

Differences in information seeking among breast, prostate, and colorectal cancer patients: Results from a population-based survey

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ABSTRACT

Objective: There is much research describing cancer patients' information needs and their use of the Internet, print media, and other sources to fulfill these needs. Yet little is known about whether patients with different types of cancer vary in their information needs and seeking behaviors. This study used population-based data to address this question.

Methods: A sample was randomly drawn from the list of patients with breast, prostate, or colorectal cancer reported to the Pennsylvania Cancer Registry in 2005. Patients completed a mail survey ($N = 2010$); respective response rates were 68%, 64%, and 61%.

Results: Colorectal cancer patients reported consistently less information seeking than breast and prostate cancer patients. Multivariate analyses revealed that differences by cancer type were not explained by sex or other demographics, disease stage, or treatment received. These differences were most pronounced among patients with early stage cancer.

Conclusion: Cancer patients have myriad information needs and use a range of sources to satisfy these needs, but there appear to be important differences in information engagement by cancer type.

Practice implications: Understanding differences in information seeking among disease-specific populations may help guide future patient education and decision making across the care continuum.

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1. Introduction

In recent years, there has been an increasing premium placed on involving patients in medical decision making, as studies have shown that such participation may improve patient satisfaction and care quality [1–3]. To participate effectively, patients typically require information on diagnosis, prognosis, and treatment options. They undoubtedly receive such information from their doctors, but the demands on physicians' time may limit the extent to which they can address all of their patients' information needs

[4]. In addition, patients may seek additional information about their cancer from other sources—even if they are satisfied with their medical care. There is also a growing quantity of health-related information available through the Internet and other media sources, some of it of dubious quality [5,6].

To understand and respond to cancer patients' information needs, considerable research has been conducted to characterize the types of needs [7–17] and sources used in information seeking [4,10,11,18–33]. There are two discernible gaps in this literature, however. First, most studies have small sample sizes, samples drawn from homogenous and less representative populations, and low response rates [7]. Such methodological limitations threaten the generalizability of study findings and make it difficult to identify patterns in patients' information engagement across studies. Second, although information needs and source use among patients with different types of cancer have been explored, there has been little effort to compare information acquisition across

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cancer types. The few studies that have attempted such comparisons were exploratory [17], had samples that were composed primarily of one cancer type [34], or were limited to patients who used a particular information source (e.g., a cancer information service) [35] or who were asked about a particular topic (e.g., psychosocial support) [24].

To address these gaps, we surveyed a population-based sample of breast, prostate, and colorectal cancer patients diagnosed in Pennsylvania in 2005. Here, we compare information needs and source use among patients with different cancers, considering both active seeking of information, as well as passive information acquisition (“information scanning”) [36,37]. In contrast to active information seeking, information scanning involves patients coming across information from other people or media sources when they are not looking for it and, to our knowledge, this concept has received little attention in previous research [20]. By understanding patients’ information engagement, and the extent to which engagement varies by cancer type, the current study may help clinicians identify which patients may benefit most from guidance to reliable and appropriate information sources, and may foster effective patient–clinician communication and care quality.

2. Methods

2.1. Sample and procedure

The sample was randomly selected in Fall 2006 from the Pennsylvania Cancer Registry’s (PCR) complete list of all breast (female only), prostate, and colorectal cancer patients diagnosed in 2005. The American Association for Public Opinion Research response rates (AAPOR RR#4) [38] for the primary sample were 68%, 64%, and 61% for the respective cancer groups. Of 2972 people originally sampled across the three cancers, 1638 returned usable questionnaires, 64 responded but claimed to have no cancer, and 347 were estimated to have died. Mortality estimates were based on Surveillance Epidemiology and End Results (SEER) cancer mortality information and Centers for Disease Control (CDC) Pennsylvania overall mortality information, taking into account age and time since diagnosis at the date questionnaires were distributed. Although the primary sample was similar to the PCR population on core demographics, we report estimates that rely on post-stratification sample weights designed to adjust the final sample to the PCR population with regard to race, age, gender, marital status, calendar quarter of diagnosis, and disease stage at diagnosis. Adjustments were made within cancer type. We oversampled for colorectal cancer, Stage IV, and African American respondents to increase sample sizes for analyses of those subgroups (adding 372 cases to the sample); however, all analyses using weights correct for this oversampling to permit the analytic sample to represent the population of interest. These sampling procedures yielded an analytic sample of 2010 patients (breast, $N = 678$; prostate, $N = 651$; and colorectal, $N = 681$).

