Original Article

Colon Cancer Patient Information Seeking and the Adoption of Targeted Therapy for On-Label and Off-Label Indications

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BACKGROUND: Despite the rise in publicly available cancer information, little is known about the association between patient information seeking and the adoption of cancer technologies. The authors of this report investigated the relation between patient information seeking and awareness about and receipt of novel targeted therapy (TT) for colon cancer among patients for whom therapy is approved by the US Food and Drug Administration (FDA) and among patients for whom therapy is not FDA approved. **METHODS:** A retrospective, population-based survey of 633 colon cancer patients were identified through the Pennsylvania Cancer Registry. Outcome measures were self-reported awareness about and receipt of TT (bevacizumab and cetuximab). **RESULTS:** After adjusting for sociodemographic characteristics, high levels of treatment information seeking were associated strongly with hearing about TT (odds ratio [OR], 2.83; 95% confidence interval [CI], 1.49-5.38) and receiving TT (OR, 3.22; 95% CI, 1.36-7.62). These associations were present for patients with metastatic disease, for whom the use of TT is FDA approved, and for patients with localized disease, for whom the use of TT is not FDA approved (P for interactions = .29). Internet use (OR, 2.88; 95% CI, 1.40-5.94) and newspaper/magazine use (OR, 3.44; 95% CI, 1.34-8.84) were associated with hearing about TT. Seeking information from nontreating physicians was associated with hearing about TT (OR, 1.95; 95% CI, 1.03-3.68) and receiving TT (OR, 2.64; 95% CI, 1.16-5.97). **CONCLUSIONS:** Patient information seeking was related to the adoption of TT for colon cancer in both appropriate and inappropriate clinical settings. These findings emphasize the importance of exploring patient influence on physician prescribing patterns and understanding the impact of information seeking on cancer outcomes. **Cancer 2009;115:1424–34.** © 2009 American Cancer Society.

KEY WORDS: cancer survivor, communication, information seeking, diffusion and adoption, targeted therapy, off-label drug use.

In the last 40 years, patients have become more involved in their healthcare as the physician-patient relationship has shifted from a largely paternalistic model to 1 that emphasizes patient autonomy.[1-5] At the same time, there has been unprecedented growth in the amount of health information that is available to patients. Widespread access to communication technologies, such as the Internet, has made health information almost ubiquitous.[6,7] This increased access is reflected in widespread health information seeking by lay individuals. For example, approximately 45% of individuals report looking for cancer information, and approximately 39% of cancer patients seek cancer information on the Internet.[6,8]

If patients' use of health information is increasing, then it remains unclear how these phenomena will influence medical outcomes. Patient access to information may erode components of the physician-patient relationship; however, increased access may lead to more informed patients and improved shared decision making.[9-12] In addition, patient information seeking may produce adverse effects, such as an increased demand for cancer-related therapies and technologies. Increased patient access to medical information also may directly influence population health by influencing health behaviors and reducing disparities in information access.[6,7,13]

Theories suggest that access to health information may have an impact on the diffusion and adoption of new medical technologies. Diffusion of innovation is a complex process that is influenced by factors as diverse as pricing, government regulation, patient, physician, and technology characteristics, and physician interpersonal networks.[14-21] Patterns of adoption of new technologies also are influenced strongly by exposure to information.[15,22] Physicians commonly encounter information in a professional context, but there is evidence that media coverage influences physician attitudes about scientific discoveries or amplifies the impact of publications in the research community.[23,24] Patients may learn about novel therapies from sources such as the media and the Internet. This phenomenon may be particularly important for cancer treatment when new therapies are developed rapidly and receive considerable media attention.

Although several studies have demonstrated that individuals who look for health information have improved knowledge, engage in more cancer-prevention behaviors, and take more active roles in decision making,

little published work exists that examines the relation between cancer information seeking and cancer treatment.[25-27] In 1 study, 47% of patients who were referred for participation in a prominent phase 1 drug trial first learned about the trial from media sources, and 51% of those patients subsequently contacted their physician for more information.[28]

Here, we report the results of a study examining the relation between cancer patient information seeking and awareness about and use of novel targeted therapy for colon cancer. We focused on treatments with targeted therapy, bevacizumab (Avastin) and cetuximab (Erbitux), because of their clinical importance, significant media coverage, and recent US Food and Drug Administration (FDA) approval. We investigated awareness and use of targeted therapy in both on-label and off-label indications, because we believed that there might be both positive and negative associations of information seeking on drug use. We hypothesized that there would be a relation between information seeking and awareness of targeted therapies for all patients with colon cancer, because information on bevacizumab and cetuximab is widely available and likely would be encountered during treatment information seeking, regardless of whether targeted therapy would be indicated. In addition, because treatment information seeking may lead patients to inquire about specific medications and, subsequently, to receive those medications, we hypothesized that information seeking would be associated with the use of targeted therapy with a greater effect in patients for whom targeted therapy is approved by the FDA.

