Seeking Cancer Information: An Appalachian Perspective

Journal of Health Disparities Research and Practice

Volume 2 | Issue 1 Article 7

2008

Seeking Cancer Information: An Appalachian Perspective

Robin C. Vanderpool , *University of Kentucky*
Bin Huang , *University of Kentucky Markey Cancer Control Program*
Brent J. Shelton , *University of Kentucky*

Recommended Citation

Vanderpool, Robin C.; Huang, Bin; and Shelton, Brent J. (2008) "Seeking Cancer Information: An Appalachian Perspective," *Journal of Health Disparities Research and Practice*: Vol. 2: Iss. 1, Article 7.
Available at: https://digitalscholarship.unlv.edu/jhdrp/vol2/iss1/7

Seeking Cancer Information: An Appalachian Perspective

Abstract

There are noted disparities by ethnicity, race, age, gender, and socioeconomic status in the reported use of and access to cancer information. Missing from this list of variables that predict these disparities are specific geographic locales, such as Appalachia, a region recognized as a medically underserved, “special population”. Through a secondary analysis of NCI’s 2003 HINTS dataset, we are able to describe the cancer information-seeking behaviors of Appalachians as compared to non-Appalachians with a focus on actual versus preferential information-seeking behaviors, information-seeking experiences, and demographics. In general, Appalachians and non-Appalachians do not significantly differ in their cancer information-seeking behaviors and experiences. However, there are subtle, important differences related to the use and trust of health care providers and the Internet for cancer information. It is important to understand the effects that geography has not only on health outcomes, but also on access to and use of cancer information.

Keywords

Appalachia Region; Cancer; Disparities; Health education; HINTS; Information behavior; Information seeking; Medically underserved areas; Social status – Health aspects

Cover Page Footnote

The authors would like to acknowledge the staff of the National Cancer Institute’s Health Communications and Informatics Branch for their provision of the re-coded 2003 HINTS dataset that included a new “Appalachia” variable. In addition, Dr. Vanderpool is grateful for the guidance and support of her DrPH capstone committee: Drs. Stephen W. Wyatt, Brent J. Shelton, and Linda J. Alexander.

Journal of Health Disparities Research and Practice
Volume 2, Number 1, Fall 2007, pp. 79- 100

School of Public Health
University of Nevada, Las Vegas

Seeking Cancer Information: An Appalachian Perspective

Robin C. Vanderpool, University of Kentucky College of Public Health
Bin Huang, University of Kentucky Markey Cancer Control Program
Brent J. Shelton, University of Kentucky Colleges of Medicine and Public Health

Abstract

There are noted disparities by ethnicity, race, age, gender, and socioeconomic status in the reported use of and access to cancer information. Missing from this list of variables that predict these disparities are specific geographic locales, such as Appalachia, a region recognized as a medically underserved, "special population". Through a secondary analysis of NCI's 2003 HINTS dataset, we are able to describe the cancer information-seeking behaviors of Appalachians as compared to non-Appalachians with a focus on actual versus preferential information-seeking behaviors, information-seeking experiences, and demographics. In general, Appalachians and non-Appalachians do not significantly differ in their cancer information-seeking behaviors and experiences. However, there are subtle, important differences related to the use and trust of health care providers and the Internet for cancer information. It is important to understand the effects that geography has not only on health outcomes, but also on access to and use of cancer information.

Key Words: cancer, information seeking, Appalachia, HINTS, disparities

Introduction

Health information can literally save lives. According to Nelson, et al. (2004), "at all stages of disease, from prevention to diagnosis, to treatment, to end of life, effective health communication can empower people to make informed health-related decisions and to engage in behaviors that can improve their health." Health information is essential for disease prevention, a central tenet of public health in that both the public and the health care community are aware of health risks, preventive measures, treatment options, and effective strategies for maintaining a high quality of life (Ray and Donohew, 1990).

Muha and colleagues (1998) assert that information can help individuals cognitively interpret an adverse event such as cancer and take the appropriate action to lessen the threat of disease. Additionally, health information positively affects social and emotional adjustment, attitudes and knowledge, behaviors, self-efficacy, and compliance with healthcare advice (Johnson, 1997).

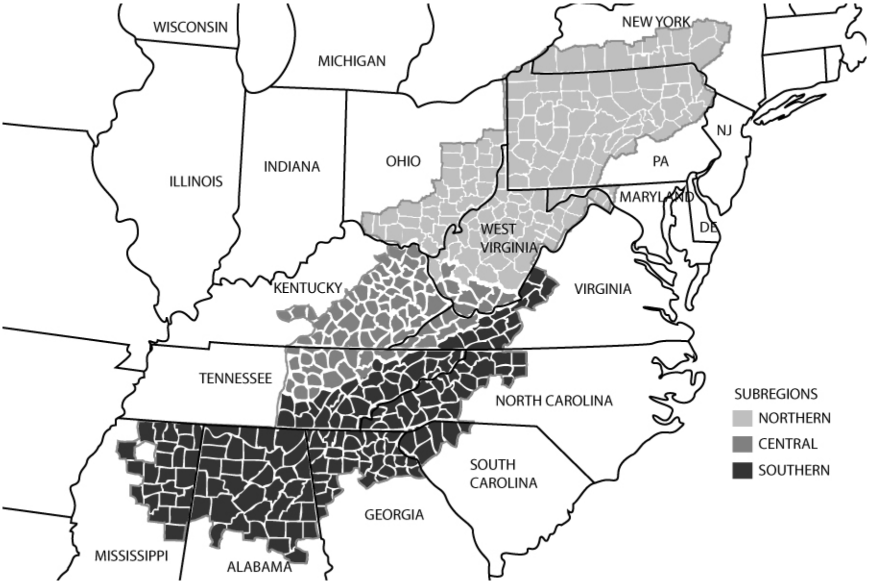
The benefits of health information, however, must be examined in the context of the advancements in healthcare, technology, and information resources over the past 50 years. Advancement often results in complexity, and in today's society health information is more complex because of complicated treatment options, constantly changing prevention and screening guidelines, and the influences of both the media and the Internet. In addition, the uneven distribution of health technologies, along with limited access to and use of the computer, has created a "digital divide" between some populations (Hesse, et al., 2005; Murray, et al., 2003; Eng, et al., 1998). Both the media and Internet can serve as credible sources of health information or can provide misinformation, resulting in harm.

