Health Information Seeking and Cancer Screening Adherence Rates

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Abstract Effective screening tools are available for many of the top cancer killers in the USA. Searching for health information has previously been found to be associated with adhering to cancer screening guidelines, but Internet information seeking has not been examined separately. The current study examines the relationship between health and cancer Internet information seeking and adherence to cancer screening guidelines for breast, cervical, and colorectal cancer in a large nationally representative dataset. The current study was conducted using data from the Health Information National Trends Survey from 2003 and 2007. The study examined age-stratified models which correlated health and cancer information seeking with getting breast, cervical, and colorectal cancer screening on schedule, while controlling for several key variables. Internet health and cancer information seeking was positively associated with getting Pap screening on schedule, while information seeking from any sources was positively associated with getting colorectal screening on schedule. People who look for health or cancer information are more likely to get screened on schedule. Some groups of people, however, do not exhibit this relationship and, thus, may be more vulnerable to under-screening. These groups may benefit more from targeted interventions that attempt to engage people in their health care more actively.

Keywords Cancer screening · Breast cancer · Cervical cancer · Colorectal cancer · Health information · Internet health information · HINTS

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Introduction

Cancer is one of the leading causes of death in the USA. For many cancers, effective screening tools are available that have demonstrated value in terms of reduced cancer mortality—mammography for breast cancer, Pap for cervical cancer, and multiple screening modalities for colorectal cancer [1]. These tests are recommended for general population screening, i.e., people of a certain age and sex should be screened regardless of their cancer risk [2–4].

Rates of adherence to screening guidelines vary by cancer type and demographics. In 2008, 78 % of women in the appropriate age range reported getting a Pap in the past 3 years, whereas 53 % of women reported having a mammogram in the past year [5]. Hispanic and Black women are less likely than Whites to be screened regularly, younger women and

much older women receive fewer screenings, and Health Management Organization (HMO) insurance is associated with higher screening rates [6–9].

Screening rates for colorectal cancer (CRC) have been increasing since 2005, although this test still has the lowest rate of adherence of all universally recommended tests [5, 10]. The Center for Disease Control and Prevention (CDC) found that rates of colorectal cancer screening, using either fecal occult blood test (FOBT) or endoscopy, rose from 54 % in 2002 to 61 % in 2006 among individuals over 50 years old [11]. Some factors that predict adherence to these tests include race (White), gender (male), education (higher attainment), and health insurance coverage (present) and knowledge about and attitudes toward CRC screening tests [12, 13].

Finding correlates of cancer screening is an important step in creating more effective health communication campaigns that can influence screening behavior for the better. The Health Information National Trends Survey (HINTS), a nationally representative National Cancer Institute-run survey, was originally designed with this mission in mind—to gather information on how people gained and used cancer-related information.[14] An association between rates of cancer screening and health information seeking has been documented in several studies. Data from the HINTS indicate that information seeking specifically about cancer is associated with compliance with colorectal cancer screening guidelines [15]. Health information scanning (a construct that assessed how much attention participants paid to health information) was associated with having had a mammogram within the past 2 years among women [16] but was not associated with colorectal cancer screening (colonoscopy) uptake [17]. However, seeking information about health and cancer over the Internet was not examined separately in these studies.

According to research conducted by the Pew Internet and American Life Project [18], 59 % of adults in the USA search for health information online. People most often search for information on specific diseases or medical problems or on medical treatments and procedures. Although doctors, nurses, and other health professionals remain the most important source of health information for US adults [19], the Internet is consistently rated as the second most important tool [19–21].

Some of the main advantages of accessing health information on the Internet, whether in general or specifically about cancer, include the short amount of time required when compared to waiting for a visit with a health-care professional, the flexibility of being able to search at the patient's convenience, and the access to abundant and usually free information [22]. Women, Whites, those with higher income and education, and younger people are all more likely to use the Internet to search for health-related information [23, 24]. Moreover, both people with and without illnesses use the Internet to search for health information [20, 25]. However, it is not clear how Internet access of health information is associated with individuals'

health behavior. Specifically for our interest, more studies are needed to ascertain whether active health information seeking is linked to engagement in cancer prevention behaviors.

