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Toward a greater understanding of breast cancer patients' decisions to discuss cancer related internet information with their doctors: An exploratory study

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Abstract

Objective—To investigate differences between breast cancer patients who do and do not discuss cancer-related internet information (CRII) with their doctors.

Methods—70 breast cancer patients completed questionnaires regarding internet use, discussions about CRII, and the doctor-patient relationship.

Results—No significant differences were noted across patient, disease, or visit characteristics, or physician reliance between those who intended to discuss CRII and those who did not. Patients who intended to discuss CRII rated significantly higher pre-consultation anxiety levels. No significant differences in satisfaction, anxiety reduction, or trust in physician were found between patients who had discussed and those who had not. Patients' reasons for discussing or not discussing are detailed.

Conclusion—Factors influencing patients' decisions to discuss CRII are complex and differ from those identified as leading patients to seek internet information. Future research about internet discussions should investigate the impact of patients' preferred role in treatment, the doctor-patient relationship, anxiety level, attributes of CRII, and physician trust.

Practice Implications—Understanding the characteristics of patients who do and do not discuss internet information is important given the impact internet information has on healthcare

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communication and the doctor-patient relationship, including the development of interventions aimed at improving such interactions.

Keywords

internet; doctor-patient communication; breast cancer

1. Introduction

Discussions involving internet information can impact several aspects of a medical encounter, the doctor-patient relationship, and patients' illness experience. Doctors find such discussions difficult (1, 2), believing they make consultations longer and increase patients' levels of confusion and anxiety (2). The internet has changed the way patients learn about health and illness (3) and make treatment decisions (4). Internet information consequently has a leveling effect on the power imbalance in the doctor-patient relationship (5, 6).

Between 24 and 42% of breast cancer patients (7, 8), 30% of melanoma patients (9), 48% of prostate cancer patients (10), 16% of lung cancer patients (11, 12), and 18% of head and neck cancer patients (12) report using the internet for health information. Oncologists estimate that approximately 30% of their patients are using the internet to obtain cancer-related information (2).

Patients who search for internet information tend to be younger, own a computer, have internet access at home, and a higher education and income level (3, 13–15). Other studies suggest being female, employed, engaging in other activities on the internet, and helping others deal with health issues influence internet use (16).

Helft et al. (3) found that 40% of internet information seekers within a mixed cancer sample reported discussing the information with their doctor. Hong (17) observed similar findings, with approximately 48% reporting internet-related discussions. Other reported rates include 36% among melanoma patients (9) and 70% among a mixed-diagnosis sample (5).

Despite a growing understanding of internet information seeking in healthcare, little is known about the factors that influence patient decisions to discuss or not discuss internet information with their doctors. Imes and colleagues (18) observed a significant difference in reasons for not discussing internet information between patients who had discussed internet information with their doctor and those who had not. Patients who had not discussed were more likely to report it was because they currently didn't have a healthcare provider or were saving face. Alternatively, those who had discussed indicated they did not discuss other internet information because it was of poor quality, they forgot to mention it, or because they perceived that their provider was closed to hearing about the information. Bylund and colleagues (19) used a similar, follow-up survey focused on cancer patients and their caregivers. They found respondents were most likely to report reasons for discussing internet information that included being proactive in improving health, appealing to the doctor as expert, and becoming more educated. Negative attributions about the quality of the information and a particular situation or circumstance (e.g., not having enough time) were most frequently cited as reasons for not discussing.

The aims of the current study were to conduct an exploratory investigation of differences between breast cancer patients who do and do not discuss cancer-related internet information (CRII) with their doctors and patients' reasons for discussing or not discussing this information. The current study builds upon previous research in several ways. Although previous work has examined reasons for discussing or not discussing CRII, these studies did not capture important clinical characteristics that may influence this decision process.

Further, these studies were retrospective in nature, relying on recalled conversations. A prospective methodological design was used in the current study with relevant clinical characteristics collected. In addition, the current study focused on breast cancer patients.

The first two aims were studied with a group of breast cancer patients who had a visit scheduled with their doctor and had read CRII within the past month. The specific aims were to:

1. Describe breast cancer patient, disease and visit characteristics associated with intent to discuss CRII with one's doctor.
2. Examine the differences in patient satisfaction, anxiety reduction, and trust in physician between patients who discussed CRII with their doctor and those who did not discuss.

