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Doctor–Patient Communication About Cancer-Related Internet Information

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Abstract

This article explores the effect of doctor–patient communication about cancer-related Internet information on self-reported outcomes. Two hundred and thirty cancer patients and caregivers completed an online survey regarding their experiences searching for and discussing with their doctors cancer-related Internet information. Participants who assertively introduced the Internet information in a consultation were more likely to have their doctor agree with the information. When doctors showed interest and involvement and took the information seriously, participants were less likely to report a desire to change the doctor's response. Taking the information seriously was also associated with greater satisfaction. This preliminary evidence that the doctor's response is associated with patient outcomes indicates the potential for improving patient-centered communication. In an effort to maximize patient-centered communication, doctors should be encouraged to take their patients and the information they present seriously, as well as show their patients that they are interested and involved.

Keywords

oncology; provider-patient communication; Internet; patient satisfaction; patient-centered communication

INTRODUCTION

Eighty percent of adult Internet users seek health information from the Internet (Fox, 2006). Consequently, given that 70% of adults report being online (Fox, 2006), more than one-half of U.S. adults (113 million people) have used the Internet to seek out health information. Of cancer patient populations from academic or community medical centers, 31% to 60% of patients or caregivers report having used the Internet to search for information about cancer (Basch, Thaler, Shi, Yakren, & Schrag, 2004; Metz et al., 2003; Monnier, Laken, & Carter, 2002; Ranson et al., 2003). Clearly, the Internet has significantly transformed the way in which patients and caregivers meet their health-related information needs.

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Patients who search for cancer-related Internet information differ considerably from those who do not. Cancer patients who search for information about cancer on the Internet are more likely to be younger, own a computer, have Internet access at home, and have a higher education level than cancer patients who do not search for cancer-related Internet information (Basch, et al., 2004; Helft, Eckles, Johnson-Calley, & Daugherty, 2005; Monnier et al., 2002). In studies of lung and breast cancer patients, education and income were positively correlated with the likelihood of using the Internet to search for cancer-related information (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Peterson & Fretz, 2003). Although younger age has been correlated with Internet use in prostate cancer and melanoma (Sabel et al., 2005; Smith et al., 2003), this is not the case in breast cancer (Fogel et al., 2002).

Health-related Internet searches can empower patients seeking to become active participants in their care (Fleisher, Bass, Ruzek, & McKeown-Conn, 2002); however, Internet information about treatment options is only empowering to the extent that the oncologist is receptive to the patient being involved in the decision-making process (Broom, 2005b). The Internet provides patients and caregivers access to information that was previously either unavailable or difficult to access, offering a leveling effect on the power imbalance in the doctor–patient relationship, specifically in terms of expert power (Bylund, Sabee, Imes, & Sanford, 2007; Makoul, 1998). It is neither surprising that such a shift affects doctor–patient communication and relationships, nor that 44% of oncologists report having difficulty with discussions about Internet information (Helft, Hlubocky, & Daugherty, 2003).

The percentage of cancer patients who have discussed cancer-related Internet information with their doctors is quite similar to a more general population of patients discussing Internet information (Diaz et al., 2002; Diaz, Sciamanna, Evangelou, Stamp, & Ferguson, 2005; Fox & Rainie, 2002; Murray et al., 2003), with 36% of melanoma patients stating that they intended to discuss Internet information with their physician (Sabel et al., 2005), and 40% of mixed cancer type patients reporting that they had already discussed Internet information with their physician (Helft et al., 2005).

Studies have shown several reasons why discussions about Internet information can be challenging for doctors and patients. Some oncologists perceive Internet-informed patients have a harmful effect on the doctor–patient relationship, particularly when patients directly challenge them or when patients have too much information (Broom, 2005a). After reading cancer-related Internet information, some patients become overwhelmed, aware of conflicting medical information, and more nervous, anxious, and confused (Fleisher et al., 2002; Helft et al., 2005; Sabel et al., 2005). Oncologists also report that Internet information can lead to unnecessary discussion during a consultation that may consequently result in conflict (Broom, 2005a). Internet discussions may result in longer consultations (Helft et al., 2003), which can be frustrating for doctors who have limited time with each patient.