The current study examines the relationship between health and cancer Internet information seeking and adherence to cancer screening guidelines for breast, cervical, and colorectal cancer in a large nationally representative dataset. We hypothesize that both kinds of information seeking are positively associated with greater compliance with screening guidelines. However, people who seek cancer information specifically are a subset of the people who seek general health information and they may be more motivated to be screened for cancer according to the guidelines.

Materials and Methods

Data used for this study are from HINTS 2003 and 2007 because these survey administration years contained all the questions needed for testing the hypothesis of the current study. HINTS is a cross-sectional survey of a nationally representative sample of American adults. It assesses use of health information from the Internet and from other sources and health behaviors, with a focus on cancer-related information and prevention [26–28]. HINTS was administered as a random digit dial survey to a representative sample of US households in 2003, whereas the 2007 survey was administered via random digit dialing and mailed interviews. Data were analyzed in 2012 with an Institutional Review Board exemption because the current study is a secondary analysis.

For the current study, recommendations from the US Preventive Services Task Force (USPSTF) that were current at the time of data collection were used to define adherence. Dichotomous variables indicating whether participants report being adherent to cancer screening guidelines were created as the primary outcome variables. For breast cancer, average-risk women were recommended to receive mammography every 1–2 years after age 40 [4, 29]. The outcome variable for breast cancer screening compliance indicates whether a woman had a mammogram in the last 2 years. Women under the age of 40 and those with a prior breast cancer diagnosis were excluded from analysis. Data on mammography were only available in HINTS 2003.

Pap screening is recommended for women who are sexually active and who have an intact cervix. Screenings should begin 3 years after sexual initiation or age 21 and continue until age 65 [2]. A dichotomous variable was created indicating whether a Pap had been received in the last 3 years. Because sexual initiation was not ascertained in HINTS, adherence was calculated for women over the age of 18. Women over 65 years of age were excluded from analysis.

For colorectal cancer, screening should begin at age 50 and continue to 75 years old and can be either an annual fecal occult blood test (FOBT), a flexible sigmoidoscopy every 5 years, or a colonoscopy every 10 years [30]. The dichotomous outcome variable for CRC screening indicated whether or not participants had a FOBT in the past year, a sigmoidoscopy in the past 5 years, or a colonoscopy in the past 10 years. Participants younger than 50 years of age were excluded from analysis, as were those over age 75.

Cancer information seeking and health information seeking were defined using data on whether patients ever sought information (cancer or health in general) at all and whether they looked first on the Internet ("Did you use the internet to seek health info for yourself?" in 2003 and "Where did you first look for cancer information?"). The second type of phrasing was present for both health and cancer information seeking in 2007. Responses were used to create separate cancer information seeking and health information seeking variables each with three possible response levels: participants who did not look for any information, those who looked to the Internet as their first source of information, and those who used all other sources (e.g., books, family, and friends) first. However, because of the wording of the questions, for 2003, we were not able to calculate the three-level response variable for seeking health information; rather, only a two-level variable (seeking Internet health information versus not) could be calculated (see Tables 2 and 3). Not seeking health information or cancer information was used as the reference categories for these analyses.

Socio-demographic variables included the following: age, gender, and household income [as a proxy for socio-economic status (SES)]. Age was measured as a continuous variable and was used to stratify participants into age ranges (corresponding to cancer screening guidelines) in which hypotheses were tested separately (see "Statistical Analysis"). The following control variables were used in the analyses: family history of cancer, self-reported health status, and health insurance status. These variables were selected because they were correlated with cancer screening behavior in our data.

Statistical Analysis

Analyses were conducted separately for data from the 2003 and 2007 administrations of the survey. All analyses, including descriptive statistics and regression modeling, were carried out using Mplus 6.11 [31]. The hypothesized relationships between health or cancer information seeking and cancer screening guidelines adherence were tested using probit regression [32]. Regression coefficients in a probit model provide an estimate of predicted change in the z-score of the outcome for each one unit change in the independent variable. This type of regression is very similar to logistic regression using a different link function to analyze the outcome variable with a binomial distribution.

