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“I don't know” my cancer risk: Implications for health behavior engagement

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Abstract

Background—Many people report uncertainty about their cancer risk. We examined whether such uncertainty was related to cancer prevention and detection behaviors.

Methods—National Health Interview Survey data from 2005 and 2010 were analyzed. Participants reported their perceived risk for colorectal and breast cancers. Responses were coded as “valid” (i.e., less/as/more likely than average) or “don't know.”

Results—In bivariate analyses for both cancer sites and survey years, “don't know” responders (DKR) engaged in less physical activity than “valid” responders ($p < .05$). DKR had lower mammography adherence than “valid” responders in 2005 and lower colorectal screening adherence in 2010 ($p < .05$). DKR had marginally lower colorectal screening adherence and fruit/vegetable consumption in 2005 ($p < .06$). Multivariable models indicated that the DKR-behavior relationship could be largely accounted for by education.

Conclusion—Interventions that help people understand their cancer risk may provide particular benefit to people with low education and might consequently reduce health disparities.

Keywords

Risk perception; Colon cancer; Breast cancer; Health disparities

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Introduction

Perceived risk is theorized to be one of many key motivators of healthy behaviors (1). Empirical research supports this assertion, but the strength of the effect is variable and often small in magnitude (2). This small effect may stem from several causes, including limitations in research design and methodology, low numeracy, and socio-ecological barriers such as a lack of safe places for exercising (3-6). Yet, the possible effects of genuine uncertainty about one's risk have been understudied. Most surveys do not offer a *don't know* (DK) response option to items assessing perceived risk, thereby assuming that DK responses are either random or reflect a tendency for respondents to provide answers that require minimal cognitive effort (7).

A non-negligible proportion of the population expresses uncertainty about their risk of developing cancer. Two studies reported that between 6.9% and 9.5% of the U.S. population reported that they did not know either their colorectal or breast cancer risk, even though neither study provided an explicit DK response option (8, 9). Non-negligible levels of DK responding and uncertainty about risk have been reported in a variety of health domains (10), including breast cancer (11), cervical cancer (12), and for overall mortality (13).

DK responding may disproportionately affect medically underserved populations. In nationally representative surveys, DK responses were more likely among individuals with lower education, lower numeracy, lower income, and minority race/ethnicity (9, 14, 15). One study examined colorectal cancer risk perceptions among patients of a clinic that primarily served a low income, racially diverse, and primarily immigrant inner city population (9). Between 49.1% and 69.3% of respondents selected the “unsure” response option. Critically, individuals of lower socioeconomic status are also less likely to engage in a number of cancer prevention and detection behaviors, including colorectal and breast cancer screening (16), physical activity (17), and fruit and vegetable consumption (18). Considering the known relationships between a) risk perception and health behavior, b) DK responding and socio-demographic characteristics, and c) socio-demographic characteristics and health behavior, it is plausible that uncertainty about cancer risk might be associated with lower levels of engagement in cancer prevention behaviors.

The primary goal of this research was to clarify the relationships among DK responding, engagement in cancer prevention and detection behaviors, and socio-demographic characteristics. We hypothesized that people who reported not knowing their risk of cancer would be less adherent to cancer screening guidelines, engage in less physical activity, and eat fewer servings of fruits and vegetables than people who provided a risk estimate (1, 2). We also explored which, if any, socio-demographic characteristics might account for any significant relationships between DK responding and health behaviors (9, 14-18). A secondary goal was to better characterize the socio-demographic correlates of DK responding. Prior research was limited by focusing on only one cancer and one year at a time (9, 14) or by combining DK responses with refusals to answer (8). Examining multiple cancers and years simultaneously provides a more robust overview than examining only one cancer site at one time point.

Methods

Data Sources and Participants

Data from the 2005 and 2010 National Health Interview Survey (NHIS) were analyzed. NHIS is a population-based, nationally representative cross-sectional survey of the civilian non-institutionalized population of the U.S. (19). The 2005 and 2010 data were selected because cancer risk perception items are included in a supplemental cancer control module, which is administered at 5 year intervals (2015 cancer control data are not yet available for analysis).

