Exposure to and Intention to Discuss Cancer-Related Internet Information Among Patients With Breast Cancer

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Abstract

Purpose: Previous studies have reported a significant number of patients with breast cancer seek cancer-related information from the Internet. Most studies have asked whether a patient has ever read Internet information since her diagnosis. The purpose of this study was to assess the frequency with which patients with breast cancer come to physician appointments having recently read and intending to discuss cancer-related information from the Internet.

Patients and Methods: We asked 558 patients with breast cancer who were waiting to see their physicians about their experiences reading cancer-related information from the Internet and their intent to discuss the information in their current visit.

Results: Fifteen percent reported reading cancer-related Internet information in the past month. Patients who had read such information in the past month were younger, had been diagnosed more recently, and were more likely to be attending a new visit. Of those who had read in the past month, 45% reported intending to discuss what they had read with their physician. Nineteen percent of patients reported having ever read breast cancer–related Internet information since their diagnosis.

Conclusion: The proportion of patients with breast cancer planning to discuss Internet information during their current physician visit was relatively small. Few characteristics were associated with recent Internet use or intent to discuss.

Introduction

Patients with cancer often use the Internet to obtain information about their disease. Reports of Internet use by patients with heterogeneous cancer or caregivers vary from 29% to 60%.[1-5] Clinical oncologists estimate that approximately 30% of patients use the Internet to obtain information about their cancer.[6] Reported rates of Internet information seeking vary by cancer type.[4,7-11]

Use of the Internet by patients with cancer for health-related information has the potential to significantly influence physician-patient communication and relationships. The Internet provides patients access to information that was previously either unavailable or difficult to access, thus leveling the power imbalance in the physician-patient relationship.[12,13] Oncologists vary in their reactions to these discussions. Some have negative reactions, including reporting having difficulty with these discussions,[6] believing Internet information can lead to unnecessary discussions that may result in conflict,[14] and finding that these discussions prolong consultations.[6] Others report positive occurrences from a discussion about information the patient read on the Internet, including learning about appropriate clinical trials and a strengthened physician-patient relationship.[6]

Several studies have aimed to characterize Internet use specifically among patients with breast cancer. These studies provide estimates between 42% and 68% of patients with breast cancer in the United States and Canada who have used the Internet to obtain information about their breast cancer treatment.[5,15-17] Studies outside the United States and Canada report lower estimates of the proportion of patients with breast cancer using the Internet.[10,18]

In these studies of patients with breast cancer, those patients who used the Internet for reasons related to their cancer were more likely to have a higher educational level,[5,10,15-17] to have a higher income,[5] to be younger,[5,10,16,17] and to be white, compared with those who did not.[5] Furthermore, neither time since diagnosis[5] nor cancer stage[5,17] was associated with Internet use.

One limitation of these and other studies assessing the proportion of patients with cancer who have used the Internet to seek cancer information is that they generally measure a broad time frame. Investigators typically ask patients if they have ever searched out Internet information on their cancer, with little to no attention paid to how often or when they searched for that information or how frequently they discussed it with their physicians. As a result, the frequency with which patients come to physician visits having recently read and planning to discuss Internet information is unclear. The distinction between patients with cancer having ever sought out cancer-related information on the Internet and patients with cancer having recently read such information is important as we try to better understand how the Internet affects patient experience. Thus, using the physician consultation as a point of time to study may provide a better approach to assess the frequency with which patients come to their physicians having recently read information on the Internet about their cancer and intending to discuss that information with their physicians.

Given current health care policy, now is a particularly important time to better understand patient experiences with the Internet as a source of health information. The Health Information Technology for Economic and Clinical Health Act, passed in conjunction with the American Recovery and Reinvestment Act of 2009, provides incentives for clinicians and hospitals to adopt certain uses of electronic health records.[19] One of these incentives is for providers and hospitals to use the electronic health record as a means to identify patient-specific education resources and provide those to the patient.[19] It seems quite likely that such resources could be provided electronically and would include online health resources. Additionally, use of online personal health records will likely increase,[20] boosting the integration of the Internet into the physician-patient relationship.