MATERIALS AND METHODS

Study Design

We conducted a retrospective, population-based survey of 633 colorectal cancer patients to identify the association between cancer information seeking and awareness about and receipt of targeted therapy for colon cancer. All patients provided informed consent before participating, and we obtained institutional board approval from the University of Pennsylvania.

Patients

We surveyed a randomly chosen sample of colon cancer patients from a list obtained from the Pennsylvania

Cancer Registry. Patients were eligible if they were diagnosed with colorectal cancer between January 2005 and December 2005 in Pennsylvania. To have the statistical power to estimate large differences in cancer information seeking by racial and stage groups, we set recruiting objectives for stage and racial subgroups before data collection. We evaluated response rates after the first wave of data collection and subsequently over-sampled patients with stage IV cancer and African-American patients, because we observed that these groups had lower response rates than other subgroups. Patients were excluded from the study if they were unable to provide informed consent.

Data Collection

We mailed surveys to 1581 potential patients in 2006, 1305 in the initial sample and 276 in the over-sample. The mailing procedures were based on the Dillman method for mail surveys.[29] The American Association for Public Opinion Research response rate was 60% for the initial sample and 32% for the over-sample.[30] Of the 682 respondents in the total sample, 633 had complete stage data and were included in our analyses.

Survey Instrument

We developed the survey based on a literature review and expert consultation and used validated measures when possible. The survey was pilot tested with 29 cancer patients. After the pilot, the questionnaire was revised and retested with a small number of respondents. No pilot data were included in the analysis.

Measures

Sociodemographic and health characteristics

We obtained self-reported information about age, race/ethnicity, education, marital status, and health status through survey questions. We obtained information about cancer type, sex, and cancer stage from the Pennsylvania Cancer Registry database. We generated an American Joint Committee on Cancer/International Union Against Cancer TNM stage for each patient by combining Pennsylvania Cancer Registry data on tumor characteristics, lymph node involvement, and metastasis. On the basis of the FDA-approved indications for bevacizumab and cetuximab use in 2005, patients were included in the

Table 1. Measures

Information seeking

Think back to the first few months after you were diagnosed with colon cancer. In making decisions about what treatments to choose, did you actively look for information about treatments from any sources? Check all that apply:

   I did not actively look for information about treatments
   I did *actively look* for information from
      My treating doctors
      Other doctors or health professionals
      Family members, friends, coworkers
      Other cancer patients
      Face-to-face support groups
      On-line support groups
      Telephone hotlines (eg from the American Cancer Society)
      Television or radio
      Books, brochures, or pamphlets
      Newspapers or magazines
      Internet (other than personal e-mail and on-line support groups)
      Other

Awareness of targeted therapy

Which of the following treatments for colon cancer have you heard of? Check all that apply:

   Surgery
   Radiation therapy
   Chemotherapy
   Complementary and alternative therapy (eg herbal treatment)
   Avastin or Erbitux

Received targeted therapy

Which treatments have you received for your colon cancer? Check all that apply:

   Surgery
   Radiation therapy
   Chemotherapy
   Complementary and alternative therapy (e.g. herbal treatment)
   Avastin or Erbitux
   Other
   I don't know

on-label group if they had metastatic disease. All other patients were included in the off-label group.

Measures

The cancer information-seeking measure and our 2 outcome measures are displayed in Table 1. We used the cancer information-seeking measure to create an index of information-seeking breadth based on number of sources that patients used to look for treatment information. Earlier work by our group indicated that cancer patients actively seek information from all listed sources, including television and radio (ie, patients deliberately watch shows

that they know will discuss cancer). The index ranged from 0 (no seeking) to 11 (seeking from 11 source categories) and did not include seeking information from the treating physician. Patients were categorized into 3 groups: nonseekers (0 sources used), low seekers (1-2 source categories used), and high seekers (≥3 source categories used). Awareness about and receipt of targeted therapy were measured with 2 questions. Patients were categorized as aware of targeted therapy if they reported having heard of "Avastin or Erbitux.". Patients were categorized as having received targeted therapy if they reported receiving "Avastin or Erbitux". Targeted therapy options for colon cancer in 2005 included cetuximab and bevacizumab. On the basis of pilot-test feedback, we used the trade names rather than the generic names in the survey to minimize patient confusion.

