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Using the Health Information National Trends Survey (HINTS)

to identify cancer knowledge gaps

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In the United States, the burden of cancer disproportionately affects underserved populations. According to the National Cancer Institute's Center to Reduce Cancer Health Disparities, disparities are defined as differential rates of cancer incidence, prevalence, or mortality for one subgroup of people (Harper & Lynch, 2005). Individuals at the lower end of the socioeconomic continuum, with less formal education and lower income, and those drawn from racial/ethnic minority groups tend to experience the burdens associated with cancer at higher rates than those individuals drawn from higher socioeconomic status groups and Caucasians (ACS, 2007A, 2007B, 2007C). Disparities operate throughout the cancer continuum, from prevention and early detection to treatment, end of life care, mortality, and survivorship. For example, African-Americans and other minorities are less likely to be adherent to screening for colorectal cancer than Caucasians (ACS, 2007A, 2007B; Ananthakrishnan, Schellhase, Sparapani, Laud, & Neuner, 2007; Lloyd et al., 2007). African-American men diagnosed with colorectal cancer are more likely to be diagnosed at a later stage than Caucasians (Polite, Dignam, & Olopade, 2005). Additionally, mortality rates from colorectal cancer are higher for African-American men as compared to Caucasian stage-matched men (ACS, 2007B; Alexander et al., 2007; Baquet & Commiskey, 1999; Du et al., 2007). Some disparities are evident in localized geographical locations, for example rural, underserved women in Appalachia have one of the highest rates of cervical cancer in the United States (Brandt et al., 2006; Drake et al., 2006; Fouad et al., 2004; Fouad et al., 2006; Powell, 2006; Yabroff et al., 2005). Similar disparities operate within other ethnicities (ACS, 2006, 2007A) and across other common cancers, such as

prostate (Chu, Tarone, & Freeman, 2003; Reddy, Shapiro, Morton, & Brawley, 2003; Vijayakumar et al., 1998), lung (Abidoeye, Ferguson, & Salgia, 2007; Alberg et al., 2006; Berger, Lund, & Brawley, 2007; Flenaugh & Henriques-Forsythe, 2006), and breast (Adams et al., 2006; Bowen et al., 2007; Du Xianglin & Gor, 2007; Du et al., 2007; Hirschman, Whitman, & Ansell, 2007; Lantz et al., 2006; Sassi, Luft, & Guadagnoli, 2006; Tammemagi, 2007).

While cancer disparities have a complex etiology, differential access to information about cancer prevention, early detection, and treatment options have been proposed as an important factor that perpetuates cancer disparities (Hiatt & Rimer, 1999). Information disseminated by mass media is acquired by those at higher socioeconomic status at a faster rate of growth than their lower socioeconomic status counterparts, so that gaps in knowledge acquisition tend to increase over time, and to be particularly dramatic in the context of new innovations (Tichenor, Donohue, & Olien, 1970; Viswanath & Finnegan, 1996; Viswanath, Kahn, Finnegan, Hertog, & et al., 1993). This “knowledge gap hypothesis” is highly relevant in the context of cancer prevention and control for those at increased risk as well as in the general population, where rapidly burgeoning knowledge of cancer risk factors, prevention strategies, and early detection recommendations and treatment options require concomitant knowledge transfer through multiple communication channels. Accordingly, the detection of cancer knowledge gaps represents an important step in pinpointing useful opportunities to help close these gaps in cancer knowledge and important health outcomes in the United States. In this chapter we will review the work we have conducted over the past few years to identify cancer prevention and control knowledge gaps in the United States utilizing the National Cancer Institute-sponsored Health Information National Trends Surveys (HINTS), conducted in 2003 and 2005 (Hesse, Moser, Rutten, & Kreps, 2006; Nelson et al., 2004; Yach, 2004). We then advance a set of research

priorities that illustrate the value of our HINTS findings in providing the groundwork for further work to close knowledge gaps in cancer prevention and control, and ultimately with disparities in important cancer outcomes.

