Published in final edited form as:

Contemp Clin Trials. 2010 May ; 31(3): 229–234. doi:10.1016/j.cct.2010.03.003.

Patient internet use surrounding cancer clinical trials: clinician perceptions and responses

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Abstract

Clinician perceptions of patient internet use related to clinical trials are not well documented. This exploratory study surveyed how cancer care providers at one NCI-designated cancer center viewed patient internet use surrounding cancer trials, including whether it affected patient decision making regarding trial enrollment. The sample included 20 oncologists (59%) and 14 (41%) nurses (n=34). Most clinicians (n=26; 76%) perceived the internet as having an effect on whether or not patients decided to enroll in a cancer trial. Two thirds (n=17; 65%) felt that this effect was positive, including in terms of enhancing patient knowledge of, access to, and enrollment in trials. Clinicians were asked if they ever discussed with their patients the topic of going online to find out more about cancer trials. Over half (n=18; 58%) who responded (n=31) to this item said yes; the rest (n=13; 42%) said no. The majority (n=10; 77%) in the “no” category were among those who reported that the internet had an effect on patient decision making. These data provisionally suggest that clinicians may see the internet as having mostly a positive effect on patient decision making about cancer trials, but that their communication efforts with patients do not always logically follow from this perception. Provider-patient discussion about internet use may be an opportunity for clinicians to contribute to improved patient knowledge of and enrollment in cancer trials. More research is needed to confirm and explain the gap between clinician perception and communication regarding trial-related internet use by cancer patients.

Keywords

internet; cancer trials; clinician perceptions

Introduction

Clinical trials have contributed to significant progress in the treatment of some cancers; yet, low enrollment rates continue to impede future progress [1,2]. In some cases, enrollment fractions into therapeutic non-surgical cancer trials are below 2 % [3]. The internet is one avenue that potentially can boost enrollment in clinical trials. Sixty-one percent of adult internet users seek health information from the internet [4], and as much as 47% of health seekers who go online report that their decisions about health care are directly affected by internet sources [5]. Cancer-related information is among the many types of health information that internet users seek [6,7]. Studies indicate that anywhere between 16–64%

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of cancer patients are using the internet to obtain health information [8] and that another 15–20% use the internet ‘indirectly’ through family and friends seeking cancer information on their behalf [9,10]. Recent evidence suggests that cancer patients are both willing to use the internet to search for clinical trials and are actively doing so [11,12]. Websites devoted to cancer clinical trials are proliferating, but researchers are only beginning to examine the internet’s potential for helping people understand and access clinical trials [13,14]. Online efforts to match individuals to particular clinical trials, including cancer trials, have also recently emerged [15,16]. Most data on these efforts are still focused on system and feasibility issues, yet early indications are that cancer patients are receptive to these matching tools, and that they may be more likely to enroll into a clinical trial if patient education and recruitment processes include online user interfaces, in addition to traditional brick-and-mortar interactions [11,17].

We conducted an initial exploratory survey to assess how cancer care providers view and respond to patient internet use related specifically to cancer clinical trials. Given the small amount of published data in this area, our goal was to examine clinician perceptions of how the internet affected patient decisions about clinical trial enrollment, whether patient decisions were affected positively and/or negatively, and whether clinicians interacted with their patients on the topic of clinical trial-related internet use. Clinician perceptions on the topic of patient internet use concerning clinical trials may be important to future efforts to improve patient knowledge about, access to, and participation in cancer clinical trials.

Material and Methods

Clinicians (oncologists, registered nurses, and nurse practitioners) in a Midwest NCI-designated cancer center were considered eligible for the study if they had participated in the care of any of the 120 cancer patients who were enrolled in the first phase of the research [10]. These patients were sampled by convenience over a 12-month period and included breast cancer, leukemia, and Non-Hodgkin’s lymphoma patients. Seventy-nine (66%) of these patients were women, 41 (34%) were men, and most (90%) were Caucasian. Eligible clinicians were identified through patient study records and a cancer center database linking patient to clinician names.

