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Navigating the cancer information environment: The reciprocal relationship between patient-clinician information engagement and information seeking from nonmedical sources

Mihaela Moldovan-Johnson, PhD¹, Andy SL Tan, PhD, MBBS, MPH, MBA², and Robert C Hornik, PhD²

¹Texas Department of State Health Services

²Center of Excellence in Cancer Communication Research, Annenberg School for Communication, University of Pennsylvania

Abstract

Prior theory has argued and empirical studies have shown that cancer patients rely on information from their health care providers as well as lay sources to understand and make decisions about their disease. However, research on the dynamic and interdependent nature of cancer patients' engagement with different information sources is lacking. This study tested the hypotheses that patient-clinician information engagement and information seeking from nonmedical sources influence one another longitudinally among a representative cohort of 1,293 cancer survivors in Pennsylvania. The study hypotheses were supported in a series of lagged multiple regression analyses. Baseline seeking information from nonmedical sources positively predicted subsequent patient-clinician information engagement at one-year follow-up. The reverse relationship was also statistically significant; baseline patient-clinician information engagement positively predicted information seeking from nonmedical sources at follow-up. These findings suggest that cancer survivors move between nonmedical to clinician sources in a dynamic way to learn about their disease.

Keywords

Patient-clinician communication; information seeking; medical and nonmedical sources

Introduction

The cancer information environment is rapidly changing to encompass a variety of emerging information technologies and increasing amounts of new cancer information (Niederdeppe, Frosch, & Hornik, 2008; Viswanath, 2005). Recognizing these transformations, it is essential to explore cancer patients' information seeking behaviors in order to better understand their experiences and address their needs in a modern informational landscape. Consequently, this study seeks to examine, through a longitudinal survey, the dynamic

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Corresponding author: Mihaela Moldovan, Address: 3620 Walnut Street, Philadelphia, PA 19104, mihaelamoldo@gmail.com.

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nature of cancer patients' engagement with information about their disease during their survivorship period. More specifically, it provides a formal test of the two-way relationship between active engagement with cancer-related information from clinician and nonmedical sources among breast, prostate and colon cancer survivors.

Informational Needs of Cancer Survivors

In recent years, researchers focused on understanding cancer patients' informational needs as well as the sources used to satisfy these needs (Luker, Beaver, Lemster, & Owens, 1996; M. E. Mills & Davidson, 2002; Nagler, Gray et al., 2010; Nagler, Romantan et al., 2010; Nair, Hickok, Roscoe, & Morrow, 2000). These studies described important patterns of information engagement among cancer patients. A central and unsurprising finding was that newly diagnosed cancer patients were very interested in acquiring information concerning their condition (Rutten, Arora, Bakos, Aziz, & Rowland, 2005).

For instance, cancer survivors wanted to learn about both the biological mechanisms of the disease and how the illness would impact their lives (Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999; Nagler, Romantan et al., 2010; Rutten et al., 2005; Squiers, Rutten, Treiman, Bright, & Hesse, 2005). Butow and colleagues (1997) noted that patients were concerned with information related to treatment options before visiting a doctor but after the visit, they were interested in topics related to care and managing fears. Similarly, individuals who called the Cancer Information Service desired general cancer-related advice, specific details about treatment, and information about support services and psychosocial issues (Squiers et al., 2005). Rutten and others further confirmed that patients have a variety of informational needs and that these needs may differ at each stage of the cancer continuum (Hesse, Arora, Burke Beckjord, & Finney Rutten, 2008; Rutten et al., 2005). Accordingly, the present study focuses on information engagement about a variety of topics among a cohort of cancer survivors one year after their treatment.

Additionally, researchers have concluded that most patients did not rely on only one source to retrieve information but rather employed multiple outlets (Mills & Davidson, 2002; Nagler, Gray et al., 2010; Nagler, Romantan et al., 2010; Nair et al., 2000; Ramsey et al., 2009). Even though the majority of patients reported their health professional as the preferred source of cancer information, information sources outside of the medical encounter including family, friends, other cancer patients, and media sources (e.g., newspaper, radio, TV, and the internet) were utilized as needed (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010; Hesse et al., 2008; Mayer et al., 2007; Nair et al., 2000; Ramsey et al., 2009; Rutten et al., 2005). While these results helped us develop a more complete understanding of the types of sources employed by cancer patients, they were fairly limited in describing the pathways of seeking across these main categories of information sources.

