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Cancer information seeking and cancer-related health outcomes: a scoping review of the Health Information National Trends Survey literature

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Abstract

Background—Cancer is a leading cause of death among United States (US) adults. Only 54% of US adults reported seeking cancer information in 2014. Cancer information seeking has been positively associated with cancer-related health outcomes such as screening adherence.

Methods—We conducted a scoping review of studies that used data from the Health Information National Trends Survey (HINTS) in order to examine cancer information seeking in depth and the relationship between cancer information seeking and cancer-related health outcomes. We searched five databases and the HINTS website.

Results—The search yielded a total of 274 article titles. After review of 114 de-duplicated titles, 66 abstracts, and 50 articles, 22 studies met inclusion criteria. Cancer information seeking was the outcome in only four studies. The other 18 studies focused on a cancer-related health outcome. Cancer beliefs, health knowledge, and information seeking experience were positive predictors of cancer information seeking. Cancer-related awareness, knowledge, beliefs, preventive behaviors, and screening adherence were higher among cancer information seekers.

Conclusions—Results from this review can inform other research study designs and primary data collection focused on specific cancer sites or aimed at populations not represented or underrepresented in the HINTS data (e.g., minority populations, those with lower socioeconomic status).

Keywords

HINTS; cancer information seeking; scoping review; cancer outcomes

Introduction

Cancer is a leading cause of death among adults in the United States (US) (Centers for Disease Control and Prevention/National Center for Health Statistics, 2015). Despite the high likelihood of either being diagnosed with or otherwise affected by cancer at some point in their lives, many US adults have never looked for information about cancer (National Cancer Institute, 2010). Among cancer information seekers in the US, the Internet was the most commonly used source of information about cancer followed by health care providers (National Cancer Institute, 2010). In fact, more than half of US adults who have ever looked for cancer information reported that the Internet was where they went first during their most recent search for information about cancer (National Cancer Institute, 2010). While online cancer information seeking is highly prevalent among US adults (National Cancer Institute, 2010), disparities in Internet use persist among minority, older, and lower socioeconomic status (SES) groups (Pew Research Center, 2013).

The Health Information National Trends Survey (HINTS) is a population-based survey that has been conducted in the US and Puerto Rico (National Cancer Institute, n.d.). Many researchers have used HINTS data to examine cancer communication (e.g., cancer information seeking) and cancer-related health outcomes (e.g., screening adherence) (Hamilton, Breen, Klabunde, Moser, Leyva, Breslau, & Kobrin, 2015). Our scoping review provides details about how the HINTS questions have been used to examine cancer information seeking. This information would be useful not only to cancer prevention and control researchers interested in using HINTS data, but also those cancer prevention and control researchers who may be interested in modifying the wording of HINTS questions for specific cancer sites. For example, some of the studies used the HINTS mental modules for specific sites such as colorectal, lung, and skin cancer (Hay 2015; Han 2009; Hay 2009; Zhao 2009).

A scoping review “provides a preliminary assessment of the potential size and scope of available research literature. It aims to identify the nature and extent of research evidence.” (Grant and Booth, 2009, p31). This scoping review aimed to summarize and disseminate knowledge about how researchers have used HINTS questions to examine cancer information seeking among US and Puerto Rican adults. Seminal scoping methodology studies (Arksey and O’Malley, 2005; Levac, Colquhoun, O’Brien, 2010) and comprehensive scoping reviews published in the past five years informed our approach for this review (Friedman et al, 2015; Renton et al, 2014).

METHODS

Arskey and O’Malley’s (2005) methodological framework for conducting scoping studies involves: (1) identifying the research question; (2) searching for relevant studies; (3) selecting studies; (4) charting the data; and (5) collating, summarizing, and reporting the results. The process may also involve consulting with relevant stakeholders to inform or validate study findings. The first four stages are described in this section. Stage five is described in the Results section.

Stage 1 – Identifying the research question

It has been suggested that health information seeking, whether it be online or offline, may have a positive impact on behavioral changes that will lead to improved health outcomes, thereby reducing health disparities (David & Case, 2012). We conducted this scoping review to answer the following five research questions (RQ) about cancer information seeking:

RQ1: Where have researchers published their findings about cancer information seeking?

RQ2: How have researchers operationalized cancer information seeking?

RQ3: Which subpopulations of adults in the US and Puerto Rico have researchers used the HINTS data to examine cancer information seeking?

RQ4: Which modifiable factors have been identified as predictors of cancer information seeking?

RQ5: Which cancer-related health outcomes were positively associated with cancer information seeking?

Stage 2 – Search for relevant studies

The primary author (LTW) searched five major databases: CINAHL Complete (n=23 abstracts located), PubMed (n=64 abstracts), Social Sciences Citation Index of the Web of Science Core Collection (n=64), Communication Abstracts (n=30); and Communication and Mass Media Complete (n=36). These online databases were searched using the following search terms and Boolean operators: (((“Health Information National Trends Survey”) AND cancer AND information) AND seek*). “Looking” and “searching” were identified during our scoping review process as alternative words to describe “seeking” and were subsequently added to our search term strategy. We repeated the search in all databases using the following search term: (((“Health Information National Trends Survey”) AND cancer AND information) AND (seek* OR look* OR search*)). We also searched the HINTS website (<http://hints.cancer.gov/research.aspx>) for additional studies that we may have missed in the database search.

Stage 3 – Selecting studies

Our study selection process (Figure 1) involved three steps: (1) 274 title reviews, (2) 66 abstract reviews, and (3) 50 full article reviews. Titles that did not focus on information seeking or a cancer-related outcome, or only focused on health information seeking were excluded from subsequent abstract and full text review. All titles that were suggestive of information seeking or a cancer-related health outcome were reviewed. Full articles were reviewed for abstracts that focused on cancer or health information seeking and a cancer-related health outcome.