A survey was developed to complement the patient interviews that were conducted in the first phase of the research. To promote survey response the instrument was limited to 16 items, including demographics. Items included measures designed to elicit clinician perceptions of the potential effect of the internet on clinical trial enrollment. Clinicians were asked, “Do you think using the internet may affect whether or not a cancer patient will enroll in a clinical trial?” If clinicians answered yes, they were prompted to consider whether this effect was potentially negative, positive, or both negative and positive. Clinicians were prompted to qualitatively explain their answer. Clinicians were also asked, “Do you ever talk to patients about using the internet to find out more about cancer clinical trials?” and were given the option of responding either “yes,” “no,” or “not relevant to me.” Items were pilot tested on three clinicians who were excluded from future mailings. Clinicians were asked to complete the survey as well as comment on the comprehensibility of the survey questions (whether the questions made sense given the kind of clinical work they performed and whether in their opinion the survey needed to cover any additional issues).

With IRB approval, a package containing the finalized survey and a letter explaining the study was mailed to 32 eligible oncologists and 15 nurses. Clinicians who did not return the survey within one month were sent a second survey with a reminder letter. One month later, those who did not return the second survey were sent a third survey with another reminder letter. If those surveys were not returned, the clinicians were considered nonresponders and

were no longer contacted. A total of 35 (74% response rate) surveys were returned, including 21 (60%) from oncologists and 14 (40%) from nurses. One survey was omitted from analysis because it came from a clinician who reported very infrequent patient contact. Data were extracted from the 34 remaining surveys and entered into an SPSS 13.0 data file, where they were reviewed for completeness and accuracy, and then analyzed. Most responses were categorical and analyzed using basic descriptive statistics (percentages, proportions, and frequencies). While the final sample was too small ($n=34$) to allow for robust multivariate analysis, a few results were analyzed using chi-square and t-test statistics in an effort to identify areas potentially meriting future quantitative research. For example, we analyzed the data to see if there were any potentially significant (at the .05 level) trends in how MDs and nurses responded to certain survey items where professional status could play a role (results appear below). To indicate the precision of the estimates, 95% confidence intervals were computed for all responses; for continuous outcomes these are conventional *t*-statistic intervals, while for dichotomous responses exact confidence intervals based on the binomial distribution were computed using the FREQ procedure in SAS for Windows, Version 9.2 (Copyright (c) 2002–2008 by SAS Institute Inc., Cary, NC, USA). Since there are 30 confidence intervals, then we expect between one and two of them (more precisely, 1.5 is the expectation) to not include the true parameter.

Results

Background data

A total of 34 clinicians participated in the study, including 20 oncologists (59%) and 14 (41%) nurses (see Table 1). The majority ($n=23$; 68%) were female. The median year of graduation from medical school (or equivalent for nurses) was 1992 ($SD=9.48$ years). The average number of years in which clinicians were involved in the care of cancer patients was 11.5 years ($SD=7.74$ years). Most clinicians ($n=28$; 82%) were Caucasian, with two (6%) self-reporting as African-American, two (6%) as Asian or Asian-American, and one (3%) as Hispanic/Latino. One (3%) clinician did not disclose their ethnicity. Most clinicians in the sample worked with more than one type of cancer patient, including breast ($n=17$; 50%), lung ($n=11$; 32%), prostate ($n=11$; 32%), colorectal ($n=10$; 29%), leukemia ($n=10$; 29%), lymphoma ($n=12$; 35%), and other cancers ($n=14$; 41%).

General patient internet use and clinician response

Clinicians were asked to estimate the proportion of their patients who used the internet in some way related to their cancer. More ($n=15$; 44%) clinicians estimated that this proportion was in the 30–50% range when compared to any other range (see Table). Clinicians were also asked to estimate the proportion of patients with whom they discussed using the internet in some way related to their cancer. All but 4 (12%) clinicians responded that they discussed using the internet with some proportion of their patients (see Table). Clinicians were also asked to estimate the percentage of such internet-related discussions that were initiated by themselves and by their patients. The mean percentage of conversations initiated by clinicians was 38.5% ($SD=31.35\%$), and the mean percentage initiated by the patient was 62.74% ($SD=30.63\%$). Nurses' estimations of the percentage of conversations initiated by themselves ($M=53.64\%$, $SD=35.36\%$) was higher than physician estimations ($M=29.74\%$, $SD=25.85\%$; $t(28)=2.13$; $p=.042$).