Understanding individuals' health information-seeking behaviors, especially as they relate to cancer – the second leading cause of death in the country – is a priority for health communication researchers at the federal, state, and local levels. As argued by Johnson (1997), "changes in public knowledge, attitudes, and behavior regarding cancer are critical in controlling cancer." Moreover, Kreps (2003) contends that cancer information that is accurate, trustworthy, understandable and effectively disseminated has great potential to help reduce cancer risk, incidence, morbidity and mortality as well as to improve quality of life.

It is discouraging, however, to find that many Americans' knowledge of cancer is limited (Breslow, et al., 1997; Loehrer, et al., 1991; Johnson, 1997; Freimuth, et al., 1989; Gansler, et al., 2005) and there are noted disparities by ethnicity, race, age, gender, and socioeconomic status in access to and use of cancer information (O'Malley, et al., 1999; Benjamin-Garner, et al., 2002; Nicholson, et al., 2003; Freimuth, et al., 1989). Missing from this list of variables that predict disparities in use of and access to information are variables by specific geographic location, such as the Appalachian region of the United States.

As defined by the federally created Appalachian Regional Commission (ARC), Appalachia is a 200,000-square-mile geographically diverse region that follows the spine of the Appalachian Mountains from southern New York to northern Mississippi (Figure 1). It includes all of West Virginia and portions of 12 other states: Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, and Virginia (ARC, 2007). In 2000, approximately 23 million people, or 8% of the US popu-

Figure 1. Map of Appalachia.



lation, lived in the 410 counties and eight independent cities of the Appalachian region. Approximately 65% of the counties in Appalachia are rural and 42% of the region's residents reside in these counties (Pollard, 2003).

While Appalachia is known for its storied history; agriculture, coal and lumber resources; beautiful mountain scenery; music, arts and crafts; and values of religion, individualism, self-sufficiency, family, hospitality, patriotism, modesty, and love of place (Helton, 1995; Williams, 2002; Peterson, 1973; Couto, 1994; Newell-Whitrow, 1997, Caudill, 1963; Weller, 1965), its residents are also identified as a "special population" because of their higher rates of acute and chronic diseases, disability, and mortality (Portnoy, 1994; IOM, 1999; Friedell, et al, 2001). Furthermore, the Appalachian region experiences higher rates of unemployment and poverty, lower rates of education, and greater geographic isolation. Appalachian populations experience higher cancer incidence and mortality rates for preventable cancers such as lung, cervix, and colorectal cancer (Huang, et al., 2002; Lengerich, et al., 2005; Hall, et al., 2000; Armstrong, et al., 2004; Halverson et al., 2004; IOM, 1999). Smoking, obesity, lower breast and cervical cancer screening rates, and poor health status are prevalent in the region, and many Appalachian communities have limited access to health care providers, health insurance, community services and new technologies (Hall, et al., 2002; Amonkar and Madhavan, 2002; Halverson, et al., 2004; Murray, et al., 2005; Behringer, 1994; Ahijevych, et al., 2003, NCI, 2005). Murray and colleagues (2005) contend that poor whites in Appalachia have a life expectancy equal to that of residents of Mexico and Panama. In addition, the Appalachian region has also been identified by some authors as "information poor" due to their lower socioeconomic status and fatalistic beliefs (Childers, 1975).

Based on these findings, it is hypothesized that residing in Appalachia negatively affects the cancer information-seeking behaviors and experiences of Appalachians compared with that of non-Appalachians as determined by analyzing data from the National Cancer Institute's (NCI) 2003 Health Information National Trends Survey (HINTS), a cross-sectional, nationally representative health survey of the American population.

The research is guided by Johnson's (1997) Comprehensive Model of Information Seeking (CMIS) which is based on the health belief model, uses and gratification research, and a model of media exposure and appraisal and is a result of research related specifically to cancer information-seeking. The model suggests that four health-related factors – demographics, direct experience, salience, and beliefs – determine the basic need to seek information.

Methods

The National Cancer Institute developed and implemented the biennial Health Information National Trends Survey (HINTS) in response to the need to learn how Americans gain access to cancer information, what sources are used, the level of trust in those sources and the information received, and the factors that positively or negatively affect cancer communication experiences (NCI, 2005). The 2003 HINTS survey is a regionally stratified, national probability telephone survey of 6,369 persons over the age of 18 years among the general population with oversampling among African Americans and Hispanics (Nelson, et al., 2004). Data was collected from October 2002 through April 2003.

The 2003 HINTS dataset is publicly available on the HINTS Web site (http://hints.cancer.gov) and allows users to analyze the data by two geographic areas – (1) US Census Regions and (2) US Department of Agriculture rural-urban continuum codes. County-level information is included in the dataset; however, at this time, the data are not available publicly because of confidentiality issues. Through a special request of the NCI Health Communications and Informatics Research Branch, the authors received a re-coded dataset that contained a newly created "Appalachia" variable. The NCI researchers matched the Federal Information Processing Standards (FIPS) Codes (US Census, 2005) for US counties and independent cities identified by the Appalachian Regional Commission as Appalachian (ARC, 2007) to the list of telephone exchanges used in the random digit dialing. Analysis of the re-coded 2003 HINTS dataset was approved by the University of Kentucky Institutional Review Board (Protocol # 05-0216-X2G) on March 17, 2005. Based on the new Appalachian variable, 540 respondents were classified as Appalachian and 5829 were classified non-Appalachian (Table 1). Appalachian respondents comprise 8.6% of the entire sample, which is comparable with the percentage of the national population that resides in the Appalachian region (8%) (Pollard, 2003).

Table 1. 2003 HINTS Sample Based on the New "Appalachia" Variable.