Much of the work we have conducted using HINTS has data focused on knowledge gaps relevant to colorectal cancer. There are a number of reasons for this. First, according to the U.S. Preventive Services Task Force (USPSTF, 2002), screening for colorectal cancer is proven efficacious. Colorectal screening is also recommended for a large proportion of society (the general population for those individuals aged 50 and older) is recommended for both men and women, and includes multiple strategies for screening that have been developed over the past recent years (ACS, 2007A; NCI, 2006; USPSTF, 2002), which presents an opportunity to examine age and gender differences in knowledge gaps. However, only 50% of the general population is adherent with colorectal cancer screening guidelines (Cokkinides, Chao, Smith, Vernon, & Thun, 2003), lagging significantly behind 2010 United States Department of Health and Human Services goals for 80% of the population to be adherent to colorectal cancer screening (USDHHS, 2007). Current guidelines for colorectal cancer screening include one of the following strategies: fecal occult blood testing annually; flexible sigmoidoscopy or double contrast barium enema every five years; or colonoscopy every 10 years (Jonas, Russell, Sandler, Chou, & Pignone, 2007; NCI, 2006). Of note, these current recommendations have only been in place for 11 years (Winawer et al., 1997) and Medicare has provided reimbursement for screening colonoscopy since then (Cooper & Doug Kou, 2008; Jonas et al., 2007; Schenck et al., 2007; Sonnenberg, Amorosi, Lacey, & Lieberman, 2008), making it a newer innovation than mammography screening. Additionally there is growing consensus that lifestyle factors play an important role in the development and prevention of colorectal cancer, so this knowledge is

critical, as well, to state-of-the-art prevention guidelines for this malignancy. For example, , engaging in regular physical activity, maintaining a healthy body weight, limiting red meat intake, avoiding high alcohol consumption, and refraining from smoking, have each been linked with a reduced risk for colorectal cancer (Calle, Rodriguez, Walker-Thurmond, & Thun, 2003; Chao et al., 2005; Cho et al., 2004; Giovannucci, 2001; Janet, Jackson-Leach, Mhurchu, & al., 2004; Samad, Taylor, Marshall, & Chapman, 2005; Slattery, 2007). We have examined colorectal cancer prevention and early detection knowledge gaps as well as demographic differences in perceived risk for colorectal cancer in our studies utilizing multiple datasets of the HINTS. We also review an additional study examining gaps in cancer information seeking among cancer survivors that provides additional perspective on the determinants of cancer knowledge gaps in the United States.

Gaps in knowledge of colorectal cancer screening guidelines

Using HINTS 2003, we examined prevalence and patterns of colon cancer screening knowledge among a subsample of 3,131 of HINTS respondents (Ford, Coups, & Hay, 2006). While the screening strategies examined are sensitive to finding cancers in the rectum as well as the colon, given that over 70% of colorectal cancer originates in the colon, and the fact that the question phrasing adopted in HINTS includes the colon only, we limit our findings to screening regarding cancers of the colon only. We excluded participants who were under the age 45, because we believed that colon cancer screening recommendations would legitimately lack salience to younger members of the general population and that knowledge of colon cancer screening would be most relevant to adults who were at or near the age of recommended screening. Also excluded were individuals who had a history of colon cancer, those who were

missing age and colon cancer history data, and those who were missing data on the screening knowledge criterion variable.

In this study, we had the unique opportunity to examine knowledge of three elements of colon screening across multiple screening modalities, including being able to name a strategy for colon cancer screening, the age at which screening should begin, and knowledge of the recommended screening interval for different types of screening. Participants in the study were denoted as “knowing” a test if they conjointly identified a colon cancer screening test, knew the start age for that test, and correctly identified its recommended screening frequency. For example, a participant with “knowledge” of fecal occult blood testing (FOBT) would have recalled that this test must be initiated by 50 years of age, and should be conducted every year. Participants were denoted as having cancer screening knowledge if they gave the correct responses reflecting knowledge of either FOBT or sigmoidoscopy/colonoscopy. In this way, we examined the joint information necessary to maintain at least one colon screening modality through recommended screening intervals.

Overall, knowledge of colon cancer screening was low, with only 21% having full “knowledge” of one type of screening strategy. Only 15% had FOBT screening knowledge, and 7% had sigmoidoscopy/colonoscopy screening knowledge. Knowledge was particularly poor among participants who were aged 45-49 or over the age of 70, where 14% and 15% from these groups, respectively, had knowledge of at least one screening modality. Rates were significantly reduced in those with less than a high school education and among unmarried individuals, with only 8% and 14%, respectively, having adequate screening knowledge. African-American participants had lower levels of screening knowledge (10%) than other racial/ethnic groups, as did those who had not visited a healthcare provider in the past year (10%). Of those who had

never undergone an FOBT, only 16% had screening knowledge. Among those individuals who had never looked for cancer information, only 16% had adequate screening knowledge.