Patient internet use and clinical trials

When asked if the internet affected whether or not their patients decided to enroll in a cancer clinical trial, 26 clinicians (76%) said yes, three (9%) said no, and five (15%) did not know. The majority ($n=17$; 65%) of clinicians who felt that the internet affected patient decisions to enroll also reported that this effect was likely to be positive. Clinicians offered various

explanations as to why patient decisions may be positively affected through online use, including that patients “see good trial results and therefore want to try the clinical trial”; that they can find information online on the “availability and location” of clinical trials; and that they can “address their fears and concerns” about clinical trials by going online. One clinician suggested that there may be a bias toward the decision to enroll in clinical trials among internet users because “patients that are searching the internet for clinical trials are interested already in participating in research.”

By contrast, a small proportion (n=4; 15%) of those clinicians who felt that patients’ decisions about clinical trials were affected by the internet also reported that this effect was negative. Explanations by these clinicians included the internet’s potential to mislead patients through erroneous or missing information about clinical trials, and that online terminology about clinical trials “may be scary.” A few (n=4; 15%) clinicians also anticipated that patient decisions might be positively as well as negatively affected by online usage by, for example, making it easier for them to obtain key information about clinical trials, while also contributing to anxiety about clinical research. Finally, one (4%) clinician reported not knowing what effect the internet potentially had on clinical trial enrollment.

Provider-patient discussion about internet

Clinicians were asked if they had ever talked to their patients about using the internet to find out more about cancer clinical trials. A total of 31 clinicians completed this item, with 18 (58%) responding yes and 13 (42%) responding no. No clinician responded that this question was not relevant to them. Among those who responded affirmatively, 14 (78%) also reported that the internet affected patient decisions about clinical trials, three (17%) said they did not know if there was an effect, and one (5%) said that the internet had no effect on patient decisions about clinical trials. Among the 13 clinicians who reported not ever talking to their patients about using the internet to find out about cancer clinical trials, 10 (77%) also said that the internet may affect patient decisions to enroll into clinical trials, two (15%) said they didn’t know, and one (8%) said there was no effect. Six of the 10 (60%) clinicians who said that they did not talk with patients about using the internet and who believed that the internet affected patient decisions about clinical trial enrollment were nurses, compared to 6 of 14 (43%) nurses who responded affirmatively to both these questions; however, this result was not statistically significant.

Discussion

General patient internet use and discussions of use

Research indicates that patient internet use can contribute positively to patients’ level of health care access, knowledge, and decision making [18]. Recent evidence suggests also that clinicians who are open to discussing internet use and internet-sourced information develop more supportive provider-patient relationships and contribute to more positive patient health outcomes [19,20].

The basic profile data from this exploratory study were relatively consistent with other published findings on patient internet use and provider-patient discussions of internet use. In our sample, the median for clinician estimates of how many of their patients used the internet in some way related to their cancer was in the 30–50% range. In a systematic survey of 591 U.S.-based oncologists, Helft et. al. [21] report a median of 30% for clinician estimates of the percentage of patients who use the internet for cancer-related purposes. In our study, 88% of clinicians reported that they talked with some proportion of their patients about using the internet. Helft et. al. [21] report a marginally higher median (96%) of oncologists who discuss online information that patients bring to them. Notably, both these

medians contrasted sharply with patient reports of whether or not they discussed internet use with their oncologists. Bylund et al. [20] reports, for example, that such discussions were recalled by only 28–48% of the cancer patients they surveyed. Similarly, in an earlier study that we conducted among cancer patients who were cared for by the same clinicians who participated in this study, less than one third of all patients who reported using the internet for cancer-related reasons also reported having had a conversation about their internet use with a member of their cancer care team [10]. One possible explanation for this discrepancy is that clinicians may have used patient-initiated discussions as the denominator for their estimates, because these were potentially more common than (or in some way qualitatively different from) internet-related discussions that were clinician initiated. Given growing evidence of the importance of provider-patient communication around the topic of patient internet use, future research may need to be more sensitive to this possible bias, for example, by developing and testing more nuanced and robust measures of clinician perceptions of provider-patient communication around internet use.