Theoretical Framework

Some researchers turned to the media displacement theory to explain how people use multiple sources of information (Dutta-Bergman, 2004a; Henke & Donohue, 1989; Kaplan, 1978). This displacement theory postulates that people dedicate a limited amount of time to

gather information, and the introduction of a new medium would reduce the time spent on existing sources. Extending from this framework of displacement, information seeking about cancer-related information is likened to a zero-sum game whereby seeking from one source would reduce an individual's seeking from other sources.

Critics, however, argued that time was not the only factor that would affect the use of various informational sources; overall interest in a specific content area might drive people to use multiple sources; also differences in the type of information offered by various outlets might mean that people use more than one media source to satisfy different needs (Dutta-Bergman, 2004a; Dutta-Bergman, 2004b; Kayany & Yelsma, 2000). These scholars further propose that the internal needs of individuals along with the differing characteristics of various sources lead individuals to use multiple sources. Dutta-Bergman, in making this claim, argued that media use would be better accounted for by an expectation of complementarity rather than by an expectation of displacement. There is some support for this expectation, including a recent study by Tian and Robinson (2008) who found support for complementary use of sources among a group of adults with and without cancer in the context of their cancer-related information seeking from the internet, traditional media, interpersonal sources, and health professionals.

It is likely that both displacement and complementarity expectations are true, under some circumstances. On one hand, if someone has only limited interest in a topic or high trust in one (probably clinician) source then use of one source may well reduce use of others, consistent with displacement theory. Contrarily, if interest is high and continuing, and/or the information needed is differentially available by source, one might well expect that use of one source will be positively associated with use of others, which is consistent with complementarity.

However, it is possible that it is not just patients' intrinsic interest in cancer-related information that drives their multisource use; the source use itself can increase one's desire to search other sources for information. Within this context, we assume that one's need for information is a dynamic phenomenon, such that upon engagement with a source, the status quo is altered to trigger additional information searches elsewhere. Content interest drives source use, as complementarity argument suggests, but source use drives new content interest as well, and that encourages the use of additional sources. So, with this study, we place our research questions within the larger field of research on information seeking behaviors and attempt to contribute to current knowledge by testing whether in addition to the negative and positive cross-sectional relationship found in displacement and complementarity studies, a longitudinal effect of the use of one source on the use of others also exists. Specifically, adjusting for individuals' interest in health information and health involvement, we would still expect to find a predictive effect of information engagement from one set of sources on additional seeking of information from other sources.

Given the complexity of attempting to assess inter-relationships from a multitude of information sources, we chose to focus on the two main categories of health information sources that are most salient to cancer patients and are documented in the literature—medical professionals with whom patients have direct interactions and information sources

outside of the medical encounter (interpersonal or media sources as described earlier). These categories of sources will be further elaborated in the methods section. Within this focused context, we hypothesize that the engagement with physician or particular events that take place during the medical encounter increase the likelihood of patients' seeking additional information from nonmedical sources. Conversely, certain elements embedded within nonmedical sources may trigger subsequent interest in engaging with clinicians for information. Since current theoretical perspectives do not explicitly expect a reciprocal relationship between seeking from different information sources, we relied on earlier observational studies that hint at the processes underlining this proposed relationship (Caiata-Zufferey et al., 2010; Chen & Siu, 2001; Lee, 2008; Murray et al., 2003; Newnham et al., 2006; Stevenson, Kerr, Murray, & Nazareth, 2007).

Patients' Engagement with Medical and Nonmedical Sources

There are prior studies which provide some support for a reciprocal relationship between engagement with information from clinician sources and nonmedical sources and suggest likely mechanisms for the effect. Lewis et al. (2009), using survey data, found that 63% of cancer patients reported bringing information from nonmedical sources such as family, friends and media to discuss with their treating physician, and 45% reported that their treating physicians often sent them to other sources. Nagler, Romantan, and colleagues (2010), making use of in depth interview data, reported that following engagement with physicians, cancer patients were likely to initiate additional information seeking from several nonmedical sources, and that engagement with nonmedical sources often led to further discussions with physicians.

Describing the reasons for the cross-source information engagement from nonmedical to medical sources, Nagler and colleagues (2010) noted that media coverage of medical innovations and patients' difficulty in understanding this novel information can trigger additional engagement with physicians for information. Other aspects of the media environment, such as the presence of direct-to-consumer advertisements, may also raise concerns among patients and prompt them to consult their doctors in order to clarify those issues (Murray, Lo, Pollack, Donelan, & Lee, 2004; Weissman et al., 2003). Finally, sources of information outside the healthcare system often advise patients to contact their physicians to obtain tailored information about specific issues being considered. From these studies, we surmise that particular content derived from media sources may be motivating patients' information seeking from their physicians.

