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# Examining Cross-Source Engagement With Cancer-Related Information and Its Impact on Doctor–Patient Relations

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Patients may bring unreliable information to the physician, complicating the physician–patient relationship, or outside information seeking may complement physician information provision, reinforcing patients’ responsibility for their health. The current descriptive evidence base is weak and focuses primarily on the Internet’s effects on physician–patient relations. This study describes how cancer patients bring information to their physicians from a range of sources and are referred by physicians to these sources; the study also examines explanations for these behaviors. Patients with breast, prostate, and colon cancer diagnosed in 2005 ( $N = 1,594$ ) were randomly drawn from the Pennsylvania Cancer Registry; participants returned mail surveys in Fall 2006 (response rate = 64%). There is evidence that both bringing information to physicians and being referred to other sources reflects patients’ engagement with health information, preference for control in medical decision making, and seeking and scanning for cancer-related information. There is also evidence that patients who bring information from a source are referred back to that source.

Patients receive a great deal of information about cancer and its treatment from their doctors and other health professionals (Carlsson & Strang, 1999; Dunkel-Schetter, 1984; Guidry, Aday, Zhang, & Winn, 1998; Newall, Gadd, & Priestman, 1987; Silliman, Dukes, Sullivan, & Kaplan, 1998). At the same time patients often obtain cancer-related

information from other nonclinical sources (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Fallowfield, Ford, & Lewis, 1994; Meredith et al., 1996). Many published studies address each of these flows of information and their effects (Epstein & Street, 2007; Luker et al., 1995; Northouse & Northouse, 1987; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). However, few studies address the intersection of these two flows of information: in particular, whether and how medical and nonmedical sources are brought together. Are patients treating these two flows of information as

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discrete, considering each separately, or is there cross-source engagement? Specifically, what do patients bring to their doctors from their nonclinical information exposures? And, recognizing that the flow may well be two-way, where do doctors send their patients? These are the questions we begin to investigate in this study, describing cross-source engagement and thus building a foundation for subsequent studies of effects. In addition, we investigate some antecedents of these behaviors.

There is a small literature that addresses this intersection between nonclinical and medical sources; however, it has three substantial limitations. First, much of it is non-empirical—articles that express concerns about how patients bringing information from outside might negatively affect the clinician–patient relationship. Second, there is very little that deals with conventional media and interpersonal sources; recent studies have tended to focus primarily on Internet use for health information seeking, and its impact on doctor–patient relations (Diaz, Griffith, Ng, Reinert, Friedmann, & Moulton, 2002; Fox & Rainie, 2000; Murray et al., 2003). Surveys of Internet use and the impact of health seeking and discussion of health information by patients on doctor–patient relations have also tended to recruit nonrepresentative samples such as Internet users (Fox & Rainie, 2000), or samples of health-care providers only (Helft, Hlubocky, & Daugherty, 2003; Newnham et al., 2005), or small samples of patients from one location (Chen & Siu, 2001). Other studies recruited samples from a limited geographical area, for example, patients from a primary care medical practice (Diaz et al., 2002), or patients with breast cancer from a medical center (Fogel, Albert, Schnabel, Ditkoff, & Neugu, 2002).

This is the first study, to our knowledge, that empirically examines the nature of cancer patients' cross-source engagement with information from a broad range of nonclinical sources. This study will provide important new information about the nature of patient engagement with clinical and non-clinical information, sharply expanding both consideration of what sources are brought to doctors and complementing consideration of the sources to which doctors refer patients for information. First, we will look at five conceptually and theoretically distinct categories of explanations that we hypothesize will account for the frequency with which cancer patients bring information from external sources: (a) demographic characteristics of cancer patients, (b) patients' skills and abilities to engage with and make sense of health information, (c) patient illness characteristics, (4) patient preference regarding decision making about treatment, and (e) frequency of seeking and scanning for treatment-related information. In addition, we will consider four theoretically distinct categories of explanations that we hypothesize will account for the frequency with which physicians refer patients to other sources: (a) demographic characteristics, (b) patients' motivation to seek additional information, (c) patients' skills and abilities to engage with and make sense of health information, (d) patient illness characteristics.

## WHAT ACCOUNTS FOR CROSS-SOURCE ENGAGEMENT AMONG CANCER PATIENTS?

### Demographic Characteristics

Several studies have found that demographic characteristics such as gender and ethnicity are associated with increased seeking of health information among cancer patients (Fogel et al., 2002; Marcus, Woodworth, & Strickland, 1993; Muha, Smith, Baum, Ter Maat, & Ward, 1998; Rakowski, Assaf, Lefebvre, Lasater, Niknian, et al., 1990). Vulnerable populations, including the elderly and members of ethnic minority groups, often have limited access to sources of key health information, especially that which is available on the Internet (Science Panel on Interactive Communication and Health, 1999). We hypothesize that individual-level characteristics such as age (younger rather than older), gender (female rather than male), race/ethnicity (White vs. African American) should account for patients' cross-source engagement with external sources of information. In addition, we examine the possibility that currently employed respondents may have better access to the Internet and similar sources than non-employed respondents and thus be more able to take advantage of these sources and bring information from them to their physicians.