Literature on characteristics associated with accessing internet information was used to inform our selection of patient, disease, and visit characteristics. These factors may play a similar role in impacting patients' decisions to discuss CRII. We also considered the impact of physician reliance, an important factor in determining role responsibility and behavior in healthcare interactions (6). For example, a physician-reliant patient may be more likely to discuss CRII she finds confusing or anxiety-provoking. Patient satisfaction, anxiety, and physician trust were selected as outcome variables as they have demonstrated correlations with effective healthcare communication (20).

To examine our third aim, we broadened the sample to include patients who had *ever* read CRII since their diagnosis.

3. Describe breast cancer patients' reasons for discussing or not discussing CRII with their doctor.

Although previous studies have focused on patients' reasons for discussing or not discussing CRII (18, 19), the current study investigates this question specifically within a breast cancer population and utilizes a different research method.

2. Methods

2.1 Data Collection

A research study assistant consecutively approached 576 patients in the waiting room of breast medical oncology and surgery clinics at Memorial Sloan-Kettering Cancer Center (MSKCC) between July 2008 to January 2010. Each patient approached met pre-screening criteria of having a breast cancer diagnosis, being female, and 21 years or older. Eighteen patients approached did not speak English and were excluded from the study, leaving 558 patients who were asked the screening question(s), described below. Fifteen doctors participated in the study (nine medical oncologists and six breast surgeons). This study was approved by the MSKCC Institutional Review Board.

The study was conducted in two recruitment phases. In Phase 1, 299 eligible patients were asked, "In the past month, have you read information on the internet related to your breast cancer?" Of those approached, 67 patients responded affirmatively and 36 (54%) of those were recruited to the study. In Phase 2, recruitment strategies were broadened to include those patients with a history of obtaining CRII, despite not accessing such information in the past month. Eligible patients were first 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 the follow-up screening question, "When was the last time you read internet information about your breast cancer?" Of the 259 patients approached during Phase

2, 17 patients reported having read CRII in the past month and six (35%) were recruited to the study. Thirty-two additional patients reported having read CRII at some point since their diagnosis, although not within the past month and 28 (87%) of those patients agreed to participate in a smaller, survey-only study. Data for these patients is included only in the analysis of Aim 3. Recruiting schema and results are presented in Figure 1.

2.2 Participants

In total, 70 patients were recruited. For Aims 1 and 2 we have analyzed data from the 42 patients who had looked up CRII within the past month. We refer to this group as Recent Internet Users (RIUs). For Aim 3 we analyzed data from patients who cited reasons for choosing to discuss or not discuss CRII with their doctors. This includes data from both RIUs and an additional 28 patients who had looked up CRII at some point since their diagnosis, but not within the past month. We refer to this second group of patients as Ever Internet Users (EIUs). Thus Aim 3 includes data from both RIUs and EIUs.

2.3 Materials

Following consent, each RIU completed questionnaires both pre and post-consultation. Prior to their scheduled appointments, RIUs completed a questionnaire that surveyed socio-demographic information, anxiety, and physician reliance. Anxiety was assessed using the Spielberger State Anxiety Inventory (STAI-S) (21) a 20-item scale, used widely with cancer patients, that instructs participants to respond to several items (e.g., “I feel nervous; I am worried”) on a 4-point scale ranging from “not at all” to “very much so.”

Physician reliance was measured by means of two items initially developed by Makoul (6). The first item represents a patient’s perceived reliance on their doctor to stay healthy, while the second item asks about patient preferences for decision making and the degree to which the respondent relies on the doctor to make health-related decisions.

Following her consultation, each RIU completed a post-consultation questionnaire assessing whether she had discussed CRII and included three relevant measures: patient satisfaction, physician trust, and patient anxiety. The 25-item Satisfaction with Consultation Scale was used to measure patient satisfaction (22, 23). This scale has been used in previous studies with cancer patients (24–26) and proven both reliable (24) and sensitive to changes in doctor behavior (25). Next, the post-consultation questionnaire included the Trust in Physician Scale (27) which assesses a patient’s interpersonal trust in their doctor within the context of chronic disease management. The scale measures three dimensions of trust: dependability of the doctor, confidence in the doctor’s knowledge and skills, and confidentiality and reliability of information exchanged. Patient state anxiety was also measured for a second time, using the STAI-S.