It is important to highlight that overall, adequate knowledge of colorectal cancer screening was low among all participants, with 80% of the entire sample evidencing knowledge gaps in colorectal cancer screening. Even among the most “advantaged” in our sample we found knowledge deficits. For example, only 30% of those at highest education levels had adequate knowledge of colon cancer screening. This study was the first to examine the combined knowledge of cancer screening tests, age at initiation, and recommended interval for completion that we believe is critical to follow-through with adherence to screening guidelines. This study indicates the presence of knowledge gaps for colon cancer screening United States that are most pronounced for those with lower educational attainment, African-Americans, the elderly, those who have never had FOBT, and those who don’t look for cancer information. Clearly, these findings justify the development of targeted interventions for those segments of the population with the greatest gaps, that could usefully engage with communication channels at multiple levels of public policies and health, including the mass media, managed care, and face-to-face exchanges between patients and physicians (Street, 2003). However, the development of interventions for specific subpopulations should not neglect general population strategies to raise level of awareness for colon cancer screening. The study also points out that communications regarding colon cancer recommendations should stress multiple aspects of the test, which may allow individuals to initiate screening, and then to retain the information required to continue screening at recommended intervals for many years.

Gaps in Colon Cancer Prevention Awareness

We also recently examined knowledge gaps regarding awareness of the role of physical activity in the prevention of colon cancer in the 2005 HINTS sample (Coups, Hay, & Ford, 2008). This study was conducted in a sample of 1,932 HINTS participants. In order to measure their awareness of the role of physical activity in cancer prevention, participants responded to the following open-ended question item: “What are some things that people can do to reduce their chances of getting colon cancer?” Participants who listed exercise or physical activity in their responses were denoted as being aware of the role of physical activity in colon cancer prevention. As with colorectal cancer screening knowledge, awareness of the role of physical activity in reducing the risk of colon cancer was low among the overall sample. Indeed, only 15% of participants indicated that physical activity reduces the risk for colon cancer. Knowledge dropped significantly in older age groups, with only 9.5% of those aged 70 and older reporting awareness of the role of physical activity in preventing colon cancer, under 9% in those with high school education attainment or less, and (7%) in those who report they are sedentary. Those who had lower levels of knowledge reported lower levels of information seeking and knowledge about cancer prevention recommendations. For instance, individuals who agreed that physical activity recommendations are confusing, those reporting not being exposed to any information about physical activity and cancer in the past year, those who have never looked for cancer information, and individuals not knowing any symptoms of colon cancer were more likely to lack knowledge of the role of physical activity in preventing colon cancer. Knowledge was not significantly different across gender or racial/ethnic subgroup.

The results of this national probability survey of U.S. adults revealed that fewer than one in six study participants (15.0%) was aware that physical activity plays a role in reducing risk for

colon cancer. This low level of awareness suggests that public health communication efforts regarding the strong protective effective of physical activity against colon cancer are lacking and/or ineffective. While we found no specific knowledge gaps for racial/ethnic groups, those who are older and less well-educated individuals could be singled out for targeted interventions. Further, the study results suggest that individuals' lack of awareness of the role of physical activity in colon cancer prevent may be one component of a broader lack of information exposure and low information seeking about cancer prevention. This study illustrates how individuals who engage in less information seeking are less knowledgeable, pointing out potential opportunities to improve the clarity and user-friendly nature of health information across multiple delivery channels.

Gaps in Knowledge of Colon Cancer Risks

In a third study (Hay, Coups, & Ford, 2006), we examined individuals' perception of their colon cancer risks. While knowledge and cancer risk perceptions are distinct constructs, knowledge gaps are likely to perpetuate inaccuracies in cancer risk perceptions in the general population and could represent one route through which knowledge gaps lead to optimistic biases about risk (Facione, 2002). In this study we utilized a subsample of 2,949 of HINTS 2003 participants who were at least 45 years of age with no personal history of colon cancer. Perceived risk for colon cancer was measured in two ways, including absolute perceived risk for developing colon cancer (responses ranged from 'very low' to 'very high') and comparative perceived colon cancer risk (responses ranged from 'much less likely' through 'much more likely' than individuals of the same age and gender).

