

Health Commun. Author manuscript; available in PMC 2011 January 21.

Published in final edited form as:

J Health Commun. 2009; 14(5): 487–502. doi:10.1080/10810730903032945.

Information-seeking styles among cancer patients before and after treatment by demographics and use of information sources

Christie Eheman, PhD¹, Zahava Berkowitz, MSPH, MSc¹, Judith W. Lee, PhD¹, Supriya G. Mohile, M.D., M.S.², Jason Q. Purnell, PhD², Joseph A. Roscoe, PhD², David B. Johnson, MD³, Jeffrey J. Kirshner, MD⁴, and Gary R. Morrow, PhD, MS²

- ¹ Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention
- ² University of Rochester Cancer Center (URCC) Community Clinical Oncology Program (CCOP)
- ³ Wichita CCOP, Wichita, KS
- ⁴ Hematology/Oncology Associates of Central NY, Syracuse, NY

Abstract

The type and quantity of information needed varies between patients who actively seek information and those who tend to avoid information. We analyzed data from a longitudinal study of adult cancer patients from outpatient clinics for whom information needs and behaviors were assessed by survey before and after treatment. We evaluated the relationships between information-seeking style (active, moderately active and passive styles) and demographics, cancer type, and health status for the pretreatment and posttreatment periods and overall. The Generalized Estimating Equations (GEE) approach was used to model the log odds of more active to more passive information-seeking preferences taking into consideration both the pretreatment and posttreatment periods.

Results—Analyses included 731 case participants, including female breast cancer patients (51%), male genitourinary cancer patients (18%), and lung cancer patients of both sexes (10%). At pretreatment, 17% reported an active information-seeking style, 69% were moderately active, and 14% were passive. During this period, 19% of those with at least some college education reported being very active compared to 14% of those with less education. With adjustment for all other covariates, male genitourinary and lung cancer patients had a higher odds of having a more active information-seeking style in the pretreatment than in the posttreatment period, with an odds of 4.5 (95% confidence interval [CI]: 2.4–8.4) and 5.4 (95% CI: 2.7–10.6), respectively. Controlling for all covariates, breast cancer patients had 1.5 (95% CI: 1.0–2.1) times higher odds of being more active in seeking information than other patients.

Conclusions—Public health researchers and clinicians must work together to develop the most effective strategy for meeting the informational needs of these patients before and after treatment.

Introduction

In 2006, an estimated 1.4 million Americans were diagnosed with cancer in the U.S. [1]. Among men, cancers of the prostate, lung and bronchus, colon or rectum, and urinary bladder were the most common. Among women, cancers of the lung and bronchus, breast, colon or rectum, and uterine corpus occurred most frequently [2]. For people diagnosed with

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

cancer, both the opportunity to provide input about their care and having information about their diagnosis, prognosis, and options for treatment are vital. Patient participation in medical decision making has increased over the last decade, and many patients have provided input into medical decisions about their cancer treatment [3–5]. However, the need for information extends beyond the desired role in decision making [6] and is important for a variety of reasons. Studies indicate that cancer patients who have adequate information benefit by increased involvement in decision making, greater satisfaction with treatment choices [7,8], improved coping skills, and reduced anxiety [9–11]. Meeting the informational needs of the patient is fundamental to successful communication [12]; however, defining what information is adequate is complex and varies between patients.

The desire for information varies considerably between individual patients and by circumstance. Individual differences in the desire for information have been categorized by the degree to which people engage in "monitoring" or "blunting" during their diagnosis and treatment [13]. Strong "monitors" actively search for information about their illness and are alert to symptoms, possible side effects of treatment, and other negative consequences. "Monitors" desire a large quantity of information and are more likely to report being dissatisfied with the information provided [13]. In contrast, patients with a "blunting" coping style actively avoid information that might be stressful or negative. These patients are more likely to report that they are satisfied with the information they receive and more content with the communication they have with their medical team [13].

Demographic variables have also been shown to influence information seeking [6]; for example, higher educational attainment has been associated with actively seeking information beyond that available in the medical care setting [14,15]. Ethnicity, race, and cultural characteristics have also been shown to influence how cancer patients seek information [16,15]. Younger age has been associated with more actively seeking information [17,18], particularly from sources outside the medical care setting such as the Internet [14]. However, a study of 75 cancer patients at an outpatient clinic found that while seeking information from medical sources decreased among older patients there was no difference by age in seeking information from outside sources [19]. The time since cancer diagnosis and the degree of illness have also been shown to influence how much and what information a patient desires [20,21].

