Cancer-Related Internet Use and Online Social Networking Among Patients in an Early-Phase Clinical Trials Clinic at a Comprehensive Cancer Center

abstract

Purpose We examined patterns, correlates, and the impact of cancer-related Internet use among patients with advanced cancer in a phase I clinical trials clinic for molecularly targeted oncologic agents.

Methods An anonymous questionnaire on Internet use for cancer-related purposes that incorporated input from phase I clinical trial oncologists and patients was self-administered by patients age ≥ 18 years in a phase I clinic. Multivariable modeling was used. Data were analyzed for the overall sample and by generation, which was defined by year of birth.

Results Of 291 patients (52% women, 82% non-Hispanic white, 50% age ≤ 60 years), 62% were cancer-related Internet users (CIUs). Cancer-related Internet use was associated with an income of $\geq \$60,000$ (odds ratio, 2.42; $P = .004$). CIUs used the Internet to learn about their cancer (85%), treatment adverse effects (65%), clinical trials (52%), new alternative treatments (42%), and symptom management (41%). CIUs most frequently used the hospital Web site (70%) to learn about clinical trials, followed by ClinicalTrials.gov (42%) and search engines (41%). The emotional impact of Internet-derived cancer information on CIUs varied—56% felt empowered, 34% anxious, 29% relieved, and 17% confused. Cancer-related Internet information made 51% of patients from the Millennial (born after 1990) and Generation X/Y (born 1965 to 1990) CIU populations anxious compared with $< 29\%$ of CIUs from older generations (born 1964 and before). Most CIUs desired more online information about new experimental drugs (91%) and US Food and Drug Administration–approved drugs for cancer (72%).

Conclusion As most phase I patients use the Internet for cancer-related purposes, the Internet overall and hospital Web sites should provide more extensive, pertinent, and helpful information on clinical trials and cancer treatment to phase I patients.

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INTRODUCTION

Given the constantly increasing amount of medical and cancer-related information on the Internet,¹ patients with cancer can easily access a plethora of online resources for a variety of cancer-related purposes.²⁻⁴ Patients can also form online connections through chat rooms and online communities of persons in similar situations⁵ and express their views through blogs.^{6,7}

Internet use by patients with newly diagnosed cancer and patients with specific types of cancer has been examined.^{2,8,9} For example, a study in a sizeable sample of general adult patients with cancer at a comprehensive cancer center found that 63% of patients searched the Internet for

information about cancer. Use of the Internet for cancer purposes was associated with younger age and higher education in univariable analyses.⁹ Other studies have found Internet use to be associated with higher income¹⁰ and superior understanding of clinical trials.¹¹ In addition, patients with early and intermediate stages of cancer have found the Internet to be a useful source of information about specific cancers.¹²

However, limited data exist on the use of the Internet for cancer-related purposes and online social networking patterns of patients with advanced cancer in phase I clinical trials clinics. Participants in phase I oncology trials tend to have advanced cancer that has not responded

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to multiple previous therapies, and they may have a relatively poor prognosis. Given the complexities of early-phase clinical trials,^{13,14} factors that influence clinical trial participation,¹⁵ and the advanced nature of their cancer, patients in phase I oncology trial clinics need accurate information as they consider enrollment or continued treatment on trials. The Internet can be a valuable source of such information. Understanding how patients with advanced cancer use online cancer-related information can help phase I oncologists and other health care providers guide patients to useful Internet-based information and influence the design of online resources for patients who are considering clinical trials.

Our goal was to examine the patterns, purposes, and correlates of cancer-related Internet use among patients with advanced cancer in a phase I clinic. The current study of Internet use patterns in phase I clinic patients also provides valuable baseline information for a major initiative of the National Cancer Institute (NCI) Cancer Moonshot, which is to make information on cancer clinical trials more accessible to patients.