	Appalachia	Non-Appalachia	Total
Population Size	18,006,229	191,448,161	209,454,391
Sample Size (%)	540 (8.6)	5829 (91.4)	6369 (100)

SUDAAN 9.0 statistical software was used to complete the analyses. SUDAAN is a commercially available and extensively used software system developed specifically for survey data analysis and is ideal for complex health surveys such as HINTS (LaVange, et al., 1996; RTI International, 2005). Frequencies and weighted distributions were calculated for Appalachian and non-Appalachian respondents' sociodemographics, health-related variables, personal and family history of cancer, and cancer information-seeking behaviors and experiences. Cross tabulations and chi-square analyses were performed to compare differences among groups. Results with $p \leq 0.05$ were considered statistically significant.

Results

Based on the findings of the current research, it is suggestive that, overall, Appalachians do not differ from non-Appalachians in their cancer information-seeking behaviors. However, there are observed differences between the two groups on selected demographic characteristics, smoking behaviors, use and trust of health care providers and the Internet for cancer information, and experiences with the Internet.

Sociodemographics and Health-related Variables. As illustrated in Table 2, Appalachian and non-Appalachian respondents differed significantly on ethnicity and race, income, and education. In analyzing selected health-related variables (Table 3), the data revealed that Appalachians rated their health status less favorably, smoked more cigarettes, and were more likely to be obese compared to their non-Appalachian counterparts. There were no significant differences between Appalachians and non-Appalachians for both personal and family history of cancer.

Cancer Information Seeking. HINTS allows researchers to explore several different areas related to past and future cancer information-seeking experiences. As presented in Table 3, Appalachians (47%) have searched for cancer information at higher rates than non-Appalachians (45%), but the difference is not statistically significant. In addition to whether respondents had ever looked for cancer information, HINTS asks where individuals actually obtain their cancer information (where they've looked most recently) versus where they would prefer to get their cancer information if a strong need for information arose.

Overall, there were no differences in where Appalachians and non-Appalachians would prefer to obtain their cancer information. The three most common responses in decreasing order for both groups were health care providers, the Internet, and the library. While both groups chose their health care provider as their preferred source of cancer information, Appalachians did so at higher rates (55% vs. 48%) and non-Appalachians chose the Internet more often (34% vs. 28%). In order to explore this trend further, additional analyses were completed that revealed that when comparing health care providers with all other potential sources of cancer information, and the Internet with all other potential sources, there was a significant distinction between Appalachians and non-Appalachians (p=0.0067 and p=0.0294, respectively). This distinction was not found for any other sources of information (i.e., the library, family/friends, cancer organizations and telephone services, print media, or electronic media).

In exploring where individuals most recently looked for cancer information (actual), there were no significant differences between Appalachians and non-Appalachians. The Internet (42% Appalachia, 46% non-Appalachia) was the most common source of cancer information for both groups. Print media were reported second for both groups, followed by health care providers. Interestingly, Appalachians (16%) actually used their health care provider for cancer information more so than non-Appalachians (10%). When compared with all other sources of information, this finding was statistically significant (p=0.0140). No other significant distinctions were found for the other sources of information.

To further explore the higher use of the Internet in both groups' most recent search for cancer information, the current research examined the Internet usage questions from HINTS (Table 4). Significantly fewer Appalachians

Table 2. Demographic Variables

	Appalachia (%)	Non-Appalachia (%)	P-Value
Age			0.1252
18 - 34	125 (28.5)	1530 (31.5)	
35 – 49	153 (27.8)	1801 (31.3)	
50 – 64	132 (24.7)	1360 (21.2)	
65 – 74	70 (11.7)	624 (9.5)	
75+	56 (7.4)	491 (6.5)	
Female	323 (51.8)	3525 (52.0)	0.9451
Non-Hispanic	498 (94.9)	4848 (87.8)	<0.0001
Race			<0.0001
White	522 (90.7)	4164 (79.5)	
Black or African American	32 (5.0)	708 (11.9)	
Other	22 (4.3)	406 (8.6)	
Education			<0.0001
Elementary or no education	20 (4.3)	275 (6.1)	
Middle/HS education/GED	257 (57.1)	2023 (41.6)\	
Some college / college graduate	250 (38.6)	3314 (52.3)	
Annual Income			<0.0001
Less than $15,000	191 (39.2)	1518 (28.1)	
Between $25,000 - $35,000	70 (15.4)	717 (13.2)	
Between $36,000 - $50,000	85 (17.7)	873 (17.3)	
Between $51,000 -$75,000	80 (17.1)	875 (17.5)	
Greater than $75,000	5 (10.6)	1161 (23.9)	
Marital Status			0.1099
Married or living together	288 (62.8)	3167 (63.7)	
Divorced or separated	89 (12.2)	899 (10.9)	
Widowed	78 (8.4)	550 (6.0)	
Never been married	73 (16.6)	992 (19.5)	
Employment Status			0.1150
Employed	283 (55.3)	3351 (60.2)	
Unemployed	36 (7.9)	301 (5.9)	
Retired	104 (16.5)	990 (14.6)	
Unable to work	34 (6.3)	248 (4.4)	
Other	71 (14.0)	715 (14.9)	

Table 3. Health-related Variables

	Appalachia (%)	Non-Appalachia (%)	P-Value
Self-report Health Status			
Excellent	49 (8.5)	758 (13.5)	0.0156
Very good	153 (28.8)	1750 (30.3)	
Good	181 (34.6)	1882 (33.5)	
Fair	107 (20.1)	992 (18.2)	
Poor	38 (8.1)	241 (4.5)	
Health Insurance Coverage	467 (86.7)	4890 (85.3)	0.4806
Smoked 100 cigarettes lifetime	257 (52.3)	2671 (48.0)	0.1039
Current Smoking Status			
Everyday	111 (43.6)	832 (34.0)	0.0149
Some days	17 (7.2)	286 (11.5)	
Not at all	129 (49.3)	1552 (54.5)	
Body Mass Index			
BMI <18.5 (underweight)	14 (3.4)	106 (1.9)	0.3354
BMI 18.5-24.9 (normal)	210 (41.3)	2305 (41.6)	
BMI 25.0-29.9 (overweight)	155 (30.5)	1847 (33.8)	
BMI 30.0+ (obese)	136 (24.9)	1214 (22.7)	
Cancer Diagnosis	73 (12.0)	690 (10.7)	0.3926
Family history of cancer	354 (63.4)	3614 (61.9)	0.6109
Ever looked for cancer information	266 (47.3)	2745 (44.7)	0.3336

(55%) ever go on-line to access the Internet or send and receive email than their counterparts (64%); however, both groups have similar home Internet use rates (83% Appalachia, 87% non-Appalachia). More Appalachians (49%) have visited a Web site to learn about cancer compared to non-Appalachians (41%). For those HINTS respondents who have Internet access at home, Appalachians (77%) use basic phone modems more so than non-Appalachians (66%). Non-Appalachians are using faster Internet technology, including broad-band connections through cable or DSL modems, more so than Appalachians.