In the opposite scenario, the flow of information seeking from clinician sources leading to seeking from nonmedical sources has several explanations too. For instance, patients may search nonmedical sources after the encounter with physicians to find answers to new questions that were raised but left unanswered by their doctors, to validate medical information, and determine whether other possibilities, besides the ones recommended by doctors, exist for treatment and care (Caiata-Zufferey et al., 2010; Nagler, Romantan et al., 2010). This movement may also reflect doctors' advice to patients to engage with other sources of information (Lewis et al., 2009) as physicians may have recognized that

providing patients with the desired amount and type of information is likely to lead to high quality patient care (Epstein & Street Jr., 2007).

It is important to note that even though we highlighted these paths as the possible underlying mechanisms for our hypothesis of reciprocal influence, in the current study we will not attempt to confirm or refute these mechanisms given that we do not have detailed narratives about the process. Rather we seek to show empirically that there is support for a reciprocal relationship in the context of a longitudinal approach. In addition, our study builds on prior research which examined the lagged influence of internet use on contact with health professionals for health information and vice-versa (Lee, 2008). This earlier study surveyed participants sampled from an internet panel and showed a positive and significant lagged relationship between internet use at baseline and physician contact at follow-up but a non-significant relationship for the reverse association. Our study furthers this area of research by focusing on a representative sample of cancer patients and by including an array of nonmedical sources (as opposed to solely Internet). Past research indicates that patients use a multitude of nonmedical sources (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010; Hesse et al., 2008; Mayer et al., 2007; Nair et al., 2000; Ramsey et al., 2009; Rutten et al., 2005). Therefore, it is necessary to incorporate a broader range of information sources in measuring patients' seeking behaviors. Furthermore, gaining insights into the different relationships that may exist related to information gathering from various sources of information may lend themselves to future theoretical developments in this field.

To summarize our discussion so far, prior studies offer indirect support for claiming that engagement with a source can trigger subsequent involvement with alternative sources. They also provide reasons for why these patterns of information seeking across medical and nonmedical sources may occur. However, most of these studies are qualitative in nature or use cross-sectional designs. To our knowledge, only one study has formally tested whether information seeking behaviors from medical and from one nonmedical source (i.e., the internet) stimulate each other over time, rather than only being associated with one another. The present study examines this relationship in data collected through two surveys one year apart from a representative cohort of cancer patients in Pennsylvania, and incorporates a broader range of nonmedical information sources.

Hypotheses

Based on prior empirical evidence and the theoretical framework described above, we propose the following two hypotheses:

- H1** Cancer survivors' topical and source breadth of information seeking from nonmedical sources about their disease will predict their subsequent engagement with physicians or health professionals for cancer-related information, controlling for baseline engagement with physicians or health professionals and confounders.
- H2** Cancer survivors' topical breadth of engagement with physicians or health professionals about their disease will predict their subsequent information

seeking from nonmedical sources, controlling for baseline information seeking from nonmedical sources and confounders.

We emphasize patients' breadth of seeking or active engagement across a variety of cancer-related topics as well as information sources for two reasons. First, we are interested here in capturing patients' active efforts to obtain information. Other studies have focused on cancer patients' attention to health information in the environment, which may imply a more passive and subconscious form of exposure (Tian & Robinson, 2008). Since research has emphasized the importance of increased patient engagement in cancer care, we find that active involvement in seeking activities may better capture that standard (Epstein & Street Jr., 2007). Second, as described earlier, cancer patients face a complex information environment that presents a variety of topics related to cancer but also a wide range of possible sources to retrieve this information (Rutten et al., 2005). While we might have restricted the searches to only specific topics (e.g. quality of life) or sources (e.g., the internet) these may have under-represented patients' true involvement in seeking activities. We chose instead to create comprehensive measures that sampled across the major topics and sources to capture broad information engagement.

Method

Participants

Pennsylvania law requires that all incident cancer cases be reported to the state cancer registry within 6 months of diagnosis. The Pennsylvania Cancer Registry (PCR), our sample frame, comprised roughly 95% of all state-wide cancer cases that would ever be reported. We randomly sampled individuals with breast, prostate and colorectal cancer who were diagnosed in 2005 and reported to the registry, to be included in the study. The sampled participants received three mail surveys, one per year, starting in the fall of 2006. Only participants who completed both the baseline (2006) and the follow-up (2007) surveys were included in this analysis (N = 1,293).