Only articles published in scientific journals were included. Journal articles that were not written in English language were excluded. Only empirical research studies that examined predictors of cancer information seeking or the association between cancer information seeking and a cancer-related health outcome were included. Thus, non-experimental and descriptive studies were excluded. Online cancer information seeking was a secondary

outcome of interest of this scoping review in an effort to further our understanding of the progress toward the *Healthy People 2020* Health Communication and Health Information Technology objective of improving access to online health information (Department of Health and Human Services, 2010).

Stage 4 – Charting the data

Two authors (LTW and DBF) developed and pilot tested an abstraction tool using Google Forms. The online abstraction tool, based on previous scoping review tools (e.g., Friedman et al., 2015), contained 53 items that included multiple-choice items, check boxes, and open-ended short and paragraph questions. After the first author conducted the initial full text abstraction, a 10% random sample of articles were reviewed by a co-author (DBF) as a quality control check. All data were entered using the Google Form, which was exported into a Microsoft Excel spreadsheet.

RESULTS

Stage 5 - Collating, summarizing, and reporting the results

The last stage of Arskey and O'Malley's (2005) six-stage methodological framework that we used for this scoping review is the collating, summarizing, and reporting the results. Below we describe the selection and overview of included studies. The rest of our results also are reported for each of our research question.

Selection and overview of included studies—After the article review, 28 of 50 studies were excluded. Figure 1 presents the scoping review process and reasons for the inclusion and exclusion of articles. A total of 22 studies were included in this review. Only four studies examined modifiable factors (e.g., cancer beliefs, health knowledge, and information seeking experience) that could impact cancer information seeking behavior. This includes one study that focused on information overload among cancer information seekers. Most (n=18) of the included studies examined the relationship between cancer information seeking and a cancer-related health outcome. Cancer site specific health outcomes included leading causes of cancer death such as colorectal cancer (n=4) (Hay 2015; Chen 2014; Hay 2006; Ling 2006). Gender-specific cancer sites included breast (n=1) (Madadi 2014), cervical (n=1) (Kontos 2012), and prostate (n=1) (Finney-Rutten 2005) cancer. Skin cancer health outcomes were also examined (n=1) (Hay 2009). Two studies looked at multiple cancer sites (i.e., colorectal, lung, skin, and prostate) (Han 2009; McQueen 2008). Several studies examined general cancer-related health outcomes such as awareness about genetic testing, health knowledge, perceptions of cancer risk and other cancer beliefs, smoking cessation, and preventive behaviors such as eating five or more servings of fruits and vegetables daily.

RQ1: Where have researchers published their study findings about cancer information seeking?: Studies were published in 14 scientific journals across the fields of communications, medicine, and public health. More than half (n=12) of the included studies were published in health communication journals such as the *Journal of Health Communication* and *Health Communication*. Researchers also published findings in high

impact medical (e.g., *Breast Cancer Research and Treatment*), and public health (e.g., *American Journal of Public Health*) journals. The HINTS 1 (2003) data was used in most (n=12) studies. It is important to note that two studies using the HINTS 1 (2003) (Madadi 2014) and HINTS 2 (2005) (Hay 2015) a decade or more since these data were collected. Only one study used each of the more recent datasets – HINTS 3 (2007) (Kontos 2012) and HINTS Puerto Rico (2009) (Ortiz 2011). (Table 1) None of the included studies used data from the fourth iteration (Cycles 1–4) of the HINTS.

RQ2: How have researchers operationalized cancer information seeking?: Most of the included studies (n=12) operationalized cancer information seeking as, *Have you ever looked for information about cancer from any source?* (yes/no) (Kontos 2012, Ortiz 2011, Keally 2010, Zhao 2010, Han 2009, Kaphingst 2009, Zhao 2009, McQueen 2008; Cerully 2006, Ford 2006; Ling 2006). Shim (2006) defined cancer information seeking in the context of having done so within the past year. Two researchers specifically focused on non-seekers (Hay 2015; Ford 2006). Several researchers also looked at surrogate seekers (i.e., having others look for information about cancer on one's behalf (n=4) (Zhao 2010; McQueen 2008; Arora 2008; Ling 2006). Other cancer information seeking constructs such as barriers encountered during the search process, self-efficacy to conduct future searches, and combinations of seeking with scanning (i.e., paying attention to health information on various media sources) were also used and are described in Table 2.

A secondary focus of our study was to examine online cancer information seeking (6 studies), which one study did by assessing participants' yes/no responses to whether or not they use the Internet to look for information about cancer (Hay 2009). Hay and colleagues (2009) also asked about sun-protection specific cancer information seeking because the skin cancer mental module included the following yes/no question, *In the past 12 months, have you looked for information on the Internet about protecting yourself from the sun?* Two studies assessed online cancer information seeking by assessing whether or not cancer information seekers used the Internet during their most recent search for information about cancer (Chen 2014; Kontos 2012). Shim and colleagues (2008) combined the online health/cancer information seeking questions to create a new variable. Finney-Rutten and colleagues (2005) also combined the online health/cancer information seeking questions, but did not provide details about how they constructed the new variable reported in their data table.

Few studies (n=5) explicitly stated that their work was informed by a conceptual model or theoretical framework. The theories or frameworks presented were: Knowledge Gap Hypothesis (Shim 2008); National Center for Research on Evaluation Standards and Student Testing Model of Problem Solving (Kim 2007); National Trends Survey Framework (Kim 2007); Precaution Adoption Process Model (Kim 2007); Precede-Proceed Model (Chen 2014); Risk Perception Attitude (RPA) Framework (Zhao 2009); and Structural Influence Model of Communication Inequalities (Kontos 2012).