Further, doctors and patients do not always agree about the characteristics of Internet information, which may lead to challenging doctor–patient consultations. For example, cancer patients often make judgments about the accuracy of information that they find on the Internet, and many perceive it to be quite accurate (Helft et al., 2005). However,

oncologists report concern over the accuracy of cancer-related Internet information, with 91% of oncologists in one study reporting that the Internet had the potential to cause harm to patients (Broom, 2005a; Newnham et al., 2005). Although 62% of cancer patients in one study reported that cancer-related Internet information made them feel more hopeful (Helft et al., 2005), 38% of oncologists who reported thinking that Internet information makes patients more hopeful viewed this negatively (Helft et al., 2003). These differing perceptions between doctors and patients about cancer-related Internet information may contribute to challenging discussions and may reduce the likelihood of patient-centered communication.

In our previous work, we conceptualized the patient's act of introducing Internet information into a doctor–patient consultation as a face-threatening act (Bylund et al., 2007). How a doctor responds to this information, and the course of the discussion that follows, can prove to either support the patient's face (by validating the patient's efforts or taking the information seriously) or further threaten the patient's face (by warning the patient about the dangers of the Internet or disagreeing with the information without any validation of efforts). Supporting, rather than threatening, the patient's face helps to support two of the key functions of the patient-centered communication model presented in the recent National Cancer Institute monograph: fostering healing relationships and exchanging information (Epstein & Street, 2007). We expect that face-saving or supporting comments and discussion from doctors will lead to better patient outcomes.

In an earlier study about patient communication with health care providers about Internet information in a non-disease-specific patient population, we found that provider disagreement with Internet information resulted in lower patient satisfaction (Bylund, Gueguen, et al., 2007). We also explored which additional strategies might moderate disagreement and found that when a provider disagreed with the Internet information, also taking the information seriously improved patient satisfaction with the interaction.

STUDY AIMS

Researchers have yet to establish effective doctor and patient communication strategies to facilitate these potentially challenging discussions. The purpose of the current study was to examine recalled conversations about Internet information between cancer patients (or caregivers) and their doctors. We focused the current study around three primary research questions.

First, what strategies do patients and caregivers use to introduce Internet information during a consultation with their doctor?

Second, what strategies do doctors use to respond to the Internet information and is the choice of strategy affected by the patient or caregiver's introduction?

Third, are the response strategies linked to outcomes of the conversation?

We hypothesized that in cases where the doctor disagreed with the patient's Internet information, taking the information seriously would improve patient outcomes.

METHOD

Participants

Two hundred and sixty-seven cancer patients and caregivers responded to a questionnaire about their experiences with Internet information about their cancer. Of the 267 survey participants, 238 (89%) reported having searched the Internet for information since the diagnosis of cancer. Of those, 38% reported always talking about the Internet information when they thought it was important; 59% said that they sometimes discussed the information when they thought it was important; and 3% reported never discussing the information, even when they thought it was important. As the current study was focused on participants' experiences discussing Internet information with their doctors, the sample of interest is the 230 participants who sometimes or always talk about Internet information with their doctors.

Participants were recruited from three online communities sponsored by the National Comprehensive Cancer Network (NCCN), a not-for-profit alliance of 21 leading cancer centers. Participants were recruited via commercially available panels and invitations on NCCN Centers' Websites. The purpose of hosting these online communities was to field surveys and discussion topics about how patients and caregivers make treatment-related decisions. In total, 900 patients and caregivers participated in these online communities. As a part of their community membership, all participants were asked to respond to a variety of discussion threads and surveys. One of these options was a survey about patients' and caregivers' experiences finding information on the Internet about cancer and the discussions they had about this information with their doctors. Although they were recruited from different online communities, each participant received the same survey. The study was reviewed and deemed exempt by our Institutional Review Board.

Table 1 displays the patient demographics from each of the three online communities. The first community of participants included a mix of patients (59%) and primary caregivers of patients (41%) with a broad range of cancer types, all newly diagnosed. The second community focused on late-stage cancer patients and those caring for people with advanced-stage cancer. In this community, 10% of participants were caregivers. The third and final community focused on four types of cancer (breast, prostate, colon/rectal, and lung) and included only patients who had an early-stage diagnosis. Caregivers reported the patient's demographics, not their own. Overall, patients tended to be female (67%–76%) and White (87%–97%). Efforts to recruit more diverse participants were not successful. Caregivers and patients were unrelated in all samples (i.e., both parties of a caregiver–patient dyad were not involved in the study).