Active and passive information seeking has been previously characterized in the literature by the sources of information used by the patient and by "monitoring" versus "blunting" coping styles, but few studies have evaluated how patients perceive their own information-seeking style. Most studies of information seeking include a small number of cancer patients and cannot evaluate differences in patterns by diagnosis. Further, additional research is needed among cancer patients on changes in seeking information from post-diagnosis through treatment. To meet these needs, we used data from a large longitudinal study of cancer patients to assess how these patients described their information-seeking behavior before and after treatment, to identify factors associated with active versus passive information seeking, and factors associated with changes in information seeking from pre- to posttreatment time. We also assessed the sources of information that patients used by how active or passive they reported themselves to be and how approaches to coping with the cancer varied.

Methods

Analyses of this data for this study was reviewed and approved by the CDC Institutional Review Board. Authors are not aware of any conflict of interest related to this manuscript. We analyzed data from a longitudinal study designed to assess the informational needs of

cancer patients, whether those needs were met, and how informational needs were addressed. Conducted by the University of Rochester Cancer Center (URCC) Community Clinical Oncology Program (CCOP), the study included patients recruited between January 30, 2001, and September 13, 2002, from 17 outpatient oncology clinics located throughout the U.S. The study's methods, including survey design, have been described previously [22]. Participating clinics were grantees of the National Cancer Institute's CCOP and members of the URCC Research Base. Eligible patients had been recently diagnosed with cancer, were aged 18 years or older, and had been scheduled for but had not yet received chemotherapy or radiation therapy. Patients were eligible if their life expectancy was 10 months or longer; including patients with previous surgical treatment and those diagnosed at an advanced stage. The study included men and women diagnosed with breast, genitourinary, lung, hematological, gastrointestinal, or head and neck cancer. A baseline interview was used to collect demographic characteristics, health status, symptoms, and cancer-related concerns. The interview was followed by self-administered surveys within 2 weeks prior to treatment, within 2 weeks after treatment, and at 6 months after treatment that collected data on information seeking and decision-making preferences, sources of information, and informational needs.

Our study examined information-seeking preferences in relation to demographic characteristics and cancer type among men and women who responded to the CCOP questionnaires before and after they underwent chemotherapy or radiotherapy. However, surgical treatment may have occurred prior to the first interview. Before and after treatment, patients were surveyed about their approach to obtaining information about their cancer. Participants were asked to categorize their approach to getting information into five categories which ranged from a strongly passive approach: "I do not seek information" to a very active approach "I seek information as a "second opinion" to my health care team's suggestion" To best capture the information on the ordinal data and use it as an outcome variable in a multivariate model, we collapsed the five categories into three ordinal levels. Table 1 provides each of the available response categories and how they were grouped for analysis. Individuals who indicated that they did not seek information or got information that happened to pass their way were categorized as passive in seeking information. Individuals who sought information to understand their disease better or because of curiosity in learning more were categorized as moderately active since they did seek information. Those who sought information as a second opinion to evaluate the information provided by their medical team were categorized as the most active since they were seeking out and evaluating very specific information about their cancer in order to make decisions. These three ordinal categories were presented in our analyses from active to passive informationseeking preferences.

We restricted our analysis to participants for whom data about information-seeking style was available in both time periods. Baseline information about sex, age, type of cancer, marital status, level of education, occupation, and care-giving status was collected before treatment. Self-reported health status was assessed in both the pretreatment and posttreatment periods. For modeling purposes, we collapsed the health status covariate into three levels (excellent, good/very good, and fair/poor) and dichotomized the education and marital status covariates. Before the analysis, we limited the group with breast cancer to women. Similarly, we decided to limit the group with genitourinary cancer to include only males in order to capture probable prostate cancer patients. The few remaining participants with these two respective types of cancer were assigned to "all other" cancers in the multivariate analysis. To assess the association of each covariate with information-seeking preferences (the response variable) while adjusting for all other covariates in the pretreatment and posttreatment periods separately, we performed 2 multivariate analyses of generalized logits using the SAS CATMOD procedure for categorical response [23]. The

logits compared active to passive information-seeking preferences and moderately active to passive information-seeking preferences. Before these analyses, we created indicator variables for those types of cancer which were most prevalent in the sample; these included breast, genitourinary, and lung cancer, each versus all other types of cancer.