RQ3: Which subpopulations of adults in the United States and Puerto Rico have researchers used the HINTS data to examine cancer information seeking?: Population characteristics of all 22 studies are described in Table 3. Only six included studies used the full HINTS sample, which was representative of US and Puerto Rican adults. The HINTS

Puerto Rico (2009) data was not subsampled. Most of the included studies (n=13) used subpopulations of the HINTS sample. These subpopulations included adults 45+ years old, females >40 years old, online adults, smokers, and adults who reported consuming less than five servings of fruits and vegetables daily (Finney-Rutten 2005, Ford 2006, Ling 2006, McQueen 2008, Chen 2014, Madadi 2014, Shim 2008, Zhao 2009, Finney-Rutten 2009, Cerully 2006). It is important to note that Finney-Rutten and colleagues (2009) combined HINTS 1 (2003) and HINTS 2 (2005) data which yielded a larger sample of smokers (n=2,257) in comparison to the 340 smokers that Zhao and colleagues (2009) used for their study with HINTS 2 (2005) data. Several studies used data from the colorectal, skin, and lung cancer mental modules (Han 2009, Hay 2009, Hay 2015). The lower age cutoffs for subpopulations used in studies that focused on a specific cancer site were informed by cancer screening guidelines and varied based on the researchers' objectives. For example, Ford and colleagues (2009) included adults five years younger (i.e., 45+ years old) than the earliest age recommended for colorectal cancer screening. Other researchers used 50 years old as their age cutoff. All of the included studies excluded adults who had been diagnosed with cancer.

RQ4: Which modifiable factors have been identified as positive predictors of cancer information seeking?: There were only four studies that examined cancer information seeking as an outcome (Kaphingst 2009; Niederdeppe 2008; Kim 2007; Shim 2006). This includes one study that examined cancer information overload (Kim 2007). Another study examined not only information scanning in addition to information seeking, but also the interaction between seeking and scanning which was used to create a typology of these two cancer communication behaviors (Shim 2006). Positive cancer beliefs and cancer information seeking experiences have been shown to be positively associated with cancer information seeking. However, included studies found that cancer information seeking self-efficacy was positively associated with cancer information seeking (Zhao 2009), and mean health knowledge score was negatively associated with the interaction between information seeking*scanning typology (Shim 2006). These results are described in Table 3.

RQ5: Which cancer-related health outcomes were positively associated with cancer information seeking?: This includes one study that focused on ambiguity about perceived colorectal, lung, and skin cancer risk (Han 2009). Most of the studies (n=5) focused on colorectal (Chen 2014, Ford 2006, Ling 2006), breast (Madadi 2014), or prostate screening adherence (Finney-Rutten 2005). One study focused preventive behaviors (i.e., sun-protection; n=1) (Hay 2009). Other studies examined on HPV awareness and knowledge (Kontos 2012), and colorectal (Hay 2015, McQueen 2008) or breast/prostate (McQueen 2008) cancer beliefs (Hay 2015). Several studies (n=7) examined cognitive, psychosocial, and preventive behaviors as cancer-related health outcomes including awareness and use of direct-to-consumer genetic tests (n=1) (Ortiz 2011); cancer knowledge (n=1) (Shim 2008); cancer beliefs (n=3) (Kealey 2010, Zhao 2010, Arora 2008), fruit and vegetable daily intake (Cerully 2006), and smoking cessation (Finney-Rutten 2009). These results are presented in Table 3.

DISCUSSION

Cancer information seeking has been shown to be positively associated with cancer-related health outcomes (David and Case 2012, Shim 2006). Although some iterations of the HINTS survey are more focused on cancer information seeking, all versions of the survey that have been administered to date ask, *Have you ever looked for information about cancer from any source?* Although earlier HINTS iterations asked *About how long ago was that?* later HINTS iterations do not include this follow-up question. We believe it is helpful that some of the included studies were able to add a timeframe to cancer information seeking such as the past year (Shim 2006) or past week (Niederdeppe 2008). This additional variable was especially important for Niederdeppe and colleagues (2008) who examined associations between cancer information seeking and recent celebrity news events, especially considering short news cycles.

Earlier versions of HINTS also asked about surrogate cancer information seekers, that is *Excluding your doctor or health care provider, has someone else ever looked for information about cancer for you?* Although later HINTS iterations do assess whether or not participants have looked for information about health or medical topics for someone else, the concept of surrogate cancer information seeking seems to have been abandoned. Nonetheless, this review paper provides a comprehensive summary of how researchers have conceptualized cancer information seeking, including the creation of a group or typology to describe self-seekers, surrogate seekers only, self-seekers and surrogate seekers, and non-seekers (Arora 2008). It is important to note, however, that Arora and colleagues (2008) did not consider surrogate seekers to be cancer information seekers.

The HINTS assessment of online cancer information seeking has varied over the years. Earlier HINTS iterations asked specifically about using the Internet to find information about cancer, e.g., *Have you ever visited an Internet web site to learn specifically about cancer?* Later HINTS iterations have assessed online cancer information seeking in various ways, leaving some researchers to combine multiple questions as a proxy measure for assessing online cancer information seeking. Recent HINTS iterations have focused more on online health information seeking, which is one of our nation's Healthy People 2020 goals (Department of Health and Human Services, 2015). The use of different questions to assess online cancer information seeking can become problematic for researchers who are interested in combining multiple years of HINTS data as Finney-Rutten (2009) did to yield a larger data sample for studying subpopulations smokers.

Research Gaps and Recommendations for Future Research

By summarizing the various ways that researchers have used HINTS to operationalize cancer information seeking, this scoping review can inform future research aimed at better understanding this multifaceted concept beyond a simple yes or no response. In addition, the potential limitation of recall bias introduced by asking survey participants about their most recent search could be addressed by giving focus group participants an opportunity to look for cancer information and then in real time ask them about their seeking experiences (Lambert and Loiselle 2008). This could enable researchers to obtain a more reliable measure of cancer information seeking which would likely increase our understanding of the

relationship between communication and health-related outcomes. Future research should also involve adapting HINTS questions to ask about people's search for information about specific cancer sites. As an example, several studies included in this review used the colorectal, lung, and skin cancer mental modules which asked questions about specific cancer types as opposed to cancer in general (Hay 2015; Han 2009; Hay 2009; Zhao 2009). Future research should also try to use more theory-driven questions to describe and explain the relationship between cancer information seeking and cancer-related outcomes. Only five studies included in this scoping review were informed by conceptual or theoretical framework.

