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Internet Use for Prediagnosis Symptom Appraisal by Colorectal Cancer Patients

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Abstract

Background—This study explored the characteristics of colorectal cancer (CRC) patients who accessed Internet-based health information as part of their symptom appraisal process prior to consulting a health care provider.

Method—Newly diagnosed CRC patients who experienced symptoms prior to diagnosis were interviewed. Brief COPE was used to measure patient coping. Logistic and linear regressions were used to assess Internet use and appraisal delay.

Results—Twenty-five percent of the sample (61/242) consulted the Internet prior to visiting a health care provider. Internet use was associated with having private health insurance (odds ratio [OR] = 2.55; 95% confidence interval [CI] = 1.20–5.43) and experiencing elimination symptoms (OR = 1.43; 95% CI = 1.14–1.80) and was marginally associated with age (OR = 0.96; 95% CI = 0.93–0.99). Internet use was not related to delayed medical care seeking.

Conclusion—Internet use did not influence decisions to seek medical care. The Internet provided a preliminary information resource for individuals who experienced embarrassing CRC symptoms, had private health insurance, and were younger.

Keywords

appraisal delay; colorectal cancer; health information-seeking behavior; Internet; symptom appraisal

Colorectal cancer (CRC) is the second leading cause of cancer death in the United States despite the ability to treat it when diagnosed early; 5-year survival rates are 91% for localized CRC (American Cancer Society, 2010). Sufficiently delayed symptom appraisal and presentation to a health care provider (HCP) can negatively affect survival. Factors found to negatively influence patient symptom appraisal include lack of knowledge (Cockburn, Paul, Tzelepis, McElduff, & Byles, 2003), fear of receiving a cancer diagnosis (Ristvedt & Trinkaus, 2005), preexisting illness (de Nooijer, Lechner, & de Vries, 2001), and systemic structural barriers such as lack of insurance (Langenbach, Schmidt, Neumann, & Zirngibl, 2003). For some, the Internet may provide an initial information source about CRC symptoms.

Internet health information seeking is influenced by age, gender, education (Baker, Wagner, Singer, & Bundorf, 2003; Flynn, Smith, & Freese, 2006), and insurance (Bundorf, Wagner,

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Singer, & Baker, 2006). To date, research has focused on consumer information needs and sources, search strategies, information comprehension, and quality assessment (Koch-Weser, Bradshaw, Gualtieri, & Gallagher, 2010). Patients use the Internet to research their diagnoses and treatment options, follow up on information provided in clinical encounters (Caiata-Zuffery, Abraham, Sommerhalder, & Schulz, 2010), and engage in online social support forums and e-mail lists (Meier, Lyons, Frydman, Forlenza, & Rimer, 2007). Internet-based interventions that provide health information and decision support have shown increased patient satisfaction with care, quality of life, and intention to participate in preventive care (Bowen et al., 2011; Gustafson et al., 1999; Shaw et al., 2007). Yet it is unclear how patient-initiated searches for health information on the Internet are used to make specific health care decisions. The purpose of this study was twofold: (a) to determine which patient characteristics were associated with consultation of the Internet for specific symptom-related information and (b) to assess whether consulting the Internet was related to delays in patient care seeking, also called appraisal delay (AD).

Method

Participant Recruitment

Individuals who were newly diagnosed with CRC were recruited from five academic and community oncology practices in Virginia and Ohio to participate in a study examining patterns of patient symptom appraisal and communication with HCPs. Eligible participants were those who had received a CRC diagnosis in the prior 6 months and had experienced symptoms prior to consulting an HCP. Participation was not restricted by stage at diagnosis; however, individuals whose CRC diagnosis resulted from routine screening were not eligible. Participants were identified postdiagnosis through chart reviews and were mailed an introductory letter describing the study. Potential participants were contacted by telephone 1 week later for a final eligibility screen. Of the 458 potential participants identified, 303 met the inclusion criteria. A total of 256 individuals consented and were interviewed during 2008–2010. This analysis is based on a sample of 242 participants for whom data collection was complete. All relevant institutional review boards approved the study procedures.

Interviews

Semistructured interviews were conducted during 2008–2010 by trained research assistants and lasted approximately 2 hours. Using open-ended questions and standardized probes, interviews focused on patient (a) sociodemographic and psychological factors, (b) symptom recognition and appraisal, and (c) communication with HCPs, friends, and family. Interviews were audio recorded and transcribed verbatim.

Data Coding

Research assistants with master's level graduate training coded verbatim transcripts using a study code manual. The code manual was developed through iterative coding of initial interviews that continued until saturation was reached. The interview data were coded into ordinal and dichotomous variables to enable use with statistical methods. Double coding was completed on 20% of the interviews. Coding discrepancies were discussed during weekly coding meetings until consensus was reached. Patient self-report data regarding the date of the first physician encounter were verified through medical chart review.