As part of a larger project studying Internet use and physician-patient communication, the primary goal of this study was to examine the incidence of patients with breast cancer coming to a physician's office having read Internet information within the past month and intending to discuss it. The secondary goal was to assess the prevalence among patients with breast cancer of ever reading Internet information about their cancer.

Patients and Methods

Participants

Patients (N = 576) were approached by a research study assistant in the waiting room of the breast medical oncology and surgery clinics at Memorial Sloan-Kettering Cancer Center over a 19-month period of time (July 2008 to January 2010). Patients who are seen in Memorial Sloan-Kettering Cancer Center Breast Service are predominantly white (83%); 9% are African American, and 7% are Asian. Patients who were approached had met the prescreening criteria of having a breast cancer diagnosis, being female, and being age 21 years or older. Of these, 18 did not speak English; thus, 558 patients were screened for the study using the process described in this article.

Fifteen physicians participated in the study: nine medical oncologists and six breast surgeons. The research study assistant accessed through an internal database the names of patients of a specific physician who consented to the study on the days that he was assigned to that particular physician's clinic and approached each patient who met the eligibility criteria. Physicians and patients provided informed consent to the study, which was approved by the institutional review board.

Data Collection

Screening was completed during two recruitment phases (Appendix Fig A1, online only). In phase one, 299 eligible patients were screened. Each eligible patient was asked, "In the past month, have you read information on the Internet related to your breast cancer?" On the basis of the clinical expertise of the research team, we chose the time frame of the last month as part of the screening process, reasoning that a longer time period would increase the chance that if the patient had wanted to discuss the Internet information, she would have already done so. Patients who had read within the past month were invited to consent to the study. After consenting to the study (consent rate, 54%), these patients filled out a questionnaire, in which they were asked if they intended to talk with the physician that day about any of the information they had read in the past month about their breast cancer.

In phase two, the research team broadened the study by first screening patients with a question, asking them if they had ever read cancer-related information on the Internet since their breast cancer diagnosis, and then proceeding with the screening process as defined for phase one. This process allowed us to compare our sample with previous research that used the "ever read" approach. In this phase, 259 eligible patients were screened. Each was asked, "Have you read information on the Internet related to your breast cancer since your diagnosis?" If the patient responded affirmatively, she was then asked a follow-up screening question: "When was the last time you read Internet information about your breast cancer?" Those who reported reading in the past month were consented (consent rate, 69%) and asked in the survey if they planned to talk with their physician about Internet information that day. In the remainder of this article, we refer to patients in either phase who had read cancer-related Internet information in the past month as recent Internet users (RIUs) and patients in phase two who had read cancer-related information on their diagnosis as ever Internet users (EIUs).

A member of the research team conducted medical record reviews of all patients approached, regardless of whether the patient was accrued to the study. Information gathered from each patient's medical record included: patient date of birth, date of diagnosis, date of first visit with the physician, number of visits with that physician, disease stage, race, and whether the patient had a recurrence of her disease.

Statistical Analyses

Comparisons of percentages across groups of respondents were performed with contingency tables and χ^2 statistics. Comparisons of continuous variables (eg, age, years since diagnosis) were made with independent sample *t*-tests. Statistical analyses were carried out using SPSS 12.0 (SPSS, Chicago, IL).

Results

Our first aim was to assess the proportion of patients with breast cancer with a scheduled visit who had read Internet information within the past month (ie, RIUs) and to assess the proportion of RIUs who intended to discuss this information with their physicians during their appointment that day. Of the total 558 patients approached for the study, 15.1% reported that they had read cancer-related information on the Internet within the past month. Of those who had read and consented to the study, 45.2% reported before consultation that they were planning to discuss cancer-related Internet information with their physician (Appendix Fig A1, online only).

