

## ORIGINAL ARTICLES

## Frustrated and Confused: The American Public Rates its Cancer-Related Information-Seeking Experiences

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**BACKGROUND:** Ensuring access to high-quality cancer-related information is important for the success of cancer prevention and control efforts.

**OBJECTIVE:** We conducted a population-based assessment of the barriers faced by people searching for cancer information.

**DESIGN:** Cross-sectional data from the National Cancer Institute's 2003 Health Information National Trends Survey.

**PARTICIPANTS:** A nationally representative sample of individuals in the USA ( $n=6,369$ ).

**MEASUREMENTS:** We assessed whether respondents had ever sought cancer-related information and examined ratings of their information-seeking experiences and beliefs regarding causes of cancer and its prevention. Linear and logistic regression models were estimated to determine predictors of negative experiences and associations between experiences and cancer beliefs.

**RESULTS:** Nearly one half (44.9%) of Americans had searched for cancer information. Many reported negative experiences, including the search process requiring a lot of effort (47.7%), expressing frustration (41.3%), and concerns about the quality of the information found (57.7%). Respondents lacking health insurance or a high school education experienced the greatest difficulty. Compared to those reporting the most positive experiences, information seekers reporting more negative experiences were more likely to report that almost everything caused cancer [odds ratio (OR) 2.0, 95% confidence interval (CI) 1.5–2.6], that not much can be done to prevent cancer (OR 2.7, 95% CI 1.9–3.8), and that it is hard to know which cancer prevention recommendations to follow (OR 3.2, 95% CI 2.3–4.5).

**CONCLUSIONS:** While a significant proportion of the American public searches for cancer information, sub-

optimal experiences are common. Facilitation of information seeking will be critical for promoting informed decision making in cancer prevention and control.

**KEY WORDS:** information seeking; cancer; national survey; health information; information needs.

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Recent reports from the Institute of Medicine (IOM)<sup>1,2</sup> have called for a redesigned health care environment where patients are the locus of control for important medical decisions. Increasingly, experts are pointing to the shared/informed decision-making paradigm as the ideal model for decision making, especially for cancer and other chronic conditions.<sup>3–5</sup> Patients themselves are expressing a preference for greater involvement in the decision-making process.<sup>6,7</sup>

This transformation in the patient's role to one of an "informed" consumer has been paralleled by a tremendous explosion in the coverage of health-related information by various media outlets.<sup>8</sup> The Internet revolution has enabled information seeking by substantially reducing barriers to accessing health information.<sup>9</sup> However, the sheer volume of such information within the reach of the public also carries risks. Information overload may overwhelm people's information processing capabilities and lead to confusion. Concerns have been raised about the quality of health information across all forms of media.<sup>8</sup> Furthermore, while patients consider their health care providers to be the most trusted source of health information,<sup>10,11</sup> they also express dissatisfaction with the information received from their providers.<sup>12</sup>

To facilitate people's participation in their care, it is critical to ensure that they are able to easily acquire and interpret health information that is most relevant to their situation. An initial step in facilitating people's health information seeking is to examine in detail their recent information-seeking experiences. We used data from the National Cancer Institute's (NCI) 2003 Health Information National Trends Survey (HINTS) to examine barriers and difficulties people face while seeking cancer-related information. The three specific aims for our study were to (1) describe the characteristics of the American

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public who had searched for cancer-related information; (2) evaluate the experiences of cancer information seekers; and (3) examine the association between people's cancer information-seeking experiences and their beliefs about cancer and its prevention.

## METHODS

### Survey Design

Details about the development and design of HINTS 2003 are reported elsewhere<sup>13</sup> (also see <http://www.cancercontrol.cancer.gov/hints>). Briefly, household telephone numbers were generated at random from a sampling frame of all telephone exchanges throughout the 50 states in the country; exchanges with high concentrations of Hispanic and African-American residents were over-sampled to ensure adequate minority representation. One adult was selected from each household to participate in the survey. Response rates were 55.0% at the household screening level (i.e., the initial contact with the household used for sampling purposes) and 62.8% at the sampled person interview level (i.e., completion of the interview by the sampled household member); thus, the overall response rate was 34.5%. The final sample included responses from 6,369 individuals. Sampling weights were created to adjust for over-sampling, non-response, and to generate estimates representative of the US population.<sup>13</sup> HINTS went through an expedited review with the NCI's Institutional Review Board that gave it an "exempt" status. Clearance was also obtained from the US government's Office of Management and Budget.

