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Perceptions of cancer as a death sentence: Prevalence and consequences

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Abstract

Research suggests that perceiving cancer as a death sentence is a critical determinant of health care-seeking behaviors. However, there is limited information regarding the prevalence of this perception in the US population. Cross-sectional analysis of data (n = 7674 adults) from the 2007–2008 administration of the nationally representative Health Information National Trends Survey (*HINTS 3*) was performed. A majority (61.6%) of respondents perceived cancer as death sentence, and more than one-third (36%) of respondents reported that they avoid seeing their physicians. In the adult US population, perceiving cancer as a death sentence is common and is associated with education level and avoidance of physicians.

Keywords

cancer; health behavior; health psychology; perception; public health psychology

“It’s not that I’m afraid to die, I just don’t want to be there when it happens.”

Woody Allen (1975)

Background

Most people would prefer not to think about their mortality. Yet for many people, the inevitable decay of their bodies and the presence of certain diseases may conjure up a sense of fatal despair. But do such propensities relate to people’s readiness to attend to health-related issues? We all must confront illness at some point in our lives, and the extent to which we associate a particular illness with death may have important ramifications for our

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behavior. A critical step in such possibilities is to first understand the prevalence of death-related associations that people attach to a particular disease.

Illness representations have been postulated to play a critical role in influencing health-related behaviors (Leventhal, 1970; Leventhal et al., 1980). Specific aspects of illness representations include beliefs about a disease's causes, time course, controllability or curability, and lethality. For illnesses such as cancer, mental representations of lethality may be especially influential. Despite encouraging increases in cancer survivorship over the years, studies suggest that the idea of cancer is strongly equated with death. For example, priming people to think about cancer increases the accessibility (i.e. availability to memory) of death-related cognitions (Arndt et al., 2007).

Yet, there are no data describing the prevalence of these cognitions in the US population. Thus, the extent to which people generally equate cancer with death is unknown. Furthermore, while illness representations are thought to interact with other psychological factors to influence behavior such as health-care seeking and avoidance, there are few, if any, population-level estimates of perceived lethality and the consequences that may ensue from such perceptions.

These are important knowledge gaps, given that people's difficulties in coping with the idea of their own mortality may have far-reaching motivational consequences. According to the Terror Management Health Model (TMHM; Goldenberg and Arndt, 2008), people are often motivated to avoid or escape situations where they are reminded of death, especially when they do not perceive a viable trajectory for reducing mortal vulnerabilities. To the extent that people associate cancer with death, they may avoid seeking health care for a variety of reasons such as fear of having the illness. In fact, there is some evidence that holding a fatalistic construal of cancer undermines compliance with screening recommendations (Chavez et al., 1997; Niederdeppe and Levy, 2007).

This work suggests that avoidance of health care may be an important outcome of perceiving cancer as a death sentence. The underuse or avoidance of appropriate services—errors of omission—seems to have a critical impact on health (Hayward et al., 2005). The empirical literature has identified several types of barriers to the use of needed services, including attributes of the health-care system (e.g. costs of care and availability of clinical services; Asch et al., 2000; Federman et al., 2005; Weinick et al., 2005). More recently, research has also begun to focus on patient-level factors including sociodemographic characteristics (e.g. Nijs et al., 2000) and psychological variables, such as disease risk perceptions, coping strategies, and social support (Friedman et al., 2006; Posluszny et al., 2004; Tromp et al., 2004).

In summary, there are theoretical and empirical grounds from which to hypothesize that people may associate cancer with death and that this patient-level, psychological factor in turn may have important health-related consequences. This study therefore sought to address this issue and to provide initial insight into several fundamental questions: (1) To what extent does the adult US population perceive cancer as a death sentence? (2) What is the prevalence of physician avoidance among US adults and what are the sociodemographic

correlates? (3) Are perceptions of cancer as a death sentence associated with physician avoidance?

