

How Do Cancer Patients Navigate the Public Information Environment? Understanding Patterns and Motivations for Movement Among Information Sources

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Abstract Little is known about how patients move among information sources to fulfill unmet needs. We interviewed 43 breast, prostate, and colorectal cancer patients. Using a grounded theory approach, we identified patterns and motivations for movement among information sources. Overall, patients reported using one source (e.g., newspaper) followed by the use of another source (e.g., Internet), and five

key motivations for such cross-source movement emerged. Patients' social networks often played a central role in this movement. Understanding how patients navigate an increasingly complex information environment may help clinicians and educators to guide patients to appropriate, high-quality sources.

Keywords Information seeking · Cross-source engagement · Grounded theory · Complementarity theory

Anca Romantan; Deceased, April 14, 2008

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Background

In recent years, there has been considerable attention devoted to understanding the information needs of cancer patients and survivors [1–14], as well as the sources they use to satisfy these needs [5, 6, 15–33]. Such efforts are warranted, as unmet needs are frequently reported [34] and associated with poorer perceived mental and physical health [35]. To date, this extensive body of research has revealed important patterns of cancer information engagement. Most patients do not receive information solely from their treating physicians and other health professionals. Rather, many turn to other sources as well, including traditional media—whether print (e.g., newspapers, magazines, books, brochures, pamphlets) or broadcast (e.g., television, radio)—new media (e.g., Internet), and non-medical interpersonal sources (e.g., family, friends, co-workers, other cancer patients) [1]. In addition, although patients want information on treatment options, they are also interested in topics such as side effect management and chances of survival or cure [1].

There has, however, been less attention to patients' movement across sources of information, or the use of one source (e.g., newspaper) followed by the use of another source (e.g., Internet) to fulfill an unmet need. Much of the

existing research in this area focuses on the role of the Internet and, more specifically, the extent to which patients discuss online information with their clinicians and the influence this discussion has on patient–clinician relations [36–39]. More recently, our group published results from a population-based sample of Pennsylvania cancer patients; findings revealed that some patients discuss information from non-medical sources with their clinicians and, in turn, clinicians refer patients to such sources [40]. However, this study did not detail the movement among non-medical sources, nor did it document the reasons driving such movement. Ultimately, “cross-source engagement” [40]—and its relationship to patients’ information needs—remains understudied terrain.

The goal of the current study, then, is to explore the movement across information sources that may characterize patients’ information seeking behavior, as well as the reasons motivating cross-source engagement. Fundamentally, the story we tell is one of almost universal use of multiple media sources as patients explore treatment options and living with cancer. We show results consistent with media complementarity theory [41, 42]. As proposed by Dutta-Bergman [41], media complementarity “suggests that people consuming one particular medium to gather information in one particular area are likely to consume other media that contain information in that specific area. This framework proposes that sources reinforce one another, rather than displace or replace one another. Source use is driven by interest in a particular topic, and, taken together, the information gleaned from distinct sources combines to fulfill information needs [41]. Complementarity theory has received empirical support [43], including recent attention in the cancer domain [44]. While such research provides evidence of cross-source use, it does not detail how or why cross-source engagement occurs. In this qualitative study, we build upon the existing literature by considering the extent to which patients’ engagement with information sources is dynamic. Specifically, we ask how patients move among a wide range of information sources and the reasons driving such movement—questions that, to our knowledge, have not been addressed in previous research. In asking these questions, we hope to provide insight into how patients navigate the public information environment. Equipped with this knowledge, clinicians and educators may guide patients toward appropriate and reliable information sources, thereby helping patients to fulfill unmet needs.

Methods

Data gleaned from a series of semi-structured interviews with breast, prostate, and colorectal cancer patients were

analyzed using a grounded theory approach [45]. Grounded theory is concerned with the discovery of meaning, and a premium is placed on reflecting participants’ constructions of the world [45]. The methodology enables researchers to draw inferences that can inform the development of new hypotheses, which can be tested rigorously in the future. In addition, findings generated can be useful in building or modifying existing theory.

We selected this approach because our goal is to establish the dimensions of interest in an area of concern. That is, we want to show that particular patterns of behavior exist (in this case, that patients move from source to source) and to organize conceptually the central motivations for that movement. While we do provide counts of the joint distribution of cross-source use and motivations, these are not intended as reliable quantitative estimates. Our aim is to provide an empirically based systematic analysis of the important dimensions of this behavior as a foundation for future research.