Trust in the Cancer Information Source. Trust in the information source is an important factor in whether an individual chooses to use a source for cancer information. HINTS asks individuals how much they would trust information about cancer from health care professionals, family or friends, print media, electronic media, and the Internet. Appalachians (65%) tend to trust cancer information "a lot" from a health care provider more so than do non-Appalachians (62%). About a quarter of Appalachians and non-Appalachians tend to "not at all" trust cancer information from the Internet (28% Appalachians, 22% non-Appalachians). When "not at all" is compared with all other responses to this specific question, there is a significant difference with the percentage of Appalachians not trusting the Internet at all compared with Appalachians (p=0.0339). There were no significant differences between the two groups for trust in other sources of information (e.g., family/friends, print media, and electronic media).

Cancer Information-Seeking Experiences. In order to further characterize an individuals' most recent search for cancer information, the HINTS survey inquires about their information-seeking experience. Experience-related variables include wanting more information, but not knowing where to find it; it took a lot of effort to get the needed information; not enough time; frustrated during the search; concerned about the information quality; the information was too hard to understand; and information satisfaction. The current research first analyzed these variables without identifying the type of information source accessed in the respondents' most recent search for cancer information. There were no significant differences between Appalachians and non-Appalachians for any of the experience-related variables.

However, when exploring the respondents' experiences based on the source of cancer information they used (e.g., Internet, health care provider) in their most recent search, 63% of Appalachians who used the Internet, strongly agreed or somewhat agreed that they wanted more information, but didn't know where to find it compared with 45% of non-Appalachians. Even though the other Internet experience-related variables were not significant, there was a trend of Appalachians requiring more effort to find information, not having enough time to get all the information needed, feeling frustrated, concerned about the quality, and finding the information too hard to understand.

None of the health care provider experience-related variables was significantly different between the two groups; however, 96% (strongly agree, somewhat agree) of Appalachians were satisfied with their experience with their health care provider compared with 86% of non-Appalachians. Interestingly, more Appalachians (66%, strongly agree and somewhat agree) were concerned about the quality of information from the health care provider than were non-Appalachians (51%), and more Appalachians (54% strongly agree and somewhat agree) wanted more information but didn't know where to find it (47% non-Appalachians).

Table 4. Internet Usage

	Appalachia (%)	Non-Appalachia (%)	P-value
Ever go on-line	290 (55.1)	3692 (63.9)	0.0021
Access Internet from home	244 (82.6)	3172 (87.19)	0.1174
Accessed cancer information via Internet	111 (49.2)	1246 (41.4)	0.0605
Home Internet Technology			
Telephone modem	187 (77.3)	2118 (65.6)	<0.0001
Cable or satellite modem	46 (19.9)	641 (22.6)	
DSL modem	7 (2.5)	337 (10.8)	
Wireless device [PDA]	1 (0.41)	15 (0.37)	
Other	--	12 (0.58)	

Discussion

There are differences between Appalachians and non-Appalachians related to demographic characteristics, smoking status, the use and trust of health care providers and the Internet for cancer information, and experiences with the Internet, but generally Appalachians and non-Appalachians exhibit similar patterns of cancer information-seeking behaviors and experiences.

Demographics and Health Behaviors

Consistent with other research (Pollard, 2003; Huttlinger, et al., 2004; Amonkar and Madhavan, 2002; Murray, et al., 2005; Ahijevch, et al., 2003; Wewers, et al., 2000), Appalachian respondents were primarily non-Hispanic white, had lower incomes, less college education, lower perceptions of their health status, and higher rates of negative health behaviors/conditions such as smoking and obesity than did non-Appalachians.

Cancer Information-Seeking Behaviors and Experiences

The analyses of the preferences for information versus actual sources of information indicated that respondents in all groups highly preferred to get cancer-related information from their health care provider, but found that the Internet and print media are much easier to access. If health care providers are not accessible or if it requires a great effort to contact them, individuals may turn to inferior sources that may be more accessible, but not necessarily credible, up-to-date, or authoritative (Johnson, 1997).

There are valid concerns that using the Internet can lead to misinformation as well as damage the doctor-patient relationship (Anderson, et al., 2003; Murray, et al., 2003; Eng and Gustafson, 1999; Berland, et al., 2001; Esyenbach, 2003). As discussed earlier, new technologies, including the Internet, also have the potential to increase the health disparities between those who have online access to health information and those who do not (Murray, et al., 2003; Eng, et al., 1998). Considering Fox and Fallows' (2003) report that half of American adults have searched online for health information and Eysenbach's (2003) calculations that 2.3 million cancer survivors and their families/friends worldwide are online, this is a primary concern for the health care community.

While the Internet poses a formidable challenge to consumers and the health care system, it still has the potential to serve as a tool for enhancing health, minimizing disease burden, and maximizing the full potential of the doctor-patient relationship (Eng and Gustafson, 1999). If made widely and easily accessible to disparate populations, there is reason to believe the Internet could provide needed cancer information in varying formats and media to those who experience an undue burden of cancer, including the residents of Appalachia. An illustration of this point was noted in the Results – when both Appalachians and non-Appalachians had Internet access at home, usage rates were similar (Appalachia 82%, non-Appalachia 87%). Johnson and colleagues (2006) state, "the Internet itself represents a cluster of information matrices that for some people may be interpersonal, authoritative, or mass media" and for this reason, regardless of status – patient or health care provider – the Internet has changed the nature and process of cancer information-seeking (Case, et al., 2004).