### Survey Measures

**Cancer Information Seeking.** Two dichotomous survey items asked respondents whether they "had ever looked for information about cancer from any source" and whether "someone else, excluding their health care provider, had ever looked for information about cancer" for them. Based on respondents' responses, we created four distinct groups: respondents who only looked for cancer information themselves; those who looked for cancer information themselves and had others look on their behalf; those who did not look themselves but had others look; and those who never looked for cancer information. We considered the first two groups as cancer information seekers (i.e., those who had looked for cancer information themselves).

**Information-Seeking Experiences.** Information-seeking experiences were assessed by asking respondents to rate (from strongly agree, somewhat agree, somewhat disagree, to strongly disagree) experiences of their most recent search for cancer information using a six-item Information Seeking Experience (ISEE) scale. Four items assessed ratings of the process of information seeking: "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;" and "You felt frustrated during your search for the information." The remaining two items assessed ratings of the actual information found: "You were concerned about the quality of the information" and "The information you found was too hard to understand." The ISEE

scale builds upon a previously published three-item measure of barriers to information access.<sup>14</sup>

**Cancer Beliefs.** HINTS assessed people's beliefs about cancer and its prevention by asking them to rate, on a four-point strongly agree to strongly disagree scale, three items: "It seems like almost everything causes cancer;" "There's not much people can do to lower their chances of getting cancer;" and "There are so many different recommendations about preventing cancer, it's hard to know which ones to follow."

All items were thoroughly tested before being included in the field administration of HINTS. First, we pretested them in cognitive interviews to ensure that they were clearly understood and reliably interpreted by potential respondents. Second, we obtained feedback on the HINTS items from ten subject matter external experts. Finally, all items were included in a national pilot test conducted with 172 adults.<sup>13</sup>

### Statistical Analyses

To describe the characteristics of the American public engaged in cancer information seeking, we estimated a logistic regression model that included age, gender, race/ethnicity, education, employment status, marital status, insurance coverage, and cancer history as independent variables and a dichotomous indicator of cancer information seeking (information seeker vs non-seeker) as the dependent variable.

We evaluated the experiences of cancer information seekers by computing the weighted percentage of respondents who reported negative information-seeking experiences using the six ISEE items. We then examined the factor structure of the ISEE scale using principal components analysis which resulted in a single factor solution accounting for 52.7% of the total item variance. We combined scores from the six items to create a composite ISEE scale (Cronbach's  $\alpha=0.82$ ); to facilitate interpretation, ISEE scores were linearly transformed to a 0–100 scale such that a higher score reflected more positive experiences. ISEE scores were fairly normally distributed (mean=55.4, SD=24.0, skewness=-0.04). The lower third of the sample reported scores ranging from 0 to 41.7; the middle third from 41.8 to 66.7, and the upper third had scores from 66.8 to 100, suggesting a broad range of information seeking experiences among respondents.

We examined the association between key respondent characteristics (age, gender, race/ethnicity, education, employment status, marital status, insurance coverage, and cancer history) and their information-seeking experiences (ISEE scores) by estimating a linear regression model. We were also interested in assessing whether people who first turn to the Internet for cancer information have different experiences from those who go first to their health care providers. Hence, we included an indicator of first information source (Internet, health care provider, other) as an additional independent variable in this model. To minimize response bias caused by potential recall effects, we controlled for time since the respondent last searched for cancer information (within the past 12 months vs more than 12 months) and a measure of self-reported current psychological distress.