METHODS

Setting

We recruited a convenience sample of patients from the Clinical Center for Targeted Therapy—the phase I clinic—at The University of Texas MD Anderson Cancer Center. This clinic provides treatment that is targeted to the molecular characteristics of patients' tumors, and is one of the largest phase I clinical trial programs in the world. Most phase I clinic patients have advanced solid tumors or lymphomas, and are either self-referred or referred by their primary oncologist.

Study Design

Patients completed an anonymous, paper-based questionnaire while waiting for their scheduled clinical appointments. The names of patients who were handed a survey were noted so that the same patient would not be asked to complete the survey a second time. Patients completed the survey by themselves, and research staff did not read questions to the patient. To ensure anonymity, patients were asked to not reveal their names on the questionnaire and to

deposit completed questionnaires into a nearby locked box.

Study Population

Eligibility criteria included being a phase I clinic patient with advanced cancer, able to read and understand English, and at least age 18 years. Patients who were not able to complete a printed questionnaire—for example, as a result of severe visual or cognitive impairment—were excluded. The study was approved by our institutional review board, and all participants provided written informed consent.

Questionnaire

The questionnaire was developed on the basis of our experience¹⁶⁻¹⁹ and literature relating to Internet use and social networking in patients with cancer.^{9,20-22} A draft of the survey instrument was provided to phase I clinic physician-oncologists for suggestions and comments. Their suggestions were incorporated, and the revised survey was pilot tested in 18 phase I clinic patients. On the basis of feedback obtained from these patients during pilot testing, the survey was further revised to improve clarity before being distributed to the final study sample. The 18 patients from the pilot test were not included in analyses reported herein.

The questionnaire asked patients, “Do you access the Internet for cancer-related purposes (for example, for cancer- or clinical trial-related information or for emotional or social support for your cancer)?” Participants were also queried on patterns and purposes of Internet use, demographic characteristics, diagnoses, and online social networking patterns. Understanding of cancer and phase I clinical trials; satisfaction with current cancer treatment; trust in referring physician; and patients' experiences of symptoms, such as fatigue and depressed or anxious feelings, were assessed using 6-point Likert scales that ranged from 0 (none) to 5 (highest/maximum).

Statistical Analysis

Statistical analyses were performed using Statistical Package for the Social Sciences for Windows version 23 (SPSS, Chicago, IL). Univariable associations between Internet use for cancer-related purposes and specific patient characteristics were examined using simple logistic

regression. Multivariable associations between Internet use and patients' characteristics were analyzed using multiple logistic regression.

We tabulated and charted percentages that represented patterns and purposes of Internet use for cancer-related purposes. As Internet use patterns may vary by age and generation, data were analyzed for the overall sample and by generation, defined by year of birth, as follows: Millennials (born after 1990) and Generation X/Y (born 1965 to 1990), grouped as Millennials/Generation X/Y; Baby Boomers (born 1946 to 1964); and the Greatest/Silent Generation (1945 and before). χ^2 tests were used to explore whether there were significant differences across the generation and age groupings for questionnaire items.

RESULTS

Participant Characteristics

A convenience sample of 291 phase I clinic patients completed the survey; 52% were women, 82% were non-Hispanic white, 50% were age ≤ 60 years, and 66% self-reported a primary diagnosis of colorectal, lung, gynecologic, head and neck, or breast cancer, or melanoma (Fig 1 and Table 1). The survey was administered from December 2011 to April 2013.

Patterns of Cancer-Related Internet Use and Online Social Networking

Overall, 62% of respondents reported that they accessed the Internet for cancer-related purposes (cancer-related Internet users [CIUs]).

Cancer-related Internet use was higher for Millennials and Generation X/Y patients (69%) and Baby Boomer patients (65%) than for the Greatest/Silent Generation patients (49%; $P < .024$). In the multivariable logistic regression model, cancer-related Internet use was associated with an annual income of $\geq \$60,000$ (Table 2).