To compare more active information-seeking preferences to more passive ones in both the pretreatment and posttreatment periods in one model, we used the Generalized Estimating Equations (GEE) approach [24]. This model accounts for the ordinal nature of the response, for the time component, and for the correlated measurements within participants (e.g., information-seeking preferences and health status) in the pretreatment and posttreatment periods. We fitted the proportional odds model, using the SAS GENMOD procedure for multinomial data, to model the cumulative odds, which is the common odds of active information-seeking preference versus moderately active and passive-seeking preferences, and active and moderately active information-seeking preferences versus passive-seeking preference. We used the above modeling technique to derive the p-values for the association between each of the covariates and the ordinal outcome of information-seeking style controlling for period (see Table 3), and in the adjusted model where covariates included period (a time-dependent covariate); age group; sex; education; marital status; health status (time-dependent covariate); indicator variables for breast, genitourinary, and lung cancer; and interactions between period and selected baseline covariates (see Table 4).

We also assessed how participants responded to a pretreatment question that asked which activities (such as reading, searching the Internet, talking to friends) they found useful when having something new to learn or understand about their health. We estimated the percent of individuals who reported using each source by the three categories of information seeking style from passive to active. We used the chi-square tests for trend to evaluate whether these percentages by information seeking style for each type of information source changed in a linear fashion (a larger percentage of more active individuals than more passive ones used the information source).

Results

Of the 1,004 cancer patients who responded to the baseline survey, 94.2% (n=946) completed the pre-treatment survey, including the questions on information-seeking style. Majorities of these participants were white (92.9%), female (65%), married (71%), and had some college or a college degree (55%). The pretreatment and posttreatment questions regarding information seeking styles were completed by 734 (73.1%) of the patients, but 2 were excluded because they were missing information on health status for the pretreatment or posttreatment period and a third because cancer type was not known, leaving 731 patients for the analyses. Table 2 provides the demographic characteristics of the 731 study subjects who responded to the baseline, pre- and post-treatment surveys and and were included in our study. The demographic characteristics (Table 2) of the participants included in our analysis (n=731) were very similar to those of all patients who responded to the pretreatment survey (n=946).

Pretreatment

At pretreatment, 17.0% (n=124) of the patients reported an active information-seeking style, 69.2% (n= 506) were moderately active, and 13.8% (n= 101) were passive. Differences were observed in information-seeking style by educational group (Table 3). Before treatment, 19.2% of those with at least some college education reported being active in seeking information, versus 14.0% of those with less education. There were also differences by occupational groups: those with professional or managerial occupations were the most often active (20.1%) and the least often passive (8.8%) (Table 3). After the multivariate model

was used to control for all other covariates, those who had some college education or a college degree were more likely to be active or moderately active (passive as referent) than those who had a high school education or less (data not shown). Also, men diagnosed with genitourinary cancer were more likely to be active (versus passive) in seeking information than were patients who had other types of cancer. These two groups (genitourinary, other types) did not differ significantly on a comparison of moderate versus passive information seeking.

Posttreatment

In the time period following treatment, more patients reported being passive in seeking information than was the case in the pretreatment period. Information-seeking style varied between categories of age, cancer type, educational status, marital status, and occupation (Table 3). For example, those aged ≥ 65 years were more often passive (26.6%) than those 45 to 64 (18.6%) or 20 to 44 (8.9%). Lung cancer(36.0%) patients were more likely to be passive in seeking information posttreatment than were other patients. Patients who were divorced, separated, single, or widowed were more likely to be passive (27.1%) than those who were married (18.2%). Using a multivariate model to control for all covariates in the post-treatment period, we found that those who were youngest (20–44) were more likely to be active or moderately active (versus being passive) in seeking information than those in other age groups. In addition, those who were married were more likely to be active (versus passive) than those who were not married (data not shown). Additionally, patients with lung cancer were more likely to be passive seekers of information than were all other cancer patients (data not shown).

Multivariate GEE modeling

Multivariate analyses using GEE models were used to adjust for the time period (pre versus post-treatment) and all other covariates in assessing the odds of reporting a more active versus less active information seeking. After adjusting for all other covariates, patients with at least some college education were more likely to be actively seeking information than those with less education (referent) (OR=1.29,95% CI: 0.99-1.69; p=0.058) (Table 4). Similarly, female breast cancer patients were more likely to be more active in seeking information when they were compared with all other cancer patients (OR=1.45,95% CI: 1.00-2.09; p=0.048).