As has been shown in many prior studies, this study confirms the existence of optimistic biases in perceptions of risk across the sample as a whole. Nearly half of the sample (48%)

reported that their risk for colon cancer was less than that for others their age and gender, and 62% reported that their risk for colon cancer was either somewhat or very low. Multivariate examination of the uniquely important predictors of comparative risk perceptions found that psychosocial factors (cancer worry, fear of finding colon cancer), family cancer history, poor/fair subjective health status, and the perception of information overload about cancer were related to increased perceptions of being at risk for colon cancer. Of all the sociodemographic factors examined, only age and Spanish language preference for the HINTS interview were related to increased perceptions of being at risk for colon cancer. These effects indicated that those aged 65 and older were more likely to perceive that they were at *reduced* risk compared to individuals of the same age and gender than were younger participants; those who completed the interview in Spanish felt they were at *increased* risk for colon cancer than were those who completed the interview in English. Nonsignificant predictors included most socioeconomic factors, including gender, education, and race, and lifestyle factors (cigarette smoking, fruit and vegetable consumption, and body mass index). Significant multivariate predictors of higher absolute perceived risk were even more limited, and included only poor/fair health status, personal and family history of colon cancer, and cancer worry and fear of finding a cancer. The findings reported here highlight, again, that knowledge gaps may be critical in the elderly, who may come to see themselves at less risk for developing colon cancer in part based on their lack of information about early detection and prevention for colon cancer. It is also valuable to note that there is much inconsistency across sociodemographic groups regarding perceived colon cancer risk, making it difficult to draw generalizations regarding which groups are most deficient in their knowledge, and why.

Gaps in Information Seeking Behaviors

In one final study (Ford, Coups, & Hay, In preparation), we examined the cancer information seeking experiences of a sample of cancer survivors using HINTS (2005). Specifically we were interested in the prevalence of, and barriers to, health information seeking which could be related to knowledge gaps among cancer survivors or subpopulations of cancer survivors. We examined 711 cancer survivors, excluding those with non-melanoma skin cancers who participated in HINTS 2005. The survivors were mostly female (65.5%), Non-Hispanic White (82.3%), currently over the age of 60 (66.7%), and had graduated from high school (84.3%). The most common cancer diagnoses reported were breast (21%), prostate (15.4%), melanoma (14.3%), cervical (10.9%), and colon (8%). Most were long-term survivors and had been diagnosed more than 5 years prior to the telephone interview (62.8%).

Overall, over half of survivors (63.6%) reported having looked for cancer information. Consistent with the knowledge gap hypothesis, our findings reveal socioeconomic, race/ethnicity, and age discrepancies in cancer information seeking among these cancer survivors. For instance, only 52% of those who were non-Hispanic African-American reported having looked for cancer information, 27% of those with less than a high school education, 50% of those with annual incomes of less than \$25,000, 48% of those over 70 years of age ever looked for information about cancer from any source. Overall, survivors were confident that they could get advice or information about cancer if they needed it (61.5% were very to completely confident) however they reported that it took a lot of effort to get the information they needed. More than a quarter (25.8%) felt frustrated during their search for information. Based on their most recent search for information about cancer, almost half (47.6%) of survivors were concerned about the quality of information they obtained. Additionally, over a quarter

(26.4%) felt that the information they found was too difficult to understand and that it took a lot of effort to get the information they needed (33.5%).

Accordingly, information seeking is reduced in those who are disadvantaged in terms of education and income, and reduced in older individuals as well as those of African-American descent. This highlights a question regarding whether some individuals avoid information seeking due to their concerns about the quality of the information they are finding. Although we did not directly assess knowledge gaps per se, it is likely given what survivors reported in the HINTS (2005) about cancer information seeking, it is possible that many survivors are not receiving the information they are interested in and/or are receiving incorrect cancer information. Additionally, they are having difficulty understanding the information and are not confident in the quality of information they are receiving. These implications point to many useful areas of future inquiry.