We mailed a survey to all potential participants after pilot-testing questionnaire items with cancer patients at the University of Pennsylvania. Our mailing procedure followed Dillman’s [39] methods for mail surveys. First, we mailed an introductory letter and a brochure about the PCR to all potential participants. The letter indicated that patients would receive a survey in a few days, and it described our study’s overall purpose: “understanding how people make decisions about their cancer” and, more specifically, “learning how [they] have used information from doctors, the mass media, the Internet, family and friends to make decisions about cancer.” The letter assured patients that their participation was voluntary and explained that they could opt out of completing the survey. Five days later, we mailed the first copy of the survey, a second letter that reiterated the information contained in the first

letter, a business reply envelope, and a cash incentive of \$3 or \$5. Two weeks after the initial mailing, we sent a reminder letter and another copy of the survey to those patients who had not yet returned the survey; no additional cash incentive was included. Note that potential participants were randomly assigned to receive \$3 or \$5 and a long (61-item) or short (33-item) version of the survey as part of a separate study that assessed whether incentive amount and length of survey influenced response rate. It was determined that neither incentive amount nor length of survey significantly affected this rate [40]. Both the long and short versions of the survey contained all of the information seeking and scanning questions used in the current study.

Patient consent was inferred from the return of the completed questionnaire. The study procedure and materials were approved by the University of Pennsylvania Institutional Review Board.

2.2. Measures

The information engagement measures explored three dimensions of information use: topics addressed (e.g., treatment options, side effect management); sources used (e.g., medical, interpersonal, media); and amount of active seeking and passive scanning performed. We first asked patients to “think back to the first few months after you were diagnosed with breast/prostate/colorectal cancer.” To ensure that patients would differentiate between active and passive information acquisition, we then provided the following clarification: “The questions below explore different situations. Sometimes you might have been **actively looking** for information about a specific cancer topic (e.g., treatment). Other times you might **not have been looking** for cancer information at all, but **just came across it**. Please note what each question asks about.” Subsequent question stems reinforced this distinction. In addition, because patients’ family members or friends may have been involved in the information seeking or scanning process, we included the following directions: “In this section of the questionnaire, whenever we ask what “you” did, this includes **you and any family member or friends** who may have helped you look for information.”

2.2.1. Active information seeking

We asked respondents whether they actively sought information about their cancer, and what sources they had used to seek that information. Source response options included “my treating doctors”, “other doctors or health professionals”, “family members, friends or co-workers”, “other cancer patients”, “face-to-face support groups”, “online support groups”, “telephone hotlines (e.g., from the American Cancer Society)”, “television or radio”, “books, brochures or pamphlets”, “newspapers or magazines”, “Internet (other than personal e-mail and online support groups)”, and “other.” Respondents were also asked about what topics they might have sought information. Topic response options included “what treatments were best for my cancer”, “which doctors or hospitals would be the best for me”, “how to manage side effects of treatments”, “emotional support for dealing with my cancer”, “further explanations of what my doctors have told me”, “second opinions about the treatments my doctors recommended”, “my chances of survival or cure”, and “other information.” All items were dichotomous; for example, a patient was classified as either a seeker or a non-seeker, and if a patient was a seeker, then he or she either did or did not use a particular source or seek about a specific topic.

Additionally, two summary measures of active information engagement were created: one for the total number of sources sought from (range = 0–12), and one for the total number of topics sought about (range = 0–8). These measures served as the dependent variables in the analyses presented in Table 5.

2.2.2. Passive information scanning

Patients were asked about the sources they used when they “came across information... even though they were not actively looking for it.” Source response options included “other doctors or health professionals (not my treating doctors)”, “family members, friends or co-workers”, “other cancer patients”, “television or radio”, “books, brochures or pamphlets”, “Internet (other than personal e-mail and online support groups)”, “mail from health organizations (e.g., hospitals, insurance companies)”, and “other.” We excluded “my treating doctors,” assuming that all patients would have come across information from their treating physicians without actively looking for it. As with the seeking measures, all items were dichotomous; for example, a patient was classified as either a scanner or a non-scanner, and if a patient was a scanner, then he or she either did or did not come across information from a particular source.

2.2.3. Patient and clinical characteristics

The survey assessed demographics including age, gender, race/ethnicity, and education. Information on stage of disease was available from the PCR; however, Stage 0 prostate cancer patients were not sampled, and due to inconsistent reporting of Gleason scores to the PCR, we considered patients with localized prostate cancer (Stages I and II) together. We asked all patients what treatments they had received for their cancer. Individual treatment items were collapsed into three broad categories: surgery, radiation therapy, and systemic therapy. Surgery included mastectomy or lumpectomy for breast patients, prostatectomy for prostate patients, and surgery for colorectal patients. Radiation therapy included external beam or brachytherapy for prostate patients and radiation for breast and colorectal patients. Systemic therapy included chemotherapy, hormonal therapy (for breast and

prostate patients), and targeted therapy (e.g., Herceptin for breast patients; Avastin or Erbitux for colorectal patients).