We also estimated the odds of having an active information-seeking style in the pretreatment period compared to the posttreatment period (Table 4). In general, more patients reported being passive in seeking information in the postreatment period than before treatment (Table 3). Significant interactions were found between the time period (pretreatment or posttreatment) and marital status and 2 cancer types, male genitourinary cancer and lung cancer (men and women combined). During pretreatment, married patients were no more likely than non-married patients to report an active information-seeking style, but following treatment married patients had an OR of 1.64 (95% CI: 1.16–2.30, p=0.005) for being more active in seeking information when they were compared with the unmarried (referent). Male genitourinary and lung cancer patients (both sexes) had significantly higher odds of having a more active information-seeking style in the pretreatment period than in the posttreatment period, with ORs of 4.5 (95% CI 2.4–8.4) and 5.4 (95% CI: 2.7–10.6) respectively.

When participants were asked how they generally tended to seek out information about their health, passive information seekers were significantly (p<0.05) less likely than the more active information seekers to report that they read as much information as possible, surfed the Internet, attended presentations or classes, or talked to a medical expert (Table 5). Those who were active seekers for cancer information were also active in general in seeking

information about their health. These participants read as much as possible, talked to a friend, or used the Internet to find information more often than the other 2 groups.

Discussion

In this study of patients around the U.S. who were being treated in outpatient clinics with chemotherapy or radiation therapy, differences in styles of seeking information were observed by age, education, marital status, and type of cancer. The time period was an important factor in seeking information as well. In general, patients were more active in seeking information before being treated than afterward. Higher levels of education and younger age were tied to an active style of seeking information, and the percentage of patients who reported they sought information passively increased with age. Patients with a poorer health status were more passive in seeking information than those with excellent health. Unmarried patients were significantly less likely to be active seekers after treatment than before treatment compared to those who were married. Male genitourinary patients and lung cancer patients (both sexes combined) were significantly more likely to have a more active information- seeking style in the pretreatment than in the post-treatment period. When the difference in time period and other factors were controlled for, female breast cancer patients had a higher odds of being active in their information seeking when compared to all other cancer patients in the study.

Our findings related to information seeking and higher educational status and younger age are similar to findings from other studies. Cancer patients with higher educational and/or socioeconomic status and those of younger age have been shown to more often seek information sources outside of the medical care environment such as the Internet and technical papers or library materials [14,15,25], but age alone is not always the deciding factor in seeking information. One study, for example, demonstrated more information seeking from nonmedical sources among older adults that was related to a strong desire for additional information [19]. Patients who reported themselves to be active information seekers in our study used Internet resources more often than other groups and were more likely to report reading as much as possible to find out about their health. The behavior of patients in our study who reported themselves to be active seekers of information is consistent with the behaviors of patients in other studies who were classified as "active" based on their use of information sources [14,15,25] or as "monitors" based on the Monitor-Blunter Style Scale (MBSS) [13].

While numerous studies have reported on the informational needs of patients diagnosed with cancer and that patients engage in information seeking, fewer studies have reported on the informational needs or the information seeking behaviors of patients through diagnosis, treatment and posttreatment. Furthermore, there is little research on the reasons why information seeking behaviors may or may not change from diagnosis to posttreatment. In our analysis, patients were more likely to be passive in seeking information after their treatment than before. We can surmise that before treatment, patients are likely involved in discussions about options for treatment. For example, prostate cancer patients may be presented with several options, such as expectant management, surgery, external-beam radiation, and brachytherapy. Research has found that men diagnosed with early-stage prostate cancer were most interested in learning information about three key topics: likelihood of cure of the disease, stage of disease, and treatment options [26]. Following treatment, patients may not be as interested in searching for additional information about therapies and/or they may be seeking different types of information, such as information about treatment side effects or long-term outcomes. Indeed, one study of prostate cancer patients and their partners found the need for information was notably less after the treatment decision was made [27]. One study found that in the 24 hours prior to treatment,

prostate cancer patients were most in need of medical or technical information such as treatment effectiveness. Twenty-four hours after treatment, the information needs shifted to the management of treatment side effects [28]. Similarly, another study found that prostate cancer patients and their partners sought information after treatment to learn about side effects and disease recurrence [29]. We found that after treatment, lung cancer patients were more passive in seeking information than they were before their treatment; this finding may be related to their limited treatment choices. Our finding that breast cancer patients were relatively more likely to be active seekers of information may be due, in part, to the vast amount of information available to patients diagnosed with breast cancer. One review has suggested that cancer patients require large amounts of information, often more than their providers can offer [30]. Married patients were more likely to be active information seekers post-treatment than non-married patients. This may be due, in part, to having a significant relationship with a spouse. The patient may be motivated to seek information out of a sense of responsibility to the spouse or the spouse may motivate the patient to continue to seek information after treatment. A study of prostate cancer patients and their partners found that after treatment, couples wanted to stay informed regarding the new treatments and research on a cure [29]. We cannot explore this finding further as the role of social support in information seeking was not a part of this study. More research is needed to examine the changes in information seeking at diagnosis, during treatment, and post-treatment and the reasons for those changes.