### Patients' Skills and Ability to Engage With Health Information

Patients' skills in engaging with and making sense of health information, which has been conceptually defined in a number of studies as *health literacy*, are increasingly recognized as a critical factor affecting patient–physician communication and health outcomes (Williams, Davis, Parker, & Weiss, 2002). Health literacy has been described as “an ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (American Medical Association, 1999; Selden, Zorn, Ratzan, & Parker, 2000). People at greatest risk for poor health outcomes include those with poor health literacy, such as the elderly, members of ethnic minority groups, or those who have limited education (Kreps, 2005). Although this study does not include a direct measure of health literacy, we use patients' education, health media use, and the availability of a proxy seeker for cancer-related information as indicators of the patient's ability to engage with health information with the expectation that these will be associated with bringing information to the physician.

H1a: Patients' education will be positively associated with bringing information from external sources to their physicians.

H1b: Patients' health media use will be positively associated with bringing information from other sources to their physicians.

H1c: Having a proxy seeker available will be positively associated with bringing information from other sources to the physician.

### Patient Illness Characteristics

We hypothesize that patients' poor general health (self-reported) and patients who report higher frequency of doctor visits will bring more information from other sources than patients whose illness characteristics are less grave. Patients in poor health are likely to be more motivated to seek out additional sources of information to address concerns about their health, and consequently more likely to bring information from these sources to their physicians. We assess patient illness characteristics by patients' general health status and the frequency of their visits to their physicians. We have no *a priori* expectations as to the effects of type of cancer or stage of cancer on variation in bringing information from external sources.

H2a: Patients reporting poor general health will bring information from a greater variety of sources to their physicians than will patients with good general health.

H2b: Frequency of doctor visits will be positively related to bringing information to physicians.

### Patient Preference Regarding Involvement in Medical Decision Making

In addition, we hypothesize that patients' preferences with regard to involvement in decision-making about treatment will be associated with bringing information to their doctor. Patients who express greater desire for control in decision making related to their treatment are expected to bring information to their physician more frequently than patients who prefer that their physician be in greater control of the decision-making process.

H3: Patients who express a desire for greater decision-making control regarding treatment will bring information from a wider range of sources to their physician than patients who prefer that their physician make decisions regarding their illness and possible treatment.

### Seeking and Scanning for Cancer-Related Information

There is a great deal of research into how seeking for health information and other sources affect decisions among cancer patients (Czaja, Manfredi, & Price, 2003; Dolinsky, Wei, Hampshire, & Metz, 2006; Markman, Markman, Belland, & Peterson, 2006; Rees & Bath, 2001; Talosig-Garcia & Davis, 2005; Zanchetta, Perreault, Kaszap, & Viens, 2006). We define *seeking* as actively searching for information related to cancer. There are also studies that look at more

passive information gathering (e.g., Atkin, 1973; Berger, 2002; Bornstein, Leone, & Galley, 1987; Case, 2002; Griffin, Dunwoody, & Newirth, 1999; Krugman & Hartley, 1970; Slater, 1997; Tewksbury, Weaver, & Maddex, 2001; Zukin & Snyder, 1984). We include a measure of passive information gathering, which we refer to as *scanning* and define here as "information acquisition that occurs within routine patterns of exposure to mediated and interpersonal sources that can be recalled with a minimal prompt" (Niederdeppe et al., 2007). To our knowledge, no comprehensive attempts have been made to examine the relationship between cancer patients' seeking and scanning behavior and cross-source engagement with external sources of information (including mass media, interactive media, and interpersonal sources) or to physician referral to these sources. We hypothesize that patients' breadth of active seeking and scanning of cancer-related information from medical, interpersonal, mass media, and interactive media sources will be positively associated with bringing information to the physician.

H4a: Patients who report actively seeking cancer-related information from a wider range of sources will report greater variation in bringing information from other sources to their physician.

H4b: Patients who report scanning cancer-related information from a wider range of sources will report greater variation in bringing information from other sources to their physician.

### What Accounts for How Often Doctors Send Their Patients to External Sources?

To address this second question, we propose hypotheses derived from four theoretically distinct categories that we expect will account for variation in physician referral: (a) demographic characteristics, (b) patients' motivation to seek additional information, (c) patients' skills and abilities to engage with and make sense of health information, and (d) patient illness characteristics. However, it should first be pointed out that one limitation of this study is that it is a survey of cancer patients and does not include direct measures of physician characteristics, behaviors, or perceptions.

### Demographic Characteristics

As discussed earlier, patient demographic characteristics such as gender and ethnicity have been shown to be related to access to health information in a number of studies and are hypothesized, in this study, to account for bringing information to physicians. We also expect that these characteristics will, in part, account for variation in the frequency with which physicians refer patients to external sources.

### Patients' Skills and Abilities to Engage With and Make Sense of Health Information

Further, we expect that doctors who perceive their patients as being capable of making use of outside sources of information will be more likely to send patients to other sources. Factors that might influence a doctor's evaluation of the patient's capability include the patients' education (higher education indicating greater capability, especially with regard to interactive media sources such as the Internet), the frequency of their health media use, their preferences regarding autonomy in decision making relating to treatment, and the availability of a proxy for information seeking.