2.3. Analytic approach

Basic frequency analyses determined patients' information needs and source use, and relevant descriptive statistics summarized these patterns. Crosstabulations were used to examine differences in topic and source use among cancer subgroups; bivariate (χ^2) analyses were performed to estimate associations between cancer type and topic and source use, and 95% confidence intervals were calculated to assess by-cancer differences. Multivariate linear regression was used to test the main and interacting effects of demographic characteristics, disease stage, and treatment received on information engagement by cancer type. Only the interaction of cancer type and stage was significant, and thus was the only one included in the final models. Fewer than 15% of cases were missing across analyses; thus, listwise deletion was used to deal with missing data. All analyses were corrected using post-stratification weights so that they represented the 2005 population of the PCR. Weighted analyses were performed using the survey data analysis commands in Stata 10 [41].

3. Results

3.1. Sample characteristics

The mean ages of breast, prostate, and colorectal cancer respondents were 64 (SD = 14), 69 (SD = 9), and 71 (SD = 13) years, respectively. Fifty percent of colorectal cancer patients were female. Additional demographic and clinical information for participants is shown in Table 1.

Table 1
Participant characteristics.^a

	Breast (N=678)		Prostate (N=651)		Colorectal (N=681)	
	No. of respondents	Weighted % or M (SD)	No. of respondents	Weighted % or M (SD)	No. of respondents	Weighted % or M (SD)
Mean age, years	677	64 (14)	651	69 (9)	681	71 (13)
Gender	678		651		681	
Female		100		–		50
Male		–		100		50
Race/ethnicity	674		650		680	
NH White		86		85		86
NH Black		10		11		9
Hispanic		3		3		4
Other		2		1		2
Education	663		645		668	
<High school		14		14		22
High school		41		38		42
Some college		25		20		19
College and above		20		28		17
Stage of disease	648		601		632	
0		22		0 ^b		15
I (and II, prostate ^b)		39		88 ^b		19
II		25		–		26
III		9		6		24
IV		5		6		16
Treatment received ^c	678		651		681	
Surgery		89		32		92
Radiation		71		59		15
Systemic		80		29		45

SD indicates standard deviation; NH, non-Hispanic.

^a Percentages may not sum to 100 due to rounding. Ns vary across items due to missing data.

^b Stage 0 prostate cancer patients were not sampled. Due to inconsistent reporting of Gleason scores to the PCR, we considered patients with localized prostate cancer (Stages I and II) together.

^c Surgery included mastectomy or lumpectomy for breast patients; prostatectomy for prostate patients; and surgery for colorectal patients. Radiation therapy included external beam or brachytherapy for prostate patients and radiation for breast and colorectal patients. Systemic therapy included chemotherapy, hormonal therapy (for breast and prostate patients), and targeted therapy (e.g., Herceptin for breast patients; Avastin or Erbitux for colorectal patients).

Table 2
Percentage of cancer patients actively seeking information from sources.

Source ^a	Weighted average % across cancers (95% CI)	Weighted % by cancer (95% CI)		
		Breast (N=666)	Prostate (N=640)	Colorectal (N=652)
Medical				
My treating doctors	75.3 (73.4–77.2)	78.1 (75.0–81.2)	83.3 (80.4–86.2)	64.6 (60.9–68.3)
Other doctors, health professionals	34.4 (32.3–36.5)	39.1 (35.4–42.8)	41.3 (37.5–45.1)	22.9 (19.7–26.1)
Interpersonal				
Family, friends, co-workers	48.0 (45.8–50.2)	56.1 (52.3–60.0)	52.0 (48.1–55.9)	35.9 (32.2–39.6)
Other cancer patients	38.1 (36.0–40.2)	46.6 (42.8–50.4)	47.7 (43.8–51.6)	19.7 (16.6–22.8)
Face-to-face support groups	3.3 (2.5–4.1)	5.5 (3.8–7.2)	3.1 (1.8–4.4)	1.2 (0.4–2.0)
Online support groups	2.2 (1.6–2.8)	3.1 (1.8–4.4)	1.7 (1.0–2.7)	1.9 (1.0–2.9)
Telephone hotlines	5.9 (4.9–6.9)	10.6 (8.3–12.9)	3.5 (2.1–4.9)	3.6 (2.2–5.0)
Media				
Television, radio	16.1 (14.5–17.7)	19.9 (16.9–22.9)	16.4 (13.5–19.3)	11.9 (9.4–14.4)
Books, brochures, pamphlets	49.9 (47.7–52.1)	58.1 (54.4–61.8)	60.5 (56.7–64.3)	31.0 (27.4–34.6)
Newspapers, magazines	22.8 (21.0–24.6)	30.5 (27.0–34.0)	23.9 (20.6–27.2)	13.7 (11.1–16.3)
Internet	27.1 (25.2–29.0)	31.0 (27.5–34.5)	31.8 (28.2–35.4)	18.4 (15.4–21.4)
Other	2.2 (1.6–2.8)	2.9 (1.6–4.2)	1.3 (0.4–2.2)	2.5 (1.3–3.7)

95% CI indicates 95% confidence interval.