Method

Data source

Data were obtained from the 2007–2008 administration of the Health Information National Trends Survey (*HINTS 3*). *HINTS* assesses the American public's use of health and cancer-related information and related knowledge, perceptions, and behaviors. These data are publicly available from the following website: <http://hints.cancer.gov/> The survey used a mixed-mode, dual-frame design with a final sample size of 7674 respondents. One frame was a list-assisted Random Digit Dial (RDD) Computer Assisted Telephone Interview (CATI), wherein one adult from each household was selected for an interview. Interviews were conducted in English or Spanish depending on respondent preference. The sample size for the RDD frame was 4092 adults. The response rate for the RDD household screener was 42.4 percent, and the response rate for the extended interview was 57.2 percent. The second frame was a comprehensive national listing of addresses available from the United States Postal Service. These households were administered a mail survey. In the mail sample, all adults in the household at each sampled address were asked to complete a questionnaire. The household response rate for the mail survey was 40 percent, and the within-household response rate was 77.4 percent. The two modes and associated samples were created such that each can be analyzed as an independent sample or combined together for a composite estimate and with a set of respective sample weights to give US population estimates. Further details on the overall design and study operations are published elsewhere (Cantor et al., 2009; Nelson et al., 2004).

Survey items

The cancer-related death perception and avoidance of physician items were created by the principal authors for the 2007–2008 administration of the survey. Each item was thoroughly evaluated in a cognitive laboratory using concurrent think-aloud techniques (Willis, 2005), and the final versions were pilot-tested in the field.

Perception of cancer as a death sentence

To assess this construct, respondents were asked to agree or disagree with the following question: “When I think of cancer, I automatically think of death.”

Underuse of care/avoidance of physicians: reasons for avoiding physician

Self-reported avoidance of physicians was assessed by the following question: “Some people avoid visiting their doctor even when they suspect they should. Would you say this is true for you, or not true for you?” Respondents who answered “True” to this question were then asked to agree or disagree with the following set of questions as to why they may be avoiding their physician: (1) “I avoid seeing my doctor because I feel uncomfortable when my body is being examined,” (2) “I avoid seeing my doctor because I fear I may have a serious illness,” (3) “I avoid seeing my doctor because it makes me think about dying.”¹

Sociodemographic variables

Respondents were asked to provide information on age (coded into 5 categories), gender, education (in 4 categories), and cancer history (yes or no, has the respondent been diagnosed with cancer or had a family member diagnosed with cancer). Race and ethnicity items were combined into one race/ethnicity variable with five mutually exclusive categories: (1) Hispanic, (2) Non-Hispanic White, (3) Non-Hispanic Black/African American, (4) Non-Hispanic Asian, (5) Non-Hispanic Other (including those self-identified as multiracial).

Data analysis

All analyses were done using SAS and SUDAAN to account for the complex sampling design of HINTS and are weighted using the combined sample weights to get nationally representative estimates. Although respondents in the mail mode had higher agreement with cancer-related death associations and higher prevalence of avoidance of physicians than respondents in the phone mode, combined weights were used because we did not believe either mode would give the “gold standard” estimates. Descriptive statistics were first conducted on the main variables of interest. Next, Chi-square tests were conducted to examine the bivariate relationships between the sociodemographic variables and the death perception variable, the avoidance variable, and the reasons for avoidance. The main analysis was a multivariable logistic regression model, regressing avoidance on the set of sociodemographic variables and the death perception variable. Responses coded as “Don’t know” and “Refused” were considered missing, and respondents who had missing values for other relevant variables used in any statistical models were excluded from the analysis. This resulted in a final analytic sample size of 6827.

Results

Demographics of analytic sample

The weighted analytic sample consisted of 51.7 percent females, of which 25 percent were college graduates. The majority of the sample comprised Non-Hispanic Whites (69.8%), but also included Hispanics (12.8%), Non-Hispanic Blacks/African Americans (11.3%), Non-Hispanic Asians (4.2%), and Non-Hispanic Others (1.9%). Most of the people in the sample were aged between 18–34 years (30.6%), followed by those aged 35–49 years (29.9%) and 50–64 years (23%). A minority had a personal/family history of cancer (28%), and a large majority had health insurance (83.4%).