- H5a: Patients' education will be positively associated with physician referral to external sources.
- H5b: Patients' health media use will be positively associated with physician referral to external sources.
- H5c: Patients who have a proxy seeker will report greater physician referral to external sources than patients without a proxy seeker.
- H5d: Patients who express a desire for greater decision-making control regarding treatment will report greater physician referral to external sources.

### Patient Illness Characteristics

In line with the rationale behind the hypotheses that these characteristics should account for patients' bringing information to their physicians, we expect that patients' illness characteristics will be associated with physician referral so that patients in poorer health and patients reporting more frequent visits to the physician will report greater physician referral than patients in better health or patients with greater certainty as to treatment. We have no *a priori* expectations as to the effects of type on cancer or stage of cancer on physician referral.

- H6a. Patients reporting poor general health will be referred by physicians to a greater variety of sources than patients with good general health.
- H6b: Patients' frequency of visits to the physician will be positively related to physician referral to external sources.

### Patients' Motivation to Seek Additional Information

Finally, we expect that doctors will respond to their perception of their patient as interested in information from external sources and will consequently refer those patients to a wider range of sources. We hypothesize that physicians will assess patient motivation to seek out outside information by how often patients bring information from these sources to the doctor and will consequently be more likely to refer patients whom they perceive as more motivated to seek additional information from other sources.

- H7: Patients' bringing of information from external sources to their physician will be positively associated with variation in physician referral to other sources.

## METHOD

Our sample includes patients diagnosed with breast cancer, colorectal cancer, and prostate cancer. These are three of the most prevalent cancer types affecting the U.S. population today (American Cancer Society, 2008). Consequently, our sample represents a sizeable population of patients diagnosed with cancer in the United States. Breast cancer ranks second as a cause of cancer death in women (after lung cancer; American Cancer Society, 2008, p. 9). Prostate cancer is the most frequently diagnosed cancer in men. Colorectal cancer is the third most common cancer in both men and women.

Breast, prostate, and colorectal cancer patients were stratified by cancer and randomly sampled from a list of patients diagnosed in 2005 obtained from the Pennsylvania Cancer Registry. Physicians and hospitals are required by law to report all incidences of cancer to the registry. The list was provided in Fall 2006; the registry estimated that its list included approximately 95% of all cases that would eventually be included on the list. Sample members were surveyed by mail following standard methodology (Schaeffer & Dillman, 1998) and received a small incentive. The overall response rate, adjusted for estimated deaths, was 68% for breast, 61% for colon, and 64% for prostate cancer (AAPOR (American Association for Public Opinion Research) response rate #4<sup>1</sup>; AAPOR, 2005.) Weights were calculated to ensure that sample participants were comparable to the population of registry cases based on the following variables: age, date of diagnosis, marital status, stage of disease, race (majority, African American, other minority), and sex (colorectal cancer only). Please refer to Table 1 for sample demographic information.

The data were collected between September and November of 2006, between 9 and 23 months after diagnosis ( $M = 15.5$  months.) The survey was a professionally designed 9 × 11 booklet and was tailored according to the type of cancer (e.g., use of breast, colon, or prostate cancer on the survey

<sup>1</sup>AAPOR response rate # 4 refers to the method by which the response rate was calculated for the survey. The American Association for Public Opinion Research has created a standardized definition of a response rate, which distinguishes between the response rate and the cooperation rate, covers household, telephone, mail, and Internet modes of administration, discusses the criteria for ineligibility, and specifies methods for calculating refusal and noncontact rates. As a result, response and nonresponse rates can now be successfully compared across surveys of different topics and organizations. In addition, these definitions and their widespread acceptance have resulted in a greater willingness of researchers to report low response rates. Researchers should always include in their survey reports the response rate, computed according to the appropriate AAPOR formula, in this case it is response rate no. 4.

TABLE 1  
Demographic Characteristics of Sample

Demographic Characteristic	Unweighted (N = 1,582)		Weighted (N = 1,594)	
	Frequency	%	Frequency	%
Female	800	50.6	803	50.4
Race/ethnicity				
White	1333	84.3	1386	87.9
African American	231	14.6	193	12.1
Hispanic	43	2.7	48	3.0
Education				
High school diploma or less	892	56.4	908	57.6
Some college/2-year degree	354	22.4	337	21.4
College graduate and beyond	336	21.2	331	21.0
Age				
24–50	180	11.4	159	10.0
51–60	361	22.8	290	18.2
61–70	443	28.0	434	27.3
71–80	400	25.3	434	27.2
81–105	198	12.5	276	17.3
Marital status				
Married	1060	67.0	957	60.8
Not married	522	33.0	616	39.2
Cancer				
Breast	518	32.7	523	32.8
Prostate	495	31.3	494	31.0
Colon (male)	287	18.1	296	18.6
Colon (female)	282	17.8	280	17.6
Stage of cancer				
<i>In situ</i> /localized	951	60.1	1059	68.3
Regional spread	343	21.7	330	21.3
Metastatic	288	18.2	161	10.4

cover as appropriate). The survey included 61 questions. The survey was pilot tested and revised using in-person interviews with cancer patients.

## Measures

All the information variables used in these analyses are dichotomies. Patients were classified as to whether or not they reported they had brought information from any other sources to their physicians and whether they brought information from each of seven specific sources of information: other doctors or health professionals; family members, friends, or coworkers; other cancer patients; books, brochures, or pamphlets; the Internet; television, radio, newspapers, or magazines; telephone hotlines, face-to-face support groups, or on-line support groups, friends, or coworkers; other cancer patients; books, brochures, or pamphlets; the Internet; television, radio, newspapers, or magazines; telephone hotlines; face-to-face support groups; on-line support groups.

