

# Using NCI-Designated Cancer Center Catchment-Area Data to Understand an Ignored but High-Need Constituent: People Uncertain or Avoidant about Their Cancer Risk

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## Abstract

In 2016, the NCI provided supplemental funding to 15 NCI-designated cancer centers to enhance cancer centers' capacity to collect critical catchment-area data across behavioral and psychosocial domains [March 2019 issue of *Cancer Epidemiology, Biomarkers & Prevention (CEBP)*—*CEBP Focus*]. In response, we highlight opportunities for cancer risk perception research when collecting and utilizing catchment-area data given the remarkably high proportions of individuals who report they are at average cancer risk, high levels of cancer risk information avoidance, and extremely negative ("death") associations with cancer. First, we advocate for enhanced measurement specificity regarding whether some participants may be uncertain regarding their cancer risk. Second, we

advocate for examination of whether the large proportion of people who rate their risk as average have common (demographic and attitudinal) characteristics, which may dictate specific and targeted cancer prevention and control intervention. Finally, we advocate for further examination of cancer risk information avoidance and negative cancer associations to clarify subgroups that may fail to engage with risk information. Given the ubiquity of risk uncertainty, information avoidance, and negative cancer associations, further research into these prevalent beliefs will enhance our ability to bring the latest information regarding cancer prevention and control to the general population of the United States.

The potential for rigor and reproducibility in cancer control science is enhanced with the use of common, standardized measures of health behavior, cancer knowledge, access to care, cancer communication, risk perceptions, and attitudes. In 2016, the NCI provided supplemental funding to 15 NCI-designated cancer centers to enhance cancer centers' capacity to collect critical catchment-area data across these domains (1). Using standardized measures (2) provides unique and ongoing opportunities to envision an overall picture of national cancer control needs and priorities, and to draw comparisons across sites (3). We read with interest the findings published in the March 2019 *Cancer Epidemiology, Biomarkers & Prevention (CEBP) Focus* related to cancer risk perceptions across multiple catchment areas (1). In this commentary, we highlight some critical findings to encourage further research utilizing these rich datasets.

Cancer risk perceptions and other cognitions and emotions motivate cancer risk reduction behaviors (4, 5). The risk perception item used in the *CEBP Focus* articles (2) assessed comparative risk perceptions, "Compared with other people your age, how

likely are you to get cancer in your lifetime?" The five response options included, "much less likely," "less likely," "about the same," "more likely," and "much more likely." In two studies, the midpoint was labeled slightly differently, as "neither likely nor unlikely" (6, 7). It appears that an "I don't know" option was not available for analyses (6–8), but several articles reported high proportions of people (40%–50%) who perceived themselves to be at the midpoint (i.e., risk of cancer as "neither likely nor unlikely" or "about the same") compared with same-age others (6–8). While many who were surveyed may believe that they were specifically at average cancer risk, another group, those who are uncertain about their cancer risk, may have endorsed this midpoint option as well. Research suggests that people who are uncertain about their risk will often select the scale midpoint if an "I don't know" option is unavailable (9, 10).

Uncertainty about personal disease risk is common and disproportionately affects populations experiencing health disparities. In nationally representative samples, when "I don't know" is explicitly provided as a response option to colorectal cancer risk perception questions, 30% to 50% of respondents will choose this option (11). Those who report they "don't know" their risk tend to have lower health literacy, education, and income, be racial or ethnic minorities, have less risk knowledge (11–13), and engage in poorer health behaviors (13). Furthermore, uncertainty about cancer risk is associated with a motivated desire to avoid cancer risk information (11) and strong negative associations of cancer with death (14). Indeed, several of the articles included in the *CEBP Focus* section report high levels (35%–47%) of cancer risk information avoidance, indicated by agreement with the phrase, "I'd rather not know my chances of getting cancer" (6, 7). In addition, nearly two thirds of participants in Texas and Indiana reported, "When I think about cancer, I

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Cancer Epidemiol Biomarkers Prev 2019;28:1955–7

doi: 10.1158/1055-9965.EPI-19-0430

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automatically think of death" (6, 7). While it appears as though a "I don't know" option was not available for the cancer risk perception question (6–8), we suspect that the rates of this response are substantial, given the overuse of the midpoint response option, a known indicator of uncertainty (9, 10), and also because of the high prevalence of factors known to be related to responding "I don't know," as well as other markers for risk uncertainty, including a motivated desire to avoid thinking about cancer, and the association of cancer with death.