Statistical Analysis

Our primary focus was on whether information seeking was related to awareness of and use of targeted therapy for those who did and did not have an FDA indication. We used logistic regression to examine the unadjusted associations between patient characteristics, FDA indication group, and information seeking with hearing about or receiving targeted therapy. We then used multiple logistic regression to adjust the associations between seeking and hearing about or receiving targeted therapy for potential confounding variables. All hypothesis tests were 2-tailed and used a significance level of $P = .05$. Missing data comprised <15% of all data and were excluded from the analysis. We used poststratification weights, which adjusted the distribution of respondents to match the colon cancer population from the Pennsylvania Cancer Registry on marital status, race, cancer stage, age, and sex, to account for the over-sample and for nonresponse. All statistical analysis was conducted in STATA version 10 (Stata Corp. College Station, Tex).

RESULTS

Patient characteristics are reported in Table 2. Fourteen percent of all colon cancer patients had heard of targeted therapy, and 10% reported receiving targeted therapy. Fifty-one percent patients with of metastatic disease and 3% of patients with nonmetastatic disease reported receiving targeted therapy. However, because 84% of

Table 2. Participant Characteristics

Characteristic	Percentage of Patients, n=633
Age, y	
Median	70
Range	26-99
Cancer stage	
0	15
I	19
II	26
III	24
IV	16
Education	
<High school degree	22
High school or GED	43
Some college	19
College degree (4 y)	7
>College degree	9
Employment	
Employed	25
Homemaker	11
Retired	60
Other	4
Marital status	
Married	56
Unmarried couple	3
Single	7
Separated/divorced	7
Widowed	27
Race*	
White	90
African American	10
Latino/Latina	3
Asian/Pacific Islander	1
Hispanic	3
Self-reported health status	
Poor	5
Fair	26
Good	43
Very good	21
Excellent	5
Sex	
Men	50
Women	50
Heard of targeted therapy	
Heard of bevacizumab or cetuximab	14
Received targeted therapy	
On-label bevacizumab or cetuximab, n=102	51
Off-label bevacizumab or cetuximab, n=527	3

GED indicates general educational development certificate.
*Some cells may not add to 100 because of multiracial identification.

respondents had nonmetastatic disease, approximately 25% of those who reported receiving the drugs were receiving it for non-FDA–approved indications. Overall, 69% of patients reported actively looking for treatment information.

The frequency of source use for seeking treatment information is reported in Table 3. We present the unadjusted associations between patient characteristics, treatment information seeking, and hearing about or receiving targeted therapy in Table 4. After adjusting for sociodemographic characteristics, health status, and FDA indication, high levels of treatment information seeking were associated strongly with both hearing about (odds ratio [OR], 2.83; 95% confidence interval [95% CI], 1.49-5.38) and receiving (OR, 3.22; 95% CI, 1.36-7.62) targeted therapy for cancer (Table 5).

We then conducted a series of analyses to determine whether the associations between information seeking and outcome differed between patients in the on-label and off-label groups. There was no significant interaction between information seeking and FDA indication ($P = .29$). However, the subgroup results are shown in Table 6 to illustrate the strength of association in each group.

In addition, we investigated whether or not information seeking was associated significantly with awareness of targeted therapy in the subgroup of patients who did not receive targeted therapy. The association between information seeking and awareness of targeted therapy trended toward significance among patients who did not receive targeted therapy (OR, 2.19; 95% CI, 0.85-5.65; $P = .10$; analysis not shown).

Table 3. Sources Used to Seek Treatment Information

Source Category Used	Percentage of Patients, n=633
Other physicians or health professionals	23
Family/friends	35
Other patients	19
Face-to-face support groups	2
Online support groups	1
Telephone hotlines	2
Television/radio	9
Books/brochures or pamphlets	27
Newspapers/magazines	13
Internet	14
Other	2
Mean no. of sources used	1.48

Table 4. Unadjusted Associations Between Patient Characteristics, Information Seeking, and Hearing About or Receiving Bevacizumab or Cetuximab