Procedure

We conducted an extensive literature review, expert consultations, a pilot study with 29 cancer patients, and made appropriate corrections based on the pilot testing results to help develop the initial questionnaire. The survey was tailored to respondents' type of cancer and included questions about demographic and disease characteristics, information seeking behaviors about cancer from various sources, treatment and quality of life issues, health behaviors, psychosocial factors, and preferred decision-making role. The surveys were administered based on Dillman's methods for mail surveys (Dillman, 2000). A more detailed description of the study design and procedures is available elsewhere (Lewis et al., 2009; Martinez, Schwartz, Freres, Frazee, & Hornik, 2009; Nagler et al., 2010). Baseline response rates (AAPOR rate RR4) were estimated at 64%. About 65% of the original respondents filled out the second questionnaire one year later.

Measures

As previously noted, the main measures focused on capturing cancer patients' breadth of active information seeking and engagement with their clinicians and with nonmedical sources. These measures reflected multiple cancer-related content areas as well as a variety of sources of information sought by cancer patients. We grouped these sources into two categories. Doctors and health professionals, historically, have been considered the preferred source of information among cancer patients (Hesse et al., 2008; Mayer et al., 2007; Rutten et al., 2005). However, in recent years, more information has become available through other outlets including media and interpersonal sources (Caiata-Zufferey et al., 2010; Mayer et al., 2007; Rutten et al., 2005). To match this change and be able to address its impact, we categorized outlets into clinician sources and nonmedical sources of cancer information. Other studies have employed a similar classification of sources (Turk-Charles, Meyerowitz, & Gatz, 1997).

Information seeking from nonmedical sources captured whether patients actively sought information about cancer treatment or other cancer-related issues and quality of life issues' from a variety of sources outside of the medical encounter including 1) family members, friends, coworkers, 2) other cancer patients, 3) face-to-face support groups, 4) on-line support groups, 5) telephone hotlines, 6) TV or radio, 7) books, brochures or pamphlets, 8) newspaper or magazines and 9) the internet. Respondents could also indicate 'other' sources in addition to the above. To better reflect the time frame of information seeking at baseline, each question was preceded by asking participants to "think back to the first few months after you were diagnosed with your cancer" (Appendix 1). The scale included 20 items that were summed to create the final measure ($M = 3.83$, $SD = 3.24$), which demonstrated good internal consistency ($KR-20 = 0.81$).

Participants were asked about their information seeking behaviors from the above nonmedical sources "in the past 12 months" at follow-up. The follow-up measure included the same number of items as the baseline scale ($M = 2.43$, $SD = 2.89$). These items also demonstrated good internal consistency ($KR-20 = 0.82$). Principal components factor analysis indicated that only one underlying factor accounted for a substantial component of the common variance among these items at each wave.

Patient-clinician information engagement (PCIE) at baseline and follow-up is defined as patients' actively seeking from their clinicians and exchanging information with their clinicians about cancer treatment or other cancer-related matters and quality of life issues. The second component of information exchange in the PCIE construct overlaps with the concept of exchange that Epstein and Street (2007) exemplified as clinicians providing to their patients information and recommendations related to the illness, patients sharing symptoms and concerns with their clinicians, or patients bringing information they obtained from discussions with other health professionals, lay sources, or media sources to consult with their clinicians (p. 20–21). Specifically in this study, participants were asked whether they: 1) actively sought information about treatments or other cancer related issues from their treating physician, 2) actively sought information about treatment or other cancer related issues from other physicians or health professionals, 3) actively sought information

about quality of life issues from their treating physician, and 4) actively sought quality of life information from other physicians or health professionals. We also included two additional items that reflected patients receiving advice from their physicians to seek information from other nonmedical sources and discussing information from nonmedical sources with their physicians. These six items were summed to form the PCIE scale. Both the baseline ($M = 2.82$, $SD = 1.68$) and the follow-up ($M = 1.55$, $SD = 1.58$) included the same number of items. However, at baseline we ask patients to report their engagement during “the first few months after you were diagnosed with your cancer” while at follow-up we ask them about their engagement “in the last 12 months.” Both measures demonstrated acceptable internal consistency ($KR-20_{\text{baseline}} = 0.70$; $KR-20_{\text{follow-up}} = 0.72$).