Limitations

One limitation of this study is the homogeneous sample. Some studies have found that the use of the Internet was lower among racial and ethnic minorities [31,32]. However, since this sample was nearly 93% white, there could be no assessment of the racial and ethnic variation in information seeking behavior. Additionally, the use of the CCOP may limit the socioeconomic variability in the sample. Another limitation of this study is the amount of time that has elapsed since the original data collection. We cannot be certain that there have not been changes in the information seeking behaviors of patients since the data were collected. Finally, this sample contained a majority of breast cancer patients. There were fewer patients diagnosed with other types of cancer which necessitated some collapsing of cancer types. This collapsing may mask some differences in information seeking for some of the cancer diagnoses. However, the value of this study is that it examines the patterns of information seeking among a group of patients with various cancer diagnoses and examines the changes in the information seeking behavior from diagnosis through posttreatment.

Conclusion

In general, public health researchers and clinicians should investigate ways to provide patients with enough information to make educated decisions prior to treatment and to assess if patients need additional treatment and disease information after treatment. McCaughan and McKenna (2007) suggest that newly diagnosed patients go through stages and that the information presented to the patient must match the particular stage [33]. Providers must be attuned to changes in a patient's ability and desire to receive information. Mayer et al (2007) also found that some do not actively seek information about their cancer diagnosis; however, among those who do seek information, a variety of sources are used including the Internet [34]. These authors suggest that providers give patients names of trusted sites on the Internet for medical information. Recent research has suggested that some patients may find the search for information about cancer diagnosis and treatment confusing and frustrating [35]. Providers may have particular cause for concern when patients do not ask questions or are not engaged in information seeking outside of the patient-provider relationship since at least one study has found a relationship between non-seeking behavior and low preventative health behaviors [36]. Providing patients with trusted information sources that match their

informational needs may assist patients with recovery. Some research suggests that information seeking among breast cancer patients was associated with better physical functioning or physical quality of life six months post-treatment [37]. Additionally, research has found that patients who are better informed report better emotional well-being [38], better satisfaction with medical treatment [39], and improved physical functioning [40]. Patient information seeking behavior, sources of information, and informational needs change over time. As researchers develop interventions and materials to educate and inform patients, this variability should be considered to provide patients with the best information and education about their health care concerns.

Acknowledgments

Supported by grant U10CA 37420 from the National Cancer Institute

References

- Jemal A, Siegel R, Ward E, Murray T, Xu J, Smigal C, Thun MJ. Cancer Statistics. CA Cancer J Clin. 2006; 56:106–130. [PubMed: 16514137]
- U.S. Cancer Statistics Working Group. United States Cancer Statistics: 2002 Incidence and Mortality. Atlanta, GA: Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2005.
- 3. Dutta-Bergman MJ. Developing a profile of consumer intention to seek out additional information beyond a doctor: The role of communicative and motivation variables. Health Commun. 2005; 17:1–16. [PubMed: 15590339]
- 4. Booske BC, Sainfort F, Hundt AS. Eliciting consumer preferences for health plans. Health Serv Res. 1999; 34:839–854. [PubMed: 10536973]
- Mallinger JK, Shields CG, Griggs JJ, Roscoe JA, Morrow GR, Rosenbluth RJ, Lord RS, Gross H. Stability of decisional role preference over the course of cancer therapy. Psychooncology. 2006; 15:297–305. [PubMed: 16041829]
- 6. Czaja R, Manfredi C, Price J. The determinants and consequences of information seeking among cancer patients. Health Commun. 2003; 8:529–562.
- 7. Luker KA, Beaver K, Leinster SJ, Owens RG, Degner LF, Sloan JA. The information needs of women newly diagnosed with breast cancer. J Adv Nurs. 1995; 22:134–141. [PubMed: 7560521]
- 8. Cawley M, Kostic J, Cappello C. Informational and psychosocial needs of women choosing conservative surgery/primary radiation for early stage breast cancer. Cancer Nurs. 1990; 13:90–94. [PubMed: 2331696]
- 9. Rees CE, Bath PA. Information-seeking behaviors of women with breast cancer. Oncol Nurs Forum. 2001; 28:899–907. [PubMed: 11421149]
- Harrison-Woermke DE, Graydon JE. Perceived informational needs of breast cancer patients receiving radiation therapy after excisional biopsy and axillary node dissection. Cancer Nurs. 1993; 16:449–455. [PubMed: 8111748]
- 11. Johnson JE, Nail LM, Lauver D, King KB, Keys H. Reducing the negative impact of radiation therapy on functional status. Cancer. 1998; 61:46–51. [PubMed: 3334952]
- Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: A systematic review of research (1980–2003). Patient Educ Couns. 2005; 57:250–261. [PubMed: 15893206]
- 13. Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. Cancer. 2005; 76:167–177. [PubMed: 8625088]
- 14. Carlsson M. Cancer patients seeking information from sources outside the health care system. Support Care Cancer. 2000; 8:453–457. [PubMed: 11094989]
- 15. Kakai H, Maskarinec G, Shumay DM, Tatsumura Y, Tasaki K. Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: An