Questionnaire

Participants completed an online questionnaire regarding their experiences with searching for cancer information on the Internet and discussing it with their doctors. They were instructed: "Think about the most recent instance since your diagnosis in which you talked with your doctor about cancer information that you found on the Internet. Please keep this situation in mind while answering the following questions." Using a conversation recall technique (Bylund, Gueguen, et al., 2007), participants were first asked to write down the

conversation that they had with the doctor in as much detail as possible. The advantage of the conversation recall technique is that it focuses on participants' perceptions of the conversation. Although it may not be completely accurate, it does represent what the participant believes she or he said and heard (Lazarus, 1991; Weiner, 1986). Participants were asked several questions about the Internet information that they discussed, including on which Websites the Internet information was found, what types of topics were discussed, if they brought a printed copy of the information with them to the consultation, and if they told the doctor the information was from the Internet.

Patient outcomes

Study participants were also asked to respond to items about the outcomes of the conversation, including (1) a Likert-type, 5-point item measuring satisfaction with the conversation; (2) what impact, if any, the conversation had on choice of doctor or where to seek treatment; and (3) how they would have changed the conversation with the doctor if they could change it.

Coding

The Internet Health Discussion Analysis System (IHDAS) (Bylund, Gueguen, et al., 2007) was used to code recalled conversation data for the strategies used by participants to introduce the information and the providers' responses. All recalled conversations were coded for each set of codes by the third author. The second author also coded a randomly selected 20% of recalled conversations. Good reliability was established across both sets of codes (Cohen's kappa = .82 for form of introduction and .81 to 1.0 for doctor response codes).

Introduction of Internet information—Consistent with the IHDAS, each recalled conversation was first coded for how the Internet information was introduced by the participant. A code of Facts was given if a statement of fact was made to the doctor without indication that the participant was “owning” the information or actively processing it (e.g., drawing a conclusion, making a decision). The Indirect/Embedded Question code was given in cases where a participant elicited a response from the doctor without using a traditional question form. The Active/Assertive code was given when the information was introduced in such a way that indicated the participant had come to a conclusion or had made a reasoned judgment about diagnosis, treatment, or the next steps that should occur. A code of Direct Question was given when the participant took a more “traditional” patient role by asking a question about the doctor's opinion or knowledge about something.

Doctor responses—Each recalled conversation was also coded for the doctor's response(s) to the Internet health information presented by the participant throughout the entirety of the recalled conversation. There were seven possible codes, and multiple codes could be applied to characterize the responses given in each conversation. Responses included the doctor (1) being Interested/Involved in the Internet information; (2) Actively Agreeing with the participant and/or Internet information; (3) being Dismissive/Argumentative; (4) giving the participant a Warning about Internet information; (5) Taking

the Information Seriously; (6) Validating the Participant's Efforts; and/or (7) Disagreeing with the participant and/or Internet information.

Analytic strategies and statistical methods—Descriptive statistics were used to report percentages and averages of the patient and doctor outcomes. Generally, contingency tables analyses using the likelihood-ratio statistics were used to test the association between outcome variables (Wickens, 1989). A special focus was on testing the association between doctors' responses in the conversation and participants' recalled outcomes of the conversation. Fisher's exact test was deemed appropriate for testing these associations because of sparse cells in some of the contingency tables. Doctors' responses were dichotomized (e.g., coded "1" if participant was "taken seriously" by the doctor and "0" otherwise). Participants' recalled outcomes of the conversation were also dichotomized. For example, satisfaction with the conversation was dichotomized as "very satisfied" versus "less than very satisfied" by the Likert-type ratings. We report odds ratios of 2 by 2 contingency tables, their statistical significance, as well as the corresponding 95% confidence intervals by Fisher's test. Fisher's tests were carried out using the statistical language R (R Development Core Team, 2004).

