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Cancer Prevention Information-Seeking among Hispanic and Non-Hispanic Users of the National Cancer Institute's Cancer Information Service: Trends in Telephone and LiveHelp Use

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Abstract

Evidence-based strategies to enable, encourage and support cancer prevention information-seeking among Hispanic populations are needed. We examined cancer prevention information requests to the Cancer Information Service (CIS) via telephone (1-800-4-CANCER toll-free telephone information service) and LiveHelp (an instant messaging service provided in English only) from 2003 to 2006. We summarized differences in the communication channel utilized by ethnicity (Hispanic vs. non-Hispanic) and, among Hispanic information seekers, the language used during the contact (English vs. Spanish). Utilization of LiveHelp was higher among non-Hispanic than Hispanic seekers of cancer prevention information. LiveHelp use for seeking cancer prevention information increased between 2003 and 2006 for both groups, but the increase was greater among non-Hispanics than Hispanics. Nearly half of Hispanics who sought cancer prevention information did so in Spanish. Because LiveHelp is not available in Spanish, the number of Spanish-only speakers who preferred to contact CIS via LiveHelp instead of telephone is unknown. When communicating cancer prevention information via multiple channels, it is important to consider differences in access to communication technologies and preferred communication channels among ethnic minority groups.

Hispanic Americans constitute the largest (U.S. Census Bureau, 2008) and fastest-growing (Guzman, 2001) ethnic minority group in the United States. Between 1990 and 2000 the Hispanic population grew 57.9%, whereas the overall population grew 13.2% (Guzman, 2001). In 2000, 12.4% of the total U.S. population self-identified as Hispanic (Grieco & Cassidy, 2001), but by 2006 that figure reached 14.8% (over 44 million individuals) (U.S. Census Bureau, 2007, 2008). The Census Bureau projects that, by the year 2050, 24.4% of the total population will have Hispanic origins (U.S. Census Bureau, 2004).

Previous research has demonstrated that Hispanic populations are more likely than non-Hispanics to encounter barriers to accessing healthcare, including lacking health insurance and a regular source of medical care. Furthermore, Hispanic populations often have limited finances, lower education and lower literacy levels than non-Hispanics (Diaz, 2002; Garbers & Chiasson, 2004; Huerta, 2003; Ku & Waidmann, 2003; Timmins, 2002). These barriers, in turn, contribute to health disparities. The relationship between barriers to healthcare and health disparities is true particularly for cancer, which is the second leading cause of death among Hispanics (American Cancer Society, 2007a).

Among Hispanic Americans in 2006, approximately 82,000 new cancer cases were diagnosed and over 23,000 individuals died from cancer (American Cancer Society, 2007a). Compared to non-Hispanics, Hispanics have higher rates for cervical, stomach, liver, and gallbladder cancers (American Cancer Society, 2007a; Huerta, 2003). Although Hispanics experience lower incidence and mortality rates than non-Hispanics for lung, breast, prostate, and colon and rectum cancers, incidence and mortality from these cancers pose a significant health burden (American Cancer Society, 2007b).

There are clear primary and/or secondary prevention strategies for colon, lung, breast, and cervical cancers. However, previous research has documented lower adherence to common cancer screening practices among Hispanic men and women, which may lead to cancers being diagnosed at more advanced stages (American Cancer Society, 2007a; Diaz, 2002; Huerta, 2003; McDougall, Madeleine, Daling, & Li, 2007). Furthermore, results from the Health Information National Trends Survey (HINTS) indicate that, in 2003, Hispanics were less familiar with cancer prevention strategies than were non-Hispanics (Hawkins, Berkowitz, & Peipins, in press). Non-Hispanic whites cited 2.2 protective strategies, but Hispanics cited only 1.5. In addition, non-Hispanic whites were more likely than Hispanics to identify three preventive strategies and were less likely to be unable to identify any. An additional gap in knowledge exists between Hispanics who do and do not prefer speaking in English. Knowledge of cancer prevention strategies was lower among Hispanics who were interviewed in Spanish than in English (1.8 vs. 1.2 strategies, respectively, Hawkins et al., in press). Considering that ethnic-based differences in access to health-related information widens gaps in knowledge and health disparities (Ramanadhan & Viswanath, 2006), the necessity of identifying, monitoring and addressing the cancer education and communication needs of Hispanic populations is clear.