- exploratory study with correspondence analysis. Soc Sci Med. 2003; 56:851–862. [PubMed: 12560017]
- Matthews AK, Sellergren SA, Manfredi C, Williams M. Factors influencing medical information seeking among African American cancer patients. J Health Commun. 2002; 7:205–219. [PubMed: 12166874]
- 17. Hopkins MB. Information-seeking and adaptational outcomes in women receiving chemotherapy for breast cancer. Cancer Nurs. 1986; 9:256–262. [PubMed: 3640676]
- Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: Decision making and information-seeking preferences among medical patients. J Gen Intern Med. 1989; 4:23–29. [PubMed: 2644407]
- 19. Turk-Charles S, Meyerowitz BE, Gatz M. Age differences in information-seeking among cancer patients. Int J Aging Hum Dev. 1997; 45:85–98. [PubMed: 9395923]
- 20. Mills ME, Sullivan K. The importance of information giving for patients newly diagnosed with cancer: A review of the literature. J Clin Nurs. 1999; 8:631–642. [PubMed: 10827609]
- Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: Cancer patients' preferences for information, involvement and support. Ann Oncol. 1997; 8:857–863.
 [PubMed: 9358935]
- Shields CG, Morrow GR, Griggs J, Mallinger J, Roscoe J, Wade JL, Dakhil SR, Fitch TR.
 Decision-making role preferences of patients receiving adjuvant cancer treatment: A University of Rochester Cancer Center community Clinical Oncology Program (URCC-CCOP). Support Cancer Ther. 2004; 1:119–126. [PubMed: 18628188]
- 23. Stokes, ME.; Davis, CS.; Coch, GG. Categorical data analysis using the SAS system. 2. Cary NC: SAS Institute Inc; 2000.
- 24. Liang KY, Zeger SL. Longitudinal data analysis using generalized linear models. Biometrika. 1986; 73:13–22.
- 25. Basch EM, Thaler HT, Shi W, Yakren S, Schrag D. Use of information resources by patients with cancer and their companions. Cancer. 2004; 100:2476–2483. [PubMed: 15160355]
- 26. Davison BJ, Degner LF, Morgan TR. Information and decision-making preference of men with prostate cancer. Oncol Nurs Forum. 1995; 22:1401–1408. [PubMed: 8539181]
- 27. Gray RE, Fitch M, Davis C, Phillips C. Interviews with men with prostate cancer about their self-help group experience. J Palliat Care. 1997; 13:15–21. [PubMed: 9105153]
- Brant B. Informational needs and selected variables in patients receiving brachytherapy. Oncol Nurs Forum. 1991; 18:1221–1129. [PubMed: 1945968]
- 29. Heyman EN, Rosner TT. Prostate cancer: an intimate view from patients and wives. Urologic Nursing. 1996; 16:37–44. [PubMed: 8826151]
- 30. Jefford M, Tattersall M. Informing and involving patients in their own care. Lancet Oncol. 2002; 3:629–637. [PubMed: 12372725]
- 31. James N, Daniels H, Rahman R, McConkey C, Derry J, Young A. A study of information seeking by cancer patients and their carers. Clin Oncol (R Coll Radiol). 2007; 19:356–362. [PubMed: 17399963]
- 32. Talosig-Garcia M, Davis SW. Information-seeking behavior of minority breast cancer patients: An exploratory study. J Health Commun. 2005; 10 (Suppl 1):53–64. [PubMed: 16377600]
- 33. McCaughan E, McKenna H. Never-ending making sense: Towards a substantive theory of the information-seeking behaviour of newly diagnosed cancer patients. J Clin Nurs. 2007; 16(11): 2096–104. [PubMed: 17331090]
- 34. Mayer DK, Terrin NC, Kreps GL, Menon U, McCance K, Parsons SK, Mooney KH. Cancer survivors information seeking behaviors: A comparison of survivors who do and do not seek information about cancer. Patient Educ Couns. 2007; 65:342–350. [PubMed: 17029864]
- 35. Arora NK, Hesse BW, Rimer BK, Viswanath K, Clayman ML, Croyle RT. Frustrated and confused: the American public rates its cancer-related information seeking experiences. J Gen Intern Med. 2008; 23:223–228. [PubMed: 17922166]
- 36. Ramanadhan S, Viswanath K. Health and the information nonseeker: A profile. Health Commun. 2006; 20:131–139. [PubMed: 16965250]