We evaluated the association between people's recent cancer information-seeking experience and their cancer beliefs by estimating three logistic regression models (one for each

cancer belief item). In all models, responses to the cancer belief items were dichotomized into an agree vs disagree format. To facilitate interpretation of effects in terms of odds ratios, we used a trichotomous indicator of respondents' information-seeking experiences based on tertiles (low, medium, and high ISEE score) instead of the continuous ISEE score as the main independent variable. All models controlled for age, gender, race/ethnicity, education, employment status, marital status, health insurance coverage, cancer history, and current psychological distress.

All respondent characteristics included in the analyses had less than 5% missing data. Income was not included because of a relatively higher missing data rate (>12%) and also a modest correlation with education ( $r=0.5$ ). All analyses incorporated sampling weights to generate nationally representative estimates and were conducted using SUDAAN version 9.01. A  $p$  value of  $\leq 0.05$  was considered statistically significant.

**RESULTS**

Table 1 describes the study sample. As shown in Table 1, 30.9% of the US population had looked for cancer information themselves. Another 14.0% looked for cancer information

themselves as well as asked others to look on their behalf. Thus, nearly one half of the American public (44.9%) had personally sought cancer information at some point in their lives; of these, 76.1% searched within the past 12 months.

During their most recent search, 47.9% of information seekers first turned to the Internet, 10.7% went to their health care provider, and 40.3% turned to other sources (books, 13.7%; magazines, 7.1%; library, 6.4%; brochures/pamphlets, 4.1%; newspapers, 2.6%; and less than 2% each first sought information from family, friends/coworkers, radio, television, or telephone services). Reliance on the Internet was significantly higher among respondents who were younger, had higher levels of education, and were non-Hispanic whites. In contrast, reliance on health care providers and other sources was higher among older respondents and those who had lower levels of education and were Hispanics. Respondents without health insurance were as likely to turn to their providers or the Internet as those with insurance.

Estimates from the logistic regression model presented in Table 2 show that compared to older adults ( $\geq 65$  years), all other age groups were more likely to engage in cancer information seeking ( $P < 0.001$ ). Men ( $P < 0.001$ ), Hispanics ( $P < 0.001$ ), and individuals without health insurance ( $P = 0.02$ ) were less likely to seek cancer information. Probability of

**Table 1. Sample Description (Unweighted N=6,369)**

Respondent characteristic	Weighted % (95% CI)*
Age (yrs; missing, 0.4%)	
18-34	31.2 (30.8, 31.6)
35-49	31.0 (30.7, 31.4)
50-64	21.5 (21.1, 21.9)
65+	16.3 (15.9, 16.7)
Gender (missing, 0%)	
Female	51.9 (51.8, 52.0)
Race/ethnicity (missing, 4.7%)	
Non-Hispanic white	71.8 (70.9, 72.6)
Non-Hispanic black	10.5 (10.1, 10.9)
Non-Hispanic other†	6.0 (5.3, 6.8)
Hispanic	11.7 (11.4, 12.0)
Education (missing, 3.6%)	
<High school	16.9 (16.6, 17.2)
High school graduate	32.0 (31.6, 32.3)
Some college	26.8 (26.5, 27.1)
College graduate	24.3 (24.0, 24.6)
Employed currently (missing, 3.7%)	
Yes	59.8 (58.1, 61.4)
Marital status (missing, 3.7%)	
Married/living as married	63.6 (62.4, 64.7)
Divorced/separated/widowed	17.2 (16.2, 18.2)
Never been married	19.2 (18.2, 20.3)
Health insurance coverage (missing, 3.7%)	
Yes	85.4 (84.3, 86.4)
Cancer History (missing, 1.0%)	
Personal history‡	10.9 (10.0, 11.8)
Family history only	54.2 (52.7, 55.8)
No personal/family history	34.9 (33.5, 36.3)
Cancer information seeking (missing, 0.2%)	
Never looked for cancer information	52.3 (50.9, 53.6)
Had others look on my behalf	2.8 (2.2, 3.4)
Looked myself	30.9 (29.6, 32.2)
Looked myself and had others look	14.0 (12.9, 15.2)

\*CI confidence interval

†Non-Hispanic other included Asians, Pacific Islanders, American Indians, Alaska natives, and members of multiple race/ethnicities.