	OR (95% CI)	
Characteristic	Heard About Bevacizumab or Cetuximab	Received Bevacizumab or Cetuximab
Age (each decade increase)	0.70 (0.58-0.84)*	0.67 (0.56-0.81)*
Race (vs white)		
Black	0.91 (0.38-2.18)	1.09 (0.40-2.96)
Other†	0.97 (0.26-3.57)	1.87 (0.56-6.23)
Married (vs not married)	1.37 (0.83-2.26)	1.41 (0.81-2.45)
Education (vs ≤high school)		
≥Some college	2.06 (1.04-4.08)‡	2.07 (0.96-4.47)
≥College graduate	4.72 (2.20-10.10)*	3.06 (1.29-7.24)‡
Health (≥very good vs ≤good)	0.86 (0.50-1.50)	0.50 (0.26-0.96)‡
Sex (women vs men)	0.82 (0.52-1.31)	0.88 (0.52-1.48)
On-label indication	12.90 (7.42-22.46)*	31.49 (16.59-59.78)*
Seeking (vs nonseeking)		
Low	0.79 (0.39-1.63)	0.95 (0.44-2.08)
High	3.98 (2.27-7.00)*	4.01 (2.12-7.57)*

OR indicates odds ratio; CI, confidence interval.
* $P < .001$.
† Other race: Latino/Latina, Asian, and Pacific Islander.
‡ $P < .005$.

Table 5. Logistic Regression Model for Hearing About or Receiving Bevacizumab or Cetuximab

	Adjusted OR (95% CI)	
Characteristic	Heard About Bevacizumab or Cetuximab	Received Bevacizumab or Cetuximab
Age (each decade increase)	0.79 (0.63-0.98)*	0.74 (0.58-0.95)*
Race (vs white)		
Black	1.09 (0.46-2.60)	1.34 (0.45-3.95)
Other†	0.63 (0.15-2.70)	1.14 (0.20-6.44)
Married (vs not married)	1.24 (0.62-2.49)	1.48 (0.66-3.33)
Education (vs ≤high school)		
≥Some college	1.95 (0.80-4.72)	2.12 (0.71-6.32)
≥College graduate	3.62 (1.34-9.79)*	2.83 (0.78-10.24)
Health (≥very good vs ≤good)	1.10 (0.52-2.35)	0.65 (0.26-1.60)
Sex (women vs men)	0.78 (0.43-1.40)	0.82 (0.40-1.67)
On-label indication	14.52 (7.84-26.89)‡	38.75 (18.87-79.54)‡
Seeking (vs nonseeking)		
Low	0.70 (0.30-1.61)	0.86 (0.34-2.17)
High	2.83 (1.49-5.38)§	3.22 (1.36-7.62)§

OR indicates odds ratio; CI, confidence interval.
* $P < .05$.
† Other race: Latino/Latina, Asian, and Pacific Islander.
‡ $P < .001$.
§ $P < .01$.

Table 6. Logistic Regression Model for Hearing About or Receiving Bevacizumab or Cetuximab by Group

	Adjusted OR (95%CI)			
	On-Label Indication		Off-Label Indication	
Characteristic	Heard About Bevacizumab or Cetuximab	Received Bevacizumab or Cetuximab	Heard About Bevacizumab or Cetuximab	Received Bevacizumab or Cetuximab
Age (each decade increase)	0.79 (0.53-1.19)	0.86 (0.57-1.29)	0.77 (0.58-1.01)	0.63 (0.46-0.86)*
Race (vs white)				
Black	3.14 (0.80-12.31)	1.48 (0.33-6.60)	0.46 (0.13-1.64)	0.75 (0.14-3.97)
Other†	0.36 (0.02-5.47)	0.46 (0.06-3.47)	1.13 (0.29-4.31)	2.65 (0.60-11.75)
Married (vs not married)	3.66 (1.0-13.39)	2.81 (0.93-8.47)	0.70 (0.29-1.68)	0.51 (0.16-1.67)
Education (vs ≤high school)				
≥Some college	5.14 (1.09-24.18)‡	4.10 (1.04-16.19)‡	0.85 (0.30-2.40)	0.54 (0.14-2.08)
≥College graduate	10.17 (1.34-77.48)‡	10.26 (1.23-85.29)‡	1.51 (0.50-4.61)	0.38 (0.07-2.10)
Health (≥very good vs ≤good)	0.18 (0.04-0.82)‡	0.31 (0.08-1.23)	1.75 (0.78-3.95)	1.44 (0.49-4.18)
Sex (women vs men)	0.81 (0.23-2.84)	1.19 (0.39-3.65)	0.78 (0.37-1.64)	0.60 (0.22-1.67)
Seeking (vs nonseeking)				
Low	0.26 (0.05-1.40)	0.62 (0.14-2.64)	1.37 (0.47-4.01)	1.92 (0.35-10.49)
High	3.09 (0.79-12.09)	2.56 (0.68-9.65)	4.09 (1.71-9.77)*	7.32 (1.48-36.11)‡

OR indicates odds ratio; CI, confidence interval.
* $P < .01$.
† Other race: Latino/Latina, Asian, and Pacific Islander.
‡ $P < .05$.