Despite efforts to oversample non-Hispanic Blacks, the HINTS population is largely non-Hispanic White, higher SES US adults. Other racial groups (e.g., American Indian/Alaska Natives) are even less represented in HINTS data. We reviewed the full articles for only two studies that collected primary data either in an attempt to include a concept (e.g., numeracy) (Hay, 2015) that was not included in the HINTS data that they were interested in, or adapt the HINTS questions to be more culturally appropriate with their target population (e.g., Haitians, Hualapai Indians not represented or underrepresented in the HINTS data (Kobetz, Dunn Mendoza, Menard, et al., 2010; Teufel-Shone, Cordova-Marks, Susanyatame, Teufel-Shone, & Irwin, 2015). Results from this scoping review can inform other research study designs and primary data collection aimed at populations (e.g., minorities, low socioeconomic status) that are consistently underrepresented in the HINTS data. For example, the survey development process described by Teufel-Shone, et al. 2015 could be useful to future researchers in their selection and adaptation of HINTS questions to be used with other underrepresented populations. Addressing these gaps in the HINTS literature will likely increase the generalizability of HINTS data to non-White, less affluent populations.

Albeit not a longitudinal dataset, HINTS is a very valuable resource for studying cancer-related questions among smaller subpopulation (e.g., cancer survivors, smokers) because several questions are repeated across multiple survey iterations. This scoping review included a study that combined multiple years of HINTS data to examine the relationship between cancer information seeking and smoking status. While cancer in general is still a rare outcome, survivorship is an increasingly important issue as advances in treatment continue to be made. Thus, it will become increasingly important to be able to access a subpopulation of cancer survivors, and to do so using HINTS data would likely require the combination of multiple years of data. The Finney-Rutten, et al. 2009 study is an example that researchers can use in the future to conduct these more complex methodologies to produce larger samples for studying cancer-related outcomes among subpopulations such as smokers and cancer survivors.

Limitations

This study had some limitations. All studies we reviewed used a cross-sectional design. This limited our ability to assess any causal relationships between predictors and cancer information seeking, or cancer information seeking and cancer-related health outcomes. More rigorous study designs are needed to better assess cancer information seeking as cause or effect of cancer-related health outcomes. The fact that we focused on cancer information

seeking (which is less studied compared to health information seeking in general) limited the total number of studies (n=22) that were included in this scoping review. However, we were able to not only review and include studies that focused on a variety of cognitive, psychosocial, and behavioral cancer-related health outcomes, but also studies that conceptualized cancer information seeking in various ways that included online and offline seeking, scanning and the interaction between seeking and scanning, seeking experiences and self-efficacy, and seekers' information overload.

While ideally it would have been useful to examine studies that used more recent HINTS data, the fact that researchers continue to publish their findings in high impact journals underscores the richness of the HINTS datasets. We also were only able to report on one study (Finney-Rutten 2009) that used multiple years of HINTS data to achieve a larger sample of smokers for their study because no full text was available for the other two studies we identified that also used multiple years of HINTS data. The fact that HINTS collects data on the same variables across multiple years is definitely a major strength. We do note, however, that some years the HINTS questions were more heavily focused on cancer information seeking compared to other years. Also, over time, some questions about cancer information seeking have been dropped so that newer questions could be added to assess emerging trends (e.g., health communication between family members and friends) while at the same time minimizing the survey time burden on participants. For example, *When was the most recent time you looked for information about cancer?*, albeit very relevant in terms of providing context as opposed to having "ever" looked for information about cancer, is not assessed on the most recent iterations of the HINTS. Nonetheless, it is extremely valuable that researchers have the HINTS battery of questions about cancer information seeking that they can use to answer their research questions among their target populations. To this end, this is the first scoping review of HINTS studies that examined cancer information seeking. Therefore, this scoping review can serve as an important resource for helping other researchers to not only examine the relationship between cancer information seeking and cancer-related health outcomes, but further to be able to conceptualize the concept of cancer information seeking which can also include seeking experiences, self-efficacy, and information overload.

Conclusions

Cancer is a leading cause of death among US adults. Vulnerable populations such as racial/ethnic minorities and those of lower SES are disproportionately burdened by cancer disease and death. While the digital divide was previously based on the lack of infrastructure (Chandrasekhar and Ghosh, 2001), communication inequalities are now largely attributed to sociodemographic characteristics (e.g., race/ethnicity, age) and socioeconomic status (SES) (Pew Research Center, 2013; Kontos E, Bennett G, Viswanath K, 2007; Lorence, Park and Fox, 2006).

Although cancer information seeking has been shown to be positively associated with some cancer-related health outcomes (David & Case 2012; Shim 2006), cancer information seeking among US adults is suboptimal and has not changed much over the past decade. This review underscores the need for efforts aimed at improving positive predictors of

cancer information seeking in an effort to increase the number of US adults who search for information about cancer and feel confident about being able to find and use cancer information if needed. These efforts should also focus on improving cancer information seeking experiences in an effort to reduce ambiguity about cancer risk, and minimize the number of consumers who feel overloaded by the plethora of information that they are able to find about cancer.

