

The Health Information National Trends Survey: Research From the Baseline

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The decades surrounding the turn of the millennium will be remembered as a time of extraordinary opportunity in cancer communication. In 1990, the number of age-adjusted deaths due to cancer in the U.S. population began a slow steady decline after a century of disparaging increase. Reasons for this decline have been attributed to long-awaited successes in primary prevention, especially related to tobacco, and early detection for cervical, breast, prostate, and colorectal cancers, as well as advances in treatment. This was also a time of unparalleled change in the cancer communication environment. Scientific health discoveries escalated with the completion of the Human Genome project in 2003, and penetration of the Internet made health information available directly to consumers. To seize the opportunity afforded by these changes, the National Cancer Institute (NCI) launched the Health Information National Trends Survey (HINTS). Fielded for the first time in 2003, the HINTS is a nationally representative, general population survey of non-institutionalized adults in the United States 18 years and older. This supplement contains a compilation of original research conducted using the data generated by the first administration of the HINTS telephone interviews. Covering topics in cancer knowledge, cancer cognition, risk perception, and information seeking, the articles represent an interdisciplinary view of cancer communication at the turn of the millennium and offer insight into the road ahead.

Context

Whether anyone knew it at the time, the year 1990 was a watershed moment for cancer communication researchers. To begin with, it was the first time that age-adjusted death rates from cancer begin to decline after a century of disparaging increases in cancer-related mortality (Ries et al., 1999). Reasons for the turn can be attributed to a constellation of factors including better detection and treatment options, but

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much of the decline can be chalked up to the success of cancer control advocacy in turning the tide on behavioral risk factors (Hiatt & Rimer, 1999). Just two and a half decades prior to 1990, at the time when the Surgeon General's report linking smoking to lung cancer was published, 45% of the population smoked and deaths from lung cancer were reaching all time highs. After two decades of steady health communication efforts, smoking rates in the United States fell to less than 25% of the adult population (Centers for Disease Control and Prevention, 1997), with a subsequent longer term drop off in lung cancer mortality. On an entirely different front, 1990 was also the year Tim Berners-Lee, a computer scientist at the CERN High Energy Physics Laboratory in Switzerland, proposed a small project to link documents through the Internet, a project he called the "World Wide Web" (Gaines, 2002).

Fast forward to 2003, the baseline year for the NCI's newly minted HINTS. Congress had just allocated its fifth year of double-digit funding increases to accelerate the nation's fight against cancer (Von Eschenbach, 2004), and public health progress in cancer prevention and control was continuing. The steady decline in age-adjusted cancer deaths continued its downward trend with progress influenced heavily by primary prevention efforts in tobacco and diet; secondary prevention efforts for breast, cervical, and colorectal cancers; and continued advances in treatment (American Cancer Society, 2006). In laboratories funded by the National Institutes of Health (NIH), scientists completed mapping the more than three billion base pairs composing the Human Genome 2 years ahead of schedule. The result was to make an unprecedented amount of common genetic data available to cancer researchers, opening up an era of tailored medicine (National Human Genome Research Institute, 2003).

The year 2003 also saw the first plateau in a geometric escalation of public Internet use, with almost two thirds of the U.S. population (63%) going online (Hesse et al., 2005). Data from the baseline administration of the HINTS revealed that roughly 45% of the general population reported looking proactively for cancer information at some point in their lives, and within that group the majority reported going to the Internet first, prior to going to their physicians, family, friends, or other media (Arora et al., 2006). From a study of on-line search engines, "cancer" appeared as the third most popular health term searched on the web, preceded only by the terms "depression" and "allergies" (Rice, 2001).

An Extraordinary Opportunity in Cancer Communication Research

This decade-long series of converging forces heralded by events set in motion in 1990 led to the identification of an "extraordinary opportunity in cancer communication" by the NCI in its annual budget to Congress in 1999. The opportunity was announced at a time in which the entire institute was rethinking its strategic approach to cancer control. Having recognized that 50%–75% of cancer deaths could be attributable to behavioral risk factors, the newly formed Division of Cancer Control and Population Sciences was positioning itself to seize the public health opportunity afforded by achieving behaviorally oriented goals. Investments in the science of cancer communication were identified as an integral part of that effort (Hiatt & Rimer, 1999).

