Illness Representations of Lung Cancer, Lung Cancer Worry, and Perceptions of Risk by Smoking Status

Lila J. Finney Rutten,
Clinical Monitoring Research Program, SAIC, Inc. - Frederick, National Cancer Institute - Frederick, Frederick, MD 21704, USA

Kelly D. Blake,
National Cancer Institute, Bethesda, MD, USA

Bradford W. Hesse,
National Cancer Institute, Bethesda, MD, USA

Erik M. Augustson, and
National Cancer Institute, Bethesda, MD, USA

Sarah Evans
US Food and Drug Administration, Silver Spring, MD, USA

Lila J. Finney Rutten: finneyl@mail.nih.gov

Abstract

We examined perceived risk, worry, and illness representations of lung cancer by smoking status using data from the 2005 Health Information National Trends Survey (*n*=1,765). Perceived lung cancer risk was rated "very high" more frequently by current (15.2%) than former (1.9%) and never (1.6%) smokers. Current smokers more frequently reported worry about lung cancer (18.4%) than former (3.1%) and never smokers (1.8%). Confusion about lung cancer prevention was higher among current (55.2%) than former (41.3%) or never smokers (38.2%). Agreement that lung cancer is caused by a person's behavior was higher among never (86.1%) and former (82.6%) than current smokers (75.4%). In multivariable models, never (OR=.07) and former smokers (OR=.16) were less likely than current smokers to perceive their lung cancer risk as high. Never smokers (OR=.21) were significantly less likely than current smokers to report worrying about lung cancer, while former and current smokers did not differ.

Keywords

Smoking; Lung cancer worry; Risk perceptions

Introduction

Tobacco use has consistently been identified as the single most avoidable cause of disease, disability, and death in the USA. An estimated 438,000 people in the USA die each year from smoking or exposure to secondhand smoke, while an additional 8.6 million people suffer from tobacco-related illness [1, 2]. Lung cancer is the leading cause of cancer death among both men and women in the USA, with approximately 80% of lung cancer deaths among women and 90% of lung cancer deaths among men attributed to smoking [3]. Despite overwhelming evidence of the harmful effects of smoking, approximately 45 million adults in the USA currently smoke cigarettes [4].

Risk, Worry, and Illness Representations: Theoretical Foundation

Beliefs about the extent to which health problems can be prevented, detected early, or effectively treated have been shown to influence self efficacy, perceived control, and subsequent health behavior. In particular, it has been theorized that the ways in which people think about (or "represent") illnesses have important implications for behavior related to disease prevention, detection, and treatment [5, 6]. Leventhal's *Common-Sense Model of Health and Illness Self-Regulation* emphasizes the significance of individuals' illness representations and delineates various components thereof including: identity (e.g., "What is the illness? What are the symptoms of this illness?"), cause (e.g., "What causes this illness?"), timeline (e.g., "Is this an acute or chronic illness?"), consequences (e.g., "How painful or debilitating is the illness?"), and controllability (e.g., "Can the illness be prevented or successfully treated?") [7]. A meta-analytic review of studies supports the theoretical suppositions of the Common-Sense Model, concluding that illness representations are associated with coping ability and health outcomes across a range of illnesses [8].

Illness representations, which encompass one class of illness cognitions, may be related to other cognitive constructs relevant to health threats, including illness worry and risk perceptions. Although worry and risk perceptions are not part of Leventhal's original model, they have been incorporated into expanded versions of the self-regulation framework. The *Extended Parallel Process Model* introduces the concept of worry, proposing that in confronting health threats, if problem-focused and emotion-focused coping efforts are ineffective or inadequate, individuals will experience fear or worry [9]. Worry has been traditionally defined as relatively uncontrollable, negative affect-laden thoughts or images [10] and has been associated with self-protective health behavior [11–14]. The *Cognitive-Social Health Information Processing* (*C-SHIP*) *model* [15] also expands on the self-regulation framework through identification of cognitive and affective processes through which different cognitive and emotional variables are processed in response to health threats or risk. In particular, the C-SHIP model incorporates encoding processes and emotional reactions that expand self-regulation to include the constructs of risk perception and worry. Risk perceptions, also referred to as perceived vulnerability, refer to individuals' beliefs about the likelihood of developing a given illness or perceptions of the likelihood of a health problem occurring. Heightened risk perceptions are theorized to be associated with self-protective health behavior [16–18].

