereas 44% never did (Fig. 1). Right after diagnosis, the proportion of patients who searched the Internet daily to several times a week for information about cancer increased to 71%, whereas those who never searched the Internet decreased to 12%. During treatment, 56% of patients searched the Internet daily to several times a week. After treatment, in the follow-up phase, 4% searched the Internet daily to several times a week, 71% searched the Internet several times a month or year, and 26% did not search the Internet at all for information about cancer.

Patients who had access to the Internet by themselves most often searched for information about the type of cancer, treatment, and the consequences of treatment in general (Table 4). Less often searched was information about trials, alternative medicine, patient support groups, health insurance, or genetics. Only 12% of the patients used the Internet to source for a good oncologist or the 'best' hospital.

In an open question, we asked patients which Web sites (if available) they preferred to get reliable information about cancer. Patients' preferences were the Web sites of their

Table 2 Patient characteristics by internet use

	Internet use; $n=254$[a]			*p* value
	Access by self; $n=153$ *n* (%)	Access by other[b]; $n=23$ *n* (%)	No access; $n=78$ *n* (%)	
Gender				
Female	85 (56)	21 (91)	56 (72)	
Male	68 (44)	2 (9)	22 (28)	0.0008
Age at time of survey				
<50 year	44 (29)	3 (13)	7 (9)	
50–59 year	55 (36)	6 (26)	24 (31)	
60–69 year	54 (35)	14 (61)	47 (60)	0.0006
Tumor				
Breast	45 (29)	13 (57)	34 (44)	
Prostate	46 (30)	2 (9)	19 (24)	
Gynecological[c]	30 (20)	7 (30)	16 (20)	
Lymphoma	32 (21)	1 (4)	9 (12)	0.017
Months since diagnosis				
10–18 months	28 (18)	5 (22)	13 (17)	
19–24 months	41 (27)	6 (26)	20 (26)	
25–30 months	31 (20)	6 (26)	11 (14)	
31–42 months	53 (35)	6 (26)	34 (44)	0.69
Education				
Primary school	20 (13)	13 (57)	43 (55)	
Secondary school	68 (44)	8 (35)	30 (38)	
College/University	65 (43)	2 (9)	5 (6)	<0.0001
Work situation				
Work	60 (39)	4 (17)	15 (19)	
Ill (insurance)	22 (14)	-	13 (17)	
Student/other	6 (4)	-	4 (5)	
No work/retired	65 (42)	19 (83)	46 (59)	0.0021
Socio-economic status[d]				
Low	20 (13)	2 (9)	23 (32)	
Medium	62 (42)	13 (59)	37 (51)	
High	67 (45)	7 (32)	12 (17)	<0.0001
Marital status				
Married/living together	123 (80)	22 (96)	65 (83)	
Partner, not living together	8 (5)	-	2 (3)	
No partner	22 (14)	1 (4)	11 (14)	0.40
Children[e]				
No	36 (24)	1 (4)	12 (16)	
Yes, living with	40 (26)	6 (26)	13 (17)	
Yes, living somewhere else	77 (50)	16 (70)	52 (67)	0.04

[a] Seven patients did not complete this question

[b] Access by others: 67% partner, 24% children, 7% other family members, 2% friends

[c] Cancer of the uterus, cervix, ovary

[d] Eleven patients in elderly home, SES not known

[e] Missing for one patient

oncologist (88%), hospital (70%), or Dutch Cancer Society (76%). Least preferable were Web sites from alternative caregivers (8%), pharmaceutical industry (15%), or scientific journals (29%). However, when we asked patients which specific Web sites they visited for cancer information, Web sites that are completely financed and created by pharmaceutical industries were most often mentioned.

Patients who used the Internet to find information about cancer felt themselves to be better informed (72%) about their disease, whereas 15% reported having more questions after searching the Web. The majority of internet users (83%) did not think that consulting the Internet increased the frequency of visiting their doctor; only 3% thought so. On the frequency of patients discussing information found on the Internet with their doctors during consultation, only 5% of patients always do so, 13% most of the time, 41% sometimes, and 41% never. Of all internet users, 20% felt that information from the Internet influenced the treatment decision made by their doctor.

