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Cancer Information-Seeking Experiences: The Implications of Hispanic Ethnicity and Spanish Language

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Abstract

Background—Strategies to support cancer information-seeking among Hispanics are needed.

Methods—We analyzed data from the 2005 Health Information National Trends Survey (HINTS) to explore cancer information-seeking experiences among respondents according to ethnicity and language of interview.

Results—Over 80% of Spanish-speaking Hispanics had never looked for cancer information. Compared to English-speaking respondents, Spanish-speaking Hispanics who sought cancer information indicated their search took a lot of effort (67%), was hard to understand (54%), and frustrating (42%). Spanish-speaking Hispanics noted minimal confidence in obtaining cancer information.

Conclusions—Language and cultural differences must be considered in the design, implementation, and dissemination of cancer information.

Hispanic Americans are the largest and fastest growing minority population in the United States. As of July 1, 2006, the US Census estimated over 44 million individuals self-identify as Hispanic.¹ It is increasingly recognized that compared to non-Hispanics, Hispanic populations are more likely to encounter barriers to optimal health including access to care, lack of health insurance and regular source of medical care, limited finances, and lower education and literacy levels.^{2–5} These barriers, in turn, contribute to health disparities, particularly related to cancer, the second leading cause of death among Hispanics.

In 2006, approximately 82,000 new cancer cases were diagnosed among Hispanic men and women in the United States.⁶ During the same time period, over 23,000 Hispanics died from cancer.⁶ Although Hispanics experience lower incidence and mortality rates for the most common cancers such as breast, prostate, colon and rectum, and lung, they have higher rates for cervix, stomach, liver, and gallbladder cancers when compared to non-Hispanics.^{4,6} In a study examining racial and ethnic differences in women diagnosed with invasive cervical cancer from 1992–2003, Hispanic whites had the highest age adjusted incidence rate of

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invasive cervical cancer (24.2/100,000) compared to other racial/ethnic groups.⁷ Research has also documented that Hispanic men and women do not regularly participate in cancer screening, which may lead to cancers being diagnosed at later, more advanced stages, leading to lower survival rates. Compared to non-Hispanic women, lower usage of Pap tests, mammography, and clinical breast exams has been documented among Hispanic women.^{5,6} Adherence to recommended screening guidelines for fecal occult blood tests or lower endoscopic exams is also lower among Hispanics compared to non-Hispanics.^{4,6}

In addition to disparities in disease burden, there are continuing gaps in access to health information among low income and minority populations in the United States. There is a growing body of research that indicates that different ethnic groups experience varied access to health-related information, leading to gaps in knowledge and widening health disparities.⁸ Accordingly, this knowledge gap hypothesis suggests people of higher socioeconomic status have enhanced information access and information-seeking skills that place them in a favorable position to obtain information and make informed medical decisions across the spectrum of health and illness.^{9,10} Of all racial and ethnic groups, low-income Hispanic populations have been documented to be the least likely to have health insurance and the most likely to encounter barriers accessing care.^{4,11} Research to date suggests Hispanics tend to utilize television, family and friendship networks, interpersonal connections with health care providers, and ethnically targeted media including TV and small community newspapers as sources for health information.^{12–16} However, little attention has been paid to the *experience* of information seeking among this growing population, particularly among those who are recent immigrants with limited English proficiency.

The specific aims of our study were to explore differences in the experience of cancer information-seeking among Hispanics who responded to the 2005 National Cancer Institute's (NCI) Health Information National Trends Survey (HINTS) in English, Hispanics who responded in Spanish, and non-Hispanic respondents who completed the survey in English. Although language fluency is but 1 of many factors that may impact health outcomes among Hispanics, it is often used as a proxy for cultural orientation.^{17–19} Spanish-speaking Hispanics can be linguistically isolated, less acculturated, or possess limited English proficiency when compared to English-speaking Hispanics and non-Hispanics.^{18,20–22} As such, Hispanics may shoulder excessive barriers to accessing and communicating with a primarily English-language health care system, receiving quality care, participating in appropriate cancer prevention and screenings activities, and obtaining relevant and practical cancer information.^{2,5,20,21} The US Census reports almost 11% of the US population, or 28.1 million people, speak Spanish as their primary language, and almost half (13.8 million) of this Spanish-speaking population speaks English less than “very well.”²³ These data indicate a large segment of the Hispanic population may be at risk for disparities in health knowledge and adverse health outcomes across the cancer continuum.^{2,10}