37. Ransom S, Jacobsen PB, Schmidt JE, Andrykowski MA. Relationship of problem-focused coping strategies to changes in quality of life following treatment for early stage breast cancer. J Pain Symptom Manage. 2005; 30:243–253. [PubMed: 16183008]

- 38. Fallowfield LJ, Hall A, Maguire P, Baum M, A'Hern RP. Psychological effects of being offered choice of surgery for breast cancer. BMJ. 1994; 309:448. [PubMed: 7920129]
- 39. Weiss SM, Wegnert PA Jr, Martinez EM, Sewall WE, Kopp K. Patient satisfaction with decision-making for breast cancer therapy. Ann Surg Oncol. 1996; 3:285–289. [PubMed: 8726184]
- 40. Greenfield S, Kaplan S, Ware J. Expanding patient involvement in care: effects on patient outcomes. Ann Intern Med. 1985; 102:520–528. [PubMed: 3977198]

Table 1Survey questions and defined information-seeking style variables

Survey Questions	Information seeking style	
Pre-treatment	"Which of the following statements best describes your approach to getting information	about your cancer?"
Post-treatment	"Which one of the following statements best describes how you got information about y treatment?"	our cancer during your
	Response options:	Categorical Variable
	"I do not seek information"	Passive
	"I get information that happens to pass my way"	Passive
	"I seek information mostly out of curiosity"	Moderately active
	"I seek information to fill in the gaps in my understanding"	Moderately active
	"I seek information as a "second opinion" to my health care team's suggestion."	Active

Table 2

Characteristics of patients who completed the baseline, pre- and posttreatment surveys and who were included in the study analysis

	Completed b	oth surveys
Characteristic	N=731	
	N	%
Age group (yrs)		
20 – 44	90	12.3
45 – 64	344	47.0
≥ 65	297	40.6
Sex		
Female	485	66.3
Male	246	33.6
Cancer group		
Breast (females)	374	51.2
Lung (both sexes)	75	10.3
Genitourinary (male)	128	17.5
Gynecologic (both sexes)	39	5.3
Hematologic (both sexes)	47	6.4
Gastrointestinal (both sexes)	50	6.8
All other	18	2.5
Marital status		
Married	528	72.2
Divorced/Separated	77	10.5
Single	51	7.0
Widowed	75	10.2
Education		
College degree	240	32.8
Some college	177	24.2
High school	254	34.7
< High school	60	8.2
Health status I		
Excellent	151	20.6
Good/very good	505	69.1
Fair/poor	75	10.3
Occupation		
Professional or management	283	38.7
Technical/Trade	131	18.3
Service/other/Clerical	228	31.2
Homemaker/Student	89	12.2
Caregiver status		
Primary	536	73.3

	Completed both	surveys
Characteristic	N=731	
	N	%
secondary	189	25.8

 $^{{\}rm ^{1}Response\ on\ pretreatment\ survey}.$

Table 3

Information-seeking style of cancer cases responding to both surveys (n=731) by demographics and other characteristics