Both groups highly preferred to go to their health provider for cancer information, but Appalachians did more so than did non-Appalachians, and non-Appalachians preferred the Internet more so than their counterparts in Appalachia. Following a similar pattern to the preference question, non-Appalachians actually used the Internet more than Appalachians for cancer information and Appalachians went to their health care providers more often than their counterparts. From these results, one could reason that even with the advent of the Internet and the wealth of health information found on the Web, Appalachians still desire and maintain a constant relationship with their health care providers. However, it is interesting to note that although Appalachians prefer health providers as their source of cancer information, the region is characterized by health professional shortages, including specialists and general preventive medicine and public health practitioners (Behringer, 1994). Physicians practicing in Appalachia tend to cluster near prosperous, higher-income counties, leaving some counties with declines in physician supply or without a primary care provider at all (Stensland, et al., 2002).

Several factors may influence this scenario of Appalachians placing a high value on their doctor-patient relationship. It is documented that Appalachian populations tend to be older (Pollard, 2003) and perhaps older Appalachian residents still covet the doctor-patient relationship and adhere to the traditional, paternalistic view of health care (Roter and Hall, 1997). Appalachian populations are also known to favor close, tight-knit, personal relationships (Helton, 1996; Helton, 1995), which usually cannot be achieved over the Internet or through media sources, but could be established with health care providers in small, rural communities. Donahue and colleagues (2005) also suggest that individuals who have a usual place of healthcare and a usual physician (i.e., continuity of care), have higher levels of trust and satisfaction in their physician. Finally, Appalachians may rely on their physicians for cancer information because other resources (e.g., community organizations, health educators, libraries, community centers) are not available in their communities or they may be in limited supply (Engelman, et al., 2005). Similar to other rural populations, Appalachians may lack awareness of national resources such as the NCI's Cancer Information Service (Engelman, et al., 2005).

In addition, it was discovered through the current research that Appalachians do not trust the Internet as readily as do non-Appalachians. Similarly, Appalachians who used the Internet in their most recent search for cancer information were inclined to want more information, but didn't know where to find it than were non-Appalachians. This finding is similar to research by Fox and Fallows (2003) that found many Internet health users would like access to health information on subscription-only Web sites, while others wanted information that already exists, but users simply didn't notice it or were unable to locate it on the Internet. Murray and colleagues (2003) also discovered that 25% of national survey respondents who went online for health information were not able to find information relevant to their needs.

Even though the other experience-related Internet variables were not statistically significant, there was a notable trend that indicated that Appalachians have a more overall negative experience with the Internet than did non-Appalachians. It is reasonable to believe that negative cancer information-seeking experiences with the Internet may contribute to lower levels of trust and use of the Internet as a source of cancer information. Similarly, Appalachians tend to use basic telephone modems (77%) to access the Internet, which are often characterized as slow and tie up the home telephone line thus leading to frustration while looking for cancer information. This finding is similar to results reported by Bell and colleagues (2004) for rural Americans (19%), who have not adopted broad-band as readily as their urban (36%) and suburban counterparts (32%). New rural Internet users (50%) are more likely to have mixed feelings about computers and technology than are new users living in urban (32%) and suburban (27%) locations (Bell, et al., 2004).

Even though both study populations are using the Internet at high rates to access cancer information, health care providers should recognize that patients still value the doctor-patient relationship and place a high level of trust in that relationship (Murray, et al., 2003; Chen and Siu, 2001). Exploring the levels of trust in various information sources can provide a wealth of information, including points for intervention. Specifically, physicians and other health care providers working in Appalachia should be made aware of the higher levels of trust Appalachians place in health professionals and the lower levels they place on the Internet.

Conclusions

As a result of the research presented here, the authors contemplated the policy implications of health disparities research in Appalachia, specifically quantitative survey research. As mentioned earlier, Appalachians have been identified by the federal government as "medically underserved" and as a "special population" (IOM, 1999; Portnoy, 1994). In response to this designation, policymakers and researchers should advocate for more survey research within Appalachia. This call has already been made for more research among other special populations, with efforts focusing on different ethnicities, races, languages, and socioeconomic levels (NCVHS, 2005; Trans-HHS Cancer Health Disparities Progress Review Group, 2004). It is suggested that federal health agencies such as NCI and CDC consider the following strategies to further the understanding of Appalachian cancer health disparities:

- Undertake a comprehensive review to determine how accurately Appalachian populations are represented in national health surveys.
- Provide technical assistance to researchers conducting survey research among Appalachian residents. This could include the NCI HINTS team working with local researchers to replicate the survey in Appalachia using university-based or private survey research centers.
- Provide funding opportunities for survey methodology, geocoding, and community-based participatory research in Appalachia.
- Explore the development of a Web portal or national print publication designed to disseminate "best practices" of survey research conducted in Appalachia.
- Supplement quantitative research with qualitative analyses of cancer information-seeking in Appalachia.

By actively pursuing and engaging in these Appalachian-related research strategies, the stage is set to inform national, regional, state, and local data collection initiatives conducted by federal health agencies, state health departments, universities, and individual researchers.

Another policy-related issue to consider is the breadth of the ARC's Appalachian designation. The ARC-designated region consists of 410 counties in 13 states. It is a heterogeneous and expansive area comprised of different racial, ethnic, cultural, and socioeconomic groups residing in a continuum of rural-urban communities. Couto (1994) laments about the ARC region that, "…the Appalachian Mountains are only part of the logic of this broad geographic definition. Other parts of that logic include economic similarities, contiguity, measures of low income and human well-being, and congressional representation of senators and members of the House of Representatives…Obviously, this geographic region is not the hidden, socioeconomically homogeneous, remote, and distinct region that may reside in the popular imagination."

One could argue that the results of this research are an artifact of comparing the entire Appalachian region to non-Appalachia. A broad, overarching look at the differences between the two large geographic areas may not be as meaningful as would detailed results by the three Appalachian sub-regions (e.g., Northern, Central, and Southern), individual Appalachian states, and individual Appalachian counties. Many communities within Central Appalachia, for example, are recognized for greater geographic isolation, lower socioeconomic status, and more negative health outcomes compared to the other two sub-regions.