MATERIALS AND METHODS

Data Collection, Response Rates, and Sample

Data for this analysis are from the NCI's 2005 HINTS. Data for HINTS 2005 was collected from February 2005 through August 2005. The survey design was a list assisted, random digit dial of all telephone exchanges in the United States administered by trained interviewers to a representative sample of US households. One adult aged 18 or older was selected during a household screener for extended interview (n = 5586). Respondents were given the choice to complete the survey in English or in Spanish. The response rate for the household screener was 34.0%, and the response rate for the extended interview was 61.3%. Further information about the sample and sampling design are reported elsewhere

(<http://www.cancercontrol.cancer.gov/hints/>—see HINTS 2005 Final Report). The HINTS 2005 survey was granted an exempt status by the NCI's Office of Human Subjects Research Internal Review Board (IRB) and by the IRB of the organization contracted to conduct the HINTS survey, Westat.

Sociodemographic Characteristics

All analyses were stratified by language of interview (Spanish or English) and ethnicity (Hispanic or non-Hispanic). Ethnicity was assessed according to the Office of Management and Budget standards.²⁴ Our analyses included the following sociodemographic characteristics: gender, age, education, household income, location of birth (United States or outside United States), level of comfort speaking English, and number of years residing in the United States.

Information-Seeking Experiences

Information-seeking experiences were assessed with a series of questions wherein respondents were asked to agree or disagree with the following statements: (1) It took a lot of effort to get the information you needed; (2) You felt frustrated during your search for the information; (3) You were concerned about the quality of the information; and (4) The information you found was too hard to understand. Respondents were also asked to rate their confidence in future information seeking: Overall, how confident are you that you could get advice or information about cancer if you needed it?

Analyses

Analyses were conducted to account for the complex survey design of HINTS 2005 using SAS-callable SUDAAN Version 9.0.²⁵ Estimates were weighted to be representative of the US population. Chi-square tests were conducted to analyze bivariate associations of sociodemographic variables with language spoken during interview and self-reported ethnicity as well as cancer information-seeking experiences. Multivariate logistic regression analyses were conducted to assess independent associations.

RESULTS

Weighted frequencies and means for sociodemographic characteristics are shown in Table 1. A total of 5344 HINTS respondents had valid responses for ethnicity; among this subpopulation, 90.8% self-identified as non-Hispanic (n = 4850) and 9.2% as Hispanic (n = 494). Of the Hispanic respondents, 46.2% completed the survey in English (n = 228; hereafter referred to as English-speaking Hispanic respondents), whereas 53.8% of Hispanic respondents completed the survey in Spanish (n = 266; hereafter referred to as Spanish-speaking Hispanic respondents).

Compared to non-Hispanics respondents (47.1%), a significantly higher percentage of English-speaking Hispanic respondents (54.9%) and Spanish-speaking Hispanic respondents (52.0%) were male. Compared to non-Hispanic respondents (58.3%), a significantly higher percentage of English-speaking Hispanic respondents (79.4%) and Spanish-speaking Hispanic respondents (81.9%) were under 50 years of age. A significantly greater proportion of Spanish-speaking Hispanic respondents (61.9%) reported incomes of less than \$25,000 per year compared to 26.0% of English-speaking Hispanic respondents and 20.8% of non-Hispanic respondents. Significant differences in level of educational attainment were also found between the 3 groups: Spanish-speaking Hispanic respondents (54.2%) were significantly more likely to have less than a high school education compared to English-speaking Hispanic respondents (19.8%) and non-Hispanics (10.3%). Significant differences also were found in the proportion of each group that reported that they were born in the

United States. Over 90% of the Spanish-speaking Hispanic respondents were born outside of the United States. A significantly greater proportion (91.4%) of English-speaking Hispanic respondents reported feeling comfortable speaking English compared to 21.2% of Spanish-speaking Hispanic respondents and 85.7% of non-Hispanic respondents. Mean number of years residing in the United States was significantly different across groups: non-Hispanics reported residing in the United States for 45.3 years compared to 34.3 years for English-speaking Hispanic respondents and 14.4 years for Spanish-speaking Hispanic respondents.