Similarly, patients reported whether they had been referred to any other sources by their physicians and whether they had been referred to each of the same seven sources of information. The analysis included the following

cancer-related and demographic variables: Type of cancer (colorectal [colon] cancer, breast cancer, or prostate cancer); stage of cancer (stages 0–4, based on Pennsylvania Cancer Registry data), availability of a proxy seeker, general health status (a 5-point item ranging from *poor* to *excellent*), frequency of doctor visits in the previous year, and patients' age (years), gender, education (years), race/ethnicity, and marital status, as well as health media use (an index summing responses to frequency of Internet, newspaper, health magazine, TV news, and general TV show health media use).

To create a measure of variation in bringing information from external sources, responses were summed across all sources so that the outcome was a continuous measure of bringing information ranging from 0 (*brought from no sources*) to 11 (*brought from all sources*). A similar measure of variation in physician referral was created when responses were summed across all sources so that the outcome was a continuous measure of physician referral from 0 (*not referred to any external sources*) to 11 (*referred to all sources*). Similarly, measures of overall seeking and overall scanning were created that summed responses across all sources.

Analyses report frequencies, ordinary least squares, and logistic regressions using Stata (release 10), using the survey programs to calculate confidence intervals corrected for weights. Analyses using ordinary least squares regression were performed with the Stata 10 survey module (Statacorp, 2007), with the ICE add-in package for multiple imputation of missing data by chained equations (Royston, 2005). Missing data on covariates were handled using multiple imputation, which produces consistent and unbiased estimates when missing-at-random assumptions are met (Allison, 2001; Little & Rubin, 2002; Rubin, 1987). Fifteen imputed data sets were generated for the analyses.

## RESULTS

The unweighted demographic characteristics of the sample are presented in Table 1. Four fifths of the sample (82%) reported actively seeking information from one or more other sources besides their physician. Of those who reported active seeking, 73.2% brought information from an outside source to their physician. Thus 62.7% reported bringing information from some outside source to their treating physician. Respondents brought a range of sources to their physician. Around one fourth of the sample reported bringing information from other medical sources, other personal contacts, cancer patients, and printed materials like books or pamphlets. Less than one in five brought information from the Internet, about the same number who brought information from a mass media source. Fewer than 1 in 10 brought information from any other source (Table 2).

Forty-four percent of the sample said their doctors sent them to other sources to obtain information (Table 3).

TABLE 2  
Frequency With Which Participants Reported Bringing Information From Other Sources to Their MD ( $n = 1,594$ )

	%
Brought information from any other sources <sup>a</sup>	62.7
% who brought information from . . . <sup>b</sup>	
Other doctors or health professionals	28.7
Family members, friends, or coworkers	33.9
Books, brochures, or pamphlets	28.2
Other cancer patients	26.2
Internet	18.6
TV, radio, newspapers, or magazines	18.1
Hotline or face-to-face or online support group	4.4

<sup>a</sup>Patients who report having actively sought information from their treating doctors are not included here.

<sup>b</sup>Across all sources, seeking and bringing information were significantly associated (chi-square test,  $p < .001$ ).

TABLE 3  
Frequency With Which Participants Reported Referral by MD to Other Sources of Information ( $n = 1,514$ )

	%
Doctor referred participant to other sources of information	44.7
% referred by doctors to . . .	
Other doctors or health professionals	24.1
Family members, friends, or coworkers	9.8
Books, brochures, or pamphlets	22.9
Other cancer patients	12.9
Internet	6.6
TV, radio, newspapers, or magazines	4.9
Hotline or face-to-face or online support group	9.8

However, the places physicians sent patients were, in part, different from those which patients brought to their physicians. Other medical professionals and printed materials were most common—one fourth of the sample, or more than half of those referred at all, were sent to those sources. Patients recalled being sent to the Internet 6.6% of the time, to other cancer patients (12.9%), other family members or friends (9.8%), or support groups (9.8%).

Tables 4 and 5 describe the factors that account for variation in bringing information from external sources (see H1–4), and variation in physician referral (see H5–7) to external sources of information. Model 2 in Table 4 and Model 2 in Table 5 were tested to see whether there were differences by cancer in variables predicting the likelihood of bringing information (Table 4) or of physician referral (Table 5). In addition, interactions between patient age, type of cancer, stage of cancer, and education were tested in these models. None of these interaction terms were significantly associated with either outcome.

Table 4 presents the results of ordinary least squares regression analyses on variation in the number of external sources from which patients brought information to their

physicians. Model 1 shows the bivariate associations between patients' demographic characteristics, skills with information engagement, illness characteristics, treatment decision-making preferences, and seeking and scanning of information from nonmedical sources on variation in bringing information. Model 2 shows the adjusted associations of these variables with the outcome, accounting for the effects of all other categories. The central column in Tables 4 and 5 shows the variance in bringing information to the physician (Table 4) and in physician referral (Table 5) accounted for by each category of explanations for these outcomes (unadjusted for other categories).