Patients’ reasons to discuss or not discuss CRII were assessed in two ways. RIUs who reported that they had discussed CRII were asked the open-ended question, “Why was it important to you to discuss this information with your doctor?” RIUs who reported not having discussed CRII responded to 14-items drawn from previous qualitative work analyzing categories of patients’ reasons for refraining from discussing CRII with their doctor (18, 19). Patients were asked to rate the degree to which each reason factored into their decision to not discuss CRII with their doctor on a three point scale ranging from “not at all” to “a great deal.”

EIUs completed a shorter pre-consultation survey only. EIUs were asked to report their reasons for discussing, or not discussing, CRII within specific instances in their past. EIUs who reported having past discussions were asked the open ended question, “Why was it important to you to discuss this information with your doctor?” Those EIUs who reported a

time in which they had refrained from discussing CRII were asked to rate the 14 items regarding reasons for not discussing CRII, as described above.

2.4 Data Analysis

Data was analyzed using independent samples *t*-tests and chi-square tests of independence.

Although Makoul (6) combined the two physician reliance items into one composite variable, our data did not support a composite variable. The distribution of the first item, *I rely on a doctor to keep me healthy*, had a mean rating of 4.69 (SD= 1.5) and the second item, *I prefer a doctor just tell me how to deal with my health problems rather than give me choices*, had a mean rating of 2.48 (SD= 1.5). The standard correlation proved extremely low ($R=-.07$). We treated the two as measuring distinct dimensions of reliance and report each variable separately (5).

Initial analysis of both the Satisfaction with Consultation Scale and the Trust in Physician Scale was conducted to evaluate internal consistency. Both measures demonstrated high levels of internal consistency ($\alpha=.90$ and $\alpha=.81$ respectively).

An established content analysis approach was used for qualitative responses of patients' reasons to discuss CRII (28). In our previous research, six categories emerged from qualitative responses of patients' reasons for discussing CRII (19). These included *be proactive in improving health*, *appeal to the doctor as expert*, *become more educated*, *meet an emotional need*, *check up on or test the doctor*, and *miscellaneous*. In the current study, the first author categorized patients' reasons into one of the six categories. After categorizing all responses, the first author and the senior author (C.B.) met to review initial assignment. Agreement was reached and discrepancies resolved for each reason coded.

3. Results

Participants were predominantly Caucasian (78.6%), married (67.2%), and highly educated (84.3% an undergraduate or postgraduate degree). Participants were between 27.5 and 79.3 years old ($M=52.5$, $SD= 10.5$). Average time since cancer diagnosis was 3.6 years (range= .03 to 21.7 yrs, $SD= 4.6$). The majority had later stage (58.6%) and non-recurrent disease (90%). Most were seeing their doctor for a follow-up visit (77.1%). (See Table 1)

3.1 Patient characteristics associated with intent to discuss internet information

Aim 1 was to describe patient, disease and visit characteristics associated with RIUs' intent to discuss CRII. Of the 42 RIUs recruited, 19 (45.2%) reported a pre-consultation intent to discuss CRII and 23 (54.8%) reported that they did not intend to discuss CRII during their visit. No significant differences were demonstrated across patient characteristics, disease characteristics, and visit characteristics. (See Table 1) Comparisons revealed no significant differences between RIUs who intended to discuss and RIUs who did not intend to discuss across either physician reliance item. RIUs who intended to discuss CRII rated significantly higher pre-consultation state anxiety ($M=44.5$) compared to those RIUs who did not intend to discuss ($M=36.2$; $t(40)=-2.58$, $p=.014$).

3.2 Differences in patient satisfaction, anxiety reduction, and trust in physician associated with discussing or not discussing internet information

Our second aim was to examine differences in patient satisfaction, anxiety reduction, and trust in physician of CRII seekers who discussed CRII with their doctor compared to those who did not. Of the 42 RIUs recruited, half ($n=21$) reported in their post-consultation survey that they had discussed CRII with their doctor and half reported they had not. (See Table 2)

Post-consultation satisfaction proved to be relatively high among RIUs as a whole. With the scale's maximum satisfaction score being 125, RIUs reported a mean satisfaction score of 113.5 (SD=10.7). Results indicated no significant differences in terms of post-consultation satisfaction between those RIUs who discussed CRII with their doctors and those who did not. Trust in physician also proved to be high among RIUs. RIUs reported a mean trust score of 48 (SD=5.4) out of a maximum score of 55. No significant differences were observed between those RIUs who discussed CRII and those who did not. Finally, no significant differences were observed in change in anxiety score when comparing those RIUs who had discussed CRII with their doctor to those who had not.