Additional analyses examined patient characteristics associated with being an RIU and with RIUs intending to discuss cancer-related Internet information with their physicians. There were several significant differences between RIUs and all other patients. As shown in Table 1, RIUs were significantly younger (53.1 *v* 58.8 years; $t = 3.8$; $P < .01$), had been diagnosed more recently (2.8 *v* 4.3 years; $t = 2.8$; $P < .01$), and were more likely to be attending a new visit with the physician ($\chi^2 = 5.6$; $P < .05$). There were no significant differences between the groups with regard to race, disease stage, presence of recurrent disease, type of physician, number of visits with the physician, or time since first visit with the physician.

Table 1. Demographics and Clinical Characteristics of Recent Internet Users Compared With All Others

	Read in Past Month (n = 84)		Did Not Read in Past Month (n = 474)		Total (n = 558)	
Characteristic	**No.**	**%**	**No.**	**%**	**No.**	**%**
Age, years*						
Mean	53.1		58.8		57.9	
SD	10.8		13.1		12.9	
Race						
White	61	72.6	376	79.3	437	78.3
Latino/Hispanic	7	8.3	23	4.9	30	5.4
African American	7	8.3	47	9.9	54	9.7
Asian	6	7.1	17	3.6	23	4.1
Unknown/other	3	3.6	11	2.3	14	2.5
Disease stage						
I	41	48.8	210	44.3	251	45
II	15	17.9	122	25.7	137	24.6
III	10	11.9	41	8.6	51	9.1
IV	18	21.4	101	21.3	119	21.3
Recurrent disease	8	9.5	53	11.2	61	10.9
Time since diagnosis, years†						
Mean	2.8		4.3		4.1	
SD	4.2		6.2		5.9	
Visit characteristics						
Type of visit†						
Follow-up	43	51.1	307	64.8	350	62.7
New visit	41	48.9	167	35.2	208	37.3
Physician						
Surgeon	33	39.3	155	32.7	188	33.7
Medical oncologist	51	60.7	319	67.3	370	66.3
No. of visits with this physician						
Mean	8.9		10.6		10.3	
SD	15.6		16.9		16.7	
Time since first visit, years						
Mean	1.6		1.9		1.9	
SD	2.8		5.2		4.9	

Abbreviation: SD, standard deviation.
* $P < .01$.
† $P < .05$.

As shown in Table 2, we also compared RIUs who planned to discuss Internet information with their physicians with all other patients. We removed from the comparison group patients who had read in the past month but did not consent to the study, because we did not know their intent to discuss. Our intent with this comparison was to explore whether there was a certain type of patient who was more likely to discuss Internet information. However, there were no significant differences between these two groups regarding any of the demographic, disease, or visit characteristics.

Table 2. Patient Demographics and Clinical Characteristics by Intent to Discuss Internet Information

	Intent to Discuss (n = 19)		Others (n = 497)*	
Characteristic	**No.**	**%**	**No.**	**%**
Age, years				
Mean	53.8		58.3	
SD	10.2		13.1	
Race				
White	17	89.5	391	78.7
African American	2	10.5	51	10.3
Latino/Hispanic	0	0	25	5
Asian	0	0	18	3.6
Unknown/other	0	0	12	2.4
Disease stage				
I	12	63.2	221	44.5
II	3	15.8	127	25.6
III	1	5.3	43	8.7
IV	3	15.8	106	21.3
Recurrent disease	3	15.8	55	11.1
Time since diagnosis, years				
Mean	4.0		4.2	
SD	5.8		6.1	
Type of visit				
Follow-up	11	57.9	324	65.2
New visit	8	42.1	173	34.8
Physician				
Surgeon	5	26.3	162	32.6
Medical oncologist	14	73.7	335	67.4
No. of visits with this physician				
Mean	10.3		10.5	
SD	16.7		16.6	
Time since first visit, years				
Mean	1.6		1.9	
SD	2.5		5.0	

Abbreviation: SD, standard deviation.
* Excluding those who had read in the past month but did not consent.