Table 3 lists Internet use patterns among CIUs. CIUs used the Internet to learn about cancer, anticancer drugs, treatment, or clinical trials, or to check their clinic schedule; they used it to a much lesser degree for emotional support. Our hospital Web site was most frequently used to learn about cancer and clinical trials, followed by ClinicalTrials.gov and general purpose search engines—for example, Google, Yahoo, or Bing—that directed patients to other Web sites with relevant information. In addition, when asked about the time during cancer care when they first accessed information on cancer or clinical trials, CIUs responded as follows: immediately after initial diagnosis (58%), before coming to the phase I clinic (24.3%), after the first round of treatment (11.2%), during subsequent visits to the phase I clinic (4.1%), or before the initial diagnosis (2.4%).

Table 4 lists blogging and online social networking patterns among CIUs. Few CIUs (11%) wrote their own blog, but 28% accessed blogs that were written by other patients with cancer. Generation X/Y CIUs were more than twice as likely as Greatest/Silent Generation CIUs to belong to an online social networking community ($P < .006$). Facebook, by far, was the most popular online social networking community among CIUs. Characteristics that patients looked for in members of their online social networking community included being supportive and being known to the patient. The predominant reasons patients joined online social networking communities were to maintain contacts online with people they already knew (57%) and to exchange perspectives on their cancer experience (31%).

Impact of Cancer-Related Internet Use and Information

Substantial proportions of CIUs reported that they learned new information from the Internet about their cancer, adverse effects of treatment,

Fig 1. Patient distribution by use of the Internet for cancer-related purposes and by generation.

Table 1. Characteristics of Phase I Clinic Patients

Characteristic	No./Total No. (%)
Generation	
Millennials and Generation X/Y	71/291 (24.4)
Baby Boomers	137/291 (47.1)
Greatest/Silent Generation	83/291 (28.5)
Sex*	
Female	151/290 (52.1)
Male	139/290 (47.9)
Race*	
Non-Hispanic white	234/287 (81.5)
Other	53/287 (18.5)
Income*	
< \$60,000/y	111/253 (43.9)
≥ \$60,000/y	142/253 (56.1)
Education*	
High school or less	68/283 (24.0)
More than high school	215/283 (76.0)
Primary cancer type*	
Colorectal cancer	38/290 (13.1)
Lung cancer	36/290 (12.4)
Head and neck cancer	28/290 (9.7)
Breast cancer	27/290 (9.3)
Melanoma	26/290 (9.0)
Ovarian cancer	25/290 (8.6)
Sarcoma	15/290 (5.2)
Prostate cancer	13/290 (4.5)
Endometrial cancer	12/290 (4.1)
Pancreatic cancer	10/290 (3.4)
Other†	60/290 (20.7)
Questionnaire scale items, 0-5 Likert scale	Median (IQR)
Fatigue experienced in the past month (increasing severity)	3.0 (2.0)
Depressive or anxious feelings experienced in the past month (increasing frequency)	2.0 (2.0)
Understanding of cancer (increasing understanding of cancer)	4.0 (2.0)
Understanding of phase I clinical trials (increasing understanding)	4.0 (2.0)
Satisfaction with current cancer treatment (increasing satisfaction)	4.0 (2.0)
Trust of referring physician (increasing trust)	5.0 (1.0)

Abbreviation: IQR, interquartile range.

*Indicates that numbers do not sum to 291 as a result of some respondents not responding to that particular question.