Characteristics	Pretrea	Pretreatment style		Posttre	Posttreatment style		Total N
	Active (Percent)	Moderate	Passive	Passive Active (Percent) Moderate	Moderate	Passive	
Age group (yrs)							
20 – 44	13.3	75.6	11.1	14.4	7.97	8.9	06
45 – 64	18.3	68.3	13.4	12.5	689	18.6	344
65 and >	16.5	68.3	15.1	13.5	59.9	26.6	297
Sex							
Female	15.5	7.07	13.8	12.2	69.1	18.8	485
Male	19.9	66.3	13.8	15.0	9.09	24.4	246
Cancer group							
Breast (females)	16.0	71.4	12.6	13.1	711.7	15.2	374
Lung (both sexes)	17.3	68.0	14.7	6.7	57.3	36.0	75
Genitourinary (male)	25.0	64.8	10.2	15.6	63.3	21.1	128
Gynecologic	15.4	71.8	12.8	12.8	61.5	25.6	39
Hematologic (both sexes)	8.5	70.2	21.3	12.8	61.7	25.5	47
Gastrointestinal (both sexes)	18.0	0.09	22.0	14.0	56.0	30.0	50
All other	0.0	77.8	22.2	22.2	61.1	16.7	18
Marital status							
Married	16.5	69.1	14.4	14.8	67.0	18.2	528
Divorced/separated/single / widowed	18.2	69.5	12.3	8.9	64.0	27.1	203
Education							
College degree/some college	19.2	70.3	10.5	12.9	70.0	17.0	417
≤ High school	14.0	8.79	18.1	13.4	61.1	25.5	314
Health status							
Excellent	23.2	64.9	11.9	16.7	71.8	11.5	78
Good/very good	15.6	70.1	14.3	12.3	67.3	20.4	260
Fair/poor	13.3	72.0	14.7	15.0	54.8	30.1	93
Occupation							
Professional or management	20.1	71.0	8.8	12.4	72.8	14.8	283
Technical/trade	18.3	64.1	17.6	13.4	54.5	32.1	134

Characteristics	Pretres	Pretreatment style		Posttrea	Posttreatment style		Total N
	Active (Percent) Moderate Passive	Moderate	Passive	Active (Percent) Moderate	Moderate	Passive	
Service/other/clerical	13.6		69.7 16.7	12.7	64.9	22.4	228
Homemaker/student	13.5	69.7	16.8	15.7	66.3	18.0	68
Caregiver status							
Primary	15.7	70.7	13.6	12.9	9.99	20.5	536
Secondary	20.6	65.1	65.1 14.3	14.3	64.6	21.2	189

Eheman et al.

Page 15

Table 4

Adjusted odds ratios and 95% confidence intervals for reporting a more active versus less active information seeking style controlling for period

Characteristics	OR	95%	6 CI	P value
\mathbf{Sex}^{I}				0.53774
Male	1.16	0.73	1.87	0.5278
Female	1.00			
Age group $(yrs)^{I}$				0.17724
20–44	1.37	0.95	1.98	0.0899
45–64	1.24	0.93	1.64	0.1374
65+	1.00			
Education I				0.06294
College degree/some college	1.29	0.99	1.69	0.0580
≤ High school	1.0			
Health status I				0.17814
Excellent	1.42	0.88	2.28	0.1518
Very good/good	1.03	0.70	1.52	0.8683
Fair/poor	1.00			
Cancer group l				
Breast cancer				0.04984
Yes	1.45	1.00	2.09	0.0479 ⁴
No	1.00			
Interactions with time period				
Married versus non-married ²				
Pretreatment	0.79	0.56	1.10	0.1660
Posttreatment	1.64	1.16	2.30	0.0048
Pretreatment versus posttreatmer	nt ³			
Genitourinary - male	4.49	2.40	8.38	< 0.0001
lung	5.38	2.73	10.60	< 0.0001

IOdds of having a more active information-seeking style, adjusted for pretreatment to posttreatment period.

 $^{^2\}mathrm{Odds}$ of married versus non-married patients being more active in the given time period.

 $^{^3}$ Odds of having a more active information-seeking style in the pretreatment than in the -posttreatment period.

⁴P value based on chi-square test for the association between the main effect and the outcome of being classified as more active versus less active in seeking information.

Table 5

How patients reported on the pretreatment survey that they sought information in general about their health

	Information seeking style							
Variable	Active N=124	Moderately active N=506	Passive N=101	P value				
	%	%	%					
Reading as much information as possible $^{\it I}$	82.26	78.06	51.49	< 0.0001				
Talking to a friend	64.52	55.93	52.48	0.0609				
Watching TV	20.16	18.38	21.78	0.8117				
Reading pamphlets	61.29	72.13	48.51	0.1002				
Talking with a medical expert	82.25	82.61	70.30	0.0354				
Watching a video	16.13	19.37	11.88	0.4951				
Surfing the Internet to find alternative explanations ${\cal I}$	47.58	36.76	14.85	< 0.0001				
Attending presentations or classes I	20.16	18.38	8.91	0.0345				

 $^{^{}I}\mathrm{P}$ value was derived from chi-square test for trends.