The secondary goal of the study was to assess the proportion of patients with breast cancer who had read Internet information since their diagnosis and examine the characteristics associated with those patients. Of the 259 patients who were screened in phase two, 18.9% reported that they had read Internet information related to their cancer since their diagnosis (ie, EIUs). We compared EIUs with those who had never read Internet information with regard to demographic, disease, and visit characteristics (phase two only). As shown in Table 3, patients who had never read cancer-related information since their diagnosis were more likely to have stage 1 disease than EIUs ($\chi^2 = 7.7$; $P < .05$). No other demographic, disease, or visit characteristics were significant, although there was a trend for those who were younger to be more likely to have read.

Table 3. Patients Who Had Ever Used Internet Compared With All Others

	Read Since Diagnosis (n = 49)		Never Read Since Diagnosis (n = 210)	
Characteristic	**No.**	**%**	**No.**	**%**
Age, years*				
Mean	55.3		58.9	
SD	13.3		12.8	
Race				
White	40	81.6	177	84.3
Latino/Hispanic	3	6.1	6	2.9
African American	2	4.1	14	6.7
Asian	2	4.1	8	3.8
Unknown/other	2	4.1	5	2.4
Disease stage				
I†	15	30.6	109	51.9
II	17	34.7	46	21.9
III	9	18.4	18	8.6
IV	8	16.3	37	17.6
Recurrent disease	2	4.1	18	8.6
Time since diagnosis, years				
Mean	3.2		3.0	
SD	4.3		5.5	
Visit type				
Follow-up	30	61.2	99	47.1
New visit	19	38.8	111	52.9
Physician				
Surgeon	19	38.8	97	46.2
Medical oncologist	30	61.2	113	53.8
No. of visits with this physician				
Mean	8.6		6.6	
SD	13.5		13.2	
Time since first visit, years				
Mean	1.6		0.8	
SD	2.7		6.7	

Abbreviation: SD, standard deviation.

* $P < .10$.

† $P < .05$ (different from three other stages combined).

Discussion

Although it is estimated that a considerable proportion of patients with breast cancer read information from the Internet about their cancer, it has not been clear how frequently physician-patient discussions of this information occur. Our results showed that a relatively small percentage of patients (15%) had read Internet information in the past month. Of those who had read Internet information in the past month, nearly half (45%) came to their visit with an intention to talk with the physician about the information that they had read. Given these data, discussion of Internet information would be expected in approximately 7% of all breast cancer consultations in our population. These results suggest that using the patient visit with the physician as a point of time to study potentially provides a lower estimate of how Internet information may influence a physician-patient consultation, as opposed to examining if patients had ever read Internet information.

RIUs were younger, had a more recent diagnosis, and were more likely to be attending a new visit with a physician than those who had not read Internet information in the past month. The finding that RIUs had been diagnosed more recently, and were consequently more likely to be attending a new visit, may point to the need to focus on when the Internet is used in the course of cancer diagnosis and treatment, because that may provide a better picture of how the Internet may interact with the doctor-patient relationship.

We found no significant differences on demographic, disease, or visit characteristics between patients who intended to discuss Internet information and patients who did not. It seems it may be more difficult to predict who will talk about Internet information using demographic, disease, or visit characteristics than it is to understand who has read cancer-related Internet information. It may be that the primary factors in decisions by patients with cancer about discussing Internet information are more about the content of the information read on the Internet and the relationship the patient has with the physician.[21]

We were also interested in examining the proportion of patients who had ever read (since their diagnosis) to compare the study population to those in past research findings. Whereas most previous studies on patients with breast cancer seeking cancer-related information on the Internet report at least 40% of patients having read, our results show approximately 19% of those patients with breast cancer approached for the current study were EIUs. It is not clear why our population had a lower prevalence of having ever read Internet information. The breast cancer studies cited in the Introduction collected data between 1997 and 2004, whereas the present study collected data in 2008 to 2010. It is possible that patients with breast cancer may not be as likely to use the Internet for cancer information as they were previously, although this seems unlikely. Future research should further investigate the role of Internet-obtained health information in the experiences of patients with cancer. Certainly there is potential benefit for patients and caregivers to receive both education and support through their use of the Internet. The amount of health information available may be overwhelming to some patients; these patients might benefit from online health information that is more directed, coming from their physician or through their personal health record.