Related to cancer information seeking, the data reveal non-Hispanics are more likely to seek information (53.2%) compared to both English-speaking Hispanics (37.1%) and Spanish-speaking Hispanics (16.7%). Bivariate associations of cancer information-seeking experiences among those who have sought cancer information, by language spoken and ethnicity, are summarized in Table 2. Results indicate that almost 70% of Spanish-speaking Hispanic respondents were significantly more likely to agree that their last search for cancer information took a lot of effort compared to 43.3% of English-speaking Hispanic respondents and 35.6% of non-Hispanic respondents. Spanish-speaking Hispanic respondents (54.7%) were also significantly more likely to agree that the information they found was hard to understand compared to the other 2 groups (24.8% of English-speaking Hispanics and 22.2% of non-Hispanics). Although Spanish-speaking Hispanics were more likely than English-speaking Hispanics and non-Hispanics to agree that they found their last search frustrating, the differences between the 3 groups was not statistically significant nor was the difference in the proportion who agreed that they were concerned about the quality of the information they found. Given the low number of Spanish-speaking Hispanic respondents who indicated they had searched for cancer information on the Internet, statistical comparisons between the 3 groups on this variable are unreliable and therefore should be interpreted cautiously.

To determine which variables were independently associated with each of the specific cancer information-seeking experiences and behaviors, 4 logistic regression models were conducted (Table 3). Independent variables for all models included gender, age, education, income, language used in the interview, and number of years in the United States.

The overall model for sought cancer information was significant ($F_{14} = 14.93$, $P < .0001$). Compared to non-Hispanics, English-speaking Hispanics (odds ratio [OR] = 0.59, confidence interval [CI] = 0.38–0.92) and Spanish-speaking Hispanics (OR = 0.25, CI = 0.15–0.43) were significantly less likely to have sought cancer information. Compared to respondents with less than a high school education, respondents who graduated from high school or had some college education (OR = 2.10, CI = 1.53–2.89) and respondents who graduated from college (OR = 3.38, CI = 2.31–4.95) were significantly more likely to have searched for cancer information. Females (OR = 1.79, CI = 1.46–2.20) were significantly more likely to have searched for cancer information than males.

The model for confidence in obtaining cancer information was also significant ($F_{14} = 21.54$, $P < .0001$). Compared to non-Hispanics, Spanish-speaking Hispanics were less likely to feel confident they could obtain cancer information (OR = 0.35, CI = 0.22–0.57). Compared to respondents earning less than \$25,000 per year, respondents earning \$50,000 to \$75,000 per year (OR = 1.40; CI = 1.01–1.94) and respondents earning greater than \$75,000 per year (OR = 1.63, CI = 1.21–2.19) were more confident they could obtain cancer information. Finally, compared to younger respondents (18–34 years of age), respondents 35 to 49 years of age (OR = 0.63, CI = 0.47–0.86) expressed lower confidence in obtaining cancer information.

The model examining information-seeking effort (It took a lot of effort ...) was significant ($F_{14} = 9.48, P < .0001$). Compared to respondents who were 18 to 34 years of age, those 50 to 64 (OR = 2.80, CI = 1.57–4.97), those 65 to 74 (OR = 3.85, CI = 1.61–9.23), and those 75 and older (OR = 6.49, CI = 2.38–17.69) were significantly more likely to report that their search took a lot of effort. Compared to respondents with less than a high school education, those who were college graduates (OR = 0.48, CI = 0.25–0.91) were less likely to report that their search took a lot of effort. There were no significant differences between non-Hispanics, English-speaking Hispanics, or Spanish-speaking Hispanics on reported information-seeking effort.