The *extraordinary opportunity* also came at a time in which the very context of health communication was changing rapidly. Cable television had broken the hold of the "Big Three" networks, with a proliferation of new channels and program choices fragmenting the media environment. Television networks, newspapers, and periodicals began narrowing definitions of target audiences, with specialty channels and

targeted publications becoming more common. The introduction of interactive media enabled “one to one,” “one to many,” and “many to many” interactions in both synchronous (real) and asynchronous (delayed) time. As video, audio, text, and electronic ordering came on-line, the new communication environment began enabling innovative types of interactions with both positive and negative consequences (Viswanath, 2005).

The Importance of Health Information

Although the benefits and drawbacks of the new communication environment for health were not yet fully known, the stakes for harnessing the impact of these new capabilities were rising. In October 2001, in the wake of public concern over bioterrorism, government website administrators were grappling with the fact that public traffic to their websites appeared to be doubling and tripling in volume. During the weeks following the anthrax scare in 2001, mass media coverage fueled a 118% spike in traffic at the Centers of Disease Control and Prevention’s website (Chan, Bumatay, & Pileggi, 2001). The “push” of news stories on anthrax from the mainstream media was creating an equally strong “pull” from the public for news from on-line health information sources (Kittler, Hobbs, Volk, Kreps, & Bates, 2004).

In the bigger scheme of things, the surge of web traffic after the terrorist attacks of September 11, 2002, should not have been surprising. Because the Internet technologies break down geographic (Hesse, Sproull, Kiesler, & Walsh, 1993), temporal (Hesse, Werner, & Altman, 1988), and even social barriers (Sproull & Kiesler, 1991), health information consumers were already learning how to bypass traditional gatekeepers to access health information directly from the source, a trend referred to by new media researchers as “disintermediation” (Wallace, 2004). Almost unnoticed by many public health administrators, traffic patterns at government websites already had begun shifting in the late 1990s to a point at which the preponderance of visitors was not made up of traditional constituencies, but of public information seekers (Hert, Liddy, Shneiderman, & Marchionini, 2003). The trend was driving millions of visitors to the NCI’s “Cancer.gov” and similar websites each year. Visitors to government and academic websites were looking for credible information on cancer to steer “vital health decisions” for themselves and for their loved ones (Fox & Fallows, 2003; Fox & Rainie, 2002).

This shift to a more proactive and questioning public was occurring at the same time that the story behind cancer-related health findings in the media was becoming more complex and nuanced. In 1971, when the national cancer program was formalized through passage of Public Law 92-218, conventional wisdom was that the “war against cancer” would be won by finding a single “cure” for a singular disease. By the 1990s it was clear that cancer was not a single disease, but a complex family of diseases with differing pathways of risk and varying implications for treatment (Von Eschenbach, 2005). Victory in the war against cancer would have to occur on multiple fronts, with a greater emphasis on prevention and early detection, and in detecting opportunities for intervention through a personalized understanding of genetic risk (NCI, 1999).

To meet the challenge of that complexity, cancer researchers began harnessing the power of large-scale informatics infrastructures in medical, biomedical, and consumer domains (Buetow, 2005; Hesse, 2005). Priorities from the U.S. Department of Health and Human Services reinforced the role of information technology as the

means for accelerating progress toward a health care system in the United States that is safe, effective (i.e., evidence-based), patient centered, timely, efficient, and equitable (Berwick, 2002; Brailer, 2005; Featheringham, 2004; Institute of Medicine (U.S.) Committee on Quality of Health Care in America., 2001). Communication researchers began experimenting with *mass customization* engines that would begin tailoring the timely delivery of health information to consumers in ways calculated to empower patients and conserve costs while elevating national gains in disease prevention (Abrams, Mills, & Bulger, 1999; Emmons et al., 2004; Kreuter et al., 2004; Kreuter & Wray, 2003; Rimer & Glassman, 1999). More work would be needed to monitor the public's use of these health information technologies, and to rethink cancer communication in the information age (Neuhauser & Kreps, 2003).