Limitations

There are important limitations to secondary analysis of survey data. The primary disadvantage is that the 2003 HINTS data were collected for purposes other than an investigation into the differences between Appalachian and non-Appalachian populations. As referenced earlier, the "Appalachia" variable was not an original variable of HINTS, but was created by NCI researchers at the request of the author. In addition, the 2003 iteration of HINTS is considered a cross-sectional survey, limited to collecting data only at one point in time. Fortunately, the results from the 2005 and 2007 HINTS surveys will provide trend data for the hundreds of variables collected in the first HINTS.

To date, the HINTS survey is primarily conducted via telephone. There are inherent limitations of a random-digit telephone surveys, including the under-representation of less educated, lower income individuals, men, younger and older adults, racial and ethnic minority groups, and individuals with less knowledge of the subject matter (Krosnick and Chang, 2003). Moreover, participation in the survey is available only to those who have a home telephone. According to Pollard (2003), 3% of Appalachian households (296,000) lack telephone service compared with 2% of homes outside the region (2000 US Census). In 23 specific Appalachian counties, phone service was absent in at least 10% of households, and in Holmes County, Ohio, an Amish community, 28% of households were without telephone service (Pollard, 2003). There is also a noticeable decline in the responses to telephone surveys most likely due to the public's greater use of cell phones, disdain for telemarketers, fear of personal information being distributed and sold to other companies, and individuals simply protecting their personal time.

Notably, self-report and selection bias may also affect the study's results. All responses are based on self-report, rather than measuring actual behavior. Respondents may misinterpret questions, inaccurately recall their most recent cancer information-seeking experience, or base their answers on social desirability or approval. Last, the HINTS findings are a result of the responses given by only those individuals who purposely chose to participate in the survey. The available HINTS data do not allow for comparisons between responders and non-responders.

Conclusion

Although the overall findings in this study revealed that Appalachians and non-Appalachians did not differ significantly in their cancer information-seeking behaviors and experiences, several important, subtle differences were observed between the two groups. These differences include Appalachian respondents' greater use of and trust in health care providers and more negative experiences with the Internet compared with non-Appalachians.

Based on the reported results, it is important for public health professionals to recognize that while the Internet has potential as an important tool in providing cancer information, it is not necessarily the preferred or most trusted source of cancer information by some populations. In addition, public health professionals, particularly those serving Appalachian residents, should promote the physician-patient relationship as the primary mechanism for discussing cancer-related questions, for encouraging people to adopt behaviors that lower their risk of getting cancer, and for obtaining referrals for trustworthy cancer information sources.

This line of thinking also calls for public health professionals to redefine their notion of "hard-to-reach" populations. Appalachian residents are often considered hard-to-reach, chronically uninformed, disadvantaged, fatalistic, and information poor. Freimuth and Mettger (1990) advocate the use of new terminology and strategies, such as describing these populations as "other advantaged" rather than "disadvantaged"; considering what makes "special populations" unique in a positive sense rather than in a negative sense; taking into account the role society plays in the individuals' plight rather than placing the blame solely on the individual; and, last, engaging the population in a complementary dialogue rather than a one-sided conversation. Adoption of this new language and empathetic strategies could greatly enhance cancer education outreach to Appalachians. Couto (1994) argues that Appalachians are just like other Americans and that as a society we need to "unlearn" many of the negative stereotypes and misconceptions that have characterized the region for so long.

In closing, this research is intended to inform health care professionals, policymakers, program planners, researchers and community members about the cancer information-seeking behaviors of a "special population" and provide those who disseminate cancer information (e.g., health organizations, the media, health care providers, cancer information specialists) with evidence to help them reach a unique, traditionally underserved population of Americans more effectively. Kaplan (1999) and Phillips and McLeroy (2004) contend that it is important for the public health research community to understand the effects that geography has on the health of individuals and populations. The authors of this paper advocate extending this line of health disparities-related research to include understanding the influence of geography on access to and use of cancer information.

Acknowledgements

The authors would like to acknowledge the staff of the National Cancer Institute's Health Communications and Informatics Branch for their provision of the re-coded 2003 HINTS dataset that included a new "Appalachia" variable. In addition, Dr. Vanderpool is grateful for the guidance and support of her DrPH capstone committee: Drs. Stephen W. Wyatt, Brent J. Shelton, and Linda J. Alexander.

References

Ahijevch K, Kuun P, Christman S, Wood T, Browning K, Wewers ME. (2003). Beliefs about Tobacco Among Appalachian Current and Former Users. Applied Nursing Research. 16(2):93-102.

Amonkar MM, Madhavan S. (2002). Compliance rates and predictors of cancer screening recommendations among Appalachian women. Journal of Health Care for the Poor and Underserved. 13(4):443-459.

Anderson JG, Rainey MR, Esysenbach G. (2003). The Impact of CyberHealthcare on the Physician-Patient Relationship. Journal of Medical Systems. 27(1):67-84.

Appalachian Regional Commission (2007). Appalachian Region. Available at: http://www.arc.gov/index.do?nodeId=2 Accessed March 31, 2007.

Armstrong LR, Thompson T, Hall HI, Coughlin SS, Steele B, Rogers JD. (2004). Colorectal Carcinoma Mortality among Appalachian Men and Women, 1969-1999. Cancer. 101:2851-8.

Behringer B. (1994). Health Care Services in Appalachia. In: Couto RA, Simpson NK, and Harris G. (Eds). Sowing Seeds in the Mountains: Community Based Coalitions for Cancer Prevention and Control. Washington, DC: National Cancer Institute. NIH Publication No. 94-3779.

Bell P, Pavani R, Rainie L. (February 2004). Rural Areas and the Internet. Washington, DC: Pew Internet & American Life Project. Available at: http://www.pewinternet.org/pdfs/PIP_Rural_Report.pdf Accessed February 12, 2006.

Benjamin-Garner R, Oakes MJ, Meishcke H, Meshack A, Stone EJ, Finnegan JR, Wallace L, Taylor J, McGovern P. (2002). Sociodemographic differences in exposure to health information. Ethnicity & Disease. 12:124-134.

Berland GK, Elliott MN, Morales LS, Algazy JI, Kravitz RL, Broder MS, Kanouse DE, Munoz JA, Puyol JA, Lara M, Watkins KE, Yang H, McGlynn EA. (2001). Health information on the Internet: Accessibility, Quality, and Readability in English and Spanish. Journal of the American Medical Association. 285(20): 2612-2621.