Since age is highly associated with both the independent and dependent variables, but in opposite directions (i.e., younger participants were more likely to seek Internet cancer or health information, whereas older participants were more likely to be screened for cancer), the data were stratified by age. For breast cancer, the age categories used were the following: 40–50, 51–65, and 66 and older. For cervical cancer, the age categories used were the following: 18–35, 36–50, and 51–65. For colorectal cancer, the categories used were the following: 50 to 60 and 61–75. Unadjusted estimates from the probit models were first calculated, and then control variables were added into the models.

Weighted root mean square residuals (WRMR) were calculated to assess model fit, where WRMR values close to and below 1.0 indicates adequate fit. Whether or not each model provides an adequate fit is indicated in the tables.

Results

Table 1 summarizes the means and standard deviations or percentages of each variable used in the analyses and the racial/ethnic composition of the samples used. The samples from 2003 and 2007 were demographically similar by design because the estimates are weighted to be nationally representative.

Cancer information seeking (from the Internet and other sources) was assessed as part of the modeling in each age group, as was health information seeking. In general, participants who were younger tended to look to the Internet for health or cancer information at higher rates than from all other sources, whereas older participants, especially those over 60 years of age, looked for Internet information the least. There were few differences between the 2003 and 2007 administrations of HINTS.

The probit regression coefficients for models for all cancers are given in Table 2 (cancer information seeking) and Table 3 (health information seeking). No significant adjusted associations between either cancer or health information seeking and breast cancer screening adherence were found.

Internet cancer information seeking, when compared to no information seeking (Table 2), was found to be significantly positively associated with getting Paps on schedule among women aged 18–35 and 36–50 in the 2003 data. In the 2003 data, Internet health information seeking was positively associated with higher rates of on-schedule Paps for women aged 36–50, and a similar association was found in the 2007 data for women aged 18–35 (Table 3).

In the 2007 data, seeking cancer information from the Internet or from other sources (Table 2) was associated with

Table 1 Weighted descriptive statistics of selected study characteristics in HINTS 2003 and 2007

Variable	2003 (n=6369) Percent/mean	2007 (n=7623) Percent/mean
Age, mean (SD)	46.21 (17.12)	45.51 (18.08)
Sex, female	51.9	51.4
Family history of cancer	61.3	69.7
Have health insurance	84.9	82.4
Self-reported health (1=excellent– 5=poor) Mean (SD)	2.67 (1.05)	2.61 (0.94)
Hispanic	11.6	12.7
Non-Hispanic Black	10.4	11.4
Non-Hispanic American Indian	1.4	0.5
Non-Hispanic Asian	2.2	4.4
Non-Hispanic Hawaiian or Pacific Islander	0.3	0.2
Non-Hispanic multiple races indicated	2.1	1.3
Non-Hispanic White	70.8	68.8
Household income: below $25,000	26.5	18.1
Household income: between $25,000 and $35,000	12.2	15.3
Household income: between $35,000 and $50,000	15.8	12.8
Household income: between $50,000 and $75,000	15.9	17.5
Household income: above $75,000	20.7	27.8
Cancer information seeking: none	55.0	60.9
Cancer information seeking: Internet	21.6	21.4
Cancer information seeking: other sources	22.9	17.3
Health information seeking: none	49.2	–
Health information seeking: Internet	50.6	–
Health information seeking :none	–	30.1
Health information seeking: Internet	–	42.6
Health information seeking: other sources	–	24.8

higher rates of getting screened for colorectal cancer according to guidelines. Also, in 2007, Internet health information seeking (Table 3) was associated with higher rates of colorectal cancer screening adherence in people aged 61–75.

Discussion

Our analysis of national data indicates that the effect of Internet cancer and health information seeking on cancer screening adherence differs by type of cancer and by patient age group.

Breast Cancer Screening

Although there was some indication of significant associations between cancer information seeking (whether from the Internet or other sources) and adherence to mammography screening guidelines, adjustment for control variables reduced these associations to non-significance. Awareness of breast cancer screening has long been a goal of some visible and influential organizations, such as the Susan G. Komen Foundation, which have spent much time, money, and energy to increase women's awareness of breast cancer screening and treatment [33]. Research has shown that campaigns like Breast Cancer Awareness Month have effects on Internet searches about breast cancer and that women receive memorable messages about breast cancer awareness and screening at quite high rates from media and family, which, in turn, are associated with higher rates of screening behaviors [34, 35]. The high visibility of breast cancer and mammography screening may have made it difficult to detect an effect of information seeking.