Origins of the Health Information National Trends Survey

Given the rising importance of health information to enable population goals, the NCI initiated creation of the HINTS in June 2001. Suggestions for the biennial trends survey came from a 1997 workshop of acknowledged leaders in the area of risk communication. Attendees at the workshop recommended a nationally representative surveillance mechanism to monitor the influence of a changing communication environment on cancer-related knowledge, perceptions, attitudes, and behaviors. The story of technology at the turn of the millennium, workshop attendees argued, is a story of broad, large-scale change—much of it unanticipated. A monitoring system would help keep track of the change from the public's perspective and would help the NCI adjust programmatic inputs to increase effectiveness for population health outcomes.

In a previous issue of the *Journal of Health Communication*, Nelson et al. (2004) offered a foundational description of the assumptions underlying the program and the rigor with which the first survey was launched. The article laid out the framework for the survey and described the various theoretical foundations that had been tapped to populate items within the baseline instrument. It also described a dissemination plan that built on assumptions of open access to the data, and informatics support for linking individual scientists to national findings.

In the same issue, two commentators (Freimuth, 2004; Yach, 2004) offered their perspectives on what the significance of the program might be for cancer communication researchers, along with the challenges the program might face. Both found value in the content of the survey, recognizing that its theory-driven approach would provide a population-level complement to work being done by grant-funded scientists. They also reinforced the values of open access, collaboration, transparency, and interdisciplinarity in making data from the nationally funded survey available and accessible to the broader scientific community.

Organization of the Supplement

It is in this spirit of scientific openness that we are pleased to offer the following compilation of published work from the HINTS baseline. Origins of the supplement can be traced back to February 16, 2004, when the NCI made the first comprehensive data set of nationally collected survey data available to the public through the HINTS website (<http://hints.cancer.gov>). It was not long after the initial public release that researchers outside of the NIH joined scientists from within the agency to explore, parse, and analyze the national data. A year later, in January 2005, the

NCI hosted a research conference to bring this vanguard group of scientists together. Following that conference, NCI program managers released a call for papers to bring the best examples of those analyses into a single volume represented by the work in this supplement. Although space did not permit publication of all the provocative and interesting papers submitted to us, we are grateful for the generous contributions of all who responded to the call.

Organization of the supplement reflects the thematic focus of questions underlying construction of the first HINTS instrument. Ultimately, the purpose of the HINTS program is to generate the research needed to improve the prevalence of evidence-based health behaviors across all segments of the population. To that end, the instrument is anchored on a set of common data elements linked from other nationally funded surveillance mechanisms on behaviors and their outcomes (e.g., the National Health Interview Survey, the Behavioral Risk Factor Surveillance System).

The distinct contribution of the HINTS program, however, is to provide communication scientists with measures of intervening process variables (knowledge, attitudes and beliefs, affect, mediating behaviors) collected concurrently with indices of change in the health communication environment. Within each vector of the measurement framework there is room for variation according to priorities across administrations of the instrument. Areas of emphasis from the baseline included foci on cancer knowledge, cancer cognition and risk perception, and cancer information seeking. We have organized the articles in the supplement to reflect those areas of emphasis.

Cancer Knowledge

Under the topic of *cancer knowledge*, we include two papers that deal directly with assessments of what people already have learned or believe regarding cancer control and prevention. Viswanath and his colleagues begin the discussion with a caveat that knowledge may not be evenly distributed throughout the population. In an age in which “information is power,” knowledge gaps can emerge that lead to serious omissions of protective behavior among disadvantaged segments. These authors’ analyses of the HINTS baseline data suggest that significant gaps in knowledge regarding tobacco and sun exposure may be directly related to socioeconomic status, with education and income playing significant roles. The data also suggest that focused use of media might attenuate the effect, giving health disparities planners a target for public awareness efforts.