Control variables

Disease Characteristics—Studies highlighted a number of disease related factors that are associated with information seeking behaviors including cancer history, type of cancer, stage of cancer and type of treatment (Mayer et al., 2007; Mills & Sullivan, 1999; Nagler et al., 2010). Type of cancer and cancer stage—based on the standard IUCC/TNM system of cancer staging (Greene et al., 2002) for each participant—were obtained from the PCR. Since two of the cancers were gender-specific, we combined gender and cancer type to create four dichotomous variables. We restricted cancer stage to two categories (‘stage IV’ and ‘stages 0 to III’) and used a binary variable to indicate whether patients were told by their doctors that the cancer spread from where it was first found to other parts of the body. Respondents reported if they underwent surgery, received radiation treatment, and/or received systemic treatment. We controlled for respondents’ experience of side-effects through an index of self-reported physical and psychological issues that ranged from zero to six issues (physical symptoms, memory or concentration problems, fertility or menstrual problems, sexual problems, changes in appearance, anxiety and depression). Frequency of visit to the doctor’s office in the past 12 months was measured on a 5-point ordinal scale ranging from ‘zero times’ to ‘more than seven times’. A standard question assessed patient’s self-reported health status on a 5-point scale ranging from ‘poor’ to ‘excellent’.

To measure participant’s preferred treatment decision-making role, we used a standard question with five response options ranging from “doctor should make the final decision without considering my option” to “I (patient) should make the final decision on the basis of the facts I learn from my doctor and elsewhere, without considering my doctor’s opinion.” To account for the effect of cancer worry, we adapted items from the “Lerman Breast Cancer Worry Scale” (Lerman et al., 1991) and controlled for cancer worry ($\alpha = 0.873$).

Demographic Characteristics—Prior research reported associations between information seeking behaviors and demographic factors such as age, gender, race and education (Hesse et al., 2008; Lambert & Loiselle, 2007; Lee, 2008; Nagler et al., 2010). Education level was coded as ‘less than high school,’ ‘high school,’ ‘some college’ and ‘college or above’. Respondents’ marital status included ‘married’ or ‘not married’. Age was measured in years and race consisted of three groups (i.e., Whites, Blacks, and other). Lastly, patients’ family history of cancer assessed if a family member (biological or non-biological) has ever had the same type of cancer as the patient.

Other confounders—To adjust for an individual's interest in a topic or his/her involvement with health issues we included general health information engagement. This scale included seven items that asked how often did patients “read about health issues in newspapers and general magazines,” “read special health or medical magazines or newsletters,” “read health info on the internet,” “watch special health segments on TV,” “watch TV programs which address health issues or focus on doctors and hospitals” and “talked to family and friends about health.” The response options ranged from “not at all” to “two or more times per week”. The responses to these items were summed to create the final health engagement scale ($\alpha = 0.72$). Finally, we also included patient's level of fruit and vegetable consumption and physical activity as a proxy measure of their health orientation. We expected that patients with higher reported levels of engagement in these behaviors would be more health-oriented compared to those who consumed less fruits and vegetables and participated in less physical activity. Fruit and vegetable consumption was measured on a 10-point scale ranging from “< than 1 servings per day” to “10 or more servings per day” and the level of physical activity ranged from “0 days per week” to “7 days per week.”

Data Analysis

Following standard procedures for data that have more than 10% missing cases, we performed multiple imputation using the ICE program in STATA 11 (Allison, 2001), and created 19 imputed datasets. Post-stratification weights were applied to adjust the final sample to the population of cancer patients from the PCR by type of cancer, age, gender, race, marital status, time of diagnosis and cancer stage at diagnosis, and used STATA SVY analysis procedures to correct confidence intervals for the presence of weights.

We conducted descriptive analyses of the distribution of the demographic and disease characteristics of the sample. Next, two lagged OLS regression analyses were conducted to address the temporal order and to test the reciprocal hypotheses directly. Specifically, these analyses examined whether information seeking from nonmedical sources at baseline predicted engagement with clinician for information at follow-up and whether engagement with clinician sources at baseline predicted information seeking from nonmedical sources at follow-up. Both analyses controlled for baseline engagement with information from both sources and other confounders.

Results

The mean age of the sample was 67 years old. Most of the participants were White (87.6%), married (61.3%) and had high school education or less (51.6%). In terms of disease characteristics, approximately 12% indicated that their cancer has recurred or spread to other organs. On average, patients reported ‘good’ health status, medium level of cancer worry and experienced two physical or mental cancer-related issues. Table 1 depicts other sample characteristics. The scores for patient-clinician information engagement and seeking information from nonmedical sources show a decline from baseline to follow-up as depicted in Table 2. This reduction is not unexpected. The scales at both time points include items on information about cancer treatment. Accordingly, at follow-up, patients have progressed along the cancer care continuum and are no longer at the treatment phase but rather at the

post-treatment stage and as expected their interest in treatment related information should have declined. This reduction in engagement with information could also be the result of having fewer opportunities for engagement since the number of doctor visits decline with reducing intensity of treatment.