^a All χ^2 significant at $p < .05$ except for “online support groups” and “other source.”

3.2. Descriptive data on information seeking and scanning

Averaging across cancers, 81.7% of patients sought information about their cancer. On average, patients sought information from 3.3 sources ($SD = 2.4$) (Table 2). The most frequently cited source was treating doctors (75.3%), although use of other medical professionals was also reported (34.4%). Use of interpersonal sources—including family members, friends or co-workers (48.0%) and other cancer patients (38.1%)—and books, brochures or pamphlets (49.9%) were common. Twenty-seven percent of patients reported seeking information about their cancer from the Internet, and few patients used support groups (3.3%, face-to-face; 2.2%, online) or telephone hotlines (5.9%).

Although treating doctors were the most frequently reported source, most patients did not seek information solely from their doctor. Across cancers, of those patients who sought information about their cancer, only 5.2% did not seek from medical sources; however, only 37.6% sought exclusively from their treating doctors and/or other doctors or health professionals. In fact, many patients sought information from all three broad categories of sources: medical, interpersonal, and media. Of those patients who reported seeking information about cancer, 56.3% sought from at least one source in each of these three broad groups.

Across cancers, most patients (78.3%) also reported coming across information about their cancer when they were not actively looking for it (Table 3). Patients scanned from an average of 2.0 sources ($SD = 1.6$), encountering information most frequently from books, brochures or pamphlets (40.9%). Other interpersonal and media sources received similar levels of attention, although

Internet scanning was less common (11.4%). Twenty-one percent of patients noted that they came across information from mail sent by health organizations, such as hospitals and insurance companies.

Patients reported seeking information about a range of cancer-related topics (Table 4). Across cancers, patients sought information about 2.9 topics ($SD = 2.3$), with treatment-related information being the most frequently reported topic (59.9%). They also reported seeking further explanations of what their doctors had told them (42.4%) and information on chances of survival or cure (47.9%).

3.3. Differences in seeking and scanning by cancer type

Stratified analyses revealed differences in seeking by cancer type. Overall, breast and prostate cancer patients tended to seek information about cancer more frequently than colorectal cancer patients (85.1% and 90.3% versus 69.8%, respectively, $p < .001$), and this pattern held for most individual sources as well (Table 2). Colorectal patients sought information from fewer sources on average than breast and prostate patients ($M = 2.3$, $SD = 2.2$ versus $M = 3.8$, $SD = 2.5$ and $M = 3.7$, $SD = 2.2$, respectively, $p < .001$). Additionally, colorectal cancer patients tended to seek about fewer cancer-related topics than breast or prostate patients ($M = 1.9$, $SD = 2.0$ versus $M = 3.3$, $SD = 2.3$ and $M = 3.4$, $SD = 2.2$, respectively, $p < .001$) (Table 4).

There were also significant differences in scanning by cancer type (Table 3). Breast and prostate patients tended to come across information about their cancer more frequently than colorectal

Table 3
Percentage of cancer patients scanning information from sources.

Source ^a	Weighted average % across cancers (95% CI)	Weighted % by cancer (95% CI)		
		Breast (N=638)	Prostate (N=608)	Colorectal (N=615)
Other doctors, health professionals	18.4 (16.7–20.1)	18.3 (15.3–21.3)	22.4 (19.1–25.7)	14.5 (11.7–17.3)
Family, friends, co-workers	40.0 (37.9–42.1)	45.0 (41.1–48.9)	40.4 (36.5–44.3)	34.5 (30.7–38.3)
Other cancer patients	33.3 (31.2–35.4)	40.1 (36.3–43.9)	35.6 (31.8–39.4)	24.0 (20.6–27.4)
Television, radio	32.3 (30.3–34.3)	40.3 (36.5–44.1)	29.8 (26.2–33.4)	26.5 (23.0–30.0)
Books, brochures, pamphlets	40.9 (38.8–43.0)	49.5 (45.6–53.4)	40.1 (36.2–44.0)	32.6 (28.9–36.3)
Internet	11.4 (10.0–12.8)	14.0 (11.3–16.7)	12.4 (10.0–15.0)	7.8 (5.7–9.9)
Mail from health organizations	21.2 (19.4–23.0)	27.8 (24.3–31.3)	17.4 (14.4–20.4)	18.1 (15.1–21.1)
Other	3.3 (2.5–4.1)	4.7 (3.1–6.3)	3.1 (1.7–4.5)	2.0 (0.9–3.1)

95% CI indicates 95% confidence interval.