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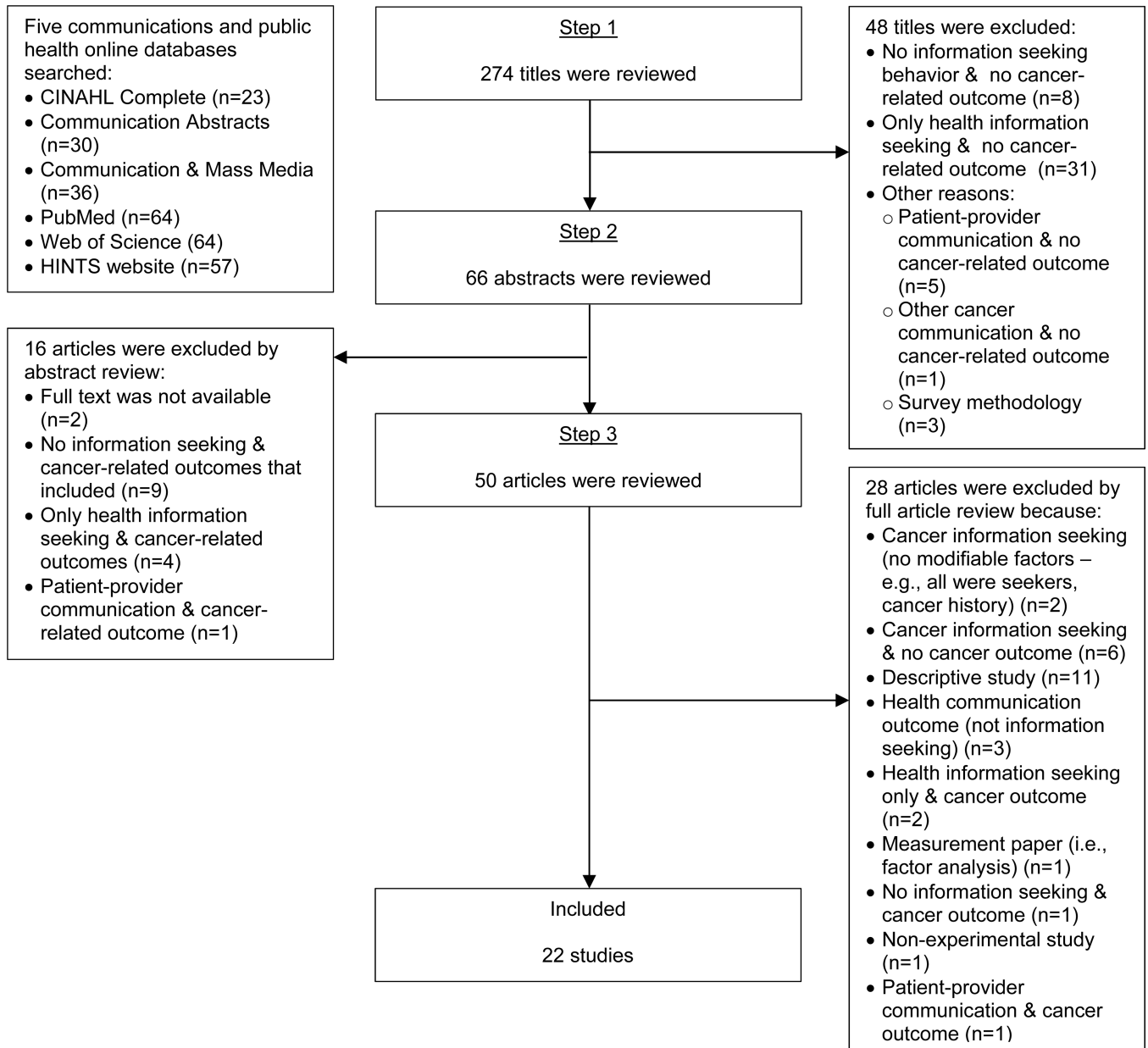


Figure 1. Flowchart of scoping review process.

Table 1

Distribution of included studies (n=22) by journal and HINTS iteration

Journal Name	2013/14 Impact Factor	#Published studies	Hay 2015	Chen 2014	Madadi 2014	Kontos 2012	Ortiz 2011	Kaaley 2010	Zhao 2010	Finney-Rutten 2009	Han 2009	Hay 2009	Kaphingst 2009	Zhao 2009	McQueen 2008	Niederdeppe 2008	Shim 2008	Arora 2007	Kim 2007	Cernly 2006	Ford 2006	Ling 2006	Shim 2006	Finney-Rutten 2005
Am J Public Health	4.23	1				C																		
Breast Cancer Res Treat	4.20	1		A																				
Health Commun	0.97	3									B			B		A								
Human Commun Res	1.84	1																						
Information Res	---	1																						
Int J Environ Res Public Health	1.82	1		A																				
J Am Acad Dermatol	5.00	1										B												
J Cancer Educ	1.05	1																						
J Gen Intern Med	3.42	1																						
J Health Commun	1.61	7						B	B											A	A	A	A	
Med Decis Making	2.27	1	B																					
Nicotine Tob Res	2.81	1																						
Prev Chronic Dis	1.96	1					D																	
Prev Med	2.93	1																						
Total	22	22																						A

Notes: 2013/2014 Impact Factor; A-HINTS 1 (2003); B-HINTS 2 (2005); C-HINTS 3 (2007); D-HINTS Puerto Rico (2009)

Table 2

Operationalization of cancer information seeking

Outcome	Question & Response Options	First Author (Year)	HINTS 1 (2003)	HINTS 2 (2005)	HINTS 3 (2007)	HINTS PR (2009)
Cancer Information Seeking	Have you ever looked for information about cancer from any source? (yes/no)	Madadi M (2014) Kontos EZ (2012) Ortiz (2011) Kealy E (2010) Zhao X (2010) Han (2009) Kaphingst KA (2009) Zhao X (2009) McQueen (2008) Cerully (2006) Ling BS (2006) Ford JS (2006)				
Cancer Information Seeking (Past Year)	Have you looked for information about cancer from any source? (yes/no) and About how long ago was that? (open-ended responses] for days, weeks, months, or years ago) were combined to create a new variable. <ul style="list-style-type: none"> Information seekers had looked for information about cancer within the last year, and Non-seekers had either never looked for information about cancer, or had not looked for information about cancer within the past year 	Shim M (2006)				
Cancer Information Seeking (Past Week)	Have you looked for information about cancer from any source? (yes/no) and About how long ago was that? (open-ended responses] for days, weeks, months, or years ago) were combined to create a new variable. <ul style="list-style-type: none"> Past week seekers Other 	Niederdeppe (2008)				
Cancer Information Seeking (Surrogate Seekers)	Excluding your doctor or health care provider, has someone else ever looked for information about cancer for you? (yes/no)	Zhao X (2010) McQueen (2008)				