We asked patients about their wishes in the use of Internet, using examples that are technically possible but not (yet) implemented in health care (Table 5). Most patients who use the Internet would like access to their own medical file (79%) or test results (81%), if possible. To

Table 3 Multivariate logistic regression analyses with internet access by self vs. no internet access by self

	Odds ratio (CI 95%)
Gender	
Female	1
Male	5.2 (0.8–35.2)
Age at time of survey	
<50 year	14.5 (3.5–59.7)
50–59 year	5.5 (2.1–14.9)
60–69 year	1
Tumor	
Breast	1
Prostate	1.1 (0.1–9.5)
Gynecological[a]	2.8 (1.0–7.5)
Lymphoma	2.5 (0.7–9.9)
Education	
Primary school	1
Secondary school	4.2 (1.9–9.2)
College/University	26.9 (8.6–84.1)
Work situation	
Work	1.0 (0.4–2.6)
Ill (insurance)	1.6 (0.5–4.6)
Student/other	0.8 (0.1–7.0)
No work/retired	1
Socio-economic status	
Low	1
Medium	3.0 (1.1–8.0)
High	5.7 (1.8–18.1)
Children	
No	1
Yes, living with	0.5 (0.2–1.7)
Yes, living somewhere else	0.7 (0.3–1.8)

CI Confidence interval

[a] Cancer of the uterus, cervix, ovary

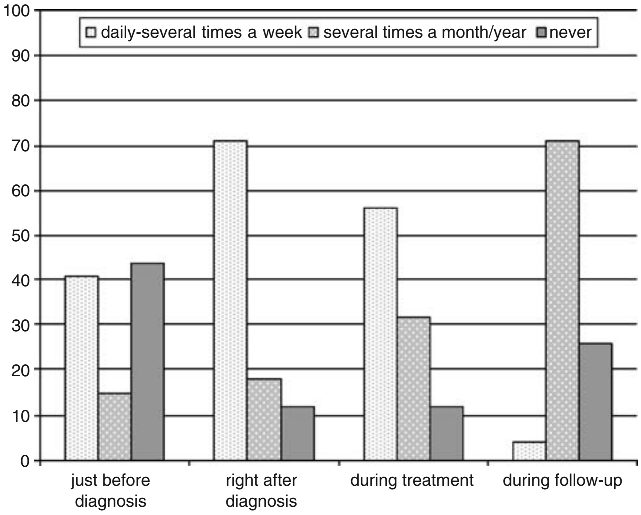

Fig. 1 Search frequency for information about cancer on the Internet during different phases of disease (n=153)

Table 4 Information that was searched for on the Internet among those who had access to Internet by self (n=153)

Information searched for	n=153 (%)
Cancer and treatment	
Type of cancer	96
Treatment	93
Treatment guidelines	59
Trials/research	31
Alternative medicine	29
Doctor and hospital	
Where to find a good oncologist	12
Which hospital is best	12
Cancer support	
Cancer support groups	37
Patient activities in region	20
Consequences of cancer and treatment	
Consequences of treatment in general	90
Consequences for sexuality	51
Fatigue	49
Consequences for future parenthood	13
Health care insurance coverage	21
Financial consequences	9
Other	
Cancer and genetics/heritability	48
End of life	13
What I can do myself	57

request prescriptions or make appointments were also mentioned frequently.

Table 5 Patients' opinions about possible future possibilities of using the Internet to

Would be interested to	Yes (%)	Neutral (%)	No (%)
Medical information			
Access to own medical file	79	9	12
Access to own test results	81	6	13
Request prescriptions	67	15	18
Request tests	42	30	28
Request referral	41	27	32
Contact with doctor			
e-mail with oncologist	50	23	27
e-mail with nurses	30	32	38
Make an appointment	68	14	18
Other			
Report complaints	55	21	24
Chat with other survivors	19	20	61
Suggest ideas	47	34	19
Do tests—self diagnosis	31	24	45

Discussion

In this well-defined sample of 261 cancer survivors, 60% had access to Internet by themselves, 9% via others, and

31% did not use the Internet. Young, educated cancer patients were the most frequent internet users. Finding information about cancer (84%) was the most reported internet application. Although 50% of patients had e-mail contact with friends and family, only 2% e-mailed with their primary-care physician, 8% with their cancer oncologist, and 6% with patient support groups.