RESULTS

Sources and Topics of Internet Information

Participants reported that the Internet information they discussed with their doctors came from a wide variety of Internet sites. As reported in Table 2, 54.3% of participants found information on a cancer organization Website (e.g., American Cancer Society) and 31.7% reported using WebMD as their source. As shown in Table 3, the most frequently reported topic was prognosis, accounting for 43.9% of the topics given. The second and third most frequently reported topics were proven or traditional treatments (29.6%) and clinical trials (22.6%). Less than one fourth of participants (23%) reported that they brought a copy of the Internet information to show to their doctor, although 41.7% reported that they specifically mentioned to the doctor that the information was from the Internet. These findings did not differ based on participant community or caregiver/patient status.

Introducing the Internet Information

One-hundred and ninety-two participants provided some form of recalled conversation, though only 123 of these recalled conversations were complete enough to be coded using the IHDAS. As shown in Table 4, participants most frequently used a direct question (46.7%), thus putting themselves in a more traditional patient role when introducing the information. The second most frequent form of introduction, accounting for 26.2% of total introductions coded, was simply stating the facts or content of the information without asking a question, followed by active/assertive introductions (22.1%) and indirect/embedded questions (4.9%). Patients (26.3%) were more likely than caregivers (4.2%) to use an assertive strategy to introduce the information ($\chi^2 = 8.47, p < .05$). Self-reported comfort level and frequency of discussing Internet information with the doctor was not associated with the form of introduction.

Doctors' Responses to Internet Information

Doctors were most likely to use the strategy of take the information seriously (82.1%), followed by disagree (20.3%), interested/involved (17.1%) and actively agree (8.9%) (see Table 5). Community number and patient/caregiver status were not associated with doctor response.

To address the second research question, we examined the association between the manner in which the participant introduced the information and the doctor's response. Doctors' responses were more often coded as interested/involved when the participant told the doctor that the information was from the Internet ($\chi^2 = 6.17, p < .05$). Second, and in line with our previous work (Bylund, Gueguen, et al., 2007), we created a dichotomous variable of participant introduction forms (as coded by the IHDAS) into less face-threatening (facts, indirect and direct questions) and more face-threatening (assertive). Doctors were more likely to use the strategy of actively agree when participants introduced the information in an assertive manner than a nonassertive manner ($\chi^2 = 12.25, p < .001$).

Effect of Doctor's Response on Participant-Reported Outcomes

We explored if certain physician response strategies were associated with participant-reported outcomes in answer to the third research question. Due to the low frequency of three of the strategies, we used the following four strategies as independent variables: interested/involved, actively agree, take the information seriously, and disagree. For these analyses, we focused on the 123 participants who recalled conversations that we were able to code.

We used three dichotomous participant outcome variables: very satisfied/less than very satisfied, positive impact/not a positive impact, and desire to change the doctor's response/no desire to change based on the measures described above. More than one half (61.2%) of participants reported being "very satisfied" with the conversation they had with the doctor about Internet information. Regarding impact, 22.7% of participants reported the conversation had a positive impact. Finally, 70.7% of responses to the question of if the participant wished he or she could change how the doctor responded were coded as desire to change.

Figure 1 displays the odds ratio of each of the three outcomes when each strategy was present. When the doctor's response was coded as being interested/involved, participants were significantly less likely to report a desire to change the doctor's response (95% Confidence Interval [CI]: .00–.65, $p < .01$), but there was no significant findings for the outcomes of very satisfied or positive impact. There were also no significant associations with any of the three outcomes when the doctor actively agreed with the patient or caregiver. When the doctor took the information seriously, participants were significantly less likely to report a desire to change the doctor's response (CI: .09–.75, $p < .01$), and they were also more likely to report high satisfaction (CI: 2.96–43.85, $p < .001$), though there was no significant finding for positive impact. Finally, when the doctor disagreed with the participant, the participant was more likely to report wanting to change the doctor's response (CI: 1.28–9.71, $p < .05$) and less likely to report being very satisfied (CI: .04–.42, $p < .001$).