Breslow RA, Sorkin JD, Frey CM, Kessler LG. (1997). Americans' Knowledge of Cancer Risk and Survival. Preventive Medicine. 26:170-177.

Case DO, Johnson JD, Andrews JA, Allard SL, Kelley KM. (2004). From two-step flow to the Internet: The changing array of sources for genetics information seeking. Journal of the American Society for Information Science and Technology. 55(8): 660-669.

Caudill HM. (1963). Night Comes to the Cumberlands: A Biography of a Depressed Area. Boston: Little, Brown and Company.

Centers for Disease Control and Prevention. BMI-Body Mass Index: BMI for Adults: What Does This All Mean? Available at: http://www.cdc.gov/nccdphp/dnpa/bmi/bmi-means.htm Accessed January 27, 2006.

Chen X, Siu LL. (2001). Impact of the Media and the Internet on Oncology: Survey of Cancer Patients and Oncologists in Canada. Journal of Clinical Oncology. 19(23):4291-4297.

Childers T. (1975). The Information-Poor in America. Metuchen, NJ: The Scarecrow Press, Inc.

Couto R. (1994). Appalachia. In: Couto RA, Simpson NK, and Harris G. (Eds). Sowing Seeds in the Mountains: Community Based Coalitions for Cancer Prevention and Control. Washington, DC: National Cancer Institute. NIH Publication No. 94-3779.

Donahue KE, Ashkin E, Pathman DE. (2005). Length of Patient-physician Relationship and Patients' Satisfaction and Preventive Service Use in the Rural South: A Cross-sectional Telephone Study. BMC Family Practice. 6:40.

Eng T, Gustafson D. (eds). Wired for Health and Well-Being: the Emergence of Interactive Health Communication. Science Panel on Interactive Communication and Health. Washington, DC: US Department of Health and Human Services, US Government Printing Office, April 1999. Available at: http://www.health.gov/scipich/pubs/finalreport.htm Accessed February 13, 2006.

Eng TR, Maxfield A, Patrick K, Deering MJ, Ratzan SC, Gustafson DH. (1998). Access to Health Information and Support: A Public Highway or Private Road. Journal of the American Medical Association. 280(15):1371-1375.

Engelman KK, Perpich DL, Peterson SL, Hall MA, Ellerbeck EF, Stanton AL. (2005). Cancer Information Needs in Rural Areas. Journal of Health Communication. 10:199-208.

Esyenbach G. (2003). The impact of the Internet on Cancer Outcomes. Cancer: A Cancer Journal for Clinicians. 53(6):356-371.

Fox S, Fallows D. (July 2003). Internet Health Resources. Washington, DC: Pew Internet & American Life Project. Available at: http://www.pewinternet.org/pdfs/PIP_Health_Report_July_2003.pdf Accessed February 11, 2006.

Friedell GH, Rubio A, Maretzki A, Garland B, Brown P, Crane M, Hickman P. (2001). Community Cancer Control in a Rural, Underserved Population: The Appalachian Leadership Initiative on Cancer Project. Journal of the Health Care for the Poor and Underserved. 12(1):5-19.

Freimuth VS and Mettger W. (1990). Is There A Hard-to-Reach Audience? Public Health Reports. 105:232-238.

Freimuth VS, Stein JA, Kean TJ. (1989). Searching for Health Information: The Cancer Information Service Model. Philadelphia: Univ of Pennsylvania Press.

Gansler T, Henley SJ, Stein K, Nehl EJ, Smigal C, Slaughter E. (2005). Sociodemographic Determinants of Cancer Treatment. Cancer. 104:653-660.

Hall HI, Rogers JD, Weir HK, Miller DS, Uhler RJ. (2000). Breast and Cervical Carcinoma Morality among Women in the Appalachian Region of the US, 1976-1996. Cancer. 89:1593-602.

Hall HI, Uhler RJ, Coughlin SS, Miller DS. (2002). Breast and Cervical Cancer Screening Among Appalachian Women. Cancer Epidemiology, Biomarkers, and Prevention. 11:137-142.

Halverson JA, Ma L, Harner EJ. (2004). An Analysis of Disparities in Health Status and Access to Health Care in the Appalachian Region. Executive Summary. Appalachian Regional Commission: Washington, DC.

Helton L. (1995). Intervention with Appalachians: Strategies for a Culturally Specific Practice. Journal of Cultural Diversity. 2(1):20-26.

Helton L. (1996). Folk Medicine and Health Beliefs: An Appalachian Perspective. Journal of Cultural Diversity. 3(4):123-128.

Hesse BW, Nelson DE, Kreps GL, Croyle RT, Arora, NK, Rimer BK, Viswanath K. (2005). Trust and Sources of Health Information. The Impact of the Internet and Its Implications for Health Care Providers: Findings from the First Health Information National Trends Survey. Archives of Internal Medicine. 165:2618-2624.

Huang B, Wyatt SW, Tucker TC, Bottorff D, Lengerich EJ, Hall HI. (2002).Cancer Death Rates Appalachia, 1994-1998. MMWR. 51(24):527-529.

Huttlinger K, Schaller-Ayers J, Lawson T. (2004). Health Care in Appalachia: A Population-Based Approach. Public Health Nursing. 21(2):103-110.

Institute of Medicine. (1999). The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved. Haynes MA and Smedley BD, Eds. Washington DC: National Academy Press.

Johnson JD. (1997). Cancer-related Information Seeking. Cresskill, NJ: Hampton Press, Inc.

Johnson JD, Case DO, Andrews J, Allard SL, Johnson NE. (2006). Fields and Pathways: Contrasting or Complementary Views of Information Seeking. Information Processing and Management. 42:569-582.

Kaplan GA. (1999). Location, Location, Location. Psychosomatic Medicine. 61:744-745.

Kreps GL. (2003). The Impact of Communication on Cancer Risk, Incidence, Morbidity, Mortality, and Quality of Life. Health Communication. 15(2):161-169.