To what extent does the adult US population perceive cancer as a death sentence? For the composite sample, 61 percent (95% confidence interval (CI) = 60.0%–63.2%) of respondents agreed that they associate cancer with death. According to the bivariate analyses, there was a consistent linear trend for education, such that higher education levels were associated with being less likely to associate cancer with death ($\chi^2 = 19.81, p < .001$).

¹Respondents were given the opportunity to write in “other” reasons for avoiding their doctors; these were not examined in this study.

What is the population-level tendency for physician avoidance and what are the sociodemographic correlates?

Approximately 36 percent (95% CI = 34.4%–37.6%) of respondents agreed that they avoid seeing their physicians. Regarding reasons for avoidance, fear of having a serious illness (12.1%; 95% CI = 11.0%–13.2%) and discomfort with being examined (12.1%; 95% CI = 11.0%–13.2%) showed the highest prevalence. Among sociodemographic variables, Chi-square test results showed that males ($\chi^2 = 13.22, p < .001$), those with less education ($\chi^2 = 10.77, p < .001$), younger respondents ($\chi^2 = 28.03, p < .001$), and those without insurance ($\chi^2 = 39.13, p < .001$) had significantly higher rates of responding that they avoid seeing their physicians. Females reported that they are more likely to avoid their physicians due to discomfort with having their bodies examined ($\chi^2 = 9.90, p < .01$).

There were again clear education effects with higher levels of education associated with lower avoidance, and reasons for avoidance. Cancer history was not related to any of the outcome variables, although respondents without a cancer history showed a higher level of agreement with physician avoidance due to reminders of dying.

Are perceptions of cancer as a death sentence associated with physician avoidance?

In the *multivariable* logistic regression model (see Table 1), cancer-related death perceptions remained a significant predictor of avoidance (odds ratio (OR)=1.44, 95% CI = (1.24 --1.66) even after controlling for sociodemographic variables. Among the sociodemographic variables, all remained significant except for race/ethnicity and cancer history, with males (OR = 1.27, 95% CI = 1.09–1.47), those with less than high school education (OR = 1.45, 95% CI = 1.10–1.90), younger respondents (OR = 2.50, 95% CI = 1.80–3.46), and those without insurance (OR = 1.77, 95% CI = 1.40–2.25) having significantly higher odds of responding that they avoid seeing their physicians.

Discussion

The goal of this study was to provide US prevalence estimates of people's tendency to perceive cancer as a death sentence and consequences of holding such perceptions for physician avoidance. Accordingly, this research documents that a majority of the US population equates cancer with death and that this perception is one factor associated with people avoiding to seek physician care. Although the cross-sectional nature of the design renders any causal inferences as tentative, the association of the cancer–death connection with avoidance was robust and persisted even after controlling for important sociodemographic variables. Other notable findings especially relevant to the challenge of improving the health of people in the United States include the following: (1) equating cancer with death is associated with lower education, (2) more than one-third of the US population reports physician avoidance, and (3) men are more likely to avoid seeing their physician than women, a result that supports many anecdotal perceptions but to our knowledge is yet to be demonstrated using population-level data.

These results raise particular concerns for cancer control efforts to the extent that illness perceptions affect health-related behaviors. For example, there is ample evidence that

physicians play a critical role in motivating people to get screened for cancer (Abdel-Malek et al., 2008; Meissner et al., 2007; Rakowski et al., 2004) and that physicians serve as important and trusted sources of information for patients regarding cancer-related preventive health behaviors (e.g. physical activity, nutrition, and smoking cessation; Colditz et al., 1996; Hesse et al., 2008). The idea of cancer, however, may still be evoking spontaneous thoughts of death, and these thoughts may paradoxically discourage some people from seeing physicians. The effects of these processes may be strongest for patients who are less educated.