Further, we were interested in testing the hypothesis that when a doctor disagreed with the information that the participant brought in, the strategy of take it seriously would improve reported outcomes. In cases where a doctor disagreed but took the participant's information seriously, Table 6 shows that 2 of 8 participants (25%) were "very satisfied" with the consultation. When the doctor did not take it seriously, 4 of 17 participants (24%) remained "very satisfied" with the consultation. By contrast, the strategy of take it seriously made a substantial difference when a doctor did not disagree; 68 of 93 participants (73%) were "very satisfied" when the doctor took it seriously, whereas none of the five participants were "very satisfied" when the doctor did not take it seriously. To better explicate the potential moderating effect of taking it seriously on disagreement, we used the bias-corrected log odds ratio as a measure of association between the "very satisfied" outcome and doctors' taking it seriously (Wickens, 1989). An odds ratio of 1.0 (equivalently, a log odds ratio of 0.0) represents a null association. In cases where the doctor disagreed with the information, the log odds ratio was close to null, at $0.14 \left(\log \frac{(2+1/2)(13+1/2)}{(6+1/2)(4+1/2)} \right)$. However, in cases where a doctor did not disagree, the log odds ratio was substantially higher, at 3.39 $\left(\log \frac{(68+1/2)(5+1/2)}{(25+1/2)(0+1/2)} \right)$. The potential moderating effect of take it seriously on the association between disagreement and a "very satisfied" outcome can be tested by fitting a conditional independence log-linear model (Wickens, 1989). The model tests the null hypothesis that the outcome is associated with disagreement across all levels of take it seriously, which was rejected by the likelihood-ratio test statistic ($G^2 = 12.47$, $df = 2$, $p < 0.002$). The association between the outcome and disagreement depends on the strategy of take it seriously, although the association was likely attributable mostly to cases where a doctor did not disagree. We were unable to test the interaction between interested/involved and disagree as there were no conversations coded with both of these strategies present.

DISCUSSION

The results of the current study support the importance of patient-centered communication in discussions about Internet information. Two patient-centered communication strategies had significant effects on participant-reported outcomes. When doctors communicated interest and involvement about the Internet information or showed that they took the information seriously, participants were less likely to report a desire to change the doctor's response. Further, when the doctor took the information seriously, participants reported high satisfaction and were less likely to report a desire to change the doctor's response. Showing interest and involvement and taking information seriously in this context can be important to fulfilling at least two key components of patient-centered communication as presented in the NCI monograph (Epstein & Street, 2007). Doctors who use these strategies improve the function of exchanging information as they are able to understand more about the information the participant has. As pointed out in Epstein and Street (2007), "The wide availability of health information on the Internet can cause patients to become frustrated by information 'overload' and their inability to clearly understand their health status and appropriate course of treatment. Clinicians must help patients and caregivers filter and understand clinical information" (p. 21). Being interested/involved and taking information seriously is key to achieving this. Further, by using these strategies, doctors are giving a

message to the patient or caregiver that their role as an active participant in clinical encounters is important, helping to foster healing relationships.

Results of the current study demonstrated that when the doctor disagreed with the information that the participant raised, participant-reported outcomes were significantly worse than if the doctor did not disagree. Understandably, at times doctors may disagree with information patients or caregivers have found on the Internet—it may not be relevant to the patient's situation or it may not be evidence based. We expected that taking the information seriously or showing interest and involvement would help to buffer disagreement by improving patient outcomes; however, this was not supported. This may have been due to the small sample size as there were just eight cases of doctors disagreeing and showing interest/involvement.

The way that the patient or caregiver introduces the Internet information was shown here to affect the doctor's response, demonstrating the mutual effect of communication (Cegala, Street, & Clinch, 2007). When patients or caregivers explicitly stated that the information was from the Internet, doctors were more likely to demonstrate interest and involvement. When patients introduced information in an active and assertive way, they were more likely to garner the response of actively agree from the doctor. In these cases, doctors may have felt threatened and a need to appease the patient (Bylund, Gueguen, et al., 2007). This latter relationship was one we also found in our earlier work with a non-cancer-specific population (Bylund, Gueguen, et al., 2007). In that study, as in this one, we also found disagreement to be related to lower patient satisfaction and taking information seriously to be associated with higher patient satisfaction. The ability to replicate findings from a different sample focused specifically on cancer patients indicates externally valid findings.

Limitations of the current study include the relative homogeneity of participants, its reliance on self-report data, and that we only were able to get the patient's perspective of the doctor–patient encounter. We are currently conducting an observational study wherein we are obtaining audio-recorded conversations between patients and doctors about Internet information and capturing doctor and patient self-report data. Other future work should further explore the way in which these conversations can be improved, particularly in cases where the information the patient has found is incorrect and misunderstandings need to be corrected. Ultimately, interventions to improve patients' Internet searching and conversations should be examined for their effects on patient and doctor outcomes.