People cannot engage in preventive behaviors if they do not know what actions to take or avoid. It is possible that ethnic-based differences in knowledge of prevention strategies are partially attributable to differences in information-seeking behaviors between Hispanics and non-Hispanics. The Internet has the potential to advance the science of cancer prevention and control, but not all populations have equal access to this technology (Institute of Medicine [IOM], 2002; Neuhauser & Kreps, 2008; Viswanath, 2005). Previous studies have found that Internet-based cancer information-seeking is lower among Hispanics than non-Hispanic Whites (Finney Rutten, Moser, Beckjord, Hesse, & Croyle, 2007; Finney Rutten, Squiers, & Hesse, 2006). By comparing the communication channels that Hispanic and non-Hispanic individuals utilize to seek prevention information, it might be possible to determine whether a certain channel is underutilized by Hispanics. If this is the case, organizations that seek to reduce the burden of cancer by providing cancer-related information or by implementing behavioral interventions might utilize these findings to maximize their communication efforts and the efficacy of their interventions.

The Cancer Information Service (CIS), a component of the National Cancer Institute (NCI), is a health communication program comprised of highly-trained, English- and Spanish-speaking Information Specialists who provide accurate and high quality cancer information through the telephone (1-800-4-CANCER), LiveHelp (an instant messaging service provided in English only that also offers assistance in navigating NCI's cancer.gov website), mail, and email. On January 1, 2008 CIS began providing email service in Spanish and English. The objective of this study was to describe the ways in which Hispanics and non-Hispanics sought cancer prevention information from CIS between 2003 and 2006. In particular, it examined whether the percentage of individuals who sought cancer prevention information via LiveHelp (versus telephone) varied by ethnicity and/or over time. It also examined whether the language individuals used to seek prevention information changed between 2003 and 2006.

Methods

Data Source

CIS Information Specialists record information about each contact on an Electronic Call Record Form (ECRF). The information recorded includes the type of information seeker requesting information (such as patient, health professional or general public) and the main subject or topic addressed during the interaction. The type of information seeker and the subject of the interaction are not explicitly assessed; rather, during the course of the call, Information Specialists determine and record the type of information seeker and summarize the subject of interaction at the conclusion of the interaction. Information Specialists are able to document up to five subjects or topics per interaction.

Data Quality

CIS Information Specialists complete an ECRF training course that covers data collection and coding procedures. Contact Center Managers monitor and review a sample of calls and ECRF records to assure coding accuracy. In addition, the ECRF data collection system contains validity checks. For example, records cannot be saved with fields that are not coded, and the fields have range checks to ensure that only codes within a designated range can be entered. For those fields that do not have automatic range checks, manual checks for invalid codes or incomplete fields are conducted prior to data analysis.

Participants

Data were collected from individuals who sought cancer prevention information from CIS via telephone (1-800-4-CANCER) or LiveHelp (linked to <http://www.cancer.gov>) between 2003 and 2006. Of the 562,640 individuals who contacted CIS, 91,883 were members of the general public, cancer patients, or caretakers who sought information about primary or secondary prevention strategies (see Table 1 for a list of prevention-related subjects of interaction). The percentage of calls that pertained to cancer prevention (rather than another topic such as cancer treatment) was similar for Hispanic (20.8%) and non-Hispanic (20.7%) information seekers.

Most people sought cancer prevention information from CIS by telephone (82,190), but 6,626 used LiveHelp, 2,820 used email, and 247 used the postal service. Demographic information was collected from a random sample of 36,478 individuals who accessed CIS services via telephone or LiveHelp. The sample used for the present analyses included the 28,021 participants who provided information about their ethnicity. This represented a 76.8% response rate. (For more detailed information on participant recruitment and study methodology, see (Finney Rutten, Squiers, & Hesse, 2007).

Statistical Analyses

All analyses were conducted using SPSS 15. First, we used chi-square tests to determine the sample's demographic characteristics and whether any of these characteristics were potential confounders of the relationship between ethnicity and communication channel. We then conducted a multiple logistic regression to examine whether ethnicity predicted the communication channel used for cancer prevention information-seeking. To test whether this relationship changed over time, we conducted a logistic regression predicting communication channel utilization from year, ethnicity, and the interaction between year and ethnicity. We then repeated these logistic regression models while controlling for the identified potential confounders. Finally, we used chi-square tests to explore whether the percent of Hispanic information seekers who sought information in Spanish changed over time. Because the CIS does not offer a Spanish-language version of LiveHelp, this analysis was restricted to telephone contacts only.