Our study examined differences in illness representations of lung cancer and perceived risk and worry about lung cancer between current, former, and never smokers, and assessed associations of illness representations with former quit attempts and intentions to quit among current smokers.

Research Aims

The specific aims of our study were to describe and identify differences in illness representations of lung cancer, worry about developing lung cancer, and perceptions of risk for current smokers, former smokers, and never smokers. We also explored associations of illness representations, worry, and risk with prior quit attempts and intentions to quit among current smokers.

Methods

Data Collection, Response Rates, and Sample

Data for this analysis are from the 2005 Health Information National Trends Survey (HINTS 2005). The HINTS is a unique national data resource that assesses cancer communication constructs, including cancer knowledge, in the US population; HINTS is among the first national surveys to capture the illness representations of cancer in the US population. In HINTS 2005, a series of items assessed cancer-related illness representations, worry, and risk perceptions.

The sample design for HINTS 2005 employed a list-assisted, random digit dial of all telephone exchanges in the USA. The survey was administered to a representative sample of US households wherein one adult aged 18 or older per household was selected during a household screener for extended interview (n=5,586). The final response rate for the screener was 34.01%, and the final response rate for extended interview was 61.25%. Greater details about the sample and sampling design are reported elsewhere (http://www.cancercontrol.cancer.gov/hints/; see HINTS 2005 Final Report).

Respondents were randomly assigned to receive illness representations of lung cancer, worry about developing lung cancer, and perceptions of risk questions related to only one of three types of cancer, resulting in the following sample sizes: colon (n=1,978), lung (n=1,872), and skin (n=1,736). Respondents who reported that they had been diagnosed with colon, lung, or skin cancer and who were randomly assigned to that cancer type were not asked the series of risk, worry, and illness representation items. Our analyses included only those respondents who were randomly assigned to questions about lung cancer.

Sociodemographic Characteristics and Smoking Status

Sociodemographic characteristics examined in our analyses included gender, age, race/ethnicity, education, and income. Ethnicity and race were assessed following the Office of Management and Budget standards [19].

Two survey items, which assessed past and current smoking behavior, were combined to define smoking status as current, former, or never smoker. Respondents were asked, "Have you smoked at least 100 cigarettes in your life?" Respondents who reported having smoked

at least 100 cigarettes were asked, "Do you now smoke cigarettes… every day, some days, or not at all?" Respondents who reported having smoked at least 100 cigarettes during their lifetime and currently smoking everyday or some days were categorized as "current smokers." Respondents who reported having smoked at least 100 cigarettes during their lifetime, but who indicated that they currently did not smoke were categorized as "former smokers." Finally, respondents who reported that they had not smoked at least 100 cigarettes during their lifetime were categorized as "never smokers."

Dependent Variables: Cancer-Related Perceptions of Risk, Worry, and Illness Representations; Quit Attempts

Perceptions of Risk—Respondents' perceptions of risk were assessed with the following items: (1) "How likely do you think it is that you develop lung cancer in the future? Would you say your chance of getting lung cancer is (very low, somewhat low, moderate, somewhat high, or very high)?" and (2) "Compared to the average person your age, would you say that you are (less likely, about as likely, or more likely) to get lung cancer?"

Cancer Worry—Respondents were asked: "How often do you worry about getting lung cancer?" Response options included "rarely or never, sometimes, often, or all the time." Worry was also assessed with the following item: "You are reluctant to get checked for lung cancer because you fear you may have it (agree/disagree)."

Illness Representations of Cancer—The following components of Leventhal's model were assessed by smoking status: identity, cause, timeline, and consequences/controllability (see Table 2). Respondents were asked to agree or disagree with the following statements: "People with lung cancer would have pain or other symptoms prior to being diagnosed," "Lung cancer is most often caused by a person's behavior or lifestyle," "It seems like everything causes lung cancer," "Lung cancer develops over a period of several years," "There are ways to slow down or disrupt the development of lung cancer," "There are so many different recommendations about preventing lung cancer that it's hard to know which ones to follow," and "There's not much you can do to lower your chances of getting lung cancer." Respondents were also asked, "Overall, how many people who develop lung cancer do you think survive at least five years?" Response options included: "less than 25%, about 25%, about 50%, about 75%, or nearly all."