Perceptions and discussions of use related to clinical trials

The majority of cancer care providers in this study reported that patient internet use may also affect patient decisions concerning clinical trial enrollment. Almost two thirds perceived this effect to be positive. Clinicians who provided qualitative feedback indicated that, from their perspective, the positive and negative effects of the internet included, but were not limited to, the decision to enroll or refrain from enrolling in a clinical trial. For clinicians who saw the internet as having a positive effect on patients, this effect included the internet's capacity to increase patient knowledge and decrease fear of clinical trials. For clinicians who saw the internet as having a negative effect, this effect included the potential anxiety and confusion that internet use surrounding clinical trials might generate among patients. These findings are reflective of other recent data suggesting that cancer care providers have a relatively complex view of patient internet use in general, spanning informational, psychosocial, and clinical outcomes [21].

Yet, while clinicians may have entertained these relatively complex views, they did not discuss with all or even most of their patients the topic of going online to find out more about clinical trials. Furthermore, our data point to a possible subset of clinicians who saw the internet as having an effect on patient decision making about clinical trials, but who reported discussing internet use with only some or a few of their patients. It is unclear from our study why these clinicians might have opted not to discuss internet use surrounding clinical trials. Their reasons were potentially similar to those cited in other studies of patient internet use in general, which indicate that many health care providers refrained from broaching discussions of internet use for a variety of reasons, including the added time and effort such discussions were believed to take [22]. Another possible explanation is that provider-patient discussions of adult cancer clinical trials tend to be scripted according to informed consent regulations and documents, neither of which formally require any discussion about internet sources of clinical trial information or support.

Recent research has found that patients are more likely to think about enrolling in clinical trials and to use an Internet tool to locate a clinical trial if this process is introduced by their clinician [23]. Thus, clinicians who do not discuss internet use with patients who are eligible for cancer research may be missing a key opportunity to encourage patient consideration of the option to participate in such research. Clinicians should ask whether their communication efforts with patients reflect the reality that more and more patients use the internet for a wide range of reasons, including to inform themselves and make decisions about clinical trial participation. Clinicians should also be cautious about assuming that internet use affects patient decision making about clinical trials either positively, negatively, or not at all. Among others, a better approach may be to ask patients if they have used or

plan to use the internet in some way related to clinical trial participation, what they hope to accomplish with such use, and how they (the clinician) could be of help in this process.

Conclusion

This exploratory study focused on clinician perceptions of patient internet use concerning cancer clinical trials. A number of limitations affect the results of the study, including sample size and the possibility that the nature of the research site (an NCI-designated cancer center) reflects a clinician population more likely to be favorably disposed to clinical trials. Future research should be expanded to consider whether similar results are likely in clinician populations less likely to enroll patients in trials or who may not refer patients to clinical trials. Since clinicians in this study were asked to think about their internet-related discussions with patients in aggregate, the study was also not able to directly compare patient and clinician assessments of the occurrence, content, and implications of mutual discussions on the topic of the internet. Future research in this area would benefit from in vivo studies in which clinician-patient pairs were asked to assess the *same* communication process surrounding internet use for clinical trials (see for example Bylund et al 2007). Based on this study, further research is also needed in an effort to better understand the variability in clinician decisions to engage patients on the topic of internet use surrounding clinical trials.