^a All χ^2 significant at $p < .05$ except for “other source.”

Table 4
Percentage of cancer patients actively seeking information about cancer-related topics.

Topic ^a	Weighted average % across cancers (95% CI)	Weighted % by cancer (95% CI)		
		Breast (N=632)	Prostate (N=600)	Colorectal (N=632)
What treatments were best for my cancer	59.9 (57.8–62.0)	66.1 (62.4–69.8)	75.5 (72.1–78.9)	38.9 (35.1–42.7)
Which doctors or hospitals would be best for me	41.5 (39.3–43.7)	42.5 (38.6–46.4)	53.0 (49.0–57.0)	29.6 (26.0–33.2)
How to manage side effects of treatments	38.9 (36.8–41.0)	48.8 (44.9–52.7)	41.0 (37.1–44.9)	27.0 (23.5–30.5)
Emotional support for dealing with my cancer	20.4 (18.6–22.2)	31.6 (28.0–35.2)	15.5 (12.6–18.4)	13.7 (11.0–16.4)
Further explanations of what my doctors have told me	42.4 (40.2–44.6)	49.3 (45.4–53.2)	49.3 (45.3–53.3)	29.0 (25.5–32.5)
Second opinions about treatments my doctors recommended	25.0 (23.1–26.9)	24.9 (21.5–28.3)	37.6 (33.7–41.5)	13.2 (10.6–15.8)
My chances of survival or cure	47.9 (45.7–50.1)	52.9 (49.0–56.8)	56.8 (52.8–60.8)	34.4 (30.7–38.1)
Other information	7.5 (6.3–8.7)	11.3 (8.8–13.8)	6.7 (4.7–8.7)	4.6 (3.0–6.2)

95% CI indicates 95% confidence interval.

^a All χ^2 significant at $p < .05$.

cancer patients (86.5% and 79.2% versus 68.9%, respectively, $p < .001$). Across sources, breast cancer patients reported the greatest amount of scanning.

To determine whether differences in information seeking by cancer type were explained by demographic and clinical characteristics, we performed multivariate linear regression. Even when adjusting for patient characteristics, cancer type remained significant in the models, suggesting that these by-cancer effects were not accounted for by demographic or clinical features. Information engagement was associated with patient age and

education (with younger and better educated patients reporting more topic and source use), and there were some main effects of treatment received (for example, patients who received systemic therapy reported seeking about more topics and from more sources than those who did not receive systemic treatment). In addition to these main effects, we examined the interaction of cancer type and disease stage. In both equations presented in Table 5, at least one of the cancer type by stage interactions was significant at $p < .05$. As shown in Fig. 1, large differences among cancers at lower stages were reduced at Stages III and IV.

Table 5
Multivariate linear regression models predicting cancer patient information engagement.

	No. of sources sought from			No. of topics sought about		
	Simple model <i>b</i> (SE)	Adjusted model <i>b</i> (SE)	Adjusted plus interaction <i>b</i> (SE)	Simple model <i>b</i> (SE)	Adjusted model <i>b</i> (SE)	Adjusted plus interaction <i>b</i> (SE)
Constant ^a	2.27 (0.09)***	3.20 (0.58)***	3.08 (0.58)***	1.90 (0.09)***	2.78 (0.54)***	2.67 (0.54)***
Cancer type						
Breast cancer	1.54 (0.14)***	0.76 (0.18)***	1.00 (0.20)***	1.37 (0.13)***	0.59 (0.19)**	0.75 (0.21)***
Prostate cancer	1.39 (0.13)***	1.64 (0.19)***	1.88 (0.19)***	1.45 (0.13)***	1.60 (0.19)***	1.79 (0.21)***
Age		−0.06 (0.005)***	−0.06 (0.005)***		−0.04 (0.005)***	−0.04 (0.005)***
Gender ^b						
Male		−0.22 (0.18)	−0.22 (0.18)		−0.24 (0.17)	−0.24 (0.17)
Race/ethnicity ^c						
NH Black		−0.20 (0.18)	−0.22 (0.18)		0.09 (0.17)	0.07 (0.17)
Hispanic		0.22 (0.38)	0.21 (0.38)		0.59 (0.37)	0.58 (0.37)
Other		−0.71 (0.40)	−0.67 (0.40)		−0.18 (0.34)	−0.16 (0.33)
Education ^d		0.18 (0.02)***	0.18 (0.02)***		0.15 (0.02)***	0.15 (0.02)***
Stage of disease ^e						
Stage III		0.20 (0.18)	0.62 (0.23)**		0.22 (0.18)	0.47 (0.22)*
Stage IV		0.16 (0.20)	0.60 (0.31)*		−0.12 (0.18)	0.23 (0.27)
Treatment received ^f						
Surgery		0.54 (0.18)**	0.54 (0.18)**		0.23 (0.18)	0.23 (0.19)
Radiation		0.20 (0.14)	0.17 (0.14)		0.17 (0.14)	0.14 (0.14)
Systemic		0.41 (0.14)**	0.34 (0.14)*		0.54 (0.14)***	0.51 (0.14)***
Interaction of cancer and stage ^g						
Breast × Stage III			−0.64 (0.45)			−0.29 (0.44)
Breast × Stage IV			−0.75 (0.42)			−0.47 (0.40)
Prostate × Stage III			−1.07 (0.42)*			−0.74 (0.43)
Prostate × Stage IV			−0.89 (0.40)*			−0.93 (0.37)*
R ²	0.08	0.25	0.25	0.09	0.21	0.21
N	1958	1797	1797	1864	1715	1715