When regressed on bringing information without adjusting for other categories of explanations for the outcome, patient characteristics account for 7.6% of the variance in bringing information. The hypothesis that demographic characteristics should account for patients' bringing information to their physician was supported at the bivariate level. Patients' age was negatively associated with bringing information ( $\beta = -0.27$ , significance  $p < .001$ ). Patients who were employed ( $\beta = 0.15$ ,  $p < .001$ ) or married ( $\beta = 0.07$ ,  $p < .05$ ) were more likely to bring information to the physician. Patients' race was not associated with bringing information. In Model 2, once other covariates were entered into the model, patients' age, race, employment, and marital status were no longer significantly associated with bringing information, consistent with their effects being mediated through other variables.

Support was found at the bivariate level for the hypothesized association between patients' skills and abilities to engage with health information and variation in bringing information to the physician (H1a–H1c). Patients' education ( $\beta = 0.20$ ,  $p < .001$ ), health media use ( $\beta = 0.32$ ,  $p < .001$ ) and availability of a seeking proxy ( $\beta = 0.23$ ,  $p < .001$ ) were all positively associated with bringing information to the physician. When regressed on bringing information without adjusting for other categories of explanations for the outcome, patients' skills and abilities to engage with health information accounted for 18.2% of the variance in bringing information. However, when adjusted for other covariates (Model 2), the magnitude of the associations between health media use ( $\beta = 0.08$ ,  $p < .001$ ) and having a proxy seeker ( $\beta = 0.09$ ,  $p < .001$ ) decreased, although remaining significant (supporting H1b and H1c), whereas education is no longer significantly associated with bringing information, suggesting its effects are mediated through other variables (H1a).

Partial support was found for the hypothesis that patients' illness characteristics would account for bringing information. At the bivariate level, the hypothesis that patients' health status would be negatively related to bringing information to the physician (H2a) was supported ( $\beta = -0.01$ ,  $p < .001$ ), as was the hypothesis (H2b) that frequency of doctor visits would be positively related to bringing information to the physician ( $\beta = 0.20$ ,  $p < .001$ ).

TABLE 4  
Predicting Variation in Patients' Bringing Cancer-Related Information from External Sources to Physician ( $n = 1,602$ )

	<i>Model 1 (Bivariate)</i>				<i>R<sup>2</sup> (By Block)</i>			<i>Model 2 (Adjusted)</i>			
	<i>On Bringing Information</i>				<i>On Bringing Information</i>			<i>On Bringing Information</i>			
	<i>B</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>R</i>	<i>R<sup>2</sup></i>	<i>p</i>	<i>B</i>	<i>SE</i>	$\beta$	<i>p</i>
(Constant)								-0.95	0.39		*
Demographic Characteristics											
Age (years)	-0.40	0.04	-0.27	***				-0.01	0.04	0.00	
Employed (employed = 1)	0.61	0.13	0.15	***				0.03	0.11	0.01	
Marital status (married = 1)	0.26	0.10	0.07	*				-0.12	0.08	-0.03	
White (reference = Hispanic)	-0.17	0.14	-0.03					0.27	0.23	0.05	
Black (reference = Hispanic)	0.24	0.14	0.04					0.26	0.25	0.05	
<i>Block 1—Demographic characteristics</i>					.276	.076	<.001				
Skills and engagement with health information											
Education (years)	0.14	0.02	0.20	***				0.03	0.02	0.04	
Health media use	0.29	0.02	0.32	***				0.07	0.02	0.08	***
Has seeking proxy	0.87	0.10	0.23	***				0.34	0.08	0.09	***
<i>Block 2—Engagement with health information</i>					.427	.182	<.01				
Illness characteristics											
Stage (reference = stage 4)											
Stage 0	-0.10	0.16	-0.02					-0.04	0.16	-0.01	
Stage 1	-0.18	0.12	-0.04					0.01	0.11	0.00	
Stage 2	0.26	0.10	0.07	***				0.14	0.09	0.04	
Stage 3	-0.07	0.15	-0.01					-0.05	0.12	-0.01	
Health status	-0.01	0.06	-0.01	***				-0.12	0.05	-0.06	*
Cancer type (reference = breast cancer)											
Prostate cancer	0.45	0.10	0.12	***				0.22	0.10	0.06	*
Colon (female)	-0.68	0.11	-0.14	***				-0.10	0.11	-0.02	
Colon (male)	-0.64	0.11	-0.14	***				0.13	0.10	0.03	
Doctor visits	0.13	0.02	0.20	***				0.02	0.01	0.04	
<i>Block 3—Illness characteristics</i>					.305	.093	<.001				
Patient decision-making preference	0.33	0.06	0.16	***				0.09	0.04	0.04	*
<i>Block 4—Patient decision-making preference</i>					.157	.025	<.01				
Seeking and scanning for information											
Overall information scanning	0.57	0.02	0.67	***				0.44	0.03	0.52	***
Overall information seeking	0.52	0.03	0.46	***				0.19	0.03	0.17	***
<i>Block 5—Seeking and scanning information</i>					0.693	0.481	<.001				
<i>R</i>								.713			
<i>R<sup>2</sup></i>								.508			
<i>p</i>								>.001			

\* $p < .05$ . \*\*\* $p < .001$ .