Outcome	Question & Response Options	First Author (Year)	HINTS 1 (2003)	HINTS 2 (2005)	HINTS 3 (2007)	HINTS PR (2009)
Cancer Information Seekers, Surrogate Seekers, and Non-seekers (4 Groups)	Cancer information seeking and surrogate seeking questions were combined to create four groups: seekers only; seekers and surrogate seekers; surrogate seekers only, non-seekers. (Seekers=seeker/seeker & surrogate seeker; Non-seekers=surrogate seeker & non-seeker).	Ling BS (2006) Arora NK (2008)				
Cancer Information Seeking (Online)	Cancer/Health Information seeking on the Internet (authors don't adequately explain how they derived this measure) Have you ever visited an Internet web site to learn specifically about cancer? (yes/no) Ever looked for information about cancer...source=Internet (Internet/Other) Ever looked for information about cancer...source =Internet (Internet seeker/Non-Internet seeker/Non-seeker) Respondents' Internet use for cancer-specific information in the past 12 months was assessed: 1 (<i>did not use the Internet to look for health or medical information</i>), 2 (<i>used the Internet for cancer-unspecific health information</i>), 3 (<i>used the Internet for cancer-specific information</i>); $M = 2.02$, $SD = .81$.	Finney-Ruttien (2009) Hay JL (2009) Chen (2014) Kontos (2012) Shim M (2008)				
Skin Cancer Information Seeking (Online)	Looked for information on the Internet about protecting themselves from the sun (in the past 12 months) (yes/no)	Hay JL (2009)				
Cancer Information Seeking Experiences	Based on the results of your most recent search for information on cancer, how much do you agree or disagree with each of the following statements: <ul style="list-style-type: none"> • It took a lot of effort to get the information you needed • You felt frustrated during your search for the information • You were concerned about the quality of the information • The information you found was too hard to understand Dichotomized (All): strongly agree/agree versus disagree/strongly disagree	Zhao X (2010)				
Cancer Information Seeking Experience	Based on the results of your most recent search for information on cancer, how much	Chen (2014)				

Outcome	Question & Response Options	First Author (Year)	HINTS 1 (2003)	HINTS 2 (2005)	HINTS 3 (2007)	HINTS PR (2009)
(ISEE) Scale	<p>do you agree or disagree with each of the following statements:</p> <ul style="list-style-type: none"> You wanted more information, but did not know where to find it It took a lot of effort to get the information you needed You did not have the time to get all the information you needed You felt frustrated during your search for the information You were concerned about the quality of the information The information you found was too hard to understand <p>Scores were coded as low/medium/high</p>	Arora (2007) Kim (2007)				
Cancer Information Overload	<p>There are so many different recommendations about preventing cancer it's hard to know which ones to follow. (Agree/Disagree)</p>	Kealy (2010) Kim (2007)				
Cancer Information Seeking Self-Efficacy	<p>Overall, how confident are you that you could get advice or information about cancer if you needed it?</p> <p>HINTS 2003: 4-point Likert scale was used (very confident/somewhat confident/slightly confident/not confident at all HINTS 2005 and beyond: 5-point Likert scale: 1=completely confident/5=not confident at all)</p> <ul style="list-style-type: none"> Dichotomized: completely/very confident versus somewhat/a little/not confident Reverse coded: 5=completely confident to 1=not confident at all 	Hay JL (2015) Chen (2014)				
Cancer/Health Information-Seeking (Summary Score)	<p>The following questions were used to calculate a summary score:</p> <ol style="list-style-type: none"> Have you ever looked for information about cancer from any source? (yes/no) Have you ever visited an Internet website to learn specifically about cancer? (yes/no) In the past 12 months, have you read the health sections of a newspaper or magazine? (yes/no) <p>Range: 0-1; Mean: 0.40 (SE=0.01)</p>	Zhao X (2010) Zhao X (2009) Hay JL (2015)				
Cancer Information Seeking/Paying Attention to Media Sources	<p>Paying attention to media sources (TV, radio, newspapers, magazines, Internet) AND ever looked for information about cancer (1=pay attention a little/not at all OR no seek; 2=pay</p>	Finney-Rutten (2005)				

Outcome	Question & Response Options	First Author (Year)	HINTS 1 (2003)	HINTS 2 (2005)	HINTS 3 (2007)	HINTS PR (2009)
Cancer Information Seeking * Scanning	attention a lot/some OR seek (range: 6-12) Pay attention and seeking variables were combined to create a typology of cancer information scanning and seeking behavior (SBB). The categories of SSB are: 'low-scan=no seekers, low-scan=seekers, high-scan=no seekers, high-scan=seekers.	Shim M (2006)				

Table 3
Population/sample characteristics, cancer information seeking behaviors, and cancer-related health outcomes