CONCLUSION

The Internet has changed the way that patients and their caregivers gain information about their cancer and has added a level of complexity to doctor–patient interactions. Although many patients use the Internet to search for cancer-related information, they are not always forthcoming with their doctors about the source of the information they have found, partially as a result of concern over their doctors' possible response to it. Furthermore, patients use a variety of strategies to introduce the information to their doctors which in turn affects their doctor's response. This preliminary evidence that the doctor's response is associated with patient outcomes indicates the potential for improving patient-centered communication.

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CLINICAL IMPLICATIONS

The way doctors respond to their patients' presentation of Internet information affects patient satisfaction and whether patients want to change elements of their encounters and their health care decisions. In an effort to maximize patient-centered communication, doctors should be encouraged to take their patients and the information they present seriously, as well as show their patients that they are interested and involved. There is potential for communication skills interventions to have an integral role for doctors to focus on and practice strategies related to this topic. Because patients who present information in an active/assertive way tend to elicit agreeable responses from their doctors, there may also be implications for communication skills interventions for patients focusing on how best to engage doctors in conversation about Internet information they have found that they wish to discuss.

FIGURE 1.
Odds ratios of response strategy on patient outcome.

TABLE 1

Demographics

	Group 1	Group 2	Group 3
Gender			
Male	26 (32.5)	18 (23.7)	19 (25.7)
Female	54 (67.5)	58 (76.3)	55 (74.3)
Ethnicity			
White/Caucasian	70 (87.5)	74 (97.4)	65 (87.8)
Other	10 (12.5)	2 (2.6)	9 (12.2)
Age (Group 1)			
25–44	17 (21.2)	<i>a</i>	<i>a</i>
45–64	54 (67.5)	<i>a</i>	<i>a</i>
65	9 (11.3)	<i>a</i>	<i>a</i>
Age (Group 2,3)			
25–39	<i>a</i>	5 (6.6)	17 (23)
40–49	<i>a</i>	25 (32.9)	25 (33.8)
50–64	<i>a</i>	38 (50)	28 (37.8)
65	<i>a</i>	8 (10.5)	4 (5.4)
Education Level			
Some High School	6 (7.5)	0 (0)	0 (0)
High School Graduate	20 (25)	12 (15.8)	5 (6.8)
Some College	22 (27.5)	22 (28.9)	9 (12.2)
College Graduate	17 (21.2)	19 (25)	31 (41.9)
Post-Graduate Education	15 (18.8)	23 (30.3)	20 (27)
Some Technical or Vocational	0 (0)	0 (0)	9 (12.1)
Marital Status			
Married	54 (67.5)	55 (72.4)	<i>a</i>
Divorced	9 (11.25)	9 (11.8)	<i>a</i>
Widowed	9 (11.25)	4 (5.3)	<i>a</i>
Single/Never Married	4 (5)	3 (3.9)	<i>a</i>
Living with Significant Other	4 (5)	5 (6.6)	<i>a</i>
Income Level			
< \$50,000	36 (45)	18 (23.7)	15 (20.3)
\$50,000–\$75,000	19 (23.75)	24 (31.6)	12 (16.2)
\$75,000–\$100,000	8 (10)	14 (18.4)	22 (29.7)
>\$100,000	14 (17.5)	11 (14.5)	19 (25.7)
Don't know/Decline to answer /Missing	3 (3.75)	9 (11.8)	6 (8.1)
Region			
Midwest	17 (21.25)	23 (30.3)	8 (10.8)