3.3 Patients' reasons for discussing or not discussing internet information

The third aim of the study was to examine patients' reasons for discussing, or not discussing, CRII with their doctor. First, RIUs who discussed CRII that day and EIUs who discussed CRII at some point in the past were asked the open-ended question: "Why was it important to you to discuss this information with your doctor?" In total, 43 participants were asked this question, and 39 participants provided a response (response rate=90.6%). This included 20 EIUs and 19 RIUs.

As displayed in Table 3, the reasons why patients discussed CRII were coded into categories previously developed in research on cancer patients' decisions about discussing CRII.

Become more educated was the most frequently coded reason, accounting for 30.7% of responses. Responses in this category were related to using the CRII as a tool to become more knowledgeable through eliciting further information from the doctor or using that information to comprehend or confirm the information provided by the doctor.

Appeal to the doctor as expert was the second most frequently coded reason, with 23% of the responses falling within this category. Reasons in this category demonstrated the patient sought the doctor's opinion, advice, or knowledge in regard to the CRII.

Be proactive in improving health was the next most frequently cited reason, accounting for 20.5% of responses. These reasons were related to the patient actively seeking to improve treatment or outcome, being actively involved in care and decision-making, and/or wanting to demonstrate to their doctor that they are proactive.

Meet a psychological or emotional need accounted for 15.3% of the responses. Reasons within this category refer to discussing the cancer-related CRII in order to seek reassurance from the doctor through expressing and attempting to resolve a negative emotional experience or concern.

Second, reasons for not discussing CRII were collected from RIUs who did not discuss CRII during their consultation that day and EIUs who reported not discussing CRII during a consultation in their past. These patients were asked to rate the degree to which 14 reasons factored into their decision to not discuss CRII. 43 patients were asked to complete the items and 43 provided responses. This included 22 EIUs and 21 RIUs. Results are presented in Table 4. We examined both the percentage of those who rated reasons as factoring into their decision "a great deal" and those who rated reasons as factoring into their decision "a great deal" or "somewhat." *"I trust my doctor"* was the most endorsed reason, with 60.5% of patients indicating it factored into their decision a great deal. Reasons within this category refer to the patient trusting that their doctor knows what they are doing, are up-to-date with the latest information, or already knows the information the patient has found (19). *"I read the information for my own learning"* was the second highest endorsed reason, with 58.1% of patients indicating it factored a great deal into their decision to not discuss. The third and

fourth most highly supported reasons for not discussing CRII were, “*The information was consistent with what the doctor had told me*” and “*The information was not relevant*” (44.2% and 27.9% of patients respectively). When collapsing response options “factored into decision a great deal” and “factored into decision somewhat” the same four reasons for not discussing remained the most Endorsed.

4. Discussion and Conclusion

4.1 Discussion

The goal of this exploratory study was to better understand the factors that influence patients’ decisions to discuss CRII with their doctors. A number of patient variables have been identified that characterize those who tend to seek health-related internet information (3, 13–15). A purpose of this project was to explore whether we could similarly characterize those who tend to discuss CRII with their doctors. However, these results do not provide a clear picture of the types of cancer patients who choose to discuss CRII. Within our sample, patient characteristics such as age, marital status, race/ethnicity, and education level did not signify an increased likelihood of intent to discuss CRII. Similarly, disease characteristics and visit characteristics did not indicate which patients were more likely to arrive at their consultation intending to discuss CRII. Further, anxiety reduction, trust in physician and physician reliance had little association with CRII discussions. These findings suggest that the likelihood of discussing CRII may be attributable to variables outside of those that explain the likelihood of having read CRII.

However, patients who were planning to discuss CRII rated significantly higher anxiety than patient who were not planning to talk about CRII. Higher anxiety levels of patients intending to discuss CRII may relate to nervousness about discussing CRII (3, 9, 19). Alternatively, these patients may be more anxious in general about their disease, leading them to seek CRII in the first place.