‡Among cancer survivors, 16.6% were diagnosed within 1 year of the study, 20.3% between 2 and 5 years, 23.4% between 6 and 10 years, and 39.6% were diagnosed 11 or more years before the study.

**Table 2. Cancer Information Seeking by Respondent Characteristics (Unweighted N=6,369)\*†**

Respondent characteristic	OR (95% CI)‡	P value	Adjusted weighted %
Age (yrs)		<0.001	
18-34	2.3 (1.7, 3.1)	<0.001	47
35-49	2.5 (1.9, 3.3)	<0.001	49
50-64	2.5 (2.0, 3.2)	<0.001	49
65+	1.0		30
Gender		<0.001	
Female	1.0		52
Male	0.5 (0.4, 0.6)		38
Race/ethnicity		<0.001	
Non-Hispanic white	1.0		47
Non-Hispanic black	0.9 (0.6, 1.1)	0.24	43
Non-Hispanic other	1.1 (0.9, 1.4)	0.44	49
Hispanic	0.6 (0.5, 0.8)	<0.001	37
Education		<0.001	
<High school	1.0		32
High school graduate	1.4 (1.0, 1.8)	0.04	38
Some college	2.3 (1.7, 3.0)	<0.001	49
College graduate	3.8 (2.9, 5.0)	<0.001	60
Employed currently		0.06	
Yes	1.0		44
No	1.2 (0.9, 1.3)		47
Marital Status		0.37	
Married/living as married	1.0		46
Divorced/separated/widowed	0.9 (0.7, 1.1)		43
Never been married	1.1 (0.8, 1.4)		47
Health insurance coverage		0.02	
Yes	1.0		46
No	0.8 (0.6, 0.9)		41
Cancer history		<0.001	
Personal history	6.0 (4.6, 7.9)	<0.001	69
Family history only	2.4 (2.0, 2.8)	<0.001	49
No personal/family history	1.0		31

\*Results are based on a logistic regression model [Model  $\chi^2(df)=1049.4$  (16),  $F=49.8$ ,  $P < 0.001$ ].

†Dependent variable: 1=information seeker (yes), 0=information seeker (no)

‡OR Odds ratio, CI confidence interval

**Table 3. Information Seeking Experience Ratings of Cancer Information Seekers: Overall and by First Information Source (Unweighted N=3,011)**

Information-seeking experience (ISEE) scale items	Total sample % agree (95% CI)*	First information source			P value
		Internet % agree	Health care provider % agree	Other % agree	
You wanted more information but did not know where to find it	49.2 (47.0, 51.5)	46.0	48.0	53.0	0.002 <sup>†</sup>
It took a lot of effort to get the information you needed	47.7 (45.6, 49.9)	44.0	46.0	52.0	<0.001 <sup>†</sup>
You did not have the time to get all the information you needed	46.1 (43.9, 48.3)	45.0	41.0	49.0	0.04 <sup>†</sup>
You felt frustrated during your search for the information	41.3 (39.0, 43.6)	41.0	39.0	42.0	0.61
You were concerned about the quality of the information	57.7 (55.8, 59.5)	58.0	54.0	58.0	0.36
The information you found was too hard to understand	36.9 (34.5, 39.3)	32.0	43.0	41.0	<0.001 <sup>†</sup>

\*% Agree was calculated by combining responses of individuals who either selected strongly agree or somewhat agree as a response to the item and dividing by the total number of information seekers. CI Confidence interval

<sup>†</sup>Post hoc comparisons showed for item 1, Internet vs Other was statistically significant; for item 2: Internet vs Other was significant; for item 3: Provider vs Other was significant; and for item 6: Internet vs Provider and Internet v/s Other were significant.

seeking information increased significantly with education level. Also, compared to people with no cancer history, those with a personal cancer history ( $P<0.001$ ) and those with a family history only ( $P<0.001$ ) were more likely to seek cancer information.