†Other primary cancers included thyroid cancer (n = 8), cervical cancer (n = 7), hepatocellular cancer (n = 3), kidney cancer (n = 3), lymphoma (n = 3), brain cancer (n = 2), and other cancer types (n = 34).

clinical trials, new alternative cancer treatments, and symptom management (Fig 2A). Only slightly more than one half of CIUs reported that the Internet had made them aware of clinical trials. Millennials and Generation X/Y and Baby Boomers were more likely than Greatest/Silent Generation patients to indicate that the Internet

informed them about treatment adverse effects ($P = .037$) and symptom management ($P = .007$). The emotional impact of Internet information on CIUs varied—56% felt empowered, 34% anxious, and 29% relieved by information from the Internet (Fig 2B). Millennials and Generation X/Y patients (51%) were more than twice as

Table 2. Associations Between Patient Characteristics and Use of the Internet for Cancer-Related Purposes Among Phase I Clinic Patients

Characteristic	Univariable OR (95% CI)	Multivariable OR (95% CI)
Male (v female)	0.95 (0.59 to 1.53)	0.79 (0.42 to 1.46)
Non-Hispanic white (v other)	2.08 (1.14 to 3.79)*	1.96 (0.90 to 4.29)
Income of > \$60,000/y (v ≤ \$60,000/y)	3.23 (1.89 to 5.53)†	2.56 (1.34 to 4.92)*
More than a high school education (v high school or less)	2.38 (1.37 to 4.15)*	1.25 (0.60 to 2.60)
Generation (v Greatest/Silent Generation)		
Millennials and Generation X/Y patients	2.28 (1.18 to 4.42)‡	1.52 (0.63 to 3.71)
Baby Boomer patients	1.90 (1.18 to 4.42)‡	1.45 (0.67 to 3.14)
Primary cancer type, colorectal (v other primary cancer type)	0.66 (0.33 to 1.30)	0.58 (0.24 to 1.38)
Questionnaire scale item		
Fatigue§	1.03 (0.86 to 1.23)	1.13 (0.86 to 1.48)
Depressed or anxious feelings§	0.91 (0.77 to 1.09)	0.87 (0.67 to 1.12)
Better understanding of cancer§	1.30 (1.05 to 1.60)*	1.22 (0.90 to 1.65)
Better understanding of phase I trials§	1.17 (1.01 to 1.37)‡	1.11 (0.88 to 1.40)
Satisfaction with current cancer treatment§	1.05 (0.89 to 1.24)	0.99 (0.78 to 1.25)
Trust in referring physician	0.88 (0.67 to 1.16)	0.75 (0.50 to 1.12)

Abbreviation: OR, odds ratio (> 1 indicates a higher likelihood of reporting accessing the Internet for cancer-related purposes).

* $P < .01$.

† $P < .001$.

‡ $P < .05$.

§OR is for a 1-unit increase in the continuous variable.

||Trust in the referring physician was assessed because some patients may have come to the phase I clinic for a consultation or to prepare to enroll in a phase I trial, and thus may not yet have established a relationship with their phase I physician.

likely as the Greatest/Silent Generation patients (22%) to indicate that information from the Internet made them feel anxious. Most CIUs desired more online information about new experimental drugs (91%) and US Food and Drug Administration–approved drugs for cancer (72%; Fig 2C).

Preferences for Internet-Based and Telephonic Communication With the Hospital

For the entire sample, the telephone was the preferred mode of communication with the treating hospital in the case of a problem (81%), followed by e-mail via the hospital's patient portal (51%). More patients preferred to be informed of their medical appointments through e-mail from the treating hospital's patient portal (79%) than by telephone (57%). Even among the Greatest/Silent Generation, 75% of patients preferred to be informed of their medical appointments through e-mail from the hospital's patient portal.

DISCUSSION

To our knowledge, this study is the first analysis of cancer-related Internet use and online social

networking among patients with advanced cancer in a phase I clinical trials clinic. Most phase I clinic patients (62%) used the Internet for cancer-related purposes, with cancer-related Internet use being associated with higher income. Most CIUs used the Internet to gain information rather than for emotional support for their cancer. In addition, the hospital Web site was most frequently used by CIUs to search for cancer- and clinical trial–related information. Most CIUs reported that the Internet made them aware of information about their cancer and treatment adverse effects. Although most CIUs desired more online information about new experimental drugs for cancer, only 52% reported that the information on the Internet had made them aware of clinical trials.