When regressed on bringing information, without adjusting for other categories of explanations for the outcome, patients' illness characteristic accounted for 9.3% of the variance in bringing information. In Model 2, when adjusting for other covariates, health status (H2a) and cancer type remained significantly associated with bringing information. As patients' self-reported health status improved, they were less likely to bring information to their physicians ( $\beta = -0.06$ ,  $p < .05$ ). Prostate cancer patients are more likely to bring information to the physician than breast cancer patients ( $\beta = 0.06$ ,  $p < .05$ ). Stage of cancer was not significantly associated with bringing information when adjusting for other covariates.

In Model 1 we see a positive bivariate association between patient preference for autonomy in decision-making and

bringing information ( $\beta = 0.16$ ,  $p < .001$ ), which is consistent with hypothesis 3. When adjusting for other covariates, the effect of this variable is reduced ( $\beta = 0.04$ ,  $p < .05$ ) but remains positively associated with bringing information and accounts for approximately 2.5% of the variance in bringing information (unadjusted).

H4a and H4b were both supported. Model 1 shows strong positive associations between seeking ( $\beta = 0.67$ ,  $p < .001$ ) and scanning ( $\beta = 0.46$ ,  $p < .001$ ) and bringing information to the physician. When regressed on bringing information, without adjusting for other categories of explanations, patients' seeking and scanning behavior accounts for 48.1% of the variance in bringing information. Consistent with H5a and H5b, even once other covariates are included in the model (Model 2), the effect



TABLE 5  
 Predicting Variation in Physician Referral to External Sources of Cancer-Related Information ( $n = 1,586$ )

	<i>Model 1 (Bivariate)</i>				<i>R<sup>2</sup> (By Block)</i>			<i>Model 2 (Adjusted)</i>			
	<i>On Bringing Information</i>				<i>On Bringing Information</i>			<i>On Bringing Information</i>			
	<i>B</i>	<i>S.E.</i>	$\beta$	<i>p</i>	<i>R</i>	<i>R<sup>2</sup></i>	<i>p</i>	<i>B</i>	<i>S.E.</i>	$\beta$	<i>p</i>
<i>(Constant)</i>								0.47	0.34		
Demographic characteristics											
Age (years)	-0.27	0.03	-0.22	***				-0.11	0.04	-0.09	**
Employed (employed = 1)	0.49	0.10	0.15	***				0.10	0.11	0.03	
Marital status (married = 1)	0.19	0.08	0.06	*				0.00	0.08	0.00	
White (reference = Hispanic)	0.19	0.12	-0.04					0.18	0.16	0.04	
Black (reference = Hispanic)	0.24	0.13	0.05					0.27	0.18	0.06	
<i>Block 1—Demographic characteristics</i>					.232	.054	<.001				
Skills and ability to engage with health information											
Education (years)	0.04	0.01	0.08	**				-0.03	0.01	-0.05	*
Health media use	0.12	0.02	0.17	***				0.01	0.02	0.02	
Has seeking proxy	0.61	0.07	0.20	***				0.29	0.07	0.09	***
Decision-making preference	0.19	0.04	0.11	***				0.02	0.04	0.01	
<i>Block 2—Engagement with health information</i>					.277	.077	<.001				
Illness characteristics											
Stage (reference = stage 4)											
Stage 0	0.00	0.14	0.00					0.18	0.14	0.04	
Stage 1	-0.10	0.10	-0.03					0.14	0.11	0.04	
Stage 2	0.23	0.08	0.08	**				0.16	0.09	0.05	
Stage 3	0.09	0.13	0.02					0.34	0.12	0.07	**
Health status	0.06	0.05	0.03	**				0.03	0.04	0.02	**
Cancer type (reference = breast cancer)											
Prostate cancer	0.41	0.09	0.13	***				0.13	0.11	0.04	
Colon (female)	-0.54	0.08	-0.14	***				-0.29	0.10	-0.08	**
Colon (male)	-0.53	0.09	-0.14	***				-0.30	0.10	-0.08	**
Doctor visits	0.05	0.02	0.10	***				0.00	0.01	-0.01	
<i>Block 3—Illness characteristics</i>					.257	.066	<.001				
Patients' motivation to seek information											
Frequency of bringing information	0.40	0.03	0.58	***				0.34	0.03	0.49	***
<i>Block 4—Motivation to seek information</i>					.488	.238	<.001				
<i>R</i>								.526			
<i>R<sup>2</sup></i>								.277			
<i>p</i>								>.001			

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

of seeking ( $\beta = 0.52, p < .001$ ) and scanning ( $\beta = 0.17, p < .001$ ) on bringing information to the physician is reduced but remains significant and positive.

Table 5 presents the results of ordinary least squares regression analyses on variation in how often doctors send their patients to external sources. Model 1 shows the bivariate associations between variables that were hypothesized to account for variation in the number of sources to which physicians refer their patients for additional information. These covariates include demographic characteristics, as well as measures of the (perceived) capability of the patient to engage with information from external sources (indicated by education, lower age, availability of a proxy seeker), the (perceived) need of the patient for additional information (health status, stage of cancer, type of cancer,

and ambiguity as to treatment options), and the patient's interest in seeking information from external sources (as indicated by variation in bringing information from external sources to the physician).