Sample

Cancer patients were recruited in March–June 2005 based on information released by the Pennsylvania Cancer Registry. The eligible population was all men and women between the ages of 40 and 70 years living in greater Philadelphia diagnosed with breast, prostate, or colorectal cancer between September 2003 and April 2004. We recruited patients who were recently diagnosed in order to achieve accurate recall of cancer-related decisions and the use of sources for information needs. We contacted 215 physicians, obtaining consent to contact 496 patients out of a potential sample of 500. Of these 496 patients, we randomly contacted 150, yielding an initial sample of 37 (response rate=25%). To meet our target enrollment, we randomly contacted another 48 patients from the initial potential sample, generating an additional six patients (response rate=13%). The final sample included 43 patients. Patients were excluded if they could not provide informed consent. Recruitment procedures were approved by the University of Pennsylvania Institutional Review Board. We believe that these sampling procedures increase the likely representativeness of our interviewee sample, compared to samples gathered from a physician’s practice or a single hospital.

Data Collection

Trained interviewers conducted hour-long, face-to-face interviews with participants. Two interviewers (BJK, RSS) conducted all but three of the interviews. Prior to the interview, patients completed a standard informed consent document approved by the University of Pennsylvania IRB.

Table 1 Semi-structured interview script

How did you first learn about your diagnosis? (Probe how many clinicians were consulted and what tests were performed.)
 What treatment decisions were made? (Probe possible treatment options that the patient does not mention^a.)
 Which information sources played a role in the treatment decision-making process? (Probe other information sources that the patient does not mention^b, and the order in which various sources were used in making decisions. Clarify whether the patient actively sought information from specific sources (“information seeking”), came across information when he or she was not looking for it (“information scanning”), or both.)
 (Conclude with questions about personal and family cancer history and demographics.)

^aWe were interested in whether patients remembered having seen or heard anything about other treatments, particularly from non-medical interpersonal or media sources

^bWe were interested in all information sources, and we recognized that specific cues might remind patients of sources they had forgotten they used

Patients were compensated with \$50 American Express gift checks. All interviews were semi-structured. The interview script, which served as a loose framework for the discussion, was based on a priori ideas about how a patient might have come to learn about his or her cancer diagnosis and make decisions about his or her treatment (Table 1). Interviewers had the flexibility to alter the script to fit a particular case. All interviews were transcribed and anonymized.

Data Analysis

Data analysis and interpretation were guided primarily by grounded theory principles. Research team members read all 43 transcripts. The constant comparative method was used to analyze and code data [46]. This technique demands that researchers be “constantly alert to the similarities and differences which exist between instances, cases and concepts, to ensure that the full diversity and complexity of the data is explored” [46]. Through this process, themes regarding patients’ information engagement emerged. As themes were identified, researchers often returned to the transcripts to reread and recode excerpts, ensuring that themes were grounded in data—an iterative quality that characterizes the constant comparative method. In addition, researchers considered the extent to which thematic categories were consistent with previous research on cancer information engagement. Deviant cases also were analyzed, providing an opportunity for researchers to challenge initial categorizations and, if necessary, modify them accordingly [46, 47].

Once thematic categories were identified, we used quantitative coding to determine the prevalence of cross-source interactions. In other words, we first identified the central reasons for cross-source engagement (Table 3) using the constant comparative method, as well as the patterns of cross-source interactions for each of these reasons (e.g., medical–traditional media interaction, traditional media–new media interaction). Researchers then worked in pairs to code the frequency of cross-source interactions for each reason (Table 3). Without quantitatively coding these

interactions, it would have been difficult to gauge the relative frequency of cross-source use. After coding independently, coders met to discuss any codes they disagreed on, with the goal of reaching consensus. All frequencies reported are based on consensus codes. Inter-coder agreement for identifying cross-source interactions was high, ranging from 86% to 94% for three pairs of independent coders. We also coded the frequency of single source use (see Table 2); again inter-coder agreement was high, ranging from 75% to 100% for three pairs of independent coders. Thus, even though this study was guided primarily by grounded theory methodology, it also has a mixed-methods character.