Patterns of Cancer-Related Internet Use and Online Social Networking

The rate of Internet use for cancer-related purposes in our phase I clinic patients (62%) was similar to that reported by patients in a thoracic surgery clinic, including patients with cancer,² and by a cancer population at another comprehensive cancer center.⁹ Consistent with other

Table 3. Internet Use Patterns Among Phase I Clinic Patients Who Reported Accessing the Internet for Cancer-Related Purposes

	Overall Phase I Clinic Cancer- Related Internet User Patients (n = 179)	Millennials/ Generation X/Y Patients (n = 49)	Baby Boomer Patients (n = 89)	Greatest/Silent Generations Patients (n = 41)	
Questionnaire Item	Count/Total (%)	Count/Total (%)	Count/Total (%)	Count/Total (%)	P*
Why do you visit cancer-related information Web sites or social networks?					
To learn more about my cancer	154/179 (86.0)	41/49 (83.7)	77/89 (86.5)	36/41 (87.8)	.839
To gain information about anticancer drugs, treatment, or clinical trials	143/179 (79.9)	40/49 (81.6)	73/89 (82.0)	29/41 (70.7)	.301
To check my clinic schedule	133/179 (74.3)	37/49 (75.5)	69/89 (77.5)	27/41 (65.9)	.358
To find emotional or social support related to my cancer diagnosis	36/179 (20.1)	12/49 (24.5)	21/89 (23.6)	3/41 (7.3)	.066
What types of Web sites, blogs, and smart phone applications do you visit to learn about cancer?					
Hospital Web site	135/173 (78.0)	39/48 (81.3)	65/85 (76.5)	31/40 (77.5)	.826
Sites accessed via search engines (Google, Yahoo, Bing)	119/173 (68.8)	38/48 (79.2)	63/85 (74.1)	18/40 (45.0)	.005
American Cancer Society Web site	102/173 (59.0)	27/48 (56.3)	49/85 (57.6)	26/40 (65.0)	.772
National Cancer Institute Web site	78/173 (45.1)	19/48 (39.6)	38/85 (44.7)	21/40 (52.5)	.635
Social networking (eg, Facebook or Twitter)	15/173 (8.7)	10/48 (20.8)	3/85 (3.5)	2/40 (5.0)	.002
Smart phone application	5/173 (2.9)	4/48 (8.3)	0/85 (0.0)	1/40 (2.5)	.022
What types of Web sites, blogs, or smart phone applications did you visit to learn about clinical trials?					
Hospital Web site	100/143 (69.9)	24/37 (64.9)	52/76 (68.4)	24/30 (80.0)	.371
ClinicalTrials.gov	60/143 (42.0)	18/37 (48.6)	33/76 (43.4)	9/30 (30.0)	.285
Sites accessed via search engines (Google, Yahoo, Bing)	58/143 (40.6)	21/37 (56.8)	27/76 (35.5)	10/30 (33.3)	.065
Hospital patient portal	55/143 (38.5)	15/37 (40.5)	30/76 (39.5)	10/30 (33.3)	.805
National Cancer Institute Web site	48/143 (33.6)	11/37 (29.7)	24/76 (31.6)	13/30 (43.3)	.616
Social networking (eg, Facebook or Twitter)	4/143 (2.8)	3/37 (8.1)	0/76 (0.0)	1/30 (3.3)	.048
How has the amount of time you spend on the Internet changed since you were first diagnosed with cancer?					
Remained the same	74/174 (42.5)	20/47 (42.6)	35/88 (39.8)	19/39 (48.7)	.876
Increased	70/174 (40.2)	20/47 (42.6)	36/88 (40.9)	14/39 (35.9)	
Decreased	30/174 (17.2)	7/47 (14.9)	17/88 (19.3)	6/39 (15.4)	
How often do you check the Internet for new information about your disease?					
Weekly	75/176 (42.6)	20/49 (40.8)	42/87 (48.3)	13/40 (32.5)	.555
Monthly	70/176 (39.8)	20/49 (40.8)	33/87 (37.9)	17/40 (42.5)	
Daily	17/176 (9.7)	6/49 (12.2)	6/87 (6.9)	5/40 (12.5)	
How often do you access the Internet by smart phone or cell phone for cancer-related or clinical trial-related information?					