Table 7. Logistic Regression Model for Sources Used and Hearing About or Receiving Bevacizumab or Cetuximab

Characteristic	Adjusted OR (95%CI)	
	Heard About Bevacizumab or Cetuximab	Received Bevacizumab or Cetuximab
Age (each decade increase)	0.79 (0.62-1.01)	0.72 (0.55-0.94)*
Race (vs white)		
Black	1.03 (0.40-2.63)	1.21 (0.36-4.01)
Other†	0.48 (0.14-1.70)	0.91 (0.19-4.27)
Married (vs not married)	1.19 (0.59-2.39)	1.41 (0.62-3.20)
Education (vs ≤high school)		
≥Some college	1.78 (0.70-4.57)	2.00 (0.62-6.43)
≥College graduate	2.64 (0.90-7.73)	2.40 (0.61-9.38)
Health (≥good vs ≤good)	1.10 (0.50-2.42)	0.69 (0.28-1.68)
Sex (women vs men)	0.80 (0.43-1.47)	0.93 (0.45-1.94)
On-label indication	15.88 (8.25-30.56)‡	43.58 (20.69-91.76)‡
Sources used		
Other physicians or health professionals	1.95 (1.03-3.68)*	2.64 (1.16-5.97)*
Television or radio	0.40 (0.14-1.18)	0.65 (0.19-2.16)
Books, brochures or pamphlets	0.88 (0.45-1.74)	0.81 (0.33-1.99)
Newspapers or magazines	3.44 (1.34-8.84)*	2.12 (0.63-7.19)
Internet	2.88 (1.40-5.94)§	1.91 (0.73-5.00)

OR indicates odds ratio; CI, confidence interval.
* $P < .05$.
† Other race: Latino/Latina, Asian, and Pacific Islander.
‡ $P < .001$.
§ $P < .01$.

When examining the associations between specific source use and outcomes (Table 7), we observed that those who sought information from the Internet and newspapers/magazines had higher odds of hearing about targeted therapy than nonseekers. Patients who reported seeking treatment information from other physicians or health professionals had significantly higher odds of both hearing about and receiving targeted therapy than nonseekers from those sources.

DISCUSSION

To our knowledge, this is the first study to report the relation between cancer information seeking and treatment-related behaviors in a large, population-based sample. Our findings suggest that cancer patient treatment information seeking is common and that it is associated with both awareness about and receipt of novel targeted therapies for colon cancer. These results have several implications for clinical practice and future research in this area.

One compelling finding is that high levels of information seeking were associated with both hearing about and receiving targeted therapy even after controlling for potential confounders. The primary question that this finding raises is whether information seeking leads to more treatment or whether receiving treatment leads to information seeking. We tried to decrease recall bias by asking patients to report seeking behavior that they engaged in while making treatment decisions. In addition, we have some evidence that the association between seeking and awareness about targeted therapy may be present even in patients who did not receive targeted therapy, although this association was not statistically significant. However, it is also possible that information seekers are more likely to recall the names of the specific therapies that they have received and, thus, may be more likely to recall receiving targeted therapy than low seekers or

noninformation seekers. Although causal order is difficult to determine in a cross-sectional study, there is a body of literature demonstrating that, when patients request specific medications, they are more likely to obtain prescriptions for those medications.[31-33] Patient inquiry may be particularly influential in the case of targeted therapies, in which there is considerable variation in physician experience. Physicians who have limited experience with new drugs may not automatically prescribe them but could be persuaded to do so at a patient's request.