Despite high levels of awareness of breast cancer and mammography, health insurance availability and SES still affect mammography utilization. The strongest predictor of getting a mammogram on schedule was health insurance in the younger (40–50) and middle-aged (51–65) groups, whereas income played a role in mammography screening for those over 65.

Cervical Cancer Screening

Use of the Internet for cancer information seeking (when contrasted to no information seeking of any kind) was positively associated with cancer screening adherence in women aged 36–50 and 51–65 in 2003. Similarly, the more general "health information seeking" was associated with cancer screening adherence in women aged 36–50 in 2003 and women aged 18–35 in 2007. Seeking information from sources other than the Internet was not significantly associated with cervical cancer screening. This result seems to suggest that, across age ranges, those women who seek Internet information about health or cancer are more likely to report receiving a Pap within the last 3 years. Data from the 2005 administration of HINTS, which were not used in the present analyses, suggested a similar result in that women who had ever searched for cancer information were more likely to be cervical cancer screening "maintainers" (i.e., have been screened in the past 3 years and intended to get screened in the next 3 years) when controlling for several variables including age, although not looking specifically at Internet information seeking [36].

The effect of more recent information and guidelines on the human papillomavirus (HPV) and cervical cancer may have impacted our results on information and cervical cancer screening as well. This virus is known to cause many common types of cervical cancer, and with the advent of the HPV vaccine, screening patterns may have changed or may change in the future. Cervical cancer screening guidelines were recently changed to include HPV screening [37]. The HPV

Table 2 Associations between cancer information seeking and cancer screening adherence in HINTS 2003 and 2007 with screening rates for each age group

Cancer type (age)	2003				2007			
	Number	Screen rate	Adj. internet seeking rate (beta)[a]	Adj. other seeking rate (beta)[a]	Number	Screen rate	Adj. internet seeking rate (beta)[a]	Adj. other seeking rate (beta)[a]
Breast (40–50)	860	0.740	−0.02 (0.16)[b]	0.17 (0.19)[b]	–	–	–	–
Breast (51–65)	859	0.840	0.20 (0.18)[b]	−0.14 (0.22)[b]	–	–	–	–
Breast (66+)	776	0.774	−0.11 (0.36)[c]	0.26 (0.44)[c]	–	–	–	–
Cervical (18–35)	1024	0.808	−0.06 (0.15)[c]	0.25 (0.19)[c]	783	0.789	0.35 (0.20)[b]	0.30 (0.33)[b]
Cervical (36–50)	1169	0.808	0.30* (0.13)[c]	0.00 (0.16)[c]	1141	0.877	0.06 (0.20)[c]	0.05 (0.16)[c]
Cervical (50–65)	859	0.799	0.41* (0.16)[b]	0.34 (0.20)[b]	1462	0.780	0.14 (0.12)[c]	−0.12 (0.14)[c]
CRC (50–60)	1030	0.579	−0.05 (0.14)[c]	0.15 (0.18)[c]	1858	0.559	0.23* (0.10)[c]	0.20* (0.10)[c]
CRC (61–75)	966	0.532	−0.21 (0.21)[c]	0.18 (0.21)[c]	1879	0.731	−0.01 (0.11)[c]	0.20 (0.11)[c]

[a] Controlling for sex, patient-physician communication, family history of cancer, self-reported health, health insurance status, and income

[b] Good or adequate model fit

[c] Poor model fit

*$p < 0.05$

vaccine was first approved by the US Food and Drug Administration in 2006 [38]. Since that time, much media attention has been allocated to the vaccine and cervical cancer, and there has been a national conversation about the vaccine and its acceptability. This may have had some repercussions on the information gathered on HINTS 2007. It may be that the link between HPV and cancer was not yet widely known during the 2003 data collection, and participants therefore may not have endorsed the cancer information seeking item when they were looking for or hearing about information on the HPV vaccine or it may be that since participants were hearing a lot about the HPV vaccine and cervical cancer, they did not

Table 3 Associations between health information seeking and cancer screening adherence in HINTS 2003 and 2007 with screening rates for each age group