Table 2 Patients’ use of information sources (n=43)

Information source	Percent
Medical source	
Physicians, other health professionals	100
Complementary and alternative medicine providers ^a	7
Non-medical interpersonal source	
Family members	100
Friends, acquaintances (e.g., co-workers)	70
Other cancer patients	67
Face-to-face support groups	14
Online support groups	7
Telephone hotlines	9
Traditional media source (broadcast or print)	
Television, radio	79
Newspapers, magazines	63
Books	37
Brochures, pamphlets	91
Medical journals	2
New media source	
Internet	58

^aAlthough complementary and alternative medicine providers may be considered “other health professionals,” we list them separately because patients tended to differentiate these providers from other allied health professionals

Results

Patterns of Cross-Source Interactions

Consistent with previous research, patients reported using a range of information sources to learn about their disease and its treatment (Table 2). Source use included active information seeking—often defined as purposive or goal-driven efforts to obtain information [48]—as well as more passive information acquisition, or “information scanning,” which involves patients coming across information from other people or media sources when they are not looking for it [49, 50]. All patients reported receiving information from physicians, other health professionals, and family members. The great majority of patients reported use of both print and broadcast media to find out about their disease. Use of the Internet and interpersonal sources, such as friends and other cancer patients, were also common, while interactive interpersonal sources, such as support groups and hotlines, were less frequently used.

The interviews produced extensive information about an additional characteristic of patients’ source use: their pattern of moving between sources. We categorized observed cross-source interactions into six major categories: movement between (1) medical and non-medical interpersonal sources, (2) medical and traditional media (e.g., broadcast and print) sources, (3) medical and new media (e.g., Internet) sources, (4) non-medical interpersonal and traditional media sources, (5) non-medical interpersonal and new media sources, and (6) traditional media and new

media sources (Table 3). Since interviews revealed that information could flow in both directions in each of these source pairs, 12 cross-source interactions are listed in Table 3. For instance, a patient might move from a medical source (e.g., oncologist) to a non-medical interpersonal source (e.g., another cancer patient), or from a non-medical interpersonal source (e.g., another cancer patient) to a medical source (e.g., a surgeon). Although it was possible for patients to move between sources within the same source category (e.g., from another cancer patient to a family member), our interest was in movement across distinct source categories—consistent with the media complementarity framework—and thus we focus on these interactions.

Reasons for Cross-Source Engagement

We complemented our analysis of these patterns of cross-source engagement with a categorization of the underlying motivations for these interactions. We organized reasons into distinct thematic categories, using excerpts from interview transcripts to illustrate how and why patients move across information sources (see Table 4). Broadly, these reasons can be considered either “patient-driven” or “social network-driven”; the former pertains to a patient’s desire to fulfill needs that are informational or emotional, whereas the latter pertains to the role of the patient’s social network in disseminating information or support. Table 3 summarizes the patterns of cross-source engagement and the reasons for movement, and Table 4 illustrates these reasons using excerpts from interview transcripts. As evident in the selection

Table 3 Patterns of and reasons for cross-source engagement (*n*=43)

	Patient-driven reasons			Social network-driven reasons	
	Verification (%)	Clarification/ elaboration (%)	Emotional support (%)	Directed contact (%)	Proxy/ surrogacy (%)
Overall cross-source interactions	35	44	12	84	63
Specific cross-source interactions					
Medical → Non-medical interpersonal	5	2	9	7	N/A
Non-medical interpersonal → Medical	7	7	0	7	19
Medical → Traditional media	2	5	0	63	N/A
Traditional media → Medical	7	16	0	2	N/A
Medical → New media	7	7	2	7	N/A
New media → Medical	9	16	0	5	N/A
Non-medical interpersonal → Traditional media	0	2	2	44	21
Traditional media → Non-medical interpersonal	0	5	0	0	N/A
Non-medical interpersonal → New media	2	7	0	23	51
New media → Non-medical interpersonal	0	2	0	0	N/A
Traditional media → New media	0	7	0	0	N/A
New media → Traditional media	0	2	0	2	N/A

of excerpts, there are often several contexts in which cross-source interactions occurred within a thematic category.