One contributing factor to whether or not patients discuss CRII may lie within attributes of the information. Within our subsample of patients who had discussed CRII, 23% believed it was important to discuss in order to seek the advice, opinion or knowledge of their doctor. Previous research has demonstrated that, counter to expectations, internet use increases health information seeking from doctors and visits to the doctor (29). Aspects of CRII may lead to uncertainty in the patient, triggering her to seek the doctor’s expertise. Further, CRII does not negate information obtained from doctors. These sources of information can coexist and complement one another (29).

Patients’ reasons for not discussing CRII also appear to be influenced by aspects of the information obtained. For example, *the information was consistent with what the doctor had told me*, *the information was not relevant*, and *I did not think the information was accurate* ranked high among reasons given the most weight in terms of decisions not to discuss CRII. Across these examples, the quality of the information most impacted patients’ decisions to not discuss it in their consultation.

Another factor contributing to patients’ decisions to discuss or not discuss CRII relates to the patient’s preferred role within their treatment and the doctor-patient relationship. Patients’ level of involvement in decision making and communication varies from a passive to a more active preference (30). A large number of patients reported they discussed CRII in order to become more educated or to be proactive in improving their health, while others said they didn’t discuss CRII because they read it for their own learning. This demonstrates that even among a highly active or participatory breast cancer patient sample, there are still

varying degrees to which these patients perceive their role in treatment and with their provider.

Still another contributing to patients' decisions to discuss or not discuss CRII relates to aspects of the doctor-patient relationship. Particularly, the level of physician trust may be contributing to the likelihood of patients discussing or not discussing. We quantitatively measured trust in physician with RIUs, and found that this factor had little interaction with internet discussions. This result is likely due our small sample size and a restricted range with most patients rating a high level of trust in their physician. Still, examination of the mean difference and confidence interval suggest that those who discussed CRII trended towards reporting higher levels of physician trust. Further, trust in physician emerged as the most endorsed reason for not discussing CRII. It has been suggested that high physician trust decreases the likelihood of a patient seeking internet information (31). If such a patient has a concern they are more likely to seek the advice and opinion of their doctor. The current results expand upon this finding, suggesting that a high level of physician trust may attenuate the need for a patient to discuss the information they read online.

The current study has several limitations. Despite our best recruiting efforts, we had difficulty accruing patients who had read CRII. As a result, our sample size is low. This limitation increases the likelihood of null findings. The majority of participants were Caucasian (78.6%) and highly educated. This limits the generalizability of our findings. Another limitation of the current study is that 47% of RIUs were recruited from one doctor. The size of our sample didn't allow for us to statistically control for this factor. It is possible that there is something unique about this particular doctor or her patient population that makes them more likely to search for and discuss CRII. Finally, the mean time since diagnosis was 3.6 years and the mean time since the first visit was 1.8 years. Although we found no differences by visit type, it is plausible that we would have found greater recent seeking and discussion of CRII closer to the time of diagnosis and treatment planning. Thus, there is a need to replicate these findings with patients more proximal to their diagnosis.

4.2 Conclusion

The internet continues to play an important role in how patients develop an understanding of their cancer, prognosis, and treatment. Patients arrive at consultations prepared to discuss treatment alternatives, statistics, and other information they have obtained on the internet. As a result, internet information impacts various aspects of healthcare communication, patient outcome, and the doctor-patient relationship. The results of this exploratory study indicate that patients' decisions about whether to discuss CRII with their doctors are complex and may have to do with factors other than patient, disease or visit characteristics. Future research should examine the influence of attributes of CRII (e.g., relevance, hopefulness, perceived accuracy, etc.), patients' anxiety-level, patients' preferred role in treatment and in the doctor-patient relationship, and physician trust.

4.3 Practice Implications

Developing an understanding of the factors that make a patient more or less likely to discuss CRII has important implications for improving quality of care and developing communication interventions to address these influential and often difficult discussions. Further, filling this gap in the literature will work toward illuminating how patients use CRII within their treatment, understanding, and healthcare interactions. Toward that end further research is warranted.