Cancer type (age)	2003			2007			
	Number	Screen rate	Adjusted internet seeking rate (beta)[a]	Number	Screen rate	Adjusted internet seeking rate (beta)[a]	Adjusted other seeking rate (beta)[a]
Breast (40–50)	624	0.784	0.17 (0.18)[c]	–	–	–	–
Breast (51–64)	493	0.867	0.00 (0.20)[c]	–	–	–	–
Breast (66+)	168	0.876	−1.35 (0.71)[c]	–	–	–	–
Cervical (18–35)	792	0.818	−0.01 (0.16)[c]	783	0.789	0.45* (0.21)[b]	0.54 (0.31)[b]
Cervical (36–50)	870	0.838	0.32** (0.12)[c]	1141	0.877	0.34 (0.25)[c]	0.43 (0.23)[c]
Cervical (50–65)	493	0.860	0.08 (0.20)[c]	1462	0.780	0.06 (0.14)[c]	0.04 (0.16)[c]
CRC (50–65)	676	0.558	−0.07 (0.12)[b]	1858	0.559	0.22 (0.13)[c]	0.19 (0.11)[c]
CRC (61–75)	374	0.560	−0.16 (0.16)[b]	1879	0.731	0.23* (0.11)[c]	0.31** (0.11)[c]

[a] Controlling for sex, patient-physician communication, family history of cancer, self-reported health, health insurance status, and income

[b] Good or adequate model fit

[c] Poor model fit

*$p < 0.05$; **$p < 0.01$

seek health or cancer information relating to this subject. Either of these may be reasons why no association was found between cancer information seeking and screening adherence in 2007, though the link was found in 2003.

As in the models examining breast cancer screening, having health insurance was positively significantly associated with screening in women aged 36–50 and 51–65, as was income. In particular, among younger women (aged 18–35) participants who reported household incomes of between $50,000 and $75,000 and above $75,000 were much more likely to get screened on schedule than those women who earned below $25,000. These findings again highlight the importance of SES on screening adherence.

Colorectal Cancer Screening

Colorectal cancer screening adherence was positively associated with cancer and health information seeking via the Internet in 2007, but not in 2003. For participants aged 50–60, cancer information seeking regardless of source was found to be associated with colorectal cancer screening adherence. For participants aged 61–75, health information seeking, again from the Internet and from other sources, was significantly associated with being screened. It seems that, unlike cervical cancer screening, for which Internet information seeking specifically was an important predictor, colorectal cancer screening adherence is higher among people who seek information from any source. As in previous analyses, health insurance was once again a strong predictor of colorectal cancer screening adherence for all age groups and for both types of information seeking in 2007.

In 2007, older participants (aged 61–75) were, in general, more adherent to colorectal cancer screening guidelines (FOBT, sigmoidoscopy, or colonoscopy), with a rate of 73 % compared to the lower rate of 56 % in the younger age group. This is consistent with findings from the 2008 National Health Information Survey, in which participants aged 66–74 were 1.64 times more likely to receive either endoscopy in the last 10 years, or FOBT at home in the last 1 year compared to their counterparts aged 50–64 years [39]. Colorectal cancer screening rates are lower than those of other universal screenings like cervical and breast cancer; although they have been rising, in 2000, only about 34 % of the eligible US population was being screened for colorectal cancer, whereas in 2008, the rate rose to over 50 % [13, 39]. In this study, we found the rates to be between 53 and 58 % in 2003 and between 56 and 73 % in 2007. Unlike breast cancer, which receives a lot of attention from non-profit and public health foundations, and cervical cancer screening, which has been used for more than 50 years, colorectal cancer screening does not seem to consistently receive the same level of advocacy and attention. Colorectal cancer screening guidelines are also more complex than the others—there is a choice of modalities and a different schedule of screening for each modality, which may be confusing. Patients who view colorectal cancer screening as difficult to arrange and/or those who do not know about different screening methods are less likely to adhere to screening guidelines [40]. On the other hand, when patients receive a recommendation for screening by a physician, they tend to be screened on schedule [12]. In the current study, we found that information seeking is positively associated with colorectal cancer screening adherence. This implies that patients who are engaged in their health care are more likely to get screened because screening is an important part of caring for oneself. Similar results were found for cervical cancer screening in terms of Internet information seeking. Further prospective or experimental studies are needed to shed light on the research questions examined in the present study.