Results

Sample Characteristics

Of the 28,021 cancer prevention information seekers, 25,110 (89.6%) reported being non-Hispanic and 2,911 (10.4%) reported being Hispanic. Compared to non-Hispanic information seekers, Hispanic information seekers were more often female, younger, and less likely to report their race (see Table 2). However, fewer Hispanic information seekers had at least some college education or were a cancer patient or caregiver for a cancer patient.

Potential Confounders

Chi-square analyses demonstrated that educational attainment, age, and race were associated with LiveHelp utilization. LiveHelp use was 2.6% among people with at least some college experience, compared to 1.3% among those with a high school diploma or less, $\chi^2 (1) = 49.5$, $p < .001$. Among information seekers younger than 40 years of age, 5.6% used LiveHelp, compared to 1.9% of those aged 40 to 59 and 0.3% of those 60 and older, $\chi^2 (3) = 484.1$, $p < .001$. LiveHelp use was 2.4% among whites, 1.0% among African Americans, 6.4% among Asian Americans, Native Hawaiians, and Pacific Islanders, 0.9% among American Indians, 2.1% among people who reported being multiracial, and 0.9% among people who did not report their race $\chi^2 (5) = 101.2$, $p < .001$. Gender and type of information seeker were not associated with LiveHelp use, $\chi^2 (1) = 0.0$, $p = .97$ and $\chi^2 (1) = 0.4$, $p = .56$, respectively.

Association between Ethnicity, Communication Channel, and Year

The vast majority of individuals who sought cancer prevention information from the CIS between 2003 and 2006 did so using the telephone (27,414; 97.8%), rather than LiveHelp (607; 2.2%). Logistic regression analysis indicated that non-Hispanic information seekers were more likely to use LiveHelp (562, 2.2%) than Hispanic information seekers (45, 1.5%), Wald $\chi^2 (1) = 5.8$, $p < .05$, OR = 1.5, 95% CI 1.1—2.0. This association remained statistically significant even after controlling for educational attainment, age, and race, Wald $\chi^2 (1) = 5.3$, $p = .021$, OR = 1.5 (95% CI 1.1—2.2).

LiveHelp use increased markedly over time, Wald $\chi^2 (3) = 30.3$, $p < .001$. In 2003 only 0.13% (22) of cancer prevention information seekers used LiveHelp, compared to 2.3% (144) in 2004, 6.6% (156) in 2005, and 11.2% (285) in 2006. With 2003 as the reference year, odds ratios were 10.4 (95% CI 2.3—46.0) for 2004, 23.7 (95% CI 5.2—107.4) for 2005, and 36.6 (95% CI 8.5—157.8) for 2006. The interaction of year of contact and ethnicity was not statistically significant, Wald $\chi^2 (3) = 2.9$, $p = .41$. However, this nonsignificant interaction might be attributable to small cell sizes among Hispanic LiveHelp users and large differences in cell sizes between LiveHelp and telephone users (see Table 3). Logistic regression analyses that were stratified by year suggest that ethnicity-based differences in LiveHelp utilization widened between 2003 and 2006, even when education, race, and age were controlled (see Table 3).

Cancer Prevention Information-Seeking among Hispanics

Among Hispanics, 44.4% (1,292) sought information about cancer prevention in Spanish, and this percentage varied over time, $\chi^2 (3) = 50.0$, $p < .001$. Whereas Spanish-speakers comprised 38.3% of the Hispanic information seekers in 2003, that proportion rose to 46.2% in 2004 and 57.8% in 2005. The percentage of Spanish-speakers dropped to 50.5% in 2006, but a contrast analysis indicated that this was only marginally lower than in 2005, $\chi^2 (1) = 3.7$, $p = .05$.

Discussion

The National Cancer Institute offers several communication channels by which individuals can seek cancer information. This study found that utilization of LiveHelp, an Internet-based instant

messaging service, was higher among non-Hispanic than Hispanic seekers of cancer prevention information. LiveHelp use for cancer prevention information increased between 2003 and 2006 for both groups, but the increase was greater among non-Hispanics than Hispanics. Nearly half of Hispanics who sought cancer prevention information did so in Spanish, and the percentage of Hispanics who sought cancer prevention information in Spanish increased over time.