Krosnick JA, Chang LC. (April 2001). A Comparison of the Random Digit Dialing Telephone Survey Methodology with Internet Survey Methodology as Implemented by Knowledge Networks and Harris Interactive. Available at: http://www.knowledgenetworks.com/ganp/docs/OSUpaper.pdf Accessed January 28, 2006.

LaVange LM, Lafata JE, Koch GG, Shah BV. (1996). Innovative Strategies using SUDAAN for Analysis of Health Surveys with Complex Samples. Statistical Methods in Medical Research. 5:311-329.

Lengerich EJ, Tucker TC, Powell RK, Colsher P, Lehman E, Ward AJ, Siedlecki JC, Wyatt SW. (2005). Cancer Incidence in Kentucky, Pennsylvania, and West Virginia: Disparities in Appalachia. Journal of Rural Health. 21(1):39-47.

Loehrer PJ, Greger HA, Weinberger M, Musick B, Miller M, Nichols C, Bryan J, Higgs D, Brock D. (1991). Knowledge and Beliefs about Cancer in a Socio-economically Disadvantaged Population. Cancer. 68(7):1665-71.

Muha C, Smith KS, Baum S, Ter Matt J, Ward JA. (1998). The Use and Selection of Sources in Information Seeking: The Cancer Information Service Experience. Journal of Health Communication. 3(Suppl):109-120.

Murray E, Lo B, Pollack L, Donelan K, Catania J, White M, Zapert K, Turner R. (2004). The Impact of Health Information on the Internet on the Physician-Patient Relationship: Patient Perceptions. Archives of Internal Medicine. 163:1727-1734.

Murray CJL, Kulkarni S, Ezzati M. (2005). Eight Americas: New Perspectives on US Health Disparities. American Journal of Preventive Medicine. 29(5S1):4-10.

National Cancer Institute. HINTS 1 Survey Instrument (English). July 2003. Available at: http://cancercontrol.cancer.gov:0/hints/docs/english_final_post_analysis.pdfAccessed April 27, 2005.

National Cancer Institute. National Health Information National Trends Survey. Available at: http://cancercontrol.cancer.gov Accessed December 30, 2005.

National Cancer Institute. (June 2005). Excess Cervical Cancer Mortality: A Marker for Low Access to Health Care in Poor Communities. NIH Publication No. 05-5282. Available at: http://crchd.nci.nih.gov/meetings/cervical_cancer_mortality/ Accessed January 28, 2006.

National Committee on Vital and Health Statistics, Subcommittee on Special Populations. (August 2005). Eliminating Health Disparities: Strengthening Data on Race, Ethnicity, and Primary Language in the United States. Available at: http://www.ncvhs.hhs.gov/051107rpt.pdf Accessed February 11, 2006.

Nelson DE, Kreps GL, Hesse BW, Croyle RT, Willis G, Arora NJ, Rimer BK, Viswanath KV, Weinstein N, Alden S. (2004). The Health Information National Trends Survey (HINTS): Development, Design, and Dissemination. Journal of Health Communication. 9:443-460.

Newell-Withrow C. (1997). A Glance at Appalachia. Journal of Cultural Diversity. 4(4):129-131.

Nicholson WK, Grason HA, Powe NR. (2003). The Relationship of Race to Women's Use of Health Information Resources. American Journal of Obstetrics and Gynecology. 188:580-5.

O'Malley AS, Kerner JF, Johnson L. (1999) Are we Getting the Message out to All? Health Information Sources and Ethnicity. Preventive Medicine. 17(3):198-202.

Peterson B. (1973). Southern Appalachia: "We Call Ourselves Hillbillies." In: National Geographic Society. American Mountain People. Washington, DC: National Geographic Society.

Phillips CD, McLeroy KR. (2004). Health in Rural America: Remembering the Importance of Place. American Journal of Public Health. 94(10):1661-1663.

Pollard K. (2003). Appalachia at the Millennium: An Overview of Results from Census 2000. Available at: http://www.arc.gov/index.do?nodeId=1839 Accessed April 27, 2005.

Portnoy B. (1994). Healthy People in Rural Areas by the Year 2000. In: Couto RA, Simpson NK, and Harris G. (Eds). Sowing Seeds in the Mountains: Community Based Coalitions for Cancer Prevention and Control. Washington, DC: National Cancer Institute. NIH Publication No. 94-3779.

Ray EB, Donohew L. (1990). Communication and Health: Systems and Applications. Hillsdale, NJ: Lawrence Erlbaum Associates.

Roter DL, Hall JA. (1997). Patient-Provider Communication. In: Glanz K, Lewis FM, Rimer BK. (Eds). Health Behavior and Education: Theory, Research, and Practice. 2nd Edition. San Francisco: Jossey-Bass.

RTI International (2005). About SUDAAN9. Available at: http://www.rti.org/sudaan/ Accessed April 27, 2005.

Stensland J, Mueller C, Sutton J. (December 2002). An Analysis of the Financial Conditions of Health Care Institutions in the Appalachian Region and their Economic Impacts. Available at: http://www.arc.gov/index.do?nodeId=1649 Accessed March 31, 2007.

US Census Bureau. Federal Information Processing Standards (FIPS) Codes. Available at: http://www.census.gov/geo/www/fips/fips65/data/national.txt Accessed April 28, 2005.

Trans-HHS Cancer Health Disparities Progress Review Group (March 2004). Making Cancer Health Disparities History. Available at: http://www.hhs.gov/chdprg/pdf/chdprg.pdf Accessed February 11, 2006.

Weller JE. (1965). Yesterday's People: Life in Contemporary Appalachia. Lexington: The University of Kentucky Press.

Wewers ME, Ahijevych KL, Chen MS, Dresbach S, Kihm KE, Kuun PA. (2000). Tobacco Use Characteristics Among Rural Ohio Appalachians. Journal of Community Health. 25(5): 337-388.

Williams JA. (2002). Appalachia: A History. Chapel Hill: The University of North Carolina Press.

Robin C. Vanderpool, DrPH, CHES, University of Kentucky College of Public Health

Bin Huang, MS, University of Kentucky Markey Cancer Control Program

Brent J. Shelton, PhD, University of Kentucky Colleges of Medicine and Public Health