(Continued on following page)

Table 3. Internet Use Patterns Among Phase I Clinic Patients Who Reported Accessing the Internet for Cancer-Related Purposes (Continued)

Questionnaire Item	Overall Phase I Clinic Cancer- Related Internet User Patients (n = 179)	Millennials/ Generation X/Y Patients (n = 49)	Baby Boomer Patients (n = 89)	Greatest/Silent Generations Patients (n = 41)	P*
	Count/Total (%)	Count/Total (%)	Count/Total (%)	Count/Total (%)	
Never	76/179 (42.5)	16/49 (32.7)	43/89 (48.3)	17/41 (41.5)	.538
Sometimes	46/179 (25.7)	13/49 (26.5)	22/89 (24.7)	11/41 (26.8)	
Often	30/179 (16.8)	10/49 (20.4)	12/89 (13.5)	8/41 (19.5)	

*P values compare across generation and age groups for each questionnaire item.

reports,^{2,23,24} our findings indicate that phase I clinic patients with higher incomes (> \$60,000 per year) were more likely to use the Internet for cancer-related purposes than those with lower incomes. These associations parallel those from the Health Information National Trends Study (HINTS), which demonstrated that seeking cancer information—independent of the source—was associated with high income.¹⁰ The association of cancer-related Internet use with higher income is interesting in light of a reported link between higher income and higher rates of clinical trial participation.²⁵

In the current study, Internet use for cancer-related purposes was associated with better self-reported understanding of phase I clinical trials among patients in the univariable analysis, but not in the multivariable model. In contrast, Leiter et al¹¹ found that greater awareness of clinical trials was associated with Internet use in multivariable models using data from the HINTS survey. These somewhat divergent findings may be explained, in part, by the fact that the Leiter/HINTS sample reflected the general US population, whereas our study included patients with advanced cancer who were already being treated in a phase I clinic and thus had firsthand knowledge of and experience with phase I clinical trials.

The most frequently used Web site for information on cancer and clinical trials was the treating hospital's Web site. This result is similar to findings in patients who underwent thoracic cancer surgery and who reported being more likely to conduct research using their hospital's Web site than other Web sites.² Reliance on hospital Web sites illustrates the importance of ensuring that updated, understandable information that is pertinent to phase I trials is easily accessible

on the Web sites of hospitals that conduct such trials. Because patients are also likely to use general purpose search engines to find clinical trial-related information, investment in search engine optimization may benefit institutions that conduct clinical trials.

Rates of online social networking and blogging were low in our sample, especially for older-generation CIUs. Given the younger patients' greater familiarity with this kind of technology, the potential of online social networking as a means of information gathering and patient support is likely to increase. Inclusion of social support sources would be in line with calls to include patients' current social networks in the design and implementation of online community networks.^{26,27} Whereas online social networking services have been attempted for generalized populations of adolescent and young adult patients with cancer^{28,29} and for other specific cancer populations,³ creation of extensive online social networking services are yet to be attempted for patients in or who are considering phase I clinical trials. Such services may be particularly helpful to Millennials and Generation X/Y patients.