When regressed on physician referral to external sources without adjusting for other categories of explanations for the outcome, patients' demographic characteristics account for 5.4% of the variation in physician referral. At the bivariate level, partial support is provided for the hypothesis that these characteristics are associated with physician referral. Patients' age is negatively associated with physician referral ( $\beta = -0.22, p < .01$ ). In addition, patients who are employed ( $\beta = 0.15, p < .001$ ) or married ( $\beta = 0.06, p < .05$ ) were more likely to report physician referral to external sources. However, when adjusting for other covariates in the model (Model 2),

patients' age is the only demographic characteristic that remains significantly and negatively associated with physician referral to other sources ( $\beta = -0.09, p < .01$ ).

Partial support was found for the hypothesis that patients' with greater skills and ability to engage with and make sense of health information will be referred by physicians to a wider range of sources (H5a–H5d). At the bivariate level (see Model 1), education ( $\beta = 0.08, p < .01$ ), health media use ( $\beta = 0.17, p < .001$ ), having a seeking proxy ( $\beta = 0.20, p < .001$ ), and preference for greater autonomy in decision-making ( $\beta = 0.11, p < .001$ ) were all positively associated with physician referral. When regressed on physician referral to external sources without adjusting for other categories of explanations for the outcome, patients' skills and ability to engage with and make sense of health information account for 7.7% of the variation in physician referral. After adjusting for the effects of other covariates, the effects of having a proxy seeker ( $\beta = 0.09, p < .001$ ) remained positive and significant, consistent with H5c. The effects of education on physician referral remain significant but are negative ( $\beta = -0.05, p < .05$ ), which is contrary to the hypothesized direction of association (H5a). Health media use (H5b) and decision-making preferences (H5d) were no longer associated with physician referral once other covariates were added to the model.

Only partial support was found for the hypothesis that patients' illness characteristics would account for variance in physician referral. This category of variables accounts for 6.6% of the variation in physician referral. Patients' health status was positively associated with physician referral, both at the bivariate level ( $\beta = 0.03, p < .01$ ) and after adjusting for other covariates ( $\beta = 0.02, p < .01$ ), supporting H6a. Stage of cancer was associated with physician referral at the bivariate level, when patients with stage 2 cancer were more likely than patients with stage 4 cancer to report physician referral to external sources ( $\beta = 0.08, p < .01$ ). After adjusting for other causally prior covariates (demographic variables), the association between stage of cancer with physician referral remained significant, but patients with stage 3 cancer were more likely than patients with stage 4 cancer to report physician referral to other sources ( $\beta = 0.07, p < .01$ ). Frequency of doctor visits was also positively associated with the likelihood of physician referral at the bivariate level ( $\beta = 0.10, p < .001$ ) but not after causally prior variables were entered into the model (H6b).

Type of cancer was also associated with physician referral. Colon cancer patients, both men and women, were less likely to report physician referral than breast cancer patients. This association between type of cancer and physician referral was evident both at the bivariate level ( $\beta = -0.14, p < .001$ ) and after adjusting for other covariates ( $\beta = -0.08, p < .01$ ). Prostate cancer patients were more likely to report physician referral to external sources than were breast cancer patients ( $\beta = 0.13, p < .001$ ), but this

association was not significant in the adjusted model (see Model 2).

Patients' perceived motivation to seek additional information was positively associated with physician referral to other sources, both at the bivariate level ( $\beta = 0.58, p < .001$ ) and after adjusting for other covariates ( $\beta = 0.49, p < .001$ ), supporting H7. Patients who brought information from a wider range of sources to their physician were more likely to be referred to a wider range of sources than patients who brought information less frequently. Frequency of bringing information to the physician, an indicator of perceived motivation to seek out additional information, accounted (unadjusted) for 23.8% of the variation in physician referral to other sources of information.

Table 6 presents odds ratios (ORs) and 95% confidence intervals (CIs) for the association of patients' bringing information to their physicians overall and across different sources with the likelihood of referral by doctor to the same source of information. The results presented are from logistic regression analyses of patients' bringing information from other sources on the likelihood of overall physician referral to other sources, as well as referral to each source separately.

The results in Table 6 show a strong association of patients' bringing information from other sources with the likelihood of overall referral to other sources (OR = 4.06,  $p < .001$ ). In addition, across all sources, patients' bringing of information from the predicted source was strongly associated with referral by doctors to the same source (ORs ranged from 4.17–10.68 across different sources). The association was strongest for interpersonal sources (OR = 6.08 for family and friends, and OR = 6.28 for other patients), support groups and telephone hotlines (OR = 6.08), and mass media sources (OR = 10.68).

TABLE 6  
Logistic Regression Analysis—Predicting Physician Referral to External Sources of Information

<i>Physician Referral to Other Source</i>	<i>OR</i>	<i>95% CI</i>
Overall physician referral	4.06***	3.06–5.39
Other doctors	4.71***	3.46–6.43
Family and friends	6.08***	3.67–10.02
Other patients	6.28***	4.12–9.57
Books, brochures, and pamphlets	4.17***	3.03–5.72
Internet	4.93***	2.76–8.80
TV, radio, newspapers, and magazines	10.68***	5.60–20.36
Telephone hotlines and support groups	6.08***	3.11–11.90

*Note.* Odds ratios (ORs) and 95% confidence intervals (CIs) for the association between variation in patients' bringing information to their physician overall and across different sources on variation in referral by doctor to the same source of information. Analyses control for demographic variables, referral by doctors to other sources (other than the predicted source), and type and stage of cancer ( $N = 1,527$ ).