SE indicates standard error; NH, non-Hispanic.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

^a In the two simple models, the constant's coefficients are the mean number of sources that colorectal cancer patients sought from, and the mean number of topics they sought about. In the controlled models, colorectal cancer is the cancer type reference category.

^b Female is the reference category.

^c NH White is the reference category.

^d For this analysis, education was recoded into a continuous variable, with a mean of 13 years (SD=2.6).

^e Stages 0, I, and II combined is the reference category (given no Stage 0 prostate patients in the sample and the grouping of Stages I and II prostate patients).

^f "Did not have surgery," "did not have radiation," and "did not have systemic therapy" are the respective reference categories.

^g The only significant interaction was cancer type and stage. For the number of sources model, the interaction block was significant at $p < .05$; for the number of topics model, the block was marginally significant at $p < .08$.

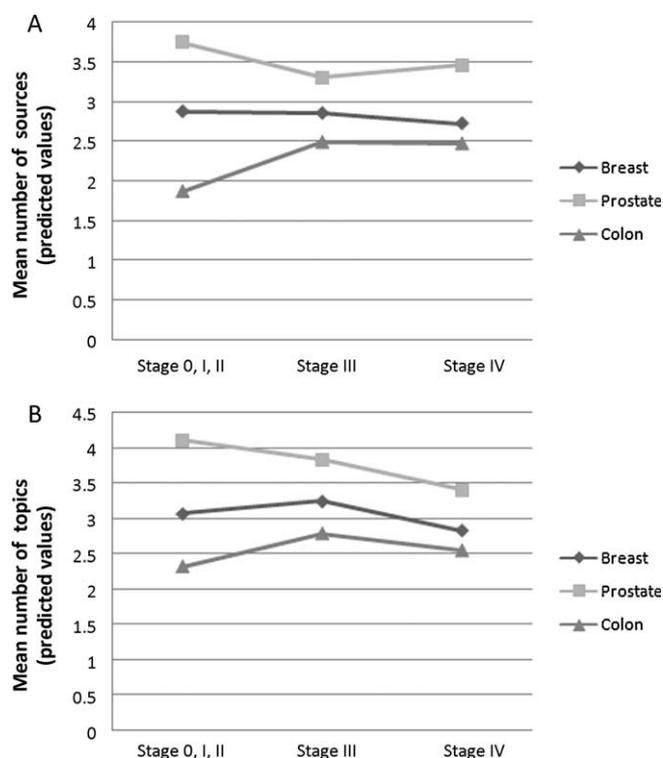


Fig. 1. (A) Interactive relationship between cancer type and stage of disease in accounting for information seeking from sources. By-cancer differences in seeking at lower stages were reduced at Stages III and IV. (B) Interactive relationship between cancer type and stage of disease in accounting for information seeking about cancer-related topics. By-cancer differences in seeking at lower stages were reduced at Stages III and IV.

4. Discussion and conclusion

4.1. Discussion

Overall, this study found that information seeking behavior varied by cancer type, with colorectal cancer patients reporting consistently less information seeking than breast and prostate patients. Patient and clinical characteristics—namely, demographics, stage, and treatment received—did not explain these observed differences; breast and prostate coefficients remained significant even after adjusting for these characteristics. Yet we found an intriguing set of results: the different seeking behaviors reported across cancers were contingent on disease stage. Patients with earlier stage breast or prostate disease were much more likely to be searching for information than were early stage colorectal patients. At later stages, the by-cancer differences were reduced.