Measures

Demographic information—Measured demographic information included patient age, gender, race, education level completed, income level, and insurance status. Demographic

information was reported by patients at the time of interview. Cancer stage at diagnosis was also collected.

Internet use—Patients were asked to describe all of the resources consulted to understand their symptoms. Specific probes were used to explore whether or not patients accessed Internet-based information and its effect on their decision to seek medical attention. This information was coded as 0 (no Internet usage) or 1 (used Internet) and 0 (Internet did not affect decision) or 1 (Internet did affect decision).

Appraisal delay—AD was measured in days and was defined as the time period from when the patient first noticed CRC symptoms to when those symptoms were reported to an HCP. Recall of symptom onset was probed in depth using calendars and memory stimulation activities such as asking participants about symptoms in relation to significant life events (e.g., birthdays and holidays). Chart reviews were used to verify the patient reported date of medical visits and symptoms reported. This definition of AD has been used extensively in the medical literature (MacArthur & Smith, 1984; Terhaar sive Droste et al., 2010).

Symptoms—Five symptom categories were identified from the transcripts: digestive symptoms (i.e., intestinal discomfort, stomach pain, heartburn, nausea, loss of appetite, burning), elimination symptoms (i.e., diarrhea, constipation, change in bowel habits, loss of bowel control, change in stool, mucous or blood in stool), rectal symptoms (i.e., rectal pain or bleeding), gynecological/urinary symptoms (i.e., change in urinary function or blood in urine), and other symptoms (e.g., dizziness, respiratory symptoms). Mean number of symptoms in each category was computed. Symptom severity for each reported symptom was rated on a scale from 1 (*not serious*) to 5 (*very serious*) and averaged across all symptoms reported to create an overall severity score.

Discussion with HCP/self-treatment—Anxiety or hesitation discussing symptoms with an HCP was measured using standardized probes to assess the nature of patient hesitancy, for example, if patients felt embarrassed or worried about receiving a cancer diagnosis. Interviews also assessed whether patients engaged in self-treatment prior to contacting an HCP. Each response was coded as 0 (no hesitation/no self-treatment) or 1 (patient felt hesitant or engaged in self-treatment).

Brief COPE—This scale was composed of 14 subscales with 28 items and measures both positive coping responses (e.g., active coping, planning) and negative coping responses (e.g., denial, venting). Respondents rate their use of various coping responses on a scale from 1 (*not at all*) to 4 (*very much*). Subscale scores range from 2 to 8 and are calculated through summation of all subscale items (Carver, 2001).

Statistical analysis—Means and frequency distributions for the demographic characteristics were compared using *t* test and chi-square based on Internet use status. To control for experiment-wide error, analysis of variance was used to compare Internet users with non-Internet users for all continuous variables (i.e., symptoms, AD, symptom severity, and hesitancy discussing with HCPs; COPE subscales). Correlation analyses were used to assess the relationships between AD, reported symptoms, and symptom severity. Because of nonnormality (skewness and kurtosis) and the presence of valid responses with a value of zero, the variable AD was log₁₀ transformed. Internet use and AD were modeled using logistic and linear regression techniques, respectively. Both regression equations were initially run using demographic variables and any other independent variable with a significant bivariate association with the outcome. Demographic variables with significant

associations remained in all models. The remaining independent variables were chosen for inclusion in final models if they were associated with the dependent variable at the .05 level.

The variables in the logistic regression model for Internet use included in the full model were insurance status, age, elimination symptoms, hesitation consulting an HCP, and two COPE subscales (venting and planning).

The linear regression model was created to assess the degree to which Internet use and other patient characteristics predicted AD. The independent variables included in the full model were Internet use, insurance status, age, engagement in self-treatment, elimination and rectal symptoms, and one COPE subscale (substance use). All statistical analyses were completed using SPSS 18.0.

Results

Sample Demographics

Demographic information for the Internet and non-Internet users can be found in Table 1. Only age and insurance status was associated with Internet use. Internet users were significantly younger ($t = 4.9, p < .01$) and significantly more likely to have private insurance, $\chi^2(1) = 19, p < .001$, as compared with non-Internet users. Internet users did not differ from non-Internet users in terms of gender, race, educational level, income, or stage at diagnosis.

Internet Use

We identified 61(25%) individuals who reported accessing the Internet as part of their symptom appraisal process prior to contacting an HCP. Most Internet users performed the searches themselves ($n = 50$), but a small proportion ($n = 11$) obtained help from family members or friends.