We identified a total of five thematic categories: (1) verification, (2) clarification/elaboration, (3) emotional support, (4) directed contact, and (5) proxy/surrogacy. The first three are patient-driven motivations for movement, and the latter two are social network-driven motivations. Verification refers to patients' double-checking information from one source by going to a second source. Most of these instances were reported in the context of treatment decision making or side effect management, and medical sources were usually one of the sources consulted. As evident in Table 4, information seemed to flow in both directions: some patients double-checked what clinicians told them by consulting other sources, while others brought information to their clinicians that they had found elsewhere.

Clarification/elaboration refers to patients' need for additional or more detailed information, often regarding treatment options. In contrast to verification, cross-source interactions in this category served to expand upon—rather than double-check—information received, and a greater range of cross-source interactions occurred (see Table 3). Overall, instances of clarification/elaboration reflect a profound engagement with information, although the context of engagement varied markedly (Table 4).

Whereas the first two categories refer to patients' efforts to fulfill information needs, the third category refers to patients' need for emotional support. Patients did not report substantial cross-source engagement to fulfill support-related needs. This is consistent with patients' relative infrequent use of support groups and hotlines (Table 2). When such interactions were reported, they involved clinicians mentioning the availability of non-medical interpersonal sources for support, such as other cancer patients or formal support groups.

Directed contact, the first social network-driven reason for cross-source engagement, refers to instances in which one source explicitly directed patients to another source. As seen in Table 3, such direction was common. What is particularly noteworthy, however, is that patients seemed to respond to directed contact in different ways (see Table 4).

Proxy/surrogacy engagement refers to instances in which non-medical interpersonal sources—typically family members or close friends—sought information on behalf of the patient, thereby serving as an information proxy or surrogate. The patient either delegated authority to the proxy or the proxy assumed this responsibility on his or her own; examples of both types of interactions are provided in Table 4. Patients recognized that the information did not come from the proxy, but from the source that he or she used. We thus consider these to be examples of cross-source use.

Discussion

To our knowledge, this is the first study to describe the patterns and motivations for movement among myriad information sources and, in so doing, underscore how cancer patients' engagement with information is dynamic. Consistent with existing research [1, 2], we found overwhelming evidence that patients use multiple sources to learn about their disease. The central contribution of this study, however, is the finding that patients did not simply use one type of information source for one purpose, another type for another purpose, and so forth. Rather, our analysis reveals that patients often moved among distinct types of sources with a particular purpose in mind—a result that is consistent with media complementarity theory [41].

We discerned six major cross-source pairs, and interviews revealed that information could flow in both directions. These pairs are interesting on a descriptive level, but they are even more compelling when we consider the central motivations for cross-source movement. First, directed contact was a frequently reported motivation. Perhaps this is not surprising, since following a diagnosis, clinicians often want to provide patients with information to involve them in their care. Similarly, for close others, cancer may become a highly salient topic, leading them to notice cancer-related information in magazines or online that they then want to share with the patient. For example, patients noted that clinicians sent them to books or pamphlets, or that family or friends directed them to magazine articles or specific websites. A patient's cross-source interactions were not improvised; rather, they involved explicit direction to information sources by members of the patient's network. As might be expected, some patients found the direction helpful, while others found themselves overwhelmed by the quantity of information.

Many interviewees also reported that their use of multiple sources involved proxies. Some proxies provided access to information that the patient was not prepared to seek and digest on his or her own. The potential for information overload was implicated in several instances of proxy engagement, in which a close other would seek and filter information, thereby shielding the patient from the vast quantity of information available. Proxy interactions took place in other contexts as well. For example, patients who considered themselves computer illiterate but wanted to learn more about their disease online might turn to relatives for assistance. The mobilization of social networks is in line with a growing body of research on the role of close others in the cancer treatment process [51, 52]. Most relevant to the current study is research on “lay information mediaries (LIMs),” defined as “those who seek information on behalf of or because of others,” regardless of whether they are asked to do so [53]. Although not necessarily

Table 4 Sample excerpts illustrating the reasons for cross-source engagement

Verification

Excerpt 1: Colorectal cancer patient used the Internet to double-check information from physicians. Underscores how some patients may distrust the way physicians communicate with them.