Young age and education have been reported consistently to be highly associated with internet use [2, 6–8, 13, 14].

Results from a National US Survey of 4764 individuals who all had internet access showed that 40% of respondents reported using the Internet for information about health care, and 6% used e-mail to communicate with a health care professional [8]. In our study, among those with internet access, almost all searched the Internet for information about cancer and its treatment. Only 8% of our study population e-mailed with their oncologist, whereas 50% would like to have e-mail contact. It is unclear whether the patient or the oncologist or perhaps both feel those barriers are to e-mail with each other. In a qualitative study among 175 cancer survivors, the Internet was used for a wide range of information and support needs at many different stages of their illness [15], whereas we found that searching for information was the most important application during the period in which they were diagnosed and treated for cancer.

Our patients preferred to get their information from reliable sites, such as Web sites of hospitals and oncologists, although in the Netherlands such sites do not often provide sufficient information on cancer and its treatment. The Dutch Cancer Society was also evaluated as reliable and frequently mentioned as a source of information. Interesting however is that when we qualitatively asked patients about the Web sites they have visited for cancer information, Web sites that are completely financed and created by pharmaceutical industries were mentioned most often. It has been reported in other studies that health seekers do not consistently check the source and date of health information they find online [7, 16].

In a study among American oncologists' view of internet use by cancer patients, 75% of oncologists reported that the Internet increased patients' understanding of their disease but also that it increased patients' level of confusion and anxiety. They estimated that only one third of the patients bring internet information for discussion during consultation [3], whereas in an Australian study, more than half of information searchers discussed the information with a health care professional [5]. We found that 72% of the patients felt to be better informed using the Internet, and that only a minority had more questions after searching the web. Indeed only 18% discuss internet information always to most of the time, whereas 41% never do. Although we also believe that discussing internet information should be viewed as an opportunity to strengthen the relationship between a patient and a doctor [3], patients search the Internet for a broad range of information about cancer, treatment, and implications. Not all this information needs to be discussed with the oncologist.

In a sample of over 3,000 Americans, the effect of taking information to the physician on the physician–patient relationship was likely to be positive as long as the physician had adequate communication skills and did not appear challenged by the patient bringing in information [17]. In our study, the medical oncologist was reported as the most important source of information, whereas Internet was only cited after other health care providers, family, and friends, in contrast to other studies in which Internet had a more important role as source of information [18].

Many of our patients (79%) were interested in having access to their own electronic medical record in the near future. This has been discussed by Viswanath as a way to incorporate the ability for patients to interact with their health-care team, provide cancer-related health information, prepare patients for their visits to their doctors, and cut down medical and information errors [19].

The present study has a few limitations. Although the response rate was high, we do not know the frequency of internet use of the non-respondents. The characteristics of the non-respondents appeared to be fairly similar to the respondents with regard to age, time since diagnosis, and type of cancer, although the non-respondents had a lower SES. Since SES and internet use were correlated, it is likely that we overestimated the use of Internet for the whole population of cancer survivors. However, an underestimation of internet use could also occur as we included more women than men in our sample. Also, as the proportion of persons with access to Internet is rapidly increasing and this survey was completed in 2005, it is likely that current internet use by cancer patients in our geographic area exceed our reported 60%.

In conclusion, many cancer patients use the Internet to find reliable information about their disease and treatment. It is therefore important that health care providers acknowledge the role of Internet in the contact with their patients and use their own Web sites to provide comprehensive information about cancer and treatment. We believe that patient information centers from hospitals should be strongly encouraged to improve disease and treatment information facilities on their hospital Web site, especially since most patients view their oncologist still as the most important source of information.

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