This finding of a relatively small proportion of patients intending to discuss Internet information with their physicians is supported by a larger trend noted recently in the United States. Using data from the Health Information National Trends Survey by the National Institutes of Health, Beckjord[22] performed a population-based study of respondents who had visited a health care provider in the past 12 months. Comparing data collected in 2005 and 2008, Beckjord found a significant decrease in the chances that a respondent would report having discussed Internet information with a health care provider (from 44.4% to 25.7%). This decrease may reflect a changing pattern in how patients are using the Internet for health information.

Our findings regarding patient characteristics associated with the prevalence of ever seeking breast cancer information on the Internet were different than those of previous research. Unlike earlier studies, we found that those who had never read and those who had ever read were not different in age, education, or race. In addition, we found that stage did make a difference; those diagnosed with stage 1 breast cancer were less likely than those at other stages to have read cancer-related Internet information. However, similar to previous research, our data showed that time since diagnosis did not predict whether the patient had ever read Internet information related to her breast cancer.

Research literature on direct-to-consumer advertising (DTCA) for patients with cancer is analogous in many ways to research on physician-patient communication about Internet information. There tends to be a fairly low percentage of patients who discuss prescription drugs advertised to them with their physicians, with one recent study finding that 17% of patients with cancer in active treatment who remembered seeing an advertisement talked to their physician about the advertised drug.[23] Additionally, many recognize that the advantages and pitfalls of DTCA are similar to those of Internet information. Both provide patients with information that can be educational and helpful as they try to understand their disease and treatment, and both can help patients to feel empowered and lead to helpful discussions with physicians. However, both can also lead to patients trusting their physicians less, physicians feeling challenged, and patients learning information that is incorrect or not applicable to them.[6,21,23,24]

There are several limitations to this study. First, our results on the frequency with which patients intended to discuss information are likely low, because it is possible that some patients may have intended to talk about Internet information they had read more than 1 month ago. Second, because we had difficulty finding and recruiting patients who were intending to discuss Internet information with their physicians, our sample size is low in some comparisons. Third, we had a relatively low consent rate to the study; thus, there may have been a selection bias in terms of the patients who agreed to be in the study and answered the question about intent to discuss information with their physicians. There may have also been a social desirability bias effect, with patients not wanting to admit that they intended to discuss Internet information with their physician. Fourth, this study was conducted at a single referral center with a highly selected population of patients. Finally, we limited our investigation to patients reading information on the Internet, rather than a family member or other support person.[25]

Future research may choose to examine if the source or type of the Internet information affects the likelihood of the patient discussing it and/or physician response. In one DTCA study, physicians were presented with a hypothetical patient asking for a prescription drug; those who were presented a scenario in which the patient stated the information source was from DTCA were less likely to answer questions and provide additional written information, a prescription, or a sample and were more likely to become annoyed, compared with those whose hypothetical patient stated the information source was from a drug reference book.[26] We might expect similar results if the difference were between a scientific journal article located on the Internet and the Web site of a lay person about his or her experiences with alternative treatments.

Although the Internet continues to play a role in the education of patients with breast cancer and their understanding of their disease and treatment, the frequency with which patients with breast cancer come to a physician visit prepared to discuss this information is low. Using the physician visit as a point of time to study, our study indicated that 15% of patients with breast cancer came to a visit having recently read Internet information, and approximately half of those intended to discuss the information with their physicians. Future work may explore the content of these conversations and how best physicians and patients can use the Internet to further the goal of quality of care.

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