A potentially important finding of the study is that clinicians evidently see the internet as having mostly a positive effect on patient decision making about cancer trials, but that clinicians' reporting communication efforts with patients do not always follow logically from this perception. With low clinical trial enrollment generally the norm in adult oncology, patient internet use related to clinical trials represents an opportunity for clinicians to meaningfully engage patients on the topic of possible research participation. Patients may be confused, anxious, or undecided about participation in a cancer clinical trial preceding or following their online efforts to find out more about cancer clinical trials, and discussions with their health care providers may help allay these reactions. Further research is needed to consider the potential benefits of having internet-use discussions with patients, including improved patient comprehension of treatment options, improved clinician understanding of patient preferences, and the potential to improve accrual rates to certain categories of clinical trials.

Acknowledgments

We thank Laura Shinkunas, Program Associate in the Bioethics and Humanities Program at the University of Iowa, for help in preparing and proofreading this manuscript. This study was conducted with the support of a National Cancer Institute (NCI/NIH) KO7 Career Development Award (CA108457).

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Table 1

Select demographic information for the entire sample

		N	%
Profession	Physician:	20	59
	(M.D., Ph.D.)	(3)	(15)
	(M.D.)	(15)	(75)
	(D.O.)	(1)	(5)
	(Degree not disclosed)	(1)	(5)
	Nurse:	14	41
	(Registered nurse)	(13)	(93)
	(Nurse practitioner)	(1)	(7)
Gender	Male	11	32
	Female	23	68
What year did you graduate from medical school?	Median	1992	
	SD	9.48 years	
How many years have you been involved in the care of adults with cancer?	Mean	11.5 years	
	SD	7.74 years	
Ethnicity	Caucasian	28	82
	African American	2	6
	Asian/Asian American	2	6
	Hispanic/Latino	1	3
	Ethnicity not disclosed	1	3

Table 2

Select frequencies for the entire sample. LCL and UCL denote upper and lower 95% confidence interval limits.

Question	Responses	N	%	LCL	UCL
What kinds of cancer patients do you normally work with?*	Breast	17	50.0	32.4	67.6
	Lung	11	32.4	17.4	50.5
	Prostate	11	32.4	17.4	50.5
	Colorectal	10	29.4	15.1	47.5
	Leukemia	10	29.4	15.1	47.5
Roughly what percentage of your cancer patients do you think use the Internet in some way related to their cancer?	Lymphoma	12	35.3	19.7	53.5
	Other	14	41.2	24.6	59.3
	0–10%	0	0	0.0	11.3
	10–20%	3	8.8	1.9	23.7
	20–30%	4	11.8	3.3	27.5
	30–50%	15	44.1	27.2	62.1
	50–75%	10	29.4	15.1	47.5
Do you have discussions about using the Internet with:	75–100%	2	5.9	0.7	19.7
	All of your patients	3	8.8	1.9	23.7
	About two-thirds	6	17.6	6.8	34.5
	About half	6	17.6	6.8	34.5
	About one-third	15	44.1	27.2	62.1
	None of them	4	11.8	3.3	27.5
Roughly what percentage of these Internet-related discussions are initiated:	By you?	Range	0–100		
		Mean	38.5	27.6	49.4
		SD	31.35		
	By the patient?	Range	10–100		
		Mean	62.74	52.1	73.4
Do you ever talk to patients about using the Internet to find out more about cancer clinical trials?		SD	30.63		
	Yes	18	58.0	39.1	75.5
	No	13	42.0	24.5	60.9
	Not relevant	0	0	0.0	11.2

Question	Responses	N	%	LCL	UCL
Do you think using the Internet may affect whether or not a cancer patient will enroll in a clinical trial?	Yes	26	76.5	58.8	89.3
	No	3	8.8	1.9	23.7
	Don't know	5	14.7	5.0	31.1
Do you think their decision is affected:	Positively	17	65.4	44.3	82.8
	Negatively	4	15.4	4.4	34.9
	Both	4	15.4	4.4	34.9
	Don't know	1	3.8	0.1	19.6

* Percentages reported for this item only were calculated using as the denominator the total sample size (n=34) and using as the numerator the number of clinicians who responded “yes” as to whether they worked with each type of cancer.