Limitations

The present results should be interpreted in light of several important limitations. First, the data used for the analyses were cross-sectional, and therefore, no conclusions can be drawn about temporal sequencing among the variables in the study, and no causality can be inferred. Second, answers to the HINTS survey questions may suffer from recall bias and socially desirable responding. The use of computer-assisted telephone interviewing (CATI) and mail surveys may have alleviated the social desirability bias, but recall bias remains a limitation, particularly for some forms of colorectal cancer screening. Third, although information seeking was assessed, it is not known exactly what information the participants were looking for. It is also unknown what information they found on the Internet or through other sources. Not all websites provide accurate or current information about cancer or about health topics in general.

Although a large nationally representative data set, HINTS suffers from fairly low response rates. Falling response rates for random digit dial surveys have been observed over the past decade across all types of survey administrations, particularly with increases in cell phone-only households and the introduction of caller ID [41, 42]. However, results from methodological studies suggest that the threat for bias introduction from low response rates may not be as potent for health surveys as originally feared, although some differences in overall estimates may persist [14, 41–43]. Moreover, efforts have been underway in the HINTS program to address these sources of potential error, including the use of dual frame administrations to combat modality bias, coverage bias, and sampling error [26]. Although the response rates may have been somewhat low, HINTS provides sampling weights that adjust the sample to be representative of the population and this is a major strength of the current study. In another limitation, the 2007 survey administration did not include information on breast cancer screening. It is also known that there is a digital divide

among people with lower SES, such that those who are most vulnerable to under-screening are also those least likely to be searching for Internet health information [44]. Although the adjusted models controlled for insurance status and income, these variables may not fully capture the impact of SES status overall. Finally, the 2003 data from HINTS is over 10 years old, which may limit its relevance if parameters have substantially changed However, rates of information seeking and cancer screening rates have remained relatively stable since 2003 [45, 46].

Implications

Some significant relationships were found among information seeking and the adherence to cancer screening guidelines in the current study. These associations need to be examined further in studies with prospective and experimental designs to facilitate understanding of the temporality of the sequence of these events and possible causes. People's information seeking preferences need to be closely studied and followed. With the ease of Internet use and the portability of mobile Internet technology, it is becoming easier to find information on health topics. However, the accuracy and relevance of that information and its impact on medical decision-making need to be systematically assessed. In addition, health literacy plays a large role in how that information is used and interpreted by people who find it, and this construct also needs to be closely examined. Finally, exploring how patients perceive the sometimes confusing cancer screening recommendations from both physicians and organizations such as the USPSTF, and how they make decisions on which to follow, will provide much needed insight into cancer screening behavior. A recent nationally representative study which looked at Internet use in relation to medical decision-making found that few people used the Internet for making cancer screening decisions (from 16.8 % for breast cancer screening to 26.3 % for colorectal cancer screening), even though people rated the Internet as second only to health-care providers as an important source of health information [47]. This disconnect between information seeking and decision-making and cancer screening adherence should be studied further. Several studies have also attempted to target electronic messages for patients as an effort to increase colorectal cancer screening in randomized controlled studies, but results have not been encouraging at improving rates of the electronic information use or increasing rates of screening [48, 49]. More research is needed to understand the most effective way to reach people who may not be active participants in their own health care; those for example who may be passive observers of information which does not trigger behavior change. These individuals may need further encouragement for cancer screening uptake.

In the present study, information seeking was found to serve as an important correlate of cancer screening adherence

in some populations. This implies that patients who are engaged in their health care are more likely to be screened. Thus, some patients who are not as engaged may require more information than they are currently receiving from their health-care providers. It is important for health-care providers to understand that patients are interested in health information generally and cancer information specifically, but some may not have the means or wherewithal to obtain that information independently.

Conclusion

Despite some limitations, the present study showed that health information seeking (general and cancer specific) from the Internet and other sources is associated with cancer screening adherence. In general, it was determined that people who look for health or cancer information are more likely to get screened on schedule. Some groups of people, however, do not exhibit this relationship and, thus, may be more vulnerable to under-screening. These specific groups, who may be more passively viewing information that is attained, may benefit more from targeted interventions that attempt to engage people in their health care more actively.

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