Ford and her colleagues used the HINTS baseline to evaluate the prevalence of colorectal screening knowledge among adults 45 years and older. Communication efforts have been launched to disseminate the message that colorectal screening can save lives, especially among those with a familial predisposition toward the disease. From their analyses of the HINTS data, these researchers found that awareness of colorectal screening guidelines in the general population appears to vary by age, marriage status, and routine access to physicians. Communication efforts would be needed to enhance awareness within these groups, they argued.

Cancer Cognition and Risk Perception

The second group of articles investigates the roles risk perception, affect, and health cognition play in interpreting messages related to cancer. Zajac and her colleagues documented evidence that perceptions of absolute risk (e.g., “What is the likelihood

that you will get cancer?”) and perceptions of relative risk (e.g., “How does your risk compare to someone similar to you?”) can be differentially related to worry when tracked in a large sample across several different types of cancer. The study’s findings reinforce conclusions from smaller sample studies, and add converging evidence to the data published from localized laboratory and field evaluations.

Han and his coauthors explored how the concept of “ambiguity” might account for documented uncertainties about cancer prevention recommendations. The article offers a meticulous tie to the decision support literature in order to develop hypotheses for relationships between perceptions of ambiguity and perceptions of cancer preventability, cancer risk, and cancer worry. The relationships specified by this a priori link to the literature are largely borne out by the HINTS population-level data, suggesting a need to resolve the communication issues surrounding health action when findings or recommendations are unclear.

Hay and her associates turned their attention to examining patterns of risk perception related to colorectal cancer among respondents in the HINTS sample who were over 45 years of age and who had no prior colon cancer history. Not unpredictably, these authors found that most respondents generally did not perceive themselves as being at high risk for colon cancer. In a more surprising vein, these researchers found a relationship between age and perceptions of comparative risk for colon cancer such that those who were over age 65 reported feeling at less risk than those in younger groups. The authors offer a compelling explanation for why this degree of “unrealistic optimism” increases with age, and they offer recommendations for how to deal with the problem in cancer communication activities.

Dillard and her colleagues investigate the cognitive correlates of unrealistic optimism to cancer myths and risk behaviors. Honing in on the area of smoking, an arena in which perceptions of unrealistic optimism have been observed to drive risky behavior, these researchers found that smokers in the HINTS sample who underestimated their risk for lung cancer were more likely to endorse lung cancer myths (e.g., smoking a few years will not lead to risk for lung cancer). More importantly, these same respondents were less likely to plan on quitting smoking, illustrating a destructive link between internal cognitions and behavioral intentions as measured throughout the population.

The last article in the section explores cognitive response patterns with respect to the area of fruit and vegetable consumption. The NCI, along with other prominent health agencies, has endorsed a goal of eating from five to nine servings of fruits or vegetables a day. Cerully and her colleagues report the unfortunate fact that 88% of the population appeared to be nonadherent to these recommendations. After dividing the HINTS sample into two groups—those who spontaneously identified “fruit and vegetable consumption” as a strategy for reducing risk and those who did not—these authors found that people who did not identify fruit and vegetable consumption as a protective strategy trusted cancer information sources less than their cognizant counterparts. Communication efforts should be revitalized, the authors argued, to create diet messages that are memorable and that come from sources that are truly perceived as being credible.

Cancer Information Seeking and Communication

In the last section, we move away from the surveillance of cancer knowledge, cognition, and affect, to investigate the more active processes associated with cancer

information scanning and seeking. Information seeking has been a topic of focused attention in the past (Freimuth, Stein, & Kean, 1989; Johnson, 1997), but has relied primarily on interviews with self-selected samples of callers to cancer information help lines. The HINTS provides an opportunity to update these earlier findings in an era of broad information access (Freimuth, 2004).

Squiers and her coauthors begin the section with an examination of awareness of the NCI's own Cancer Information Services (CIS). Results showed that awareness of the CIS was generally eclipsed by awareness of other national organizations, including the American Cancer Society and the NIH. Results also revealed an interesting trend reversal based on minority/ethnic group, education, and income consistent with dissemination efforts by the CIS partnership program.