Prior and Intended Quit Attempts Among Current Smokers—To assess prior quit attempts, current smokers were asked, "During the past 12 months, have you tried to quit smoking completely?" Intention to quit was assessed among smokers with a question asking "Are you seriously considering quitting smoking within the next six months?"

Analyses

To account for the complex survey design of HINTS 2005, analyses were conducted using SAS-callable SUDAAN Version 9.0 [20]; all estimates were weighted to be representative of the US population. Descriptive analyses, including frequencies, percentages, and means for relevant variables, were conducted. Bivariate associations were assessed using chi-square tests of independence. A multinomial regression analysis was conducted to identify

independent associations of cancer-relevant risk, worry, and illness representations with smoking status, controlling for socio-demographic variables. All variables significantly associated with smoking status in the chi-square analysis were included in the multivariate model using a forced entry method of variable selection. To examine the association of risk, worry, and illness representations with prior or intended quit attempts among smokers, bivariate analyses and subsequent logistic regression analysis including variables found to be significant at the bivariate level were conducted.

Results

Sociodemographic Characteristics and Smoking Status

Table 1 summarizes the cross-tabulation with chi-square of key sociodemographic characteristics by smoking status. Over half (52.8%) of respondents were classified as never smokers, while 25.1% were former smokers, and 22.1% were current smokers. A higher percentage of former (53.3%) and current smokers (53.8%) were male than were never smokers (38.6%). Current smokers, compared with never and former smokers, tended to have lower levels of education and income and were generally younger.

Cancer-Related Perceptions of Risk, Worry, and Illness Representations: Bivariate Associations by Smoking Status

Table 2 summarizes the cross-tabulation with chi-square of cancer-related perceptions of risk, worry, and illness representations by smoking status. Measures of perceived risk and worry were significantly associated with smoking status with current smokers reporting the greatest perceived risk and worry. Specifically, the percentage of respondents reporting that their chance of developing lung cancer was very high was highest among current smokers (15.2%) compared to never (1.6%) and former smokers (1.9%). Similarly, current smokers (34.3%) more frequently than never (2.2%) and former smokers (9.0%) reported that they were more likely than an average person their age to develop lung cancer. Worry about developing lung cancer was highest among current smokers (18.4%) compared to never (1.8%) and former smokers (3.1%). Reluctance to get checked for lung cancer because of worry was highest among current smokers (23.4%) compared to never (9.8%) and former smokers (13.3%). Measures of illness representations assessing the constructs of cause and consequences/controllability were significantly associated with smoking status. Current smokers (75.4%) agreed less frequently than never smokers (86.1%) and former smokers (82.6%) that lung cancer is caused most often by a person's lifestyle or behavior, whereas current smokers (26.2%) more frequently agreed that "it seems like everything causes lung cancer" than former smokers (17.2%) and never smokers (15.4%). A similar pattern of responses was observed for agreement with the statement that "there are so many different recommendations about preventing lung cancer that it is hard to know which ones to follow," wherein current smokers (55.2%) more frequently agreed than former (41.3%) and never smokers (38.2%).

Independent Associations of Cancer-Related Perceptions of Risk, Worry, and Illness Representations, by Smoking Status

Results of the multinomial regression predicting cancer risk perceptions, worry, and illness representations, by smoking status controlling for sociodemographic variables, are shown in Table 3. Compared with current smokers, never smokers (OR=.07) and former smokers (OR=.16) were significantly less likely to perceive their risk of developing lung cancer as somewhat to very high. Compared with current smokers, never smokers (OR=.20) and former smokers (OR=.49) were less likely to perceive their risk of developing lung cancer as similar to an average, age-matched person. Furthermore, never smokers (OR=.08) were significantly less likely than current smokers to perceive their risk of developing lung cancer as more likely than the average, age-matched person while current and former smokers did not differ significantly on perceptions of relative risk. Compared to current smokers, never smokers (OR=.21) were significantly less likely to report worrying about lung cancer; however, former and current smokers did not differ significantly on worry. Smoking status was not associated with any of the illness representation measures included in the model.

Correlates of Prior and Intended Quit Attempts Among Current Smokers

Prior quit attempts were not significantly associated with any of the sociodemographic, risk, worry, or illness representation variables. In bivariate analyses, intention to quit within the next 6 months was significantly associated with age (chi-square=4.15 (3), $p<.05$) and with worry (chi-square=3.05 (3), $p<.05$). Generally, younger respondents and those who reported greater worry more frequently reported intention to quit smoking within the next 6 months. However, when age and risk were entered into a multivariate logistic regression analysis to predict intention to quit, only age remained significant, with respondents aged 35–49 (OR= 4.33) reporting greater intention to quit smoking than those aged 18–34.