These data are consistent with population-based studies from 2003 and 2005 demonstrating that Internet-based cancer information seeking is lower among Hispanics than non-Hispanic Whites (Finney Rutten, Moser, Beckjord, Hesse, & Croyle, 2007; Finney Rutten, Squiers, & Hesse, 2006). This difference might be due to ethnic-based differences in general Internet use. In 2006, 56% of Hispanics accessed the Internet “at least occasionally,” compared to 60% of Blacks and 71% of Whites (Fox & Livingston, 2007). These differences were attributed to socioeconomic differences such as lower educational attainment, income, and English proficiency among Hispanics. Accessibility to the Internet was also a significant barrier. Whereas 53% of Hispanics who did not go online did not have access to the Internet, only 30% of non-Internet using Whites did not have access (Fox & Livingston, 2007).

The communication landscape has undergone profound changes over the past 15 years. The search engines Yahoo! and Google accounted for 73% of all Internet searches conducted in 2006 in the United States (Sullivan, 2006), but only began operating in 1994 and 1998, respectively (Google, 2008; Yahoo, 2008). It is impossible to predict what the communication landscape will resemble in another 15 years. It seems reasonable to assume that it will become faster, have increased wireless capabilities and be able to communicate even more immense amounts of information. The amount of health information available to the public today has never been greater, but access to such information varies according to race, ethnicity, educational attainment, and income (Viswanath, 2005). If disparities in access to communication technologies and cancer information are not resolved, it seems unlikely that sociodemographic disparities in cancer burden will be completely ameliorated.

Considering the growing Hispanic population, it is possible that ethnic-based disparities in knowledge of cancer prevention strategies could worsen cancer morbidity and mortality among Hispanics. Clearly, it is important to facilitate the information-seeking process for this difficult-to-reach group (Diaz, 2002; Garbers & Chiasson, 2004; Huerta, 2003; Ku & Waidmann, 2003; Timmins, 2002). Organizations that provide cancer information have reported a large increase in the number of people using Spanish-language services (Oncolink, 2007). In addition, it is important for organizations that provide cancer information to have multiple communication channels available (Bright et al., 2005; IOM, 2002). A combination of traditional and contemporary communication channels that are sensitive to the cultural, social and economic contexts within which people live can empower people and facilitate their access to important health information (IOM, 2002). It is also important to have these channels available during the times which underserved groups might most benefit. For example, having Spanish-speaking operators available only during certain working hours could make it more difficult for Spanish-speakers to seek cancer prevention information, particularly if few alternative Spanish-language channels exist. Communicating cancer information via cell phone text-messaging might provide a way to reach out to Hispanics who do not have Internet access and who may not have the time to have extensive voice-based telephone conversations. In fact, in 2006 18% of Hispanics who did not go online had a cell phone, and 49% of those who had a cell phone used it to send text messages (Fox & Livingston, 2007).

Limitations

This study's limitations are similar to other studies that use CIS data (Finney Rutten et al., 2007). For example, because the subject of interaction is often summarized by CIS Information Specialists, it is possible that some of the calls were misclassified. This might result in the

exclusion of individuals who sought prevention information or the inclusion of individuals who did not seek prevention information. In addition, a smaller percentage of LiveHelp users provided demographic information than telephone users (10.9% vs. 33.4%, respectively). As a result, the actual demographic characteristics of LiveHelp users might differ from the characteristics presented here.

Another concern is that the numbers of Hispanics who used LiveHelp to seek information was very small (only two individuals in 2003), and the proportion of telephone users to LiveHelp users was very large (see Table 3). Consequently, the results from the analyses that controlled for demographic variables should be interpreted with caution. In addition, the small numbers of Hispanics who contacted CIS might not be representative of the larger Hispanic population in the United States. The data do not indicate how many of the Hispanic callers who spoke English were calling for a Spanish-speaker. Furthermore, CIS does not at this time provide a Spanish-version of LiveHelp. Additional research should investigate the extent to which Spanish-speakers prefer (and have access to) online resources to seek cancer prevention information.

Public Health Implications

Although the past decades have witnessed an explosion of health information on the Internet, our findings are consistent with prior research demonstrating considerable variability in the extent to which Internet-based health information resources are accessed by racial and ethnic groups (Fox & Livingston, 2007; Lorence, Park, & Fox, 2006). Differences in preferred and accessed sources of health information among ethnic or racial minority groups in the U.S. necessitate the use of alternative channels and messages to provide health information that is consistent with language preferences and literacy levels of targeted groups (Cheong, 2007; Viswanath et al., 2006). Further examination of the source and channel preferences of Hispanic populations, particularly among recent immigrants or those with limited English proficiency, is encouraged.