Impact of Cancer-Related Internet Use

Overall, CIUs in the current study reported that the Internet had a positive impact, with more CIUs reporting feeling empowered or relieved rather than anxious or confused by Internet information. Most CIUs reported informational gains from the Internet about cancer and treatment adverse effects, which is similar to previous studies.¹² Of interest, 65% of CIUs reported that the Internet had made them more aware of the adverse effects of treatment. Our findings are consistent with results from a qualitative study

Table 4. Blogging and Online Social Networking Patterns Among Phase I Clinic Patients Who Reported Accessing the Internet for Cancer-Related Purposes

Questionnaire Item	Overall Phase I Clinic Cancer- Related Internet User Patients (n = 179)	Millennials/ Generation X/Y Patients (n = 49)	Baby Boomer Patients (n = 89)	Greatest/Silent Generations Patients (n = 41)	P*
	Count/Total (%)	Count/Total (%)	Count/Total (%)	Count/Total (%)	
Do you write your own blog?					
No	131/147 (89.1)	41/47 (87.2)	66/75 (88.0)	24/25 (96.0)	.475
Yes	16/147 (10.9)	6/47 (12.8)	9/75 (12.0)	1/25 (4.0)	
Do you visit blogs of other patients with cancer?					
No	119/166 (71.7)	28/48 (58.3)	59/82 (72.0)	32/36 (88.9)	.009
Yes	47/166 (28.3)	20/48 (41.7)	23/82 (28.0)	4/36 (11.1)	
Do you belong to an online social networking community?					
No	96/174 (55.2)	18/48 (37.5)	49/87 (56.3)	29/39 (74.4)	.039
Yes	78/174 (44.8)	30/48 (62.5)	38/87 (43.7)	10/39 (25.6)	
Which online social networking community do you belong to?					
Facebook	71/78 (91.0)	29/30 (96.7)	32/38 (84.2)	10/10 (100.0)	.554
Caring Bridge	15/78 (19.2)	5/30 (16.7)	9/38 (23.7)	1/10 (10.0)	.851
Cancer Forum	14/78 (17.9)	1/30 (3.3)	12/38 (31.6)	1/10 (10.0)	.021
LinkedIn	11/78 (14.1)	4/30 (13.3)	6/38 (15.8)	1/10 (10.0)	.953
Twitter	4/78 (5.1)	4/30 (13.3)	0/38 (0.0)	0/10 (0.0)	.026
What characteristics do you look for in members of your online social networking community?					
They should support me	30/63 (47.6)	10/25 (40.0)	16/31 (51.6)	4/7 (57.1)	.374
Other (they should be family or close friends, I must know them, they should be positive and upbeat, they pray for me)	20/63 (31.7)	13/25 (52.0)	5/31 (16.1)	2/7 (28.6)	.042
They should have or have had cancer	19/63 (30.2)	3/25 (12.0)	16/31 (51.6)	0/7 (0.0)	.004
They should be empathetic/sympathetic	15/63 (23.8)	5/25 (20.0)	9/31 (29.0)	2/7 (28.6)	.354
Do you trust the members of your online community?					
Yes	65/71 (91.5)	21/27 (77.8)	35/35 (100)	9/9 (100)	.062
No	6/71 (8.5)	6/27 (22.2)	0/35 (0.0)	0/9 (0.0)	
Do you feel comfortable sharing your personal medical history with your online community?					
Yes	44/75 (58.7)	15/29 (51.7)	25/37 (67.6)	4/9 (44.4)	.314
No	31/75 (41.3)	14/29 (48.3)	12/37 (32.4)	5/9 (55.6)	

*P values compare across generation and age groups for each questionnaire item.

in patients with non–small-cell lung cancer who were referred for stereotactic ablative radiotherapy and who reported accessing the Internet for additional information about stereotactic ablative radiotherapy, including possible adverse effects of treatment.³⁰ The proportion of patients in our sample who gained information from the Internet about adverse effects was slightly higher than a related estimate in patients with varying stages

of gynecologic cancers who searched for information about the management of symptoms and treatment-related toxicity (59%).³¹

Strengths, Limitations, and Future Directions

That this is the first analysis, to our knowledge, of Internet use for cancer-related purposes and social networking among patients