It is interesting to note the results of those who have personal experience with cancer, either themselves or through a family member. Previous research suggests that this group tends to have a different set of information and communication needs than the general public (Arora et al., 2002; Beckjord et al., 2008; Rutten et al., 2005, 2006). Indeed, a null finding suggested that people with personal experience with the disease are not more or less likely to think of cancer as a death sentence or to avoid their doctors as a result. However, the effects of cancer history may be masked by combining those with a personal history and those who only had a family member diagnosed. Future research may wish to explore this issue further. Nevertheless, there still exists a nontrivial percentage of cancer survivors who avoid seeing their physicians; a disconcerting result from a population that is especially vulnerable to recurrence, secondary neoplasms, and late-stage complications from treatment (Hewitt et al., 2006). This finding is especially important given the ever-growing population of cancer survivors in the United States.

Limitations

There are some limitations of this research. First, as noted above, the data are cross-sectional, and one cannot make causal inferences between avoidance and the other variables such as cancer–death associations. Nevertheless, it is worth noting that experimental studies indicate that reminding participants of their mortality (vs a control topic) can decrease screening and other health-related intentions (Arndt et al., 2006; Cooper et al., 2010). Another potential limitation results from survey methodology that relies on single items to measure the key variables investigated in this study. The chief effect of single-item measures is to reduce reliability, which in turn lessens the chances of identifying significant relationships. Given that we did find associations, this limitation may be relatively unimportant. Finally, there were limitations related to the focus of our main variables of interest. For instance, the cancer-related perception variable focused on death per se but not other general health concerns to test for other predictors of avoidance. Likewise, this study did not examine other theoretically important reasons for avoidance, such as financial concerns. The avoidance question was general and not cancer-specific. It is possible that we may have found different results had the relevant item been specific to some other disease (e.g. “when I think of heart disease, I automatically think of death”), or a specific cancer (e.g. “when I think of breast cancer, I automatically think of death”), or if the avoidance of physicians item was cancer-related (e.g. “I avoid seeing my doctor because I’m concerned I may have cancer”). However, the fact that cancer–death associations were associated with generalized physician avoidance renders the present findings especially notable in

implicating a potentially broad array of consequences from this type of illness representation.

Conclusion

Unfortunately, for a majority of Americans, thinking about cancer automatically means thinking about death. Among those who do make this association, thinking about death is related to avoiding their doctors, perhaps in a self-fulfillment of fatalistic thinking.

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Table 1

Multivariable logistic regression model including odds ratios (ORs) and 95% confidence interval (CI) (n=6827).

Characteristic	OR	95% CI OR
Perceiving cancer as a death sentence		
Yes	1.44	(1.24, 1.66)
No (ref)	1.00	—
Gender		
Male	1.27	(1.09, 1.47)
Female (ref)	1.00	—
Education		
Less than high school	1.45	(1.10, 1.90)
High school graduate	1.35	(1.11, 1.65)
Some college	1.21	(1.03, 1.42)
College graduate (ref)	1.00	—
Race/ethnicity		
White (ref)	1.00	—
Non-Hispanic Black/African American	0.84	(0.62, 1.13)
Non-Hispanic Asian	0.72	(0.43, 1.22)
Hispanic	0.96	(0.74, 1.24)
Non-Hispanic Other	1.19	(0.75, 1.89)
Age group (years)		
18–34	2.50	(1.80, 3.46)
35–49	2.59	(1.91, 3.51)
50–64	1.99	(1.52, 2.59)
65–74	1.28	(0.94, 1.75)
75+ (ref)	1.00	—
Cancer history (self or family)		
Yes	1.00	(0.80, 1.24)
No (ref)	1.00	—
Insurance		
Yes (ref)	1.00	—
No	1.77	(1.40, 2.25)

Outcome = avoidance of physicians.