Patient 1: [A] lot of doctors tell you what is textbook: "Oh gee, you know, I can't tell the patient no matter what we do they are going to die." They don't want to put that on the patient. I don't know if that is part of the medical teamwork that [is] drilled into their heads during college and stuff like that, but it is the wrong way to think....Basically, I would tell anybody if you want good information, listen to your doctors...yes, definitely, and check everything out yourself. And keep your own records.... Like I said, I did my own research. But the way I come to that conclusion is after I do this – [downloaded from the Internet] last night over my numbness of my fingers. Okay, you might have got rid of cancer this way but, hey, you didn't tell me I can get diabetes, my liver could malfunction, I could get an infection in the other parts of the colon and urine tract. I have it all here so when I go back next week I will say to [my doctor], "Hey, remember the big long word you gave me? Hey, I did Yahoo again" ...Yahoo is very good.

Excerpt 2: Prostate cancer patient used the Internet to double-check information from physicians. Reflects a degree of doubt in physician recommendations, rather than overt distrust.

Interviewer: And, so, what source would you say was the most important for your decision making?

Patient 10: The Internet—what we found on the Internet.

Interviewer: More important than the doctor?

Patient 10: I mean, the doctor was important. Let's just say [they're] about the same... [we used] the Internet to kind of verify what the doctor said, more or less.

Interviewer: OK.

Patient 10: You know, to make sure that he wasn't out in left field with what everybody else was doing.

Interviewer: You saw this on the Internet you said?

Patient 40: Yes. Mayoclinic.com and cancerfacts.com became some of my best friends.

Interviewer: Really.

Patient 40: And I realize that you are not supposed to believe everything that you read on the Internet, which is why we printed everything and took them back to the doctor and said "I realize that you are not supposed to believe everything but this says this. What does this mean?" or "What is it for." They were really good, they really answered our questions, and if something came up you can call them on the phone if you had to and we got that answer, they made me feel comfortable, they were reachable.

Clarification/Elaboration

Excerpt 1: Prostate cancer patient used the Internet to clarify information received from his physician. Reveals a sense of agency that prompted him to learn—in as much detail as possible—what would be best for his care.

Excerpt 2: Breast cancer patient consulted non-medical information sources and discussed the information with her physician. Driven by uncertainty about what a specific treatment involved.

Patient 12: The side effects, I believe, are the same regardless of how you treat it. It's the only time in my medical history that the choice of treatment was left to me.

Interviewer: Really.

Patient 12: Yeah. So, from that standpoint I had to try to get some information as to which I thought would be best and, so, I did get on the Internet for better clarification of the choices and the side effects [described by my physician].

Patient 25: And when I found out I started reading up on the radiation; you get a little, about ten-page booklet on radiation and if you don't understand it, you're still in trouble...[and] some of the stuff I read about [in books and other sources], I didn't understand.

Interviewer: Did you have anybody to ask?

Patient 25: No, I said well by then I got it only seen my surgeon every Thursday every six months so I would write down little notes and for my doctor and so I asked him because if you forget, you're in trouble because you don't see them every six months.

Interviewer: So what happens when you go and take the information?

Patient 25: When I asked him, he do answer it. That's the one thing good about the doctor but you've got to know what to ask. A lot of times you don't really know what to ask.

Excerpt 3: Colorectal cancer patient discussed information from magazines and newspapers with his physicians. Prompted by mass media coverage of medical innovations and a desire for more detailed information.

Patient 18: Yeah. They would be put out by different organizations and you would see it in like a magazine or a health-related magazine or the *Wall Street Journal* would carry something like that or the *New York Times* and they'd say something like people who had adjuvant care had a 20% better rate than the other group, okay? Or, and this was lucky for me too, at the same time Erbitux was coming out, Avastin was coming out, so all those studies were in the news, that really helped me and I even suggested [to my physician], should I be taking this? Should I be taking that?

Interviewer: Okay. So you would bring things back to your doctor?

Patient 18: Oh yeah. And they would normally say, you know, you don't want to use all your arrows at once. Save that. Save that. So that really was probably the best thing for me...it was in the news.

Emotional Support

Excerpt 1: Prostate cancer patient consulted formal support resources having learned about them from his physicians. Underscores how such resources can help to normalize the cancer experience.

Patient 7: And, [my physicians mentioned] Advocates and clubs that have gotten together, you understand, and a support system. So, [that I could] look for people with my type of cancer. Interviewer: And, did you do that, did you look for some support groups online?

Patient 7: Yeah.

Interviewer: Did you find them?

Patient 7: Yeah, a lot of them.