Our data supported our hypothesis that that there would be a relation between information seeking and awareness of targeted therapy in all colon cancer patients. We also observed evidence that the association between treatment information seeking and the use of targeted therapy is present both in patients for whom therapy would be FDA approved and in patients for whom therapy would not be approved. Previous work has indicated that off-label drug use is common in many fields of medicine, including oncology.[34-36] Kocs et al evaluated the use of rituximab (a targeted therapy for non-Hodgkin lymphoma) between 1998 and 2001 and observed that it was administered 75% of the time for off-label indications, and off-label use was not associated with clinical trials.[36] Bevacizumab and cetuximab are considered part of the standard of care for palliative treatment of advanced colon cancer; however, current data do not support the routine use of these drugs in the adjuvant setting.[37-40] Adjuvant use of targeted therapy is an area of active research, but some experts fear that oncologists may inappropriately consider using adjuvant targeted therapy in selected patients.[40] Although off-label drug use is legal, it often is done in the absence of good supporting data.[34,41] Kocs et al suggest that the diffusion of information may be a key factor in off-label use and that media exposure and direct to consumer advertising (DTCA) may alter the demand for new technologies. Specifically, they suggest that DTCA may lead to a relative expansion in the use of interventions for off-label indications, because of a possible 'spillover' effect from approved indications.[36]

If patient information seeking is related to treatment choices, then there are several implications worth considering. First, if patients are influencing the diffusion and adoption of medical technologies, then it is important to consider how direct patient demand may influence the quality of care patients receive and the cost of care at a population level. If patient information seeking increases access to targeted therapy in indicated situations, then there may be an overall improvement in the quality of care. However, if patient information seeking leads to an increase in inappropriate access, then we may find overall reductions in the quality of care or, worse still, an increase in patient harm. Significant concerns already have been raised about the possible relations between heavy marketing, inappropriate drug use, and patient harm in the setting of erythropoiesis-stimulating agents and cyclooxygenase-2 inhibitors.[42,43] In addition cetuximab and bevacizumab are extremely expensive. Bevacizumab has a projected societal cost of $1.5 billion per year when used for metastatic colon cancer; and, as a society, we have not yet determined how to deal with these costs.[44] If patient demand for targeted therapy influences use, then it too may need to be addressed as we work to strike a balance between access to innovation and cost control.

Our results also suggest that different sources of information may play different roles in the dissemination of information related to targeted therapy for cancer. Two source categories, the Internet and newspapers/magazines, were associated with awareness but not with the receipt of targeted therapy. Although our study may be underpowered to find differences for specific sources, these data provide some evidence that disparate use of information technology, the "digital divide," may not necessarily have an impact on the therapies that patients receive.[45,46] However, other studies have demonstrated that health information seeking is less common in men, Hispanics, and individuals who are less educated, older, and of lower socioeconomic status.[25,26,47-49] More work is needed to determine whether or not information seeking relates to or exacerbates cancer disparities.

In addition, our analysis suggests that information from other physicians (as distinguished from the patient's treating physician) is associated with both hearing about and receiving targeted therapy for colon cancer. Bevacizumab and cetuximab were approved in 2004, and patients who needed targeted therapy in 2005 may have had to get it from a specialized oncologist who had novel drug experience. Work by Mellink et al has indicated that patients who seek a second opinion are motivated by a high need for information about their disease, possible treatments, and prognosis.[50] "Second opinions" are important in

oncology, reportedly have produced discrepant conclusions from the original consultation in 16% to 32% of patients, and have produced significant changes in prognostic or clinical management in 2% to 5% of patients.[51,52] Information seeking in the form of "second opinions" should be evaluated further as a possible factor in the early adoption of medical technologies.

Our study has several limitations. The first limitation, as noted above, is that it is a retrospective, cross-sectional study; therefore, causal order is ambiguous. Only a prospective study that links cancer patients' information seeking and therapies received will be able to determine whether information seeking leads to the increased use of targeted therapy. The second limitation is that our seeking index does not adequately allow us to determine the intensity of seeking from any specific source. For example, a patient who sought heavily from the Internet but not from other sources would rate lower on our seeking scale than someone who sought a little from 2 or 3 sources. The current scale may underestimate the actual amount of information that patients sought. The third limitation is that we are relying on self-reported treatment data. Although there is a paucity of data on self-reported treatment data in cancer, other authors have observed that self-reported treatment data have moderate-to-excellent validity in other chronic diseases.[53-55] Another limitation is that, although this is a large, population-based sample, all of our participants were diagnosed in Pennsylvania; therefore, these results may not generalize to other populations. Finally, although our measures of treatment information seeking were generated after a careful literature review, expert consultation, and pilot testing with cancer patients, they have not been validated by other groups.

Despite these limitations, the current results provide strong evidence that most cancer patients are trying to engage with treatment information and that high levels of information seeking may be associated with both appropriate and inappropriate treatment. Given the enormous cost and potential benefit of novel targeted therapies in cancer, future research should be directed toward understanding how and whether variations in patient information seeking contribute to cancer outcomes.

Conflict of Interest Disclosures

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