Table 3 displays the correlations between the main independent and dependent variables at baseline and follow-up. PCIE and seeking from nonmedical sources were positively correlated across both rounds of the survey. The results of the lagged regression analyses supported hypotheses H1 and H2 of this study (Table 4). More specifically, PCIE at baseline predicted seeking from nonmedical sources at follow-up ($B = 0.110$, $SE = 0.055$, $p = 0.044$), controlling for baseline seeking from nonmedical sources and confounders. Similarly, there was a positive and significant relationship between seeking from nonmedical sources at baseline and PCIE at follow-up ($B = 0.089$, $SE = 0.021$, $p < 0.001$), adjusting for baseline PCIE and the same set of controls.¹

The results highlighted several other predictors that were significantly related with both outcomes. In particular, receiving treatments other than radiation therapy, and health engagement predicted increased PCIE and seeking from nonmedical sources at follow-up. The main predictors and the confounders accounted for 26.6% and 35.1% of the variance of PCIE and seeking from nonmedical sources respectively.

Discussion

For some time now, researchers have been concerned about how the availability of large amounts of new cancer information and the open and free access to numerous sources of information have affected cancer patients' use of certain outlets of information to learn about their disease. Our study aimed to enhance the understanding of this phenomenon by examining the two-way relationship between engagement with information from clinician sources and nonmedical sources among a representative cohort of cancer survivors. Specifically, we hypothesized that cancer survivors' information seeking from nonmedical sources at baseline would predict higher subsequent involvement with physicians and health professionals for information and vice-versa. The findings in this study supported these hypotheses and showed that engaging with clinician for information and information seeking from nonmedical sources are mutually reinforcing behaviors. Respondents navigated between these two types of sources in what we suspect was an attempt to satisfy their multidimensional and changing needs for information. The results from this longitudinal

¹An alternative version of the PCIE measure was tested to determine the robustness of these results. Specifically, there were concerns that the item referring to discussing information from nonmedical sources artificially inflated the relationship between the two main variables since this particular variable implied that patients had already searched for information from nonmedical sources. When removing this item from the baseline PCIE measure, the results remained essentially unchanged, PCIE predicted seeking from nonmedical sources ($B = 0.125$, $SE = 0.064$, $p = 0.051$) and vice-versa ($B = 0.058$, $SE = 0.018$, $p = 0.001$). Similarly, the item about physicians making suggestions to patients to seek information from nonmedical sources raised concerns about whether the association between PCIE and seeking from nonmedical sources is because there is something novel about seeking information from one's doctor that motivates future information seeking behavior or if it is simply a measure of the degree to which respondents follow their doctors' orders. When this item was removed from the scale, baseline seeking from nonmedical sources predicted PCIE ($B = 0.038$, $se = 0.015$, $p = 0.011$). In the reverse scenario, PCIE was positively related to seeking from not medical sources but marginally non-significant ($B = 0.126$, $se = 0.075$, $p = 0.091$). Based on these two results, we are confident in the measures and the relationships portrayed above. Furthermore, this item may in fact reflect an important component of the mechanism through which medical contact leads to nonmedical seeking. The dynamic may indeed reflect this substantive advice.

analysis corroborated the findings from other studies (Lee, 2008; Lewis et al., 2009; Nagler, Romantan et al., 2010).

While we have not tested specific mechanisms that may motivate cancer patients to navigate across sources, earlier studies have proposed processes to explain patients' movement between various outlets of information. In particular, information in nonmedical sources is generally broader and does not address patient's specific disease circumstances. So, scholars have suggested that the large amounts and variety of information available from nonmedical sources can trigger a need for tailored information from physician or clarifications from medical professionals (Nagler, Romantan et al., 2010). This mechanism may be at play when patients who sought information from nonmedical sources engaged with their clinicians for additional information. Alternatively, scholars have also argued that the introduction of new issues in a clinical consultation may prompt new questions in the minds of patients, which would in turn prompt them to search from additional nonmedical sources (Caiata-Zufferey et al., 2010; Nagler, Romantan et al., 2010). In the context of the current paper, it is also plausible that doctors' advice to patients to look for additional information in nonmedical sources about topics that were discussed during the encounter played a role in patients' subsequent information seeking activities from those sources. Further research is warranted to clarify these potential mechanisms underlying the observed results in this study.