Interviewer: Did you find them to be helpful?

Patient 7: Yeah. Because, first being diagnosed with cancer you feel like you are the only one in the world with this problem, then you find out that it's a world wide problem, you feel a little better obviously knowing that other people have gone through what you are going through.

Interviewer: Yeah, okay. So talking to other people really helped you?

Patient 22: Yes, support groups were really good.

Interviewer: Now did you go to a formal support group?

Patient 22: No.

Interviewer: Or just people around you?

Patient 22: People around me, like I said the nurse [mentioned that I could reach out to other patients]. She was...really good.

Interviewer: Right. Did you...when you were talking with other people who had gone through [prostate cancer], did you look for them or did they come to you?

Patient 22: I knew that guy had the problem, I searched for him. Some acquaintances from high school and they gone through it, then they gave me another name and I went after that name.

Interviewer: Okay. And you found again, talking to people was useful to you in making your decisions?

Patient 22: Yes.

Directed Contact

Excerpt 1: Prostate cancer patient directed to brochures/pamphlets by clinicians. Describes an information acquisition snowball effect.

Patient 22: I started to do a small amount of things on my own.

Interviewer: Like what?

Patient 22: Just reading about [cancer]. I got some material from [my physician's] office that I brought home. Then after the biopsy, they gave me more. I went to the cancer center and they gave me more. Then it started to snowball.

Excerpt 2: Breast cancer patient directed to magazine articles and books by family, friends, and clinicians. Underscores how directed contact can be tremendously valuable yet can also approach information overload.

Excerpt 3: Breast cancer patient received information on recommended physicians and hospitals from her social network, both with and without solicitation. Suggests that directed contact may encourage some patients to actively engage in information acquisition—including those who are otherwise more passive information gatherers.

Proxy/Surrogacy

Excerpt 1: Breast cancer patient turned to her daughter to acquire online information on her behalf. Reveals that some patients do not have computer access or the computer literacy skills necessary to search the Internet for cancer-related information.

Excerpt 2: Prostate cancer patient described how his wife sought online information on his behalf. Underscores how proxies can shield patients from an avalanche of information that might prove overwhelming and upsetting.

Excerpt 3: Prostate cancer patient described his daughter's role in seeking information on his behalf. Highlights the ways in which medical decision making is often a collective rather than an individual process.

Patient 22: Just reading about [cancer]. I got some material from [my physician's] office that I brought home. Then after the biopsy, they gave me more. I went to the cancer center and they gave me more. Then it started to snowball.

Patient 13: Oh yeah, it's amazing. People are so really wonderful. Everybody is supportive. Everybody sent you articles, actually from magazines. I was getting magazine articles from my nieces and nephews and just everybody had things that they were looking up on what to do, things that were helpful for you....

Patient 13: [I] had at least three different books people had given me. You become overwhelmed with information when this strikes. Everybody who has ever had cancer or anything starts giving you books and actually at...the cancer center where I was going, they have a library there and they gave me books from there to to take home and read, so I had lots of books.

Interviewer: It seems like you had a lot of social resources of people who went through it before you. Did you search these people out or did they come to you?

Patient 42: I would say half and half. And also I read up a bit on things. But I am also – in today's world that is not too great – I am a creature of "go with the flow" or that I feel good about something and I would just go with it. I am in some ways but in other ways I just felt comfortable.

Patient 42: I had my daughter go on the web, because I am computer illiterate, and see what they had to say about these drugs that I was taking....

Interviewer: Did you find the web...useful?

Patient 42: I think that if I was computer literate I probably would have been on there 24/7.

Patient 33: [When] I was diagnosed with prostate cancer, at least for the first couple of weeks I was almost just turning in circles. I was so upset. [My wife] was able to do research and find the best people or supposedly where the best hospitals were...and also researched studies. When I talk about my wife, she really was the person to research where and what hospital they were doing various things that I might participate in, even if they were experimental. So she did a lot of reading, a lot of reading on the Net and discovered that there were a lot of trials going on in various places.... I could not – literally I could not focus on doing research. Usually I am a very good detective in my job, trying to find out information and who to contact and things like that. But I couldn't do it. I just couldn't focus. If I focused on it was right in front of me every minute, every day and I was trying to put it in the back of my head.

Interviewer: Okay.