Participants who reported consulting the Internet prior to an HCP were asked how the information influenced their decision to seek medical treatment. Twenty-eight percent ($n = 17$) reported that the information influenced their thinking that it was cancer, that it was a serious problem ($n = 9$; 15%), and that they should visit an HCP ($n = 15$; 25%). Of the remaining Internet users, 26% ($n = 16$) reported that the Internet-based information influenced their thinking that it was not cancer or did not require medical attention ($n = 5$; 8.2%) and 15% ($n = 10$) reported no influence on their thinking.

Appraisal Delay

AD (nontransformed) ranged from 0 to 59 months (mean = 4.6). Compared with patients who did not consult the Internet, Internet users experienced significantly longer AD: $F(1, 239) = 3.98, p < .05$.

Symptoms/Discussion

With HCP/Self-Treatment—Digestive and elimination symptoms were most commonly reported. Patients experienced 0 to 6 (mean = 1.4, $SD = 1.3$) different digestive symptoms and 0 to 7 (mean = 1.6, $SD = 1.4$) different elimination symptoms. Patients experienced fewer rectal (0–2; mean = 0.36, $SD = 0.56$), gynecological/urinary (0–2; mean = 0.08, $SD = 0.32$), or other symptoms (0–1; mean = 0.62, $SD = 1.0$). Internet users reported significantly more elimination symptoms as compared with non-Internet users: $F(1, 240) = 13.2, p < .001$. There were no other symptom-level differences between Internet and non-Internet users (data not shown). A larger proportion of Internet users ($n = 20/61$; 33%) reported feeling hesitant about discussing their symptoms with an HCP, as compared with non-

Internet users ($n = 35/179$; 20%): $\chi^2(1) = 4.5$, $p = .05$. Elimination symptoms ($r = .23$, $p = .001$) and rectal symptoms ($r = .23$, $p < .001$) were significantly, positively correlated with AD. Similar proportions of Internet users ($n = 42$; 72%) and nonusers ($n = 101$; 63%) initially self-treated their symptoms. Symptom severity scores ranged from 1 to 5 with a mean of 2.8 ($SD = 1.2$). There were no differences between Internet users and non-Internet users for reported symptom severity: $F(1, 226) = 1.42$, $p > .20$.

Brief COPE

Only three COPE subscales were significantly related to either Internet use or AD. Internet users used significantly more planning or strategy development, $F(1, 234) = 4.83$, $p < .03$, and venting (i.e., focusing on the stress), $F(1, 234) = 5.21$, $p < .03$, coping strategies compared with non-Internet users. A positive association was identified between substance use and AD ($r = .14$, $p < .05$). No significant relationships were found for the remaining subscales.

Multivariate Modeling

A logistic regression model was used to assess whether patient characteristics were related to Internet use for symptom appraisal. The final model, shown in Table 2, was significant, $\chi^2(4df) = 36.65$, $p < .001$. Compared with patients who did not consult the Internet, patients who consulted the Internet about their symptoms were 2.55 (95% confidence interval [CI] = 1.2–5.4) times more likely to have private insurance, were more likely to be younger (odds ratio = 0.96; 95% CI = 0.93–0.99), and 1.43 (95% CI = 1.1–1.8) times more likely to experience elimination symptoms.

A linear regression model to predict AD found that consulting the Internet about symptoms did not predict AD. Estimates from the linear regression model are shown in Table 2: $F(5, 213) = 4.55$, $p = .001$, $R^2 = .10$. Experience of rectal symptoms significantly predicted AD ($p < .01$) and engagement in self-treatment marginally predicted AD ($p < .01$).

Discussion

Our finding that Internet users were better insured and younger as compared with patients who did not consult the Internet is consistent with the literature. Younger individuals often have more experience and comfort consulting the Internet. Previous research has suggested that in the face of access barriers (i.e., lack of insurance), online health information seeking may increase (Terhaar sive Droste et al., 2010). In this study, having private insurance as compared with Medicare or being uninsured was associated with greater use of the Internet for symptom appraisal. Private insurance may have acted as a proxy measure for Internet access. The socioeconomic status indicators education and income, which positively correlate with private insurance status, are associated with increased health information seeking on the Internet (Couper et al., 2010; Viswanath & Ackerson, 2011). Individuals who had private insurance may have had better access. We found that Internet use was associated with experiencing embarrassing CRC symptoms (i.e., elimination symptoms), hesitancy consulting an HCP, and increased use of coping through planning/strategizing. Thus, the Internet may have provided a private, less embarrassing option for obtaining initial information to aid decision making.