Discussion

There are some important overarching themes to our findings reported across four studies. First off, despite our focus on gaps in knowledge, we found universally low levels of knowledge *across all groups*. Given that only 21% had adequate colon cancer screening knowledge, and only 15% had knowledge of the role of physical activity in preventing colon cancer, strategies to improve dissemination of colorectal cancer prevention and control information would be useful at the population level. We also found that most participants (62%) saw themselves as being at very or somewhat low risk; 48% thought that their risk was less than for others their age and sex. Knowledge gaps the United States regarding screening and prevention strategies for cancer were noted over 10 years ago in the 1992 National Health

Interview Survey Cancer Control Supplement (Breslow, Sorkin, Frey, & Kessler, 1997); colorectal cancer-specific knowledge gaps have been confirmed recently as well, in a large survey study conducted across 21 European countries (Keighley et al., 2004). Knowledge about the risks associated with colon cancer are likely important predictors of risk perceptions for the disease (Robb, Miles, & Wardle, 2004), so knowledge gaps may set the stage for this unrealistic optimism concerning colorectal cancer risk.. Inadequate knowledge concerning what factors contribute to risk for various cancers has been confirmed in recent studies in the general population (Breslow et al., 1997; Keighley et al., 2004). Some of this may be explained by the fact that people are aware that dietary factors and adequate exercise contribute to good health overall, but do not necessarily relate these factors to the prevention of specific cancers (Goldman et al., 2006). Unfortunately, efforts to increase awareness of cancer risk factors could compound the problem; a recent population-based national survey reported that 50% of those surveyed believe that there are so many recommendations for cancer risk reduction that it is difficult to know what to believe (HINTS, NCI 2003). Perhaps a team effort to develop unified media messages linking prevention and early detection information for many cancers, or cancer and heart disease, could limit overload and frustration.

In terms of race, our results were mixed, showing that it is not the only -or the most important - factor in determining the knowledge gaps we examined. We found some evidence for knowledge gaps among African-American participants as well as those who completed their interview in Spanish. Recently, Shokar and colleagues (Shokar, Vernon, & Weller, 2005) conducted qualitative individual interviews with African-American, Hispanic, and white participants, and found knowledge gaps in the nonwhite populations, but not expected fatalistic attitudes about cancer, pointing the way for possibly high levels of receptivity for early detection

messages in diverse populations. But while race/ethnicity may be an important factor to consider when addressing cancer knowledge disparities, it is clearly not the only one to take into account. Therefore, we need to think about our efforts in targeted and tailored interventions.

Alternatively, older individuals show consistent gaps in cancer knowledge based on our HINTS findings, and these gaps may be even greater in less educated, non-white older adults populations and across other cancer sites (Donovan & Tucker, 2000; Hislop et al., 2004; Jones et al., 2003; Loehrer et al., 1991; Ralston et al., 2003; Viswanath et al., 2006). For instance, Jones and colleagues (Jones et al., 2003) have noted the increased need for mammography and clinical breast examination education in older African-American women. Further, true population-based samples may be even less knowledgeable than those who are self-referred for survey research (Henrikson, Harris, & Bowen, 2007). Research is certainly warranted to examine the multiple sources of knowledge gaps in the elderly. This research represents a valuable priority given the heightened cancer risk faced by the elderly that dictates a need for them to maintain cancer screening strategies, in particular, over the age of 65 (Gorin, Gaunthier, Hay, Miles, & Wardle, In Press). Finally, further research regarding the predictors of cancer information seeking are an important priority, as reduced information seeking is consistently related to knowledge gaps. In the case of cancer survivors, participants reported that they have trouble trusting the quality of the information, and /or may not understand the information they have obtained. Perhaps clinicians and health behavior interventionists need to develop strategies to assist people throughout the information seeking process starting from the point of eliciting unmet informational needs and directing people to the most reliable sources.

In summary, our collective research from HINTS indicates that cancer knowledge gaps in general population subgroups continue to exist. In our studies we focused, largely, on

knowledge and risk perceptions regarding colon cancer, and we find that these gaps are most consistently problematic in the elderly, the less educated, and among those who do not look for cancer information. Individuals from racial/ethnic subgroups evince knowledge gaps as well, but more inconsistently so. Importantly, our results also indicate that knowledge regarding colon cancer screening modalities, physical activity as a prevention strategy for colon cancer, are not adequate in more advantaged groups, either. Ultimately, our findings from HINTS will be useful starting points for intervention development studies and mechanistic research to move from the confirmation of these ongoing deficits, to finding ways to address and surmount cancer knowledge gaps in the United States.

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