Patient 33: I know [cancer] is there, I know I have it but I didn't want to look at it. And every time I started to do research and read this stuff I was very focused on it and I just couldn't do it. She was fantastic.

Patient 15: My [adopted] daughter...became an expert in prostate cancer.

Interviewer: Oh really?

Patient 15: She decided that she was going to become the expert and she handled all the research along with a lot of the media information and the relevant paperwork. She spent hours on the Internet looking up and finding things and then printing them out and giving them to me.

Interviewer: Wow.

Patient 15: She went with me to the doctors, as my wife did. All the decisions were family oriented.

referred to as LIMs, researchers have identified proxy seekers in the cancer domain [54]—findings that are consistent with the proxy engagement reported here.

Of the patient-driven motivations, clarification/elaboration was a common motive for cross-source use. Despite the relative scarcity of research on cross-source engagement, one study described the value of a single source (e.g., Cancer Information Service, or CIS) in “augmenting” information gleaned from another source (e.g., Internet; [55]). In our study, some patients reported using traditional or new media sources because they did not fully understand the information provided by their clinicians (i.e., clarification), while others reported looking to non-medical sources to help them make informed decisions regarding treatment and side effect management (i.e., elaboration of information provided by clinicians). Regardless of context, the sheer quantity of cross-source interactions for clarification/elaboration purposes reflects patients’ strong interest in acquiring cancer-related information. This interest is consistent with the paradigm of the patient as an active consumer of health care [56], as well as with research showing that many—although not all—patients want information about their disease and its treatment [57, 58].

Our data also provide insight into the role of clinicians in patients’ verification efforts. On the one hand, a number of patients reported verifying information obtained from non-medical sources (most notably, the Internet) with health professionals. In fact, nearly 10% of patients described instances in which they printed out information from the Internet that they then discussed with a clinician. This finding is encouraging, as research has shown that only some patients who seek information online discuss it with their clinicians [36]. On the other hand, several patients also reported verifying information obtained from health professionals with non-medical sources, such as family, other cancer patients, or media sources. Interviews revealed that, in some cases, the latter pattern reflects a mistrust of medical sources—a finding that provides support for continued research attention to patient–physician trust [59, 60]. That said, mistrust did not drive all such verification efforts. For example, some patients turned to non-medical sources due to a more generalized doubt about their disease and how it should be addressed. Regardless of the specific motivation, the crucial point is that medical sources, although clearly central to information exchange, are not always considered the definitive information source. Patients may turn to other sources to verify information provided by clinicians.

Our study has several limitations. Although we used robust sampling methods and interviewed nearly 50 patients from the greater Philadelphia area, the study sample is not intended to be representative of the general population of cancer patients. It is possible that those

patients who agreed to participate in our study may exhibit different information engagement patterns than those who did not or those in other geographic regions. In addition, even though our data suggest that some motivations for cross-source engagement may be more common than others (e.g., clarification/elaboration is more common than emotional support), the prevalence and correlates of such motivations should be tested using a large, population-based sample of patients. There are other important research questions that are beyond the scope of this study. Future research should explore sociodemographic differences in cross-source engagement, the potential consequences of such engagement on health outcomes, and the extent to which patterns and motivations for cross-source movement vary across the cancer care continuum—particularly since research has shown that information engagement does not diminish over time [13].

The goal of this study was to understand how cancer patients find their way in an increasingly complex information landscape. There is a vast amount of readily accessible information on cancer treatment available today, whether in news media, the Internet, or other public channels [61]—and at least some of this information may be of dubious quality [62]. Because this information climate has the potential to influence patient–clinician information exchange [61], it is important to understand how patients interact with information sources to learn about their disease and its treatment. This study builds upon previous research by demonstrating that patients often do not use only one source to fulfill an unmet need. Instead, they use multiple sources, moving among them for specific purposes, such as verifying or clarifying information. Patients’ social networks often play an important role in this process. Ultimately, this dynamic movement has implications for cancer care and education. It creates a clear opportunity for clinicians to guide patients to accurate and useful information outlets. Discussions of information needs and source use, led by clinicians and educators, may empower patients to participate in their care. In addition, educators may design interventions to help clinicians identify patients’ information preferences and needs, as well as learn which reputable online and offline sources may prove most useful to patients. Taken together, such efforts may enhance patient–clinician communication and promote quality care.

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