Inclusion criteria for our study were: at least 18 years old and no prior cancer diagnosis. Participants who were younger than the recommended screening ages were included for the analyses unrelated to cancer screening because engaging in healthy behaviors (e.g., physical activity) may be especially effective for reducing risk if they begin at young ages and continue throughout the lifespan (20). Thus, younger people who are uncertain about their risk may not engage in cancer prevention activities until much opportunity for risk reduction has passed.

Measures

Perceived risk—Comparative risk perceptions were assessed with the item, “Compared to the average [man/woman] your age, would you say that you are more likely to get [colon or rectal cancer / breast cancer], less likely, or about as likely?” Responses were recoded to represent whether participants provided any valid response (i.e., more, less, or about as likely) or responded “don't know.” NHIS did not provide an explicit DK response option, but a DK response was recorded if participants proactively stated that they did not know.

Socio-demographic and health characteristics—The following were included as covariates (9): sex, age, educational attainment, marital status, race, Hispanic ethnicity, speaking Spanish in the home, U.S. nativity, income, insurance status, and family history of any cancer.

Behavior—Behaviors were assessed via self-report. Adherence to colorectal cancer screening guidelines was defined as being at least age 51 and having obtained a fecal occult blood test in the prior year, or having obtained a sigmoidoscopy in the last 5 years, or having obtained a colonoscopy in the last 10 years (21). Adherence to colorectal cancer screening was assessed among participants age 51 and older to avoid misclassifying as non-adherent those individuals who turned 50 in the year the survey was conducted but had not yet undergone screening. Adherence to breast cancer screening guidelines was defined as being female, at least age 41, and having obtained a mammogram in the previous year (21). Minutes of physical activity per week and servings of fruits and vegetables consumed daily were treated as continuous (22).

Results

Data were analyzed separately for each of the surveys and for each of the cancer sites. Analyses used SAS 9.4 SURVEYFREQ, SURVEYLOGISTIC and SURVEYREGRESSION

procedures with Taylor series linearization variance estimation (19) and listwise deletion. Data were weighted to yield estimates representative of the U.S. adult population.

Prevalence of Don't Know Responding (DKR)

Prevalence of DKR for colorectal cancer was 6.9% in 2005, representing a weighted population estimate of 14,144,195 individuals, and 4.6% in 2010, representing 9,674,354 individuals. DKR for breast cancer was 6.0% in 2005 (weighted $n = 6,341,944$) and 3.8% in 2010 (weighted $n = 4,092,014$). Participant characteristics are located in Supplemental Table 1.

Behavioral Associations with DKR

Logistic and linear regressions were used to examine bivariate relationships between DKR and behavioral outcomes (Supplemental Table 2). DKR was associated with less cancer screening behavior for both colorectal and breast cancer in 2005 and 2010. These relationships reached statistical significance ($p < .05$) for colorectal cancer in 2010 (OR=0.73, 95% CI 0.60 to 0.88) and breast cancer in 2005 (OR=0.73, 95% CI 0.61 to 0.88), and marginal significance ($p = .06$) for colorectal cancer in 2005 (OR=0.86, 95% CI 0.73 to 1.00). DKR was also associated with engaging in significantly fewer minutes of exercise per week for colorectal and breast cancer in 2005 ($b = -31.20$, 95% CI -43.38 to -19.03 and $b = -46.68$, 95% CI -60.71 to -32.64, respectively) and 2010 ($b = -49.90$, 95% CI -63.67 to -36.13 and $b = -45.42$, 95% CI -65.07 to -25.76, respectively). DKR was not significantly associated with breast screening in 2010 or with the number of servings of fruits and vegetables consumed daily.

The multivariable models examining DKR and behavior included socio-demographic and health characteristics as covariates (Supplemental Table 2). The relation between DKR and cancer screening remained statistically significant for colorectal cancer in 2010 (OR=0.75, 95% CI 0.60 to 0.94). It was not significant for colorectal screening in 2005 or breast screening in 2005 or 2010. DKR was no longer associated with physical activity (except for colorectal cancer in 2010, $b = -23.88$, 95% CI -40.31 to -7.46), nor was it associated with fruit/vegetable consumption for either cancer site in either year.