Fig 2. Impact of Internet use among patients who accessed the Internet for cancer-related purposes. (A) Responses to “Do you think the information on the Internet made you aware of...?” (B) Responses to “Do you think the information on the internet made you feel...?” (C) Responses to “How else would you like the Internet to serve patients with cancer....? Providing more information on...” FDA, US Food and Drug Administration.

in an early-phase clinical trials clinic, as well as the large sample size, are strengths of the current study. In addition, the Internet survey

questionnaire that we used incorporated input from oncologists and patients from the phase I clinic. Study limitations include the following:

data on how many patients declined to participate were not collected; therefore, the response rate cannot be determined and participation bias cannot be ruled out, as it may be possible that respondents were particularly interested in the topic or more likely to be Internet users. In addition, only patients who chose to come to the phase I clinic at this institution were included. A future study might investigate responses to the same questions from phase I patients in a different practice setting—for example, private practice, a practice in the US Oncology Network, or a different geographical region. Given that technology is constantly evolving, future research should periodically re-examine Internet and social networking use to track evolution over time.

Conclusions and Recommendations for Clinical Practice

As most phase I clinical trial patients use the Internet for cancer-related purposes, leveraging the Internet to provide accurate and easy-to-use information to these patients, as well as to improve patient communication, should be a priority. More resources may be needed to ensure that hospital Web sites are updated with the latest available clinical trials and trial-related information for patients. More information on new experimental drugs for cancer should be available on the Internet.

Abel et al³² found wide variations in the quality of oncology clinical trial information available on the Internet. Some clinical trial–related Web sites were difficult to understand, had inadequate information about the risks and benefits of clinical trials, or provided little in the way of interactive interfaces that would allow patients to customize searches.³² As precision medicine has spurred the development of oncology drugs that are targeted to an individual's disease or genomic characteristics, interactive Web sites can help patients customize their searches—even by genetic information—and identify suitable clinical trials. Governmental and public health Web sites, such as those of the NCI and [ClinicalTrials.gov](https://www.clinicaltrials.gov), have significant information relating to clinical trials, but patients may not realize that these Web sites exist. During an initial phase I clinic visit, patients could be offered Internet guides that list accurate, up-to-date, searchable, and easy-to-navigate Web sites with information on clinical trials, cancer, cancer treatment, and prognosis.

Phase I physicians and other health care providers in the clinical trial setting should familiarize themselves with Internet resources that would be valuable to phase I patients so that they can guide patients to such Web sites. Continuing medical education for phase I oncologists and annual training lectures may include modules and sessions on the most useful Web sites and other technologic resources for patients.

Although our research focused on cancer care, Internet use is broadly applicable to other areas of health care, such as telemedicine,³³ online symptom checkers,³⁴ and personalized digital interventions for positive lifestyle changes—for example, reduced alcohol consumption³⁵ and weight management.³⁶ Innovative possibilities include the use of biometric sensors for the aged or infirm that automatically relay information to a computer center where artificial intelligence algorithms flag potential problems—for example, the detection of a change in night-time toilet habits could signal a possible urinary tract infection, which, in turn, might trigger alerts to a medical team for intervention.³⁷ In addition, digital transportation network companies, such as Lyft and Uber, have announced programs to provide transportation to Medicaid or Medicare enrollees who are in need of nonemergency medical care.³⁸ The wide-ranging applications of the Internet are surely bound to increasingly impact patients with cancer in the future.

For non-CIUs (38% of our sample), alternative education methods can be considered. For example, some patients may be more comfortable with one-on-one interaction with their health care providers during the clinic visit itself, and they would benefit from having more time to ask questions and receive information. Others may prefer to use the telephone, and they would make the best use of contact information for phone-based help lines, such as those of the NCI and the American Cancer Society, that are dedicated to answering questions relating to cancer and clinical trials. Future research could explore the use of voice-controlled personal digital assistants as an alternative approach for accessing clinical trial information on the Internet for patients who may be unfamiliar with browsing the Internet or who prefer the convenience of voice activation.

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