The influence of Internet-based health information has been examined for outcomes such as satisfaction with care, quality of life, confidence contacting physicians and participating in decision making, and intentions to participate in preventive care such as cancer screening (Bowen et al., 2011; Gustafson et al., 1999; Shaw et al., 2007). Although much research has focused on the (over)availability of poor information and its potential impact on patient

decisions (Eysenbach, 2003), fewer studies have examined the influence of purposive Internet information seeking on specific medical decisions (Couper et al., 2010). In this sample, we found that the Internet did not influence (positively or negatively) the length of time it took patients to seek medical attention for their symptoms. Yet 49% reported that the information persuaded them that the symptoms were not serious, and 15% reported no effect on their thinking. This may be related to the information retrieved or patient comprehension and/or confusion about the information reviewed. Search methods, such as choice of search engine and the keywords used (e.g., using generic vs. medical terms), are known to influence search outcomes (Lorence & Grenberg, 2006). For example, using search engines that tailor results based on prior search histories may further differentiate the type and quality of information retrieved between users (Pariser, 2011). Patients who found it difficult to find information, became frustrated, or were concerned about the quality of information retrieved may have found it less influential.

There are some limitations in this work. Detailed data about the nature of the Internet searches (e.g., websites accessed, information quality, or patient comprehension of the information) were not collected. Future studies need to explore such issues. These factors likely affect information use and patient decision making. There is evidence to suggest that in addition to socioeconomic factors, the type of health decision under consideration also influences whether the Internet is consulted (Couper et al., 2010). CRC primarily affects older adults. As older age is significantly, negatively associated with Internet use, patients who seek information about health issues may access and use Internet health information differently as compared with CRC patients. However, this study is novel in that it assessed Internet use by individuals as part of their initial symptom recognition process prior to seeking medical care, an area in which little is known about online health information-seeking behavior.

Practice Implications

Although Internet use was not implicated in AD, among those who had access (i.e., private health insurance), experienced embarrassing symptoms, and who were hesitant to speak with an HCP, it served as an initial information resource. Although there are differences in the types of health decisions that people seek Internet-based information about (Couper et al., 2010), research suggests that consulting the Internet is associated with an increase in physician visits (Lee, 2008). In this study, poor information quality may be partially responsible for the lack of association between Internet use and AD. Accessing low-quality CRC information may be because of user search strategies or information content that does not meet the user's needs. Future CRC education campaigns should focus on the embarrassing CRC symptoms (i.e., elimination or rectal symptoms) to dispel associated embarrassment and encourage individuals to seek care. This may be accomplished by using short video tutorials or symptom checklists to trigger users to seek medical attention. Capitalizing on the interactivity of the Internet to provide information about health services and clinics available in the patient's area may also encourage care seeking. As users of Internet-based information were embarrassed and hesitant to speak with HCPs about their symptoms, future research is needed to identify the type of CRC information that will inspire interest, decrease embarrassment, and encourage health care seeking. Creators of Internet-based information may also need to be aware of the visibility of their online content. As search engine query results and social networking sites become increasingly tailored to individual preferences (Pariser, 2011), users may unwittingly experience a new barrier in retrieving unbiased, reliable, and credible sources of online health information.

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Table 1

Demographics by Internet Use Status

Variable	Internet Users (<i>n</i> = 61)	Non-Internet Users (<i>n</i> = 181)
Age in years; mean (<i>SD</i>) *	53 (10.4)	60 (12.1)
Gender; <i>n</i> (%)		
Male	28 (46)	98 (54)
Race; <i>n</i> (%)		
African American	26 (43)	78 (45)
Education; <i>n</i> (%)		
<High school	7 (11)	42 (23)
High school	17 (28)	50 (28)
College	22 (36)	56 (31)
Graduate degree	15 (25)	32 (18)
Income (×1000\$); <i>n</i> (%)		
<30	19 (33)	78 (45)
30–75	19 (33)	53 (31)
>75	20 (34)	41 (24)
Insurance **; <i>n</i> (%)		
Private	41 (67)	68 (37)
Medicaid/Medicare	6 (10)	62 (34)
Cancer stage; <i>n</i> (%)		
Early (Stage1–2)	22 (36)	57 (32)

*
 $p < .01$.

**
 $p < .001$.

Table 2**Multivariate Models Examining Internet Use and Appraisal Delay**

Logistic Regression Model for Internet Use			
Variable	β	Wald	Odds Ratio [95% Confidence Interval]
Private insurance *	.94	5.91	2.55 [1.20, 5.43]
Medicare	-.19	0.01	0.83 [0.25, 2.79]
Age *	-.04	4.12	0.96 [0.93, 0.99]
Elimination symptoms **	.36	9.63	1.43 [1.14, 1.80]
Regression Model Predicting the Influence of Internet Use on Appraisal Delay			
Variable	β	<i>p</i> Value	95% Confidence Interval
Private insurance	-.07	.2	[-0.18, -0.04]
Medicare	-.08	.26	[-0.23, -0.06]
Age	.01	.72	[-0.004, -0.006]
Self-treatment	-.14	.005	[-0.24, -0.04]
Rectal symptoms	.13	.002	[0.05, 0.21]

*
 $p < .05$.

**
 $p < .01$.