To better understand the interrelationships among DKR, socio-demographics, and behavior, we explored which covariate(s) might account for the most variation in the DKR-behavior relationship. To accomplish this, we examined the unique effect of each covariate on the size of the point estimate for each DKR-behavior pairing that was statistically significant at the bivariate level but not at the multivariable level. Education most strongly and consistently accounted for the DKR-behavior relationship across behaviors (data not shown).

To better understand the interrelationships among DKR, perceived risk generally, and behavior, we closely examined the behaviors that were associated with DKR at the bivariate level: cancer screening and physical activity. Specifically, we compared levels of cancer prevention and detection behaviors for DK responders with levels of behavior among participants at each level of perceived risk. This analysis was intended to discover if engagement in healthy behaviors was lower among DK responders than among people who provided a valid response at any or at only one level of perceived risk (e.g., those who report

high risk perceptions). The answer to this question depended on the behavior. In both 2005 and 2010, DK responders had lower adherence to colorectal and breast cancer screening guidelines only when compared to those who perceived that they were at higher than average risk of colorectal and breast cancer, respectively (Supplemental Table 3). In contrast, physical activity was generally lower among DK responders than among individuals who provided any valid response to the colorectal and breast cancer perceived risk question. The exception was for colorectal cancer in 2005; DK responders engaged in less physical activity only when compared to people who perceived they were at lower than average or average risk, but not when compared to people who perceived that they were at higher risk for colorectal cancer.

Sensitivity analyses examined whether dichotomizing physical activity and fruit/ vegetable intake (i.e., adherent/not adherent to national recommendations) would change the study results. As in the original analyses, DKR was associated with point estimates indicating less engagement in healthy behaviors. However, the multivariable relationship between DKR-colon 2010 and physical activity was no longer statistically significant (OR=0.93, 95% CI 0.78-1.12). For fruit/vegetable intake, two previously non-significant relationships became newly statistically significant: the bivariate relationship for DKR-colon 2005 (OR=0.70, CI=0.53-0.91), and the multivariable relationship for DKR-breast 2005 (OR=0.61, 95% CI=0.39-0.95). As in the main analyses, education was the most influential covariate. Controlling for physician recommendation to screen for colorectal cancer eliminated the significant relationship between DKR and colorectal cancer screening in 2010 (OR = 0.58, 95% CI 0.12-2.04). However, with that exception, physician recommendation did not affect the size or the direction of the DKR-behavior relationship for colon screening, breast screening, or physical activity in either year.

Socio-demographic and Health Characteristics as Predictors of DKR

Bivariate and multivariable logistic regressions examined the relationships between DKR and socio-demographic and health characteristics (Supplemental Table 4). Bivariate analyses indicated that, for both years and cancer sites, DKR was generally more common among more vulnerable populations (e.g., non-white, lower education). Several of these relationships remained statistically significant at the multivariable level across cancer sites and years: being older, non-white, born outside the U.S., and less formal education ($p<.05$). Being widowed or never married was associated with higher DKR for colorectal cancer in 2005 and 2010. Being male was also associated with higher odds of DKR for colorectal cancer, but this was significant only for 2010. Having low income was associated with DKR only for breast cancer in 2005.

Discussion

This study examined the behavioral and socio-demographic correlates of expressing uncertainty about one's risk of developing cancer. We found that engaging in physical activity and cancer screening behaviors was generally lower among people who indicated they did not know their cancer risk than among people who provided a valid response. This relationship was largely accounted for by education, which suggests that education might be

a distal determinant of both don't know responding (DKR) and lower engagement in health protective behavior.

The importance of education for DKR and its relationship with behavior is consistent with research suggesting that DKR might be attributable, in part, to gaps in knowledge between people who do and do not express uncertainty about their risk (14, 15). It is also consistent with our current data and others' reports (8, 9, 12, 14, 15) that DKR was higher among socio-demographic groups that are disproportionately more likely to have limited formal education (e.g., African Americans, immigrants) and/or limited health literacy. One possible explanation is that socio-demographic factors in general, and education in particular, may place some individuals at risk of having limited health literacy and subsequent low knowledge of cancer risk factors. Low risk factor knowledge could result in uncertainty about the extent to which one is at risk of developing cancer. A second possible mechanism is that the education, health literacy and/or knowledge limitations that underlie DKR may also lead to a lack of awareness of appropriate preventive behaviors. The fact that DKR was associated with less engagement in physical activity than even those with low perceived risk suggests that those who respond don't know may be an important subpopulation that may have had very limited access to messages about cancer risk and risk reduction recommendations that are appropriate for their level of health literacy. This is consistent with theories of health behavior that hypothesize that knowledge is a key precursor to the formation of risk perceptions (23). Future research should investigate the validity of this framework and explore other possible mechanisms for DKR, including poor understanding of the messages due to limited health literacy, defensive processing of threatening health information, and lack of motivation to respond to survey items.