First Author (Year)	Population/Subpopulation (Sample Size)	Sample Characteristics	Cancer Information Seeking Behavioral & Psychosocial Factors	Cancer-Related Health Outcomes & Theoretical Frameworks	Cancer Type	HINTS (Year)
Hay (2015)	Participants 18+ years old who completed the colorectal cancer mental module (1,789/1,937) 148=missing data	Race/ethnicity: 7.8% Hispanic 11.6% Foreign born 20.3 ± 1.58 years in US ^a SES: 57.3% Some college+ 24.9% \$29K Cancer History: 10.3% family history of colorectal cancer	Lower cancer/health information seeking summary score was positively associated with ambiguity about CRC risk perceptions. Self-efficacy (n.s.)	7.5% did not know their comparative CRC risk 8.7% did not know their absolute CRC risk	CRC	HINTS 2 (2005)
Chen (2014)	55+ year old adults (1,818)	Race/ethnicity: 78% White 10% Hispanic SES: 56% Some college+ 58% \$35K Cancer History: 66% family history of cancer	Online cancer information seeking was positively associated with CRC screening adherence. Seeking experiences (n.s.) Self-efficacy (n.s.)	64% were compliant based on the following CRC screening guidelines: <ul style="list-style-type: none"> • Colonoscopy <10 years • Sigmoidoscopy <5 years • FOBT <2 years 	CRC	HINTS 1 (2003)
Madadi (2014)	Adherent and non-adherent women >40 years old (2,370)	Race/ethnicity: 77% White SES: 56% Some college+ 36% \$25,000/year 49% Employed Cancer History: 75% Family member had cancer	The association between cancer information seeking and mammography attitudes/screening adherence was not statistically significant.	70% adherent <ul style="list-style-type: none"> • 73% of women 40–64 years were adherent • 65% of women 65+ years old were adherent 56% of non-adherent women were thinking about getting a mammogram	Breast cancer	HINTS 1 (2003)
Kontos (2012)	Online and offline cancer information seekers & non-seekers (7,674)	Race/ethnicity: 65% NH White 12% Hispanic SES: 60% Some college+ 30% <\$35,000/year Cancer History: Not reported	Online cancer information seeking was positively associated with HPV vaccine awareness and knowledge, which was significantly higher compared to non-seekers. Offline vs. online (n.s.)	70% heard of HPV vaccine 70% HPV was a STI 75% HPV cause cervical cancer (Note: Awareness/knowledge highest among online seekers) Structural Influence Model of Communication Inequalities	Cervical cancer	HINTS 3 (2007)
Ortiz (2011)	Puerto Rican adults (611)	Race/ethnicity: Not reported SES: 44.5% College+ ^d 40.2% Employed Cancer History: Not reported	Cancer information seekers were more aware of genetic testing than non-seekers.	55.8% had heard of direct-to-consumer genetic tests 4.3% reported ever having a genetic test.	Genetic Testing	HINTS PR (2009)

First Author (Year)	Population/Subpopulation (Sample Size)	Sample Characteristics	Cancer Information Seeking Behavioral & Psychosocial Factors	Cancer-Related Health Outcomes & Theoretical Frameworks	Cancer Type	HINTS (Year)
Keahey (2010)	US adults (5,586)	Race/ethnicity: 76.9% White 9.3% Hispanic SES: 60.3% Some college+ 40.7% <\$35,000/year Cancer History: Not reported	Cancer information seekers experienced significantly less cancer information overload than non-seekers. Cancer information seeking was not significantly associated with cancer beliefs or risk perceptions.	Cancer information overload (i.e., ambiguity about how to prevent cancer), beliefs about behavioral/lifestyle cancer risk factors, and perceptions of comparative risk of getting cancer were assessed.	All cancers	HINTS 2 (2005)
Zhao (2010)	US adults (5,586)	Race/ethnicity: 69.9% White 13.0% Hispanic SES: 55.6% College+ 58.6% Employed Cancer History: 11.4% Had cancer	Cancer information seeking/self-efficacy was inversely associated with having undesirable beliefs about cancer among Whites only. Surrogate seeking (n.s.)	Undesirable cancer beliefs were compared between US and foreign born Whites and Hispanics: <ul style="list-style-type: none"> • Cannot lower risk • Too many recommendations • Everything causes cancer • Reluctant to get checked 	All cancers	HINTS 2 (2005)
Finney-Rutten (2009)	Smokers (2,257)	Sociodemographics: 59.7% NH White 13.9% Hispanic SES: 41.8% College+ 38.9% <\$25,000/year Cancer History: 11.4% Had cancer	The relationship between online cancer/health information seeking and smoking status was not statistically significant.	Cancer communication outcomes were assessed among moderate-heavy, light, and intermittent tobacco users.	Lung cancer (smoking is also a risk factor for other types of cancer)	HINTS 1 (2003) & HINTS 2 (2005)
Han (2009)	CRC skin and lung cancer mental health participants (5,159)	Race/ethnicity: 79.9% White SES: 51.7% College+ Cancer History: Not reported	Cancer information seeking was inversely associated with ambiguity about CRC prevention. Skin cancer (n.s.) Lung cancer (n.s.)	Ambiguity about CRC, skin, and lung cancer prevention was assessed.	CRC, skin, and lung cancer	HINTS 2 (2005)
Hay (2009)	Skin cancer mental module participants (1,633)	Race/ethnicity: 66.9% NH White 14.7% Hispanic SES: 52.6% College+ Cancer History: 9.9% Family member had skin cancer 5.1% Melanoma 4.8% Non-melanoma	Skin cancer information seeking was a positively associated with some protective behaviors (i.e., using sunscreen, wearing sun-protective clothing). Skin cancer knowledge (n.s.) Skin cancer beliefs (n.s.) Staying in the shade (n.s.)	Skin cancer knowledge, beliefs, and protective behaviors were assessed. Protective behaviors were: <ul style="list-style-type: none"> • Sunscreen use • Staying in the shade • Use of sun-protective clothing 	Skin cancer	HINTS 2 (2005)