These findings further our understanding about the complex ways that cancer patients use various information sources in the context of their disease. Given that obtaining information only from one source of information may provide a one-sided view of the health issue being considered, it is reassuring to learn that patients engaged with multiple sources of information. The current literature argues for empowering patients, increasing their participation in the healthcare setting and promoting a shared decision making role (Epstein & Street Jr., 2007). It is encouraging to find that, following engagement with their clinicians, patients turn to nonmedical sources, possibly to complement, validate or challenge the information received during their consultation (Caiata-Zufferey et al., 2010). The movement from clinician to nonmedical sources may indicate this shift towards a more active patient model.

Turning to the theoretical framework that was described in the introduction, these results are consistent with complementarity arguments. From the cross-sectional analyses, seeking from nonmedical and medical sources are positively and significantly related (Table 3). However, our study also makes a case that the tendency to use clinical sources is not only the result of individual differences in need for information influencing individuals' multi-source engagement (i.e., the analyses controlled for patients' interest in health or health orientation), but is also the result of direct influence of using the source itself on the subsequent use of other sources. This evidence was unavailable in earlier studies, to the best of our knowledge. By testing these relationships in cross-sectional and longitudinal analyses, and relying on data from population-based samples of cancer patients, we are taking steps to enrich our empirical knowledge in this area, enhance the current theoretical frameworks, or develop new ones.

This study was strengthened by several design features. Our analyses were based on a longitudinal study design and controlled for an extensive set of disease-related confounders. The use of a probability sample of Pennsylvania cancer patients represents another strength of this analysis and increases the generalizability of the findings compared to other studies that relied on internet panels (Lee, 2008), cancer-free populations (Lee, 2008) or non-US respondents (Chen & Siu, 2001; Stevenson et al., 2007). Similarly, including patients with three types of cancers may increase the applicability of these results across survivors with these cancers.

There were some limitations in this study as well. Due to the geographical location of respondents and their disease type, we cannot extrapolate our findings to patients in other areas of the U.S. or to patients with other kinds of cancers, although we have no reason to expect that the effects would be distinct. The reliance on self-report to obtain details about patients' information seeking behaviors and contact with physicians and health professionals represented another limitation of the study. We assumed that cancer survivors accurately remember and report their engagement with clinicians and nonmedical sources for information related to their cancer. We have assumed that error of measurement does not undermine our inferences; we recognize that correlated error of measurement over time for the outcome variable may bias coefficients, it is likely that this bias would lead to an underestimate of the hypothesized cross source effect rather than an overestimate of it. We collected data over a one-year time lag; this has the risk of missing effects that happen quicker and are forgotten, or effects that take longer to be realized.

Other limitations were related to the development of the two main variables. PCIE and seeking from nonmedical sources were created for the purpose of this study and have not been externally validated. However, their initial development was guided by existing research and pilot testing to determine their usefulness. There were some concerns that the two items reflecting patient-physician interaction may not fit with the rest of the items in the PCIE scale which reflected active information seeking behaviors. In sensitivity analyses that omitted these two items (i.e., patients discussing information from nonmedical sources with their doctors and physicians suggesting patients to seek information elsewhere), the results were substantively similar to the findings reported here.

A related limitation is that these measures focused on the quantity rather than quality of information found across these sources. Even though we were not able to assess quality directly, Martinez and colleagues (2009) suggested that engagement with clinicians led to patients' perceptions of feeling informed and treatment satisfaction. Future research may examine the external validity of these measures and also explore if the quality of information retrieved from various sources affects cross-source engagement. Finally, we were unable to assess in detail the content that patients retrieved when seeking information from nonmedical sources or while engaging with physician. We know the information was related to cancer treatment, other cancer-related issues and quality of life. However, we cannot point to the exact content that may have sent patients to other sources. Future research might examine what about the experience with each source drives subsequent engagement with other sources. We have been able to show evidence for the plausibility of a reciprocal relationship on a large scale, real life, and representative sample within the

context of medical and nonmedical source use for cancer-related information. The next step for this research agenda is to explore mechanism(s) and contexts of how these two categories of sources trigger additional information engagement.

Despite these limitations, this study provides considerable empirical support for reciprocal patterns in how cancer survivors navigate the modern information environment across clinicians and nonmedical sources that have not been shown previously. We advise continued monitoring of sources from which cancer survivors obtain their information and periodic evaluation of how they move across these sources to track trends in these shifts and address existing opportunities and challenges in a climate of increasing cancer information access.