We can only speculate as to the explanation for these results. First, it may be that there is more information available about early stage breast and prostate cancer, so it may prove easier for patients to search for information. A Nexis search of major U.S. newspapers for 2005 found 11,862 articles about “breast cancer,” 3310 about “prostate cancer,” and 2513 for “colon or colorectal cancer.” Additionally, a 2008 Google search shows a pattern that also may have applied in 2005: a “breast cancer” search produced 50 million hits, “prostate cancer” produced 14.5 million, but “colon or colorectal cancer” produced 1.5 million. In addition to information available on the Internet and in the news media, colorectal cancer patients may have fewer opportunities to discuss cancer-related topics with their friends and family. Among our respondents with the respective cancers, 71% and 64% of those with breast or prostate cancer had a close friend or family member with the

disease; a substantially smaller 45% reported a similar contact for colorectal cancer.

Second, the results may be explained in part by varying levels of professional uncertainty and controversy surrounding early stage treatment of the three cancers. Early stage colorectal cancer typically involves a straightforward and well agreed upon plan of care, whereas there can be several equivalent treatment options for early stage breast and prostate patients—treatments that vary not by disease outcome, but by potential late effects (e.g., radical prostatectomy versus external beam radiation). There are also several scenarios in breast and prostate treatment where there is significant controversy regarding the most effective treatment (e.g., adjuvant taxanes in estrogen-receptor positive early breast cancer). The relative ambiguity about the best treatment options in early stage breast and prostate cancer may create a situation in which patients need to be more actively involved medical decision making and thus could motivate them to seek more information about their disease. In addition, these patients might receive contradictory or confusing information from different clinicians. If a patient’s radiation oncologist recommends one course of action, but the patient’s surgeon suggests another course, then such discrepancies may lead patients to seek further information to help reconcile these competing treatment recommendations.

A related potential explanation for this set of findings involves treatment experience. Treatment for colorectal cancer at early stages may have few long-term side effects and require minimum follow-up care (e.g., polypectomy followed by regular monitoring through colonoscopy). In contrast, both breast and prostate cancer, even at early stages, are more likely to involve longer periods of treatment, and treatments can have notable and longer lasting side effects. Such effects may lead to greater seeking about side effect management or other issues among early stage breast and prostate patients compared with colorectal patients. Lastly, both breast and, to a lesser extent, prostate cancer have substantial lay communities who have experienced these diseases and have generated a culture of engagement. Perhaps this, in turn, encourages patients and their families to engage in seeking. Although these are plausible explanations for the disease differences observed, future research should attempt to explore these distinctions.

Looking across cancers, our findings are consistent with previous research [7,42]: cancer patients have numerous information needs and use a variety of sources to satisfy these needs. They both actively seek information about cancer and come across it when they are not looking for it. Although the use of medical sources is common, patients do not limit themselves to seeking information from their doctors or other health professionals. Rather, more than half of patients reported seeking from at least one medical, interpersonal, and media source, demonstrating a breadth of source use. In fact, although we found that nearly a third of patients reported seeking information from the Internet, they continued to use offline sources, such as books and pamphlets, to learn about their disease and its treatment—another finding that echoes previous research [43]. Similarly, patients most frequently reported seeking about treatment information, but they desired information about other topics, too, including their chances of survival or cure. There is already a growing body of research examining the information needs and source use of cancer survivors [44–46], and our results suggest that continued attention to patients’ needs across the care continuum is warranted.

There are several limitations to our study. First, given the high response rates, the sample likely represents the 2005 population of diagnosed breast, prostate, and colorectal cancer patients in Pennsylvania, but it does not represent patients in other states or with other cancers or in other time periods. Second, patterns of information engagement, particularly with sources such as the Internet, may have changed since data were collected in 2006.

Third, we did not ask which sources patients used to gain information about particular topics. Pretesting showed that patients had a difficult time recalling which topic-related information came from which sources. Fourth, our measures of seeking and scanning were developed for the purposes of this research and have not been independently validated. Fifth, these responses reported on a particular period post cancer diagnosis; information needs and behavior will likely vary over time. Sixth, these data are self-reports, and we assume that patients accurately recalled and reported their seeking and scanning behavior and that the accuracy was similar across cancer types. Finally, because we administered a mail questionnaire, we were unable to prevent patients from skipping items and limit the amount of missing data. However, no single seeking or scanning question had more than 7% missing, and multivariate analyses had fewer than 15% missing.