Table 3 presents the ratings of cancer information seekers on the six ISEE items. Negative experiences were common, ranging from more than a third reporting the information they found to be too hard to understand to more than one half expressing concerns about the quality of the information they found. Ratings of experiences were similar on five of the six items among those who turned to the Internet and those who first went to their health care providers; however, a significantly lower proportion of Internet users reported the information they found to be hard to understand ( $P<0.01$ ).

Linear regression analysis conducted to identify correlates of people's information-seeking experiences showed an almost linear association between education and ISEE scores such that those with higher education had more positive experiences ( $P<0.001$ ). A difference of 7.0 points between individuals with less than high school education and those with a college degree was obtained. Given the SD of 24.0 on the ISEE scale, this represents between a small and a medium size effect of 0.3. Information seekers who had health insurance coverage also had better experiences than those without insurance ( $P=0.001$ ); a difference of 6.8 points (effect size=0.3) was obtained. Also, individuals with a family history of cancer had significantly worse experiences compared to those with no cancer history ( $P=0.02$ ); score difference was 3.6 points (effect size=0.2). Age, gender, race/ethnicity, employment, marital status, and first information source were not significantly associated with ISEE scores. Overall, the model only accounted for 7.6% of the total variance in ISEE scores.

With respect to cancer beliefs, 51.3% of information seekers agreed that almost everything caused cancer, 23.8% agreed that not much could be done to prevent cancer, and 75.2% agreed that there were too many cancer prevention recommendations and it was hard to know which to follow. As seen from Table 4, compared to respondents who had very positive information-seeking experiences (high ISEE group), those who had the least positive experiences (low ISEE group) were more likely to believe that everything caused cancer ( $P<0.001$ ); that not much could be done to prevent cancer ( $P<0.001$ ); and that

they were confused about which recommendations to follow ( $P<0.001$ ).

## DISCUSSION

We found that 94 million adults in the USA (45% of the adult population) had searched for cancer-related information at some point in their lives, with three out of four doing so in the past 12 months. Previous studies of cancer information seeking typically have been limited to one channel, usually

**Table 4. Cancer-Related Beliefs by Information-Seeking Experience (ISEE) Scale Score\***

	OR (95% CI) <sup>†</sup>	P value	Adjusted weighted %
Almost everything causes cancer		<0.001	
Low ISEE score (0–41.7)	2.0 (1.5, 2.6)	<0.001	61
Medium ISEE score (41.8–66.7)	1.1 (0.9, 1.4)	0.46	48
High ISEE score (66.8–100)	1.0		46
Not much can be done to prevent cancer		<0.001	
Low ISEE score (0–41.7)	2.7 (1.9, 3.8)	<0.001	33
Medium ISEE score (41.8–66.7)	1.4 (1.0, 1.9)	0.03	21
High ISEE score (66.8–100)	1.0		16
There are too many recommendations for preventing cancer		<0.001	
Low ISEE score (0–41.7)	3.2 (2.3, 4.5)	<0.001	85
Medium ISEE score (41.8–66.7)	1.7 (1.3, 2.2)	<0.001	75
High ISEE score (66.8–100)	1.0		65

\*Results are based on logistic regression models; models controlled for respondent's age, gender, race/ethnicity, education, employment status, marital status, health insurance status, cancer history, and current psychological distress.

<sup>†</sup>OR Odds ratio, CI confidence interval

through studies of online behavior<sup>15-17</sup> or from access to call data from sources like NCI's Cancer Information Service.<sup>18</sup> Nationally representative HINTS data portray a broader picture of the prevalence of cancer information seeking as a phenomenon in the general population across multiple information channels.

Population estimates from HINTS suggested that women, those who were younger than 65 years in age and those with higher levels of education, were more likely to have sought cancer-related information. These findings are consistent with existing reports that show gender, age, and education to be the main sociodemographic characteristics that differentiate people who actively seek health information and desire greater involvement in decision making from those who do not.<sup>6,7,19</sup>

The finding that seniors are less likely than other age groups to seek cancer information, however, stands in contrast to the observation that they are more likely to be diagnosed with cancer. Several studies suggest a generational cohort effect with those from the World War II generation taking a more acquiescent stance to medical decision making and the post-war Baby Boomers tending to be more assertive and interested in shared decision making.<sup>10,20</sup> If the effect is generational, then the "graying of the Baby Boomers" may reduce or even eliminate the disparity in cancer information seeking by age reported in this study. Future administrations of HINTS can help track these trends over time.