As the information environment becomes increasingly populated and complex, especially with regard to cancer prevention and control, efforts to support public awareness of and access to appropriate information and education channels and resources are critical to the delivery of effective public health messages. Information resources must be accessible and comprehensible to diverse populations that may not speak English. The dearth of Spanish-language websites that communicate cancer information is a major challenge that Spanish-speakers might encounter when seeking health information (Neuhauser & Kreps, 2008). Neglecting to account for diversity in literacy levels, English proficiency, and cultural norms and practices might inadvertently hinder cancer control efforts on a population level. Indeed, negative experiences with cancer information-seeking might result in unnecessary confusion and fatalism (Arora et al., 2008). As information resources become more automated and dependent upon the Internet, it becomes more essential that language, cultural, and literacy factors be considered when designing cancer communication websites. As a first step in overcoming the cancer information-seeking barriers of the heterogeneous Hispanic population, future research should identify information resources and channels that Hispanics use when searching for cancer information.

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Table 1
Categories used to classify Cancer Information Service (CIS) users' subjects of interaction related to primary and secondary prevention.

Type of Prevention	Subject of Interaction
Primary	Environmental risk factors Diet and nutrition for prevention Heredity/genetics Hormones HPV vaccine Smoking/tobacco use Other prevention/other risk factors Prevention trial (including specific requests for Selenium and Vitamin E Cancer Prevention Trial [SELECT], and Study of Tamoxifen and Raloxifene [STAR])
Secondary	Colonoscopy Screening Screening Mammograms Screening Trials (including specific requests for National Lung Screening Trial [NLST])

Table 2

Participant characteristics by ethnicity (N = 28,021)

Demographic Variable	Ethnicity				χ^2	p
	Non-Hispanic (n=25,110)		Hispanic (n=2,911)			
	n	%	n	%		
Gender					61.3	< .001
Male	7,018	27.9	615	21.1		
Female	18,092	72.1	2,296	78.9		
Race					11013.5	< .001
White	19,508	77.7	984	34.0		
Black	3886	15.5	79	2.7		
Asian, Native Hawaiian, Pacific Islander	552	2.2	46	1.6		
American Indian	281	1.1	168	5.8		
Multiracial	351	0.8	23	1.4		
Missing	532	2.1	1611	55.1		
Educational Attainment					425.5	< .001
High school or less	8,032	32.0	1,488	51.1		
Some college or more	17,078	68.0	1,423	48.9		
Age Category					1383.1	< .001
Less than 40	4,610	18.4	1,335	45.9		
40 to 59	11,717	46.7	1,243	42.7		
60 or older	8,783	35.0	333	11.4		
Type of Information Seeker					40.0	< .001
Patient or caregiver	3,024	12.0	235	8.1		
General public	22,086	88.0	2,676	91.9		

Note. Percentages may not add to 100% due to rounding error.

Table 3
Ethnic differences in trends of LiveHelp utilization between 2003 and 2006 (N = 28,021)

Year	Communication channel	Ethnicity				Difference (% Non-Hisp. - % Hisp.)	Wald χ^2 <i>p</i>	Wald χ^2 <i>p</i> [†]	OR (95% CI) [†]
		Non-Hispanic (n=25,110)		Hispanic (n=2,911)					
		N	%	N	%				
2003	LiveHelp	20	0.1	2	0.1	0.0	0.03	0.3	0.7 (0.2—3.0)
	Telephone	15,375	99.9	1,352	99.9		.86	.69	
2004	LiveHelp	131	2.4	13	1.5	0.9	2.5	1.1	1.4 (0.7—2.8)
	Telephone	5,372	97.6	849	98.5		.11	.23	
2005	LiveHelp	145	7.1	11	3.4	3.7	6.1	4.3	3.1 (1.1—5.2)
	Telephone	1,887	92.9	314	96.6		.014	.038	
2006	LiveHelp	266	12.2	19	5.1	7.1	14.9	5.4	1.9 (1.1—3.4)
	Telephone	1,914	87.8	351	94.9		<.001	.02	

[†]: adjusted for educational attainment, age, and race.