4.2. Conclusion

To our knowledge, this is the first study to document differences in information engagement across cancer types using population-based data. Colorectal cancer patients reported consistently less information seeking than breast and prostate patients, even after adjusting for demographic and clinical characteristics—and these differences were most pronounced among patients with early stage disease. Although we offer some potential explanations for this set of findings, future research should explore further the by-cancer differences observed in this study. A qualitative study might help to ascertain whether colorectal cancer patients seek less information because they encounter specific barriers to information seeking (such as a perceived paucity of trustworthy information sources or decreased interpersonal discussions due to fear of stigmatization) or because they find little need for information above and beyond what they receive in the clinical encounter. While we have speculated that differences in treatment-related decision making may explain some of the differences in information seeking between colorectal cancer and breast and prostate cancer patients, we still need to account for the fact that colorectal patients seek less often about topics other than treatment (e.g., their chances of survival or cure). A qualitative study could provide great insight into the information seeking behavior of colorectal patients and, if needed, identify areas for potential intervention. Additionally, more work on information seeking needs to be done with other types of cancers. We have seen heterogeneity across colorectal, breast, and prostate cancer and would expect that there may be differences in information seeking in other, more rare cancers (e.g., ovarian cancer or sarcoma) or in highly stigmatized cancers (e.g., lung cancer).

Future studies also should consider the potential impact of cancer information seeking in general and of discrepancies in information engagement in particular. For example, do high levels of information seeking result in improved cancer patient satisfaction or greater patient participation in medical decision making? Does cancer patient information seeking lead to improved medical outcomes? In the context of colorectal cancer information seeking specifically, it would be important to identify the potential ramifications of low levels of information engagement. On the one hand, colorectal patients may be at increased risk for experiencing unmet psychosocial needs, as they may have less information to help them cope with issues surrounding their disease and its treatment. On the other hand, their decreased engagement may be protective, as some have speculated that access to more information—absent knowledge of how to evaluate and digest that information—can produce greater levels of unmet needs [47].

4.3. Practice implications

We have seen important differences in information seeking among three disease-specific populations. Given this heterogeneity, clinicians cannot assume that cancer patients have similar patterns of information engagement and instead should ask patients about their particular seeking behaviors. Although there is evidence that some clinicians direct patients to medical and non-medical information sources [48,49], research suggests that clinicians may not routinely ask patients about their information seeking practices [48]. It is essential that clinicians know if patients are looking for cancer-related information, where they are looking for information, and if they need guidance in this process because seeking has been linked to a wide range of outcomes—including, on the one hand, increased confidence in actively participating in treatment decisions and asking physicians questions and, on the other hand, increased confusion and anxiety [25,50,51].

In addition, while many patients actively seek cancer-related information, we found that almost 20% of patients did not engage in this behavior. There are many reasons why cancer patients may not seek information. As previously noted, patients may not look for information if their care is relatively straightforward. However, there are other possible explanations for non-seeking behavior: some patients may actively avoid information to prevent anxiety or stress (a behavior referred to as “blunting”) [52]; some may prefer to receive information via a proxy or surrogate (e.g., a family member or other caregiver who seeks on the patient’s behalf) [48]; and some patients may not have the opportunity or ability to locate information [53]. Once the provider understands if and how a given patient engages with cancer-related information, he or she can tailor the way in which he or she counsels the patient. For example, if a patient is an active information seeker and is using reliable information sources, it is likely that there is no need for further counseling; rather, the clinician might take greater opportunity to discuss information the patient has found. If the patient is an active information seeker but is using unreliable information sources, or if the patient is a non-seeker who has access to information resources and wants to engage with information, then the clinician can guide him or her to high-quality, cancer-specific materials. The latter scenario may be particularly relevant to colorectal cancer patients, if future research reveals that these patients encounter certain barriers to information seeking that could be addressed by cancer-specific source referrals. Alternatively, if a patient prefers to rely on proxy information seekers, providers may want to ensure that those individuals are present for key discussions about cancer care. Finally, if a patient wants to engage with cancer-related information but does not have the ability to obtain information—for example, a patient who lacks Internet access, or a patient for whom English is a second language—then very different interventions may be needed. Specifically, clinicians might procure patient navigators to aid with information acquisition, provide tailored cancer education “classes” at local health clinics, or develop interventions to increase access to computers and the Internet, providing patients with the skills necessary to use them. Solutions that deal specifically with health information access have the potential to reduce communication and health inequalities [53,54].

Ultimately, clinicians should initiate a conversation with patients not only about their information needs [55], but also about their information seeking preferences and practices. This information exchange may enable clinicians to tailor patient education efforts, which, in turn, may enhance patient–clinician communication and the quality of care provided. Designing interventions to help clinicians identify patients’ information seeking preferences and needs—as well as learn which reputable

online and offline sources may prove most useful to patients—may be well-advised.

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Conflict of interest

None of the authors has any conflicts of interest to disclose.

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