Finally, the model for difficulty in understanding information (information ... was hard to understand) was significant ($F_{14} = 37.90, P < .0001$). Compared to respondents 18 to 34 years of age, all other age groups were significantly more likely to indicate that the information was hard to understand: 35- to 49-year-olds (OR = 2.03, CI = 1.20–3.46); 50- to 64-year-olds (OR = 3.31, CI = 1.48–7.39); 65- to 74-year-olds (OR = 3.17, CI = 1.03–9.73); and 75 years of age and older (OR = 3.97, CI = 1.03–15.36). Compared to respondents earning \$25,000 or less, respondents earning \$50,000 to 75,000 per year (OR = 0.63, CI = 0.42–0.93) and respondents earning \$75,000 or more (OR = 0.54, CI = 0.34–0.86) were significantly less likely to report that information was hard to understand.

DISCUSSION

There are important differences between Hispanics and non-Hispanics related to cancer information-seeking experiences. Overall, when compared to non-Hispanics, both Spanish- and English-speaking Hispanics fared worse on sociodemographic measures and were more likely to perceive their cancer information-seeking experiences negatively. Respondents who answered the survey in Spanish demonstrated greater disparities, suggesting that language may also play a role in contributing significantly to cancer health disparities. In the context of what is known about the elevated health risks of Hispanics who have poor access to care and are underinsured, the greater barriers to information seeking identified in our analyses underscore the isolation of this population. Low-income Hispanics in the United States are the least likely to have health insurance and the most likely to meet difficulties in accessing care.^{4,11,16} Our analyses suggest that Hispanics also encounter multiple difficulties and have minimal confidence in accessing health information. Disparities in cancer information-seeking and information access have the potential to negatively shape health knowledge, attitudes, behaviors, and medical decisions and can therefore contribute to disparities in health outcomes.^{8,26,27} Similar to findings by Tortolero-Luna and colleagues²⁸, the cancer information-seeking disparities noted in this article suggest that Hispanics, particularly those who responded to the survey in Spanish, may experience multiple challenges and barriers in seeking and interpreting cancer information and in making informed or shared decisions about their health. These information-seeking disparities, combined with known challenges related to communication with providers, health insurance coverage, access to care, and knowledge of available and appropriate health care services, contribute to the inequality in the cancer burden.

Limitations

Response rates for HINTS 2005 were fairly low; the final response rate for the household screener was 34.0%, and the final response rate for extended interview was 61.3%. However, these rates are comparable to other national telephone surveys and reflect the decreasing trend in response rates for telephone surveys.²⁹ HINTS 2005 is not a prospective study; therefore, results of our analyses provide a cross-sectional snapshot of information seeking among Hispanic and non-Hispanic populations. Longitudinal examination of information seeking among sociodemographically defined subgroups would provide

valuable insight for cancer educators and planners. Although HINTS does ask respondents if they were born in the United States, what year they came to live in the United States, and level of comfort in speaking English, the survey does not currently differentiate Hispanic respondents by country of origin or paternal/maternal country of origin, which would yield additional information related to the varying cultural backgrounds of the survey participants. Last, our reliance on language as a proxy for preferred language may not adequately capture cultural orientation. The authors readily recognize the heterogeneity of the Hispanic population and that health information seeking is a complex and multifaceted behavior influenced by a combination of factors including culture; socioeconomic status; degree of ethnic identity; health literacy, knowledge, attitudes and beliefs; familial involvement; and access to information sources.^{16,30} Nonetheless, this national snapshot does contribute to the growing body of work examining the information-seeking experiences and behaviors of Hispanics in this country and reinforces the need to understand Hispanics' communication behaviors to more effectively support this population in a rapidly evolving and increasingly complex health information environment.