	Group 1	Group 2	Group 3
Northeast	22 (27.5)	13 (17.1)	24 (32.4)
Southern	23 (28.75)	28 (36.8)	26 (35.1)
West	18 (22.5)	12 (15.8)	16 (21.6)
Time Since Diagnosis			
< 6 mos	38 (47.5)	10 (13.2)	10 (13.5)
6 mos–1 yr.	23 (28.75)	11 (14.5)	23 (31.1)
1 yr.–3 yrs.	19 (23.75)	21 (27.6)	34 (45.9)
3 yrs.–5 yrs.	0 (0)	19 (25)	4 (5.4)
>5 yrs.	0 (0)	15 (19.7)	3 (4.1)
Cancer Type			
Breast	26 (32.5)	28 (36.8)	43 (58.1)
Lung	9 (11.25)	10 (13.2)	9 (12.2)
Gynecological	5 (6.25)	1 (1.3)	0 (0)
Gastrointestinal	8 (10)	15 (19.7)	16 (21.6)
Leukemia/Lymphoma	7 (8.75)	1 (1.3)	0 (0)
Genitourinary	8 (10)	9 (11.8)	6 (8.1)
Multiple	0 (0)	10 (13.2)	0 (0)
Other	17 (21.25)	2 (2.6)	0 (0)
Type of Facility ^b			
Specialty Oncology Physician	42 (52.5)	50 (65.8)	36 (48.6)
Academic/Teaching Hospital	17 (21.25)	14 (18.4)	12 (16.2)
Community Hospital	21 (26.25)	15 (19.7)	22 (29.7)
NCI Designated Center	10 (12.5)	10 (13.2)	14 (18.9)

NCI = National Cancer Institute.

^aData not collected.

^bMultiple responses allowed.

TABLE 2

Sources of Online Information that Participants Discussed Most Recently with Doctors. *N* = How Many Provided This Information^a

Online source	<i>n</i> (%)
Cancer organization website (e.g., American Cancer Society)	125 (54.3)
WebMD	73 (31.7)
Hospital/Cancer Center website	56 (24.3)
Foundation website (e.g., Susan G. Komen Breast Cancer Foundation)	54 (23.5)
Government website (e.g., NIH, NCI, CDC)	53 (23)
Pharmaceutical company or drug website	40 (17.4)
Online scientific journal article	35 (15.2)
Health chat room or message board	28 (12.2)
PubMed lit search	25 (10.9)
Other	23 (10)
Comprehensive internet service provider (e.g., AOL, Yahoo, MSN)	20 (8.7)
Media website (e.g., CNN.com)	16 (7)
Individuals' home pages or blog	11 (4.8)

NIH = National Institutes of Health; NCI = National Cancer Institute; CDC = Centers for Disease Control.

^aMultiple responses allowed.

TABLE 3

Topics of Online Information that Participants Discussed Most Recently with Doctors. *N* = How Many People Provided This Information^a

Topic of Discussion	<i>n</i> (%)
Prognosis	101 (43.9)
Proven or Traditional Treatments	68 (29.6)
Clinical Trials	52 (22.6)
Alternative Therapies	48 (20.9)
Diagnosis	44 (19.1)
Experiences of other patients	41 (17.8)
Treatments offered by other MD's or Centers	40 (17.4)
Other	23 (10)

^aMultiple responses allowed.

TABLE 4

Participant Strategies for Introducing Internet Information in Their Most Recent Discussion with Doctors

Code Name	Example	<i>n</i> (%)
Direct question	“What are the chances the cancer will return?”	57 (46.7)
Facts	“According to what I have found on the Internet, the prognosis is up to five years.”	32 (26.2)
Active/ Assertive	“I’m interested in having a new test done to see if I’m metabolizing Tamoxifen.”	27 (22.1)
Indirect/Embedded question	“I am concerned that the cancer might come back.”	6 (4.9)

TABLE 5**Doctors' Responses to Patient-Introduced Internet Information**

Doctor Response Codes	Example	<i>n</i> (%)
Take the information seriously	"Let's wait until a month or so has passed and do a few more tests to determine if hormone treatment is necessary."	101 (82.1)
Disagree	"Absolutely not."	25 (20.3)
Interested/Involved	"I will research it and see if it is something that you would be able to use."	21 (17.1)
Actively agree	"Yes, that would be a good idea. You can talk to him or we can refer you to a surgeon."	11 (8.9)
Warning	"Don't believe everything you read on the Internet."	5 (4.1)
Dismissive / Argumentative	"That's not really going to do anything. We need to stay focused on the treatment you are already on."	4 (3.3)
Validating patient efforts	"You're a lot more up to date than most of my patients."	3 (2.4)

TABLE 6

Participant Outcome by Doctor Response

		<u>Disagree = No</u>		<u>Disagree = Yes</u>	
		<u>Serious</u>		<u>Serious</u>	
		No	Yes	No	Yes
Patient outcome	not “very satisfied”	5	25	13	6
	“very satisfied”	0	68	4	2