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Figure 1.
Study Design and Recruitment Schema

Table 1

Descriptive Statistics of Demographic and Key Study Variables

	Participants (n= 70)	Intent to Discuss (n=19)	No Intent to Discuss (n=23)
Demographics			
Age	M= 52.5 (SD= 10.5)	M=53.8 (SD=10.2)	M=48.9 (SD=9.2)
Race			
<i>Caucasian</i>	55 (78.6%)	17 (89.5%)	15 (65.2%)
<i>Non-Caucasian</i>	15 (21.4%)	2 (10.5%)	8 (34.8%)
Marital Status			
<i>Married</i>	47 (67.2%)	14 (73.7%)	13 (56.5%)
<i>Non-Married</i>	22 (31.4%)	5 (26.3%)	10 (43.5%)
<i>Unknown</i>	1 (1.4%)	0 (0%)	0 (0%)
Education Level			
<i>High School/Technical Degree</i>	11 (15.7%)	4 (21.1%)	4 (17.4%)
<i>Undergraduate Degree</i>	28 (40%)	5 (26.3%)	8 (34.8%)
<i>Graduate Degree</i>	31 (44.3%)	10 (52.6%)	11 (47.8%)
Disease Characteristics			
Disease Stage			
<i>Early Stage Disease (Stage I)</i>	29 (41.4%)	12 (63.2%)	11 (47.8%)
<i>Later Stage Disease (Stage II, III, or IV)</i>	41 (58.6%)	7 (36.8%)	12 (52.2%)
Recurrent Disease	7 (10%)	3 (15.8%)	2 (8.7%)
Time Since Diagnosis	M= 3.6 yrs (SD=4.6)	M=3.9 yrs (SD=5.8)	M=2.3 yrs (SD=3.2)
Visit Characteristics			
Visit Type			
<i>Follow-up</i>	54 (77.1%)	11 (57.8%)	17 (73.9%)
<i>New Visit</i>	16 (22.9%)	8 (42.1%)	6 (26.1%)
Number of Visits	M= 10.2 (SD= 13.6)	M=10.3 (SD=16.6)	M=8.2 (SD=10)
Time Since 1st Visit	M= 1.8 yrs (SD=2.6)	M=1.6 yrs (SD=2.5)	M=1.6 yrs (SD=2.5)

Table 2

Satisfaction, Trust in Physician, and Anxiety Ratings for Aim 2 Comparison Groups.

	CRII Discussions		
	Yes (n=21)	No (n=21)	Total (n=42)
	Mean (SD)	Mean (SD)	Mean (SD)
Satisfaction (Post-consultation)	116 (9.4)	111 (11.5)	113.5 (10.7)
Trust in Physician (Post-consultation)	49 (4.9)	46.9 (5.7)	48 (5.4)
State Anxiety (Pre-consultation)	42.1 (12.6)	37.7 (9)	39.9 (11.1)
State Anxiety (Post-consultation)	38.1 (15.9)	32.9 (11.2)	35.6 (13.9)

Table 3

Patients' Reasons for Discussing Internet Information

Reason Code	Frequency	Percent
Become more educated	12	30.7%
Appeal to the doctor as expert	9	23%
Be proactive in improving health	8	20.5%
Meet a psychological or emotional need	6	15.3%
Miscellaneous	4	10.2%

Table 4

Patients' Reasons for Not Discussing Internet Information

	Factored Into Decision
Reason for Not Discussing	<i>Combined (a great deal + somewhat)</i>
I read the information for my own learning.	36 (83.7%)
I trust my doctor.	32 (74.4%)
The information was consistent with what the doctor had told me.	29 (67.4%)
The information was not relevant.	25 (58.1%)
I already spoke to my doctor about it.	14 (32.6%)
I did not think the information was accurate.	14 (32.6%)
It seemed that there was not enough time to discuss it.	14 (32.6%)
I already spoke to another doctor about it.	11 (25.6%)
I didn't want the doctor to feel offended or threatened that I had read the information.	6 (14%)
My doctor does not view the type of treatment I read about as valid.	4 (9.3%)
My doctor wouldn't have been interested in this information.	3 (7%)
I didn't want to bother my doctor with the information.	3 (7%)
I would have been embarrassed to tell the doctor that I had been reading internet information.	2 (4.7%)
I didn't want the doctor to think I was overly concerned.	2 (4.7%)