\*\*\* $p < 0.001$ .

## DISCUSSION

Consistent with other studies, it is clear that most cancer patients (82%) report actively looking for information concerning their treatment choices. A large proportion of these seekers (and 62% of the whole sample) then brought information they found in other sources to their physicians. However, the sources they reported bringing information from were not limited to the Internet. Although the published literature often focuses on the Internet as the predominant source that physicians must respond to, less than 20% of all patients reported bringing Internet information. This finding highlights the need to broaden the focus of studies beyond looking at patients' engagement with information from the Internet or from other doctors.

This study explored factors associated with physician referral to external sources, which had not yet been examined to date among a representative sample of cancer patients. We found that information interaction is not unidirectional; nearly half of all patients (44%) reported that their physicians sent them to other sources, albeit in a narrower range. They were most commonly sent to other health professionals but also to books and pamphlets, and less frequently to other cancer patients. Less than 10% reported being sent to other personal sources, the Internet, telephone hotlines, or support groups. Patients do vary in their bringing of all sources, and in their likelihood of being referred. Most substantially, information use begets information use. Patients were far more likely to be sent to other sources overall (OR = 4.1) if they brought information from outside sources; they were far more likely to be sent to any specific source if they brought information from that source (ORs from 4.2–10.7.)

The effects of demographic characteristics and illness characteristics appear to be mostly mediated through more direct measures of patient's skills and abilities to engage with health information and the frequency with which they seek and scan for information. In particular, having a proxy seeker available and more frequent use of health media by patients appear to play important roles in facilitating access to information from a wider variety of sources, which is then more likely to be brought by the patient to the doctor-patient interaction, and also to be associated with physician referral to external sources of information. Although the effects of most demographic characteristics were mediated through other variables, patient age has an independent influence on physician referral, such that older patients are markedly less likely to report physician referral to other sources. This finding seems to suggest that older patients are perceived by physicians as less capable of making use of external sources than younger patients.

Patients' skills and abilities to engage with health information were shown to be associated with physician referral. Patients with more years of education were less likely to be referred to a wide range of sources, and patients who had a seeking proxy available to them were more likely to be

referred by physicians to external sources. The negative association between education and physician referral is not substantial but is contrary to expectations and perhaps of minor interest. It appears only once downstream variables are controlled, particularly seeking and scanning behavior. Educated people were less likely to be referred only when the strong tendency for them to seek out information that had a strong positive influence on referral was adjusted for.

Patients who brought information from other sources to their physician were also more likely to be referred to a greater variety of other sources, and in particular to the same source from which they brought information. This finding suggests that doctors who perceive their patients as motivated to use other sources respond positively to this behavior by encouraging the patients' engagement with external sources. However, the frequency of physician referral by source (Table 3) might suggest that, given that the majority of physician referrals are to other physicians, such referrals are a way of discounting the credibility of the patient-provided information. However, this seems less likely when one examines the association between the patients' bringing of information to the physician and physician referral across all sources (see Table 6). For any source, physician referral was at least 4 times as likely for patients who brought information from that source compared to patients who did not bring information from that source. If physicians were discounting the credibility of patient-supplied information, we might not expect this pattern. Thus, the heavier referral to other physicians and interpersonal sources may reflect a preference among physicians for those sources rather than a specific discounting of patient preferences.

The strong association between active seeking of and scanning for cancer-related information and variation in bringing information and physician referral reflects that seeking or scanning is a minimum condition for cross-source engagement, but also may suggest that there is an underlying style of information engagement among patients diagnosed with cancer, which is linked to all of these behaviors and attitudes. Future research should explore whether a comprehensive measure of a style of engagement with health information among cancer patients might lead to improved coping or other psychosocial and medical outcomes.

## Limitations

The study is cross-sectional, and consequently temporal order of observed associations cannot be established in many cases. For example, although Table 5 notes that doctors are more likely to send patients to information from sources they have brought to the doctors, the causal order is unclear. That is to say that we cannot know whether physician referral is a response to patients' bringing information or precedes it. Another limitation of the study is that reported frequency of bringing information and of referral

by doctors are based on patients' recall, and thus may potentially be an inaccurate reflection of the actual frequency of these events. A further limitation of the study is that the measures used have not been previously validated. However, a pretest of the measures was conducted with cancer patients, and existing literature was used to guide the development of these measures. Finally, the sample for this study was drawn from Pennsylvania, so our findings may not be generalizable to cancer patients in other areas

## CONCLUSIONS

This study moves the literature substantially forward in its use of a representative sample of patients, in its documentation of the wide variety of sources patients use in their discussions with their physicians, and in the recognition that patients not only bring information to their doctors but often are sent to other sources by their doctors. This study suggests that the Internet, although used by some patients, is only one of many sources being used in this cross-source conversation. Physician recognition of the frequency and breadth of patient information source use may help them guide their patients toward more productive use of these sources. Future research should document topics for which each source was used, and what the consequences of differential bringing and referral of information might be to cancer patient health outcomes.

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