It might be appealing to dismiss the importance of DKR as being a phenomenon of socioeconomic status. Socio-demographic characteristics are indeed critical to the manifestation and behavioral correlates of DKR, but perceived risk is a more proximal mechanism that, although potentially influenced by socioeconomic status, has a more direct influence on health behavior adoption and is likely more amenable to intervention (1, 6). For example, reducing socioeconomic disparities in health behavior adoption might be achieved more readily by helping people understand their risk than by attempting to increase educational attainment.

This research also provides guidance for survey development. Most studies do not offer a DK response option to risk perception items. This forces participants to indicate an answer even if they genuinely do not know how to respond, which could, in turn, obscure (at best) or systematically bias (at worst) the observed perceived risk-behavior relationship. Including a DK response option and excluding individuals who select it from analyses (e.g., 11) is also not desirable because it may inadvertently exclude an important group of individuals from risk perception research: individuals who, despite public health efforts to communicate risk-based prevention messages, may remain uncertain about their risk. Assessing health literacy and its relationship to perceived risk and message comprehension may also be beneficial.

Strengths, Limitations, and Future Research

Our use of nationally representative, population-based datasets with appropriate weighting and variance estimation procedures enables us to draw inferences that are generalizable to the U.S. population (19). Examining data from two different years and examining DKR related to two different cancer sites allows for greater generalization across time and cancer sites than prior research (8, 9, 14), which focused on only one survey year and one cancer site. Furthermore, our focus on the potential behavioral consequences of DKR extends prior research, which did not examine behavior. In sum, this study adds significantly to our understanding of the scope of DKR in the U.S., the potential consequences of DKR on health behaviors, and the role of socio-demographic characteristics in DKR. Yet, future research should examine the extent to which these findings extend to non-U.S. populations.

Despite these strengths, because the NHIS datasets are cross-sectional it is not possible to infer causation. In addition, self-reported behaviors are vulnerable to reporting bias. Another concern is whether DKR is due to lack of motivation to answer a survey question or the use of cognitive shortcuts (7, 24). However, the strong relationship between DKR and education described here and elsewhere (8, 9, 12, 14, 15) and the link between DKR and low knowledge about cancer prevention and detection even after controlling for socio-demographic covariates (14), suggests that the findings cannot be explained only by lack of motivation. Thus, it appears that DKR may be signalling researchers to highly relevant content: that a subset of the population may not be *able* to appraise their risk with certainty due to limited knowledge.

Future experimental, longitudinal, and qualitative research should examine the cognitive and affective processes that prompt DKR and under what circumstances not knowing one's risk may or may not affect engagement in healthy behaviors. Examples of such processes that were not included in the NHIS questionnaires include cancer worry and lack of knowledge about how to engage in prevention behaviors. It is also important for researchers to examine DKR outside of the cancer context. For example, is not knowing one's risk of heart disease, stroke, or diabetes also associated with less engagement in healthy behaviors? How does DKR interact with other behavioral determinants, including socio-ecological barriers such as a lack of safe places for engaging in physical activity (6)? Answering these questions is critical for advancing the development and refinement of health behavior theories and interventions.

Conclusions

Perceptions of risk are critical drivers of volitional health behaviors (1, 2, 25, 26). However, millions of people in the U.S. express uncertainty about their risk of two common and serious health conditions: colorectal cancer and breast cancer. These individuals tend to engage in fewer cancer prevention and detection behaviors than people who report having risk perceptions and, consequently, may be particularly vulnerable to experiencing disproportionate cancer morbidity and mortality. Interventions that help people more fully understand their risk may, in conjunction with interventions to address other barriers (6), help contribute to the eventual alleviation of cancer and other health disparities.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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