First Author (Year)	Population/Subpopulation (Sample Size)	Sample Characteristics	Cancer Information Seeking Behavioral & Psychosocial Factors	Cancer-Related Health Outcomes & Theoretical Frameworks	Cancer Type	HINTS (Year)
Kaphingst (2009)	US adults (n=5,813)	Race/ethnicity: 75% NH White SES: 60% <\$50,000/year Cancer history: 13% Had cancer 65% Family member had cancer	Positive beliefs about the relationship between knowing one's family history/genes and cancer risk reduction was positively associated with cancer information seeking.	N/A – Cancer information seeking was the outcome of interest	All cancers	HINTS 1 (2003)
Zhao (2009)	Smokers who completed the lung cancer mental module (n=340)	Race/ethnicity: Race/Ethnicity SES: Education Cancer history: Not reported (Descriptive statistics were not reported)	Cancer information seeking was positively associated with absolute risk, the interaction of absolute * comparative risk, response self-efficacy about lung cancer, and self-efficacy. Comparative risk (n.s.)	Lung cancer risk perceptions and response efficacy (i.e., not much one can do to lower their lung cancer risk) were assessed. Risk Perception Attitude (RPA) Framework	Lung cancer (smoking is also a risk factor for other cancers)	HINTS 2 (2005)
McQueen (2008)	50+ year old adults (2,519)	Race/ethnicity: 74.5% NH White 6.7% Hispanic SES: Not reported Cancer History: Not reported	Cancer information seeking (including surrogate seeking) was not significantly associated with cancer beliefs (i.e., worry, risk perceptions).	Cancer worry and risk perceptions were assessed.	Breast, CRC, prostate cancer	HINTS 1 (2003)
Niederdeppe 2008	US adults (n=5,585)	Race/ethnicity: Race/ethnicity were not reported SES: 57.5% Some college+ Cancer History: 11.3% Had cancer 71.5% Family member had cancer	Health knowledge was positively associated with cancer information seeking. Interactions between cancer news events and education, health knowledge, and social networks were also positively associated with cancer information seeking.	N/A – Cancer information seeking was the outcome of interest Knowledge Gap Theory	Breast and lung cancer, Hodgkin's lymphoma	HINTS 2 (2005)
Shim (2008)	Online adults (3,982)	Race/ethnicity: 76% NH White 8% Hispanic SES: 75% Some college+ Cancer History: 10% Had cancer 65% Family member had cancer	Online cancer information seeking was positively associated with cancer knowledge.	Cancer knowledge about preventive behaviors/lifestyle factors and screening was assessed. Knowledge Gap Theory	All cancers	HINTS 1 (2003)
Arora (2007)	Cancer information seekers, surrogate seekers, and non-seekers (6,369)	Race/ethnicity: 71.8% NH White 11.7% Hispanic SES: 51.1% Some college+ 59.8% Employed Cancer History:	Cancer information seeking experiences were positively associated with cancer beliefs.	Cancer information seeking experiences and the following cancer beliefs were examined: <ul style="list-style-type: none"> • Almost everything causes cancer • Not much can be done to prevent cancer 	All cancers	HINTS 1 (2003)

First Author (Year)	Population/Subpopulation (Sample Size)	Sample Characteristics	Cancer Information Seeking Behavioral & Psychosocial Factors	Cancer-Related Health Outcomes & Theoretical Frameworks	Cancer Type	HINTS (Year)
Kim (2007)	US adults (n=6,369)	10.9% Had cancer 54.2% Family member had cancer Race/ethnicity: 76.2% NH White 7.3% Hispanic SES: 29.9% Some college 24.7% <\$25,000 60.7% Employed Cancer history: 5.3% had cancer 44.3% Family member had cancer Descriptive statistics reported for overloaded	Health literacy was inversely associated with cancer information overload. However, seekers who were concerned about the quality of the information they found were more likely to feel overloaded.	<ul style="list-style-type: none"> There are too many recommendations for preventing cancer N/A – Cancer information overload was the outcome of interest National Center for Research on Evaluation Standards and Student Testing Model of Problem Solving National Trends Survey Framework Precaution Adoption Process Model 	All cancers	HINTS 1 (2003)
Cerully (2006)	US adults who reported consuming <5 servings of fruits and vegetables daily (5,265)	Descriptive statistics were not reported	Nonlisters (i.e., did not list F/V consumption for self or others) were unexpectedly more likely to be seekers, but less likely to trust sources of cancer information as expected.	Cancer communication, knowledge, and beliefs were examined among adults who consumed less than five servings of fruits and vegetables daily.	All cancers	HINTS 1 (2003)
Ford (2006)	45+ year old adults (3,131)	Race/ethnicity: 77.9% NH White 7.6% Hispanic SES: 47.6% Some college 31.2% <\$25,000 Cancer history: 16.7% had cancer 67.3% Family member had cancer	Non-seekers were less knowledgeable about CRC screening	Knowledge of CRC screening recommendations was examined	CRC	HINTS 1 (2003)
Ling (2006)	>50 years old adults (2,670)	Race/ethnicity: 80.0% White Hispanic not reported SES: 28.1% Some college+ Income not reported Cancer History: Not reported	Both seekers and those who had surrogate seekers were more likely to be up-to-date on CRC screening.	CRC cancer screening adherence was assessed.	CRC	HINTS 1 (2003)
Shim (2006)	US adults (n=6,369)	Race/ethnicity: 70.3% White 12.7% Hispanic SES: 31.3% Some college+ Cancer History: 12.0% Had cancer 62.8% Family member	Cancer prevention knowledge, lifestyle behaviors, and screening adherence were positively associated with cancer information seeking and scanning. However, knowledge was inversely associated with the	N/A – Seeking and scanning behaviors were the outcomes of interest	CRC, breast, and prostate	HINTS 1 (2003)

First Author (Year)	Population/Subpopulation (Sample Size)	Sample Characteristics	Cancer Information Seeking Behavioral & Psychosocial Factors	Cancer-Related Health Outcomes & Theoretical Frameworks	Cancer Type	HINTS (Year)
Finney-Rutten (2005)	50+ year old males (927)	had cancer Race/ethnicity: 79.5% NH White 7.0% Hispanic SES: 27.8% \$25,000 49.6% Some college+ Cancer History: Not reported	interaction of seeking behaviors. Attention/seeking was not associated with PSA testing	PSA testing	Prostate cancer	HINTS 1 (2003)

Footnotes:

^a Mean ± Standard Error;

^b Mean ± Standard Deviation;

^c Includes cohabitating (or living with a partner);

^d Does not include vocational/technical training;

AOR=adjusted odds ratio with 95% confidence interval; CRC=colorectal cancer; FOBT=fecal occult blood test; NH=non-Hispanic; NR=not reported; STI=sexually transmitted infection |

* p<0.05;

** p<0.01;

*** p<0.001