The high prevalence of cancer risk information avoidance and associations of cancer with death reported in the *CEBP Focus* section suggests that uncertainty about cancer risk may be similarly prevalent, despite our inability to measure it directly. This is important yet problematic because each of these beliefs are associated with less engagement in cancer prevention and detection behaviors, including cancer screening (15), obtaining genetic test results (16), and seeking care from physicians (17). Other negative beliefs like cancer fatalism are also related to cancer risk information avoidance (18). Therefore, we argue that effectively assessing and reporting "I don't know" responses as a reflection of risk uncertainty would be a low-cost way of meaningfully improving future research related to the already impressive work reflected in the *CEBP Focus* section. Specifically, accounting for uncertainty about personal risk would enhance the rigor of behavioral cancer prevention and control research by most accurately characterizing the knowledge, attitudes, and beliefs of catchment-area populations and by clarifying and specifying the relation of risk to behavior (13, 19, 20).

We present recommendations for researchers using the catchment-area datasets that may also be helpful for others seeking to improve cancer prevention and control messaging. First, if spontaneous "I don't know" responses to risk perception questions are available for analysis, researchers should examine and report on it, including examination of demographic and behavioral correlates to identify intervention needs among individuals who report uncertainty about cancer risk. More precise measurements of risk uncertainty will further enhance these efforts. Affective and intuitive aspects of risk perceptions (21–23) may be less susceptible to uncertainty and may be important elements of how risks are conceptualized in real world contexts and may thus include additional solutions worth considering.

Second, it may be useful to understand whether a relatively large proportion of those who rate their risk as "average," or at the midpoint, have common characteristics associated with perceived risk uncertainty, such as low health literacy, cancer risk information avoidance, or negative cancer associations (i.e., death), which may dictate specific and targeted intervention approaches. Given the

large proportions of the general population who report that they "don't know" their risk, we should continue to explore strategies to address these deficits and increase engagement with accurate cancer risk and cancer risk reduction information.

Third, using measures of cancer risk information avoidance and negative cancer associations (i.e., "death") may clarify for whom and under what conditions study participants may fail to engage with risk information or become nonadherent with prevention and control interventions. Given the very common belief that cancer is a death sentence, along with high levels of cancer information avoidance, cancer prevention communications should explicitly anticipate avoidance reactions from the general population, those at higher risk, and vulnerable populations. Attention is needed, given that individuals with these beliefs might be more likely to refuse participation in cancer prevention intervention studies, more likely to drop out of such studies, and clinically to avoid health care interactions surrounding cancer prevention (screening and risk counseling).

Fourth, collecting data in the future about "I don't know" responses will facilitate the surveillance of trends in the prevalence and demographic correlates of these meaningful responses. These efforts could shape the development of meaningfully distinct knowledge-based and avoidance-based interventions to enhance cancer prevention and control behaviors.

In summary, we argue that collecting information on "I don't know" responding and how risk and uncertainty might relate to health behavior adoption, cancer screening, and other significant outcomes, is a public health priority. The articles in the March 2019 *CEBP Focus* section further our understanding of why cancer risk messaging often falls on deaf ears. Given the ubiquity of risk uncertainty, cancer risk information avoidance and negative cancer associations, further research into these prevalent beliefs is needed to enhance our ability to bring the latest information regarding cancer prevention and control to the general population of the United States.

#### Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

#### Acknowledgments

The authors acknowledge the grant support provided by R01 CA197351 (to H. Orom, J.L. Hay, and multiple principal investigators) and Memorial Sloan Kettering support grant (P30 CA008748).

Received April 16, 2019; revised June 17, 2019; accepted September 4, 2019; published first September 9, 2019.

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*Cancer Epidemiol Biomarkers Prev* 2019;28:1955-1957. Published OnlineFirst September 9, 2019.

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