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Table 1

Descriptive Statistics based on the Weighted and Imputed Sample Responses (n = 1,293)

	Mean	SD	%
Demographic Characteristics			
Age	67.8	12.4	
Race/Ethnicity			
White			87.6%
African-American			7.9%
Other Race/Ethnicity			4.5%
Marital Status			
Married			61.3%
Not Married			38.7%
Education			
Less than High School			13.9%
High School			37.7%
Some College			22.8%
College or Above			25.6%
Disease Characteristics			
Cancer History			
Yes			43.4%
No			56.6%
Cancer Stage			
Stage IV			11.0%
Stage 0-III			89.0%
Metastatic Condition			
Yes			11.6%
No			88.4%
Cancer Type			
Breast Cancer			35.0%
Prostate Cancer			33.5%
Colon Cancer Males			15.3%
Colon Cancer Females			16.2%
Health Status	3.2	0.9	
Physician Visits	3.5	1.2	
Type of Treatment			
Surgery			72.7%
Radiation			49.4%
Systemic			51.7%
Experience Side Effects	1.9	1.4	
Other Confounders			
Worry	7.0	2.9	
Decision Making Style	1.1	0.3	

	Mean	SD	%
Health Engagement	2.3	0.6	
Fruit & Vegetable Consumption	3.8	2.1	
Physical Activity	2.9	2.2	

Table 2

Descriptive Statistics of Main Independent and Dependent Variables based on the Weighted and Imputed Sample Responses (n = 1,293)

	Mean	SD
Seeking Nonmedical Sources Baseline	3.8	3.2
Seeking Nonmedical Source Follow-up	2.4	2.9
PCIE Baseline	2.8	1.7
PCIE Follow-up	1.6	1.6

Table 3

Correlation Matrix for the Main Independent and Dependent Variables (n = 1,293)

	Seeking Nonmedical Sources Follow-up	PCIE Baseline	PCIE Follow-up
PCIE Baseline	0.362		
PCIE Follow-up	0.633	0.419	
Seeking Nonmedical Sources Baseline	0.567	0.572	0.439

All correlations are significant at p-value <.0001

Table 4

Lagged OLS Regression Analyses Predicting Patient Clinician Information Engagement (PCIE) and Seeking Information from Nonmedical Sources at Follow-up (Weighted and Imputed)

	PCIE Follow-up (n = 1,272)		Seeking Nonmedical Sources Follow-up (n = 1,279)	
	B	SE	B	SE
Independent Variable				
PCIE Baseline	0.089***	0.021	0.110*	0.054
Seeking Nonmedical Sources Baseline	0.235***	0.036	0.364***	0.035
Demographic Characteristics				
Age	0.004	0.005	−0.001	0.275
African-American	0.309*	0.145	0.454	0.275
Other Race/Ethnicity	0.224	0.227	0.510	0.443
Married	−0.051	0.103	−0.053	0.169
Less than High School	−0.122	0.152	0.005	0.008
High School	−0.076	0.117	0.176	0.196
Some College	0.066	0.141	0.331	0.211
Disease Characteristics				
Cancer History	0.034	0.091	0.086	0.151
Stage IV	−0.036	0.188	0.046	0.256
Metastatic Condition	0.266	0.187	−0.078	0.268
Breast Cancer	−0.030	0.142	−0.274	0.225
Prostate Cancer	−0.041	0.173	−0.827***	0.259
Colon Cancer Males	−0.082	0.165	−0.164	0.244
Health Status	−0.016	0.054	0.032	0.092
Physician Visits	0.088*	0.042	0.053	0.069
Received Surgery	−0.179	0.139	−0.671**	0.221
Receive Radiation	−0.217*	0.110	−0.442**	0.169
Received Systemic	0.048	0.107	0.128	0.173
Experience Side Effects	0.065	0.038	0.159*	0.065
Other Confounders				
Worry	0.037*	0.017	0.045	0.028
Decision Making Style	−0.279*	0.133	−0.048	0.209
Health Engagement	0.369***	0.089	0.868***	0.144
Fruit & Vegetable Consumption	0.027	0.025	0.047	0.042
Physical Activity	0.036	0.027	0.095*	0.043
R-squared	0.29		0.42	

Note. Reference category for race/ethnicity is White; reference category for cancer type is colon cancer (female).

* p-value < 0.05,

**
p-value < 0.01,

***
p-value < 0.001