Rutten and her colleagues switch their emphasis to quality of interactions as reported by the public with their health care providers. These authors find that ratings of communication quality do not vary by traditional sociodemographic variables, but by access to health care (insurance status, primary care physician) and by self-reports of health status and depressive symptomology. Similar to the Viswanath et al., Rutten and her colleagues caution that lack of access to quality health information may contribute substantively to issues of health disparities. Rutten also provided a brief analysis of the cancer topics reported in an open-ended question from the HINTS interview in a brief research note. The note provides a valuable glimpse at the public's information needs related to cancer.

Three papers investigate the relationship between the process of attending to cancer information, either passively or actively, and reports of adherence to evidence-based health behaviors. Shim et al. begin the section by making an important conceptual distinction between information seeking and information scanning. Seeking, they reason, can be considered to be a relatively active process of looking for cancer information when a specific information need arises, while scanning may be considered to be a more passive state of vigilance to the health information environment. Using the HINTS baseline data, they partition respondents into groups of high versus low scanning and seeking versus nonseeking. From their analyses, the authors found that both scanning and seeking were significantly related to increased knowledge about cancer, engagement in preventive health behaviors, and colorectal and prostate cancer screening. Only scanning was related to reports of recent mammography, suggesting a less engaged degree of vigilance for this particular type of screening test.

Nguyen and Bellamy investigated the hypothesis that significant cultural differences may exist between Asian Americans and Whites in information-seeking preferences and experiences. In general, they found that Asian Americans differed significantly from Whites in awareness of cancer information resources, the importance of primary and secondary prevention strategies, and personal risk, again reinforcing concerns over knowledge gaps for this growing minority group. For the most part, preferences were similar between Asian Americans and Whites for information sources, with both groups expressing high trust in physicians, though the Asian American group expressed preferences for print material as a channel for cancer information.

Ling and colleagues finish this section by looking for associations between information-seeking preferences and adherence to recommendations for colorectal cancer screening. The researchers focused their analytic efforts on a cohort of respondents 50 years or older. That cohort generally reported preferences for getting

information relevant to screening through personalized materials, directly from their physicians, or from published materials. Trust in health information from their physicians was a factor most associated with being up to date on recommended screenings, a finding in line with previous literature highlighting the role of the physician in encouraging routine screening tests (Finney Rutten, Meissner, Breen, Vernon, & Rimer, 2005; Meissner et al., 1998; Meissner, Potosky, & Convisser, 1992). The authors reinforce the importance of the physician in keeping patients adherent with screening recommendations, but also point to the emergence of the Internet as a tool for apprising the public.

Conclusion

By developing a nationally representative survey to monitor the public's use of cancer-related health information, and by presenting data from the first administration of that survey on-line to cancer communication scientists, the NCI sought to catalyze an evolution of resources in the fight against cancer. The evolution is not without its caveats. The HINTS is only one tool in the collective armamentarium of methodological resources that individual scientists bring with them to solve the puzzles of cancer control and prevention. The contributing authors to this supplement all have recognized that strict inferences of causality are not possible with cross-sectional data. For insight into causality, individual researchers must turn back to the laboratory or to quasi-experimental designs to test the hypotheses generated by their foray into national data. Nor should the HINTS program, with resources for sampling slightly fewer than 7,000 adults on each administration, be made to answer the surveillance questions better addressed by larger, more costly national surveys.

Nevertheless, the contributions of HINTS as a linking pin between the local scope and control of the laboratory on the one hand, and the broad scope and generalizability of a nationally representative sample on the other, cannot be overstated. For science to address the seemingly intractable problems of the twenty-first century, it must elevate itself beyond parochial self-interests (Sellers, Caporaso, Lapidus, Petersen, & Trent, 2006). It must become transdisciplinary, bringing the converging methods of complementary sciences to solve novel problems in novel ways (Mitchell, 2005; Stokols, Harvey, Gress, Fuqua, & Phillips, 2005). Science also must become telescopic, spanning levels of analysis from the psychological considerations of the individual to the ecological considerations of cultivating one's health in a fragmented information environment (Smith, Orleans, & Jenkins, 2004). We hope that this supplement initiates a step down that evolutionary path.

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