Conclusions and Future Research

Health planners and practitioners often rely on trusted and established mainstream information sources to reach populations at risk for disease and poor health outcomes. Yet, increasing differences in preferred and trusted sources for health information among racial and ethnic groups in this country may necessitate the use of alternative channels and messages to provide health information that support and reinforce cultural norms, language preferences, literacy levels, and other values specific to unique cultural identities.^{16,27} The explosion of health information in the Internet has certainly opened pathways to disseminate health information. However, our research is consistent with prior research demonstrating that Web-based health information resources are not accessed equally by all.^{31,32} Given the low usage of the Internet among the Spanish-speaking HINTS respondents (79% are not online) and the multiple barriers and frustrations experienced by these respondents in seeking cancer information both offline and online, it is clear that sociodemographic and cultural factors, including language, interact with and influence cancer information-seeking behaviors. Additionally, information source preferences and use among Hispanics, particularly recent immigrants and those with limited English proficiency, is an area that needs further examination.

Cancer information itself is complicated, as there are numerous recommendations related to prevention, screening, and treatment that are accompanied by a long list of medical terms related to specific types and stages of cancer. As new findings related to cancer prevention, screening, diagnosis, and treatment are covered by the media each day, the public is stimulated to stay up to date on the latest advancements and recommendations by searching for more detailed information. To effectively search for appropriate information, the public must be aware of and able to access information and education channels and sources; be able to choose credible sources that deliver appropriate and accurate information; and utilize negotiation, management, and comprehension skills to prioritize, process, and act on applicable information.^{27,33} These sources must be easily accessible and also provide information that is understandable and culturally competent, leaving the information seeker feeling confident in his or her ability to seek and find relevant information in the future. Findings from this study reveal this experience is compromised and frustrating for specific subgroups. For Hispanics, future studies should investigate the specific resources and channels used in searching for cancer information and identify where these resources, materials, and messages fall short in addressing the specific needs of this at-risk population. Only then can we begin to overcome the cancer information-seeking barriers of this

heterogeneous population and contribute to the larger goal of eliminating communication inequities and cancer health disparities.

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Table 1

Sociodemographic Characteristics by Language Spoken and Ethnicity

	Non-Hispanic (n = 4850)		Hispanic Ethnicity English Language (n = 228)		Hispanic Ethnicity Spanish Language (n = 266)		P Value
	n	%	n	%	n	%	
Total (n = 5344)							
Gender							.0142
Male	1647	47.1	88	54.9	102	52.0	
Female	3203	52.9	140	45.1	164	48.0	
Age group (y)							.0001
18–34	804	28.4	74	43.7	114	53.0	
35–49	1259	29.9	89	35.7	91	28.9	
50–64	1398	24.7	35	11.3	40	12.0	
65–74	744	9.8	21	6.7	14	4.7	
75+	645	7.2	9	2.6	7	1.5	
Household income							.0001
Less than \$25,000	990	20.8	58	26.0	134	61.9	
\$25,000 to <\$50,000	1106	25.7	50	26.4	55	22.8	
\$50,000 to <\$75,000	860	22.7	38	21.7	21	13.1	
\$75,000 or more	1089	30.8	52	25.8	4	2.3	
Education							.0001
Less than high school	459	10.3	43	19.8	165	54.2	
High school graduate or some college	2768	64.1	124	63.3	86	41.3	
College graduate	1607	25.6	61	16.9	13	4.5	
Born in the United States							.0001
Yes	4610	94.3	160	73.0	16	7.5	
No	240	5.7	68	27.0	250	92.5	
Comfort speaking English							.0001
Completely/very comfortable	202	85.7	200	91.4	39	21.2	
Somewhat or a little comfortable	27	14.1	19	8.1	119	62.3	
Not at all comfortable	1	0.3	2	0.5	45	16.5	
Years in the United States, n (mean)	4844 (45.3)		227 (34.3)		257 (14.4)		.0001