Our findings also provide insights into the public's experiences of seeking cancer-related information and estimate 37% to 58% of cancer information seekers (approximately, 35 million to 55 million adults in the USA) to have negative experiences with the process and/or outcome of their information-seeking efforts. Certainly, steps can be taken to make searches easier and to provide help/tutorials and other supports to aid people in becoming more adept information seekers.

Concerns about the quality of health information available to the public have been raised in several reports; these concerns, however, have largely focused on information available through the Internet.<sup>21-24</sup> HINTS data emphasize that the failure to support effective information seeking is a problem that transcends channels—respondents who first went online to search for cancer information were as likely to report negative experiences as those who first turned to their health care providers. Our data support the arguments raised in the IOM's "Crossing the Quality Chasm" report that quality and safety need to be considered as system properties.<sup>2</sup> All channels of information, from public health messages to health-specific web sites to interactions with providers, must come together to provide people with an unflinching environment of support.

Our findings suggest that cancer information seekers' education level and their ability to gain access to health care (depending upon their health insurance status) may influence how well they are able to navigate the information environment. Given that as many as 32% of adults in the USA with less than high school education and 41% of the uninsured were engaged in cancer information seeking, interventions aimed at enhancing information-seeking experiences should pay special attention to these disadvantaged subgroups. We also found negative information-seeking experiences to be associated with fatalistic cancer beliefs and confusion about cancer prevention recommendations. To what extent improvements in information-seeking experiences result in changes in cancer beliefs and previously documented "knowledge gaps"

regarding cancer prevention among disadvantaged populations<sup>25</sup> needs to be investigated.

Also noteworthy is a lack of significant association in our study between key respondent sociodemographic characteristics and ratings of their information-seeking experience. Although there were differences by age, race/ethnicity, and gender in respondents' desire for cancer information, people across all age, racial/ethnic, and gender subgroups reported similar problems when they actually looked for cancer information. Moreover, individual-level variables only explained 7.6% of the variance in ISEE scores. These findings suggest that factors resulting in suboptimal experiences may be more environmental or systemic in nature than related to individual information seekers.

While HINTS data were derived from a nationally representative sample of US adults, our results must be interpreted in light of the fact that these are cross-sectional self-reported data that limit our ability to infer causality. The causal direction of the associations reported here should be confirmed within the context of additional longitudinal investigations. The modest overall response rate of 34.5% is a potential limitation, but is consistent with the recent decline in response rates reported by other large-scale telephone surveys.<sup>26</sup> While lower response rates raise concerns about non-response bias in population estimates, such concerns have not been confirmed in several recent empirical survey-based studies.<sup>26,27</sup> The implication of decreasing response rates on non-response bias are unclear at this time and need to be further evaluated.

Despite these limitations, we believe that our findings provide unique insights into the American public's cancer information-seeking practices and experiences. These results should lay the foundation for future efforts aimed at minimizing barriers faced by the American public in accessing health information. Furthermore, the ISEE scale developed and tested as part of HINTS fills an important void in the literature that has been lacking a psychometrically sound measure of people's health information seeking experiences.

## CONCLUSION

Nationally representative data from HINTS show that while a significant proportion of the American public searches for cancer information, suboptimal information-seeking experiences are common. Individuals with more negative experiences are also more likely to report confusion about cancer-related issues. Facilitation of the public's information-seeking activities will, thus, have to be a key component of efforts focused on promoting informed decision making and greater patient involvement in cancer prevention and control efforts. As system-wide changes are implemented to enhance the public's information-seeking experiences, surveillance mechanisms such as HINTS will be needed to track and evaluate the impact of those changes at a population level.

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