Table 2

Information-Seeking Experiences by Language Spoken and Ethnicity

	Non-Hispanic		Hispanic Ethnicity English Language		Hispanic Ethnicity Spanish Language		P Value
	n	%	n	%	n	%	
Took a lot of effort (n = 2822)							.0005
Agree	955	35.6	36	43.3	40	67.2	
Disagree	1718	64.4	58	56.7	15	32.8	
Concerns about the quality of information (n = 2807)							.1036
Agree	1222	46.2	54	59.8	35	58.2	
Disagree	1438	53.8	39	40.2	19	41.8	
Information was hard to understand (n = 2818)							.0008
Agree	625	22.2	24	24.8	31	54.7	
Disagree	2046	77.8	70	75.2	22	45.3	
Search was frustrating (n = 2819)							.1905
Agree	722	26.3	23	24.7	24	42.6	
Disagree	1949	73.7	71	75.3	30	57.4	
Ever visited an Internet site to learn about cancer (n = 840)							.2095
Yes	312	37.1	11	54.3	2	20.2	
No	495	62.8	12	45.8	8	79.8	
Confidence in obtaining cancer information (n = 5309)							.0001
Completely confident	1326	29.1	68	33.2	80	27.3	
Very confident	2049	42.1	88	34.7	49	17.1	
Somewhat confident	1155	22.8	50	20.7	63	27.4	
A little confident	228	4.7	15	8.7	48	21.0	
Not confident at all	64	1.3	5	2.8	21	7.2	

Table 3

Logistic Regression of Sociodemographic Characteristics onto Cancer Information Experiences*

	Sought Cancer Information	Confidence in Obtaining Information	Took a Lot of Effort	Information Hard to Understand
Gender				
Male	1.00	1.00	1.00	1.00
Female	1.79 (1.46–2.20)	1.17 (0.95–1.44)	0.92 (0.66–1.27)	0.89 (0.68–1.15)
Age group (y)				
18–34	1.00	1.00	1.00	1.00
35–49	1.20 (0.92–1.55)	0.63 (0.47–0.86)	1.42 (0.88–2.29)	2.03 (1.20–3.46)
50–64	1.14 (0.74–1.75)	0.82 (0.51–1.30)	2.80 (1.57–4.97)	3.31 (1.48–7.39)
65–74	0.78 (0.43–1.44)	0.73 (0.37–1.45)	3.85 (1.61–9.23)	3.17 (1.03–9.73)
75+	0.48 (0.21–1.11)	0.76 (0.35–1.68)	6.49 (2.38–17.69)	3.97 (1.03–15.36)
Education				
Less than high school	1.00	1.00	1.00	1.00
High school graduate or some college	2.10 (1.53–2.89)	0.98 (0.78–1.25)	0.68 (0.41–1.14)	0.56 (0.39–0.81)
College graduate	3.38 (2.31–4.95)	1.19 (0.88–1.60)	0.48 (0.25–0.91)	0.27 (0.16–0.44)
Household income				
Less than \$25,000	1.00	1.00	1.00	1.00
\$25,000 to <\$50,000	1.04 (0.81–1.35)	1.09 (0.83–1.43)	0.86 (0.59–1.25)	0.75 (0.52–1.08)
\$50,000 to <\$75,000	1.09 (0.84–1.40)	1.40 (1.01–1.94)	0.68 (0.44–1.05)	0.63 (0.42–0.93)
\$75,000 or more	1.22 (0.94–1.59)	1.63 (1.21–2.19)	0.65 (0.42–1.00)	0.54 (0.34–0.86)
Language of interview				
Non-Hispanic	1.00	1.00	1.00	1.00
Hispanic/Spanish Language	0.25 (0.15–0.43)	0.35 (0.22–0.57)	2.56 (0.94–6.95)	2.35 (0.92–6.01)
Hispanic/English Language	0.59 (0.38–0.92)	0.97 (0.68–1.39)	1.55 (0.88–2.73)	1.44 (0.59–3.53)
Years in the United States	1.00 (0.99–1.02)	1.00 (1.00–1.01)	0.98 (0.96–0.99)	0.99 (0.97–1.01)
Model χ^2	$\chi^2_{14} = 14.93 P < .0001$	$\chi^2_{14} = 21.54 P < .0001$	$\chi^2_{14} = 9.48 P < .0001$	$\chi^2_{14} = 37.90 P < .0001$

* Odds ratio (95% Confidence Interval).