Conclusions

Leventhal's *Common-Sense Model of Health and Illness Self-Regulation* integrates social and contextual factors with cognitive and affective factors to explain lay representations of illness. Employing this framework, risky behaviors such as tobacco use are conceptualized as being influenced, in part, by cognitive and emotive self-regulatory processes involving the components of illness representation. Our findings expand the evidence base around understanding the ways in which smokers' illness representations of lung cancer, perceptions of risk, and worry differ from non-smokers' and relate to intentions to quit.

Consistent with the Extended Parallel Process Model and the C-SHIP model which identify worry and risk as factors associated with health behavior [9, 11–15], current smokers were more likely to report worrying about lung cancer and more likely than never smokers to perceive their risk of developing lung cancer as higher than the average person of the same age. While our study found that current smokers were significantly more likely to feel at risk for developing lung cancer than never and former smokers, only 15.2% of current smokers reported perceiving their chance of getting lung cancer as "very high," signaling a need to reach more current smokers with information about risk factors for lung cancer.

Greater worry and heightened risk perceptions are theorized to be associated with self-protective health behavior [11–14, 16–18]. Thus, the greater risk perceptions and worry identified in our research among current smokers could be leveraged in future efforts to promote the benefits of quitting. Interestingly, however, none of the risk, worry, or illness representation variables in our study was found to be independently associated with prior or intended quit attempts, signaling a greater need to understand the mechanisms by which these constructs can be beneficial or detrimental to efforts to promote smoking cessation. Clearly, perceived risk and worry are not sufficient to motivate quit attempts in the absence of information on cessation support and other supportive contextual factors (e.g., tobacco taxes, indoor air laws) that influence smoking behavior in the population. Indeed, as decades of tobacco control research have shown, comprehensive programs that address both individual- and policy-level influences have the most impact.

Acknowledgments

References

1. CDC (Centers for Disease Control and Prevention). Best practices for comprehensive tobacco control programs—2007. Atlanta, GA: Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 2007. http://www.cdc.gov/tobacco/tobacco_control_programs/stateandcommunity/best_practices/index.htm [Accessed December 2009]

2. CDC (Centers for Disease Control and Prevention). [Accessed December 2009] Targeting tobacco use: the nation's leading cause of preventable death at a glance 2008. 2008. http://www.cdc.gov/NCCDPHP/publications/aag/osh.htm

3. CDC (Centers for Disease Control and Prevention). The health consequences of smoking: a report of the Surgeon General. Dept. of Health and Human Services, Centers for Disease Control and Prevention; Atlanta, Ga: National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; Washington, D.C: 2004. For sale by the Supt. of Docs., U.S. G.P.O., 2004http://www.surgeongeneral.gov/library/smokingconsequences/ [Accessed December 2009]

4. Fiore, MC., et al. Treating tobacco use and dependence: 2008 Update. U.S. Department of Health and Human Services; Rockville, MD: Public Health Service; 2008. http://www.ahrq.gov/path/tobacco.htm [Accessed December 2009]

5. Cameron, LD.; Leventhal, H. The self-regulation of health and illness behavior. Routledge; New York: 2003.

6. Leventhal, H.; Meyer, D.; Nerenz, D. The common sense model of illness danger. In: Rachman, S., editor. Medical psychology. Vol. 2. Pergamon; New York: 1980. p. 7-30.

7. Leventhal, H.; Brissette, I.; Leventhal, EA. The common-sense model of self-regulation of health and illness. In: Cameron, LD.; Leventhal, H., editors. The self-regulation of health and illness behaviour. Routledge; London: 2003. p. 42-65.

8. Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. Psychol Health. 2003; 18:141–184.10.1080/0887044403100081321

9. Witte, K. Fear as motivator, fear as inhibitor: using the extended parallel process model to explain fear appeal successes and failures. In: Anderson, PA.; Guerrero, LK., editors. Handbook of communication and emotion: research, theory applications, and contexts. Academic Press; New York: 1998. p. 423-450.

10. Borkovec TD, Robinson E, Pruzinsky T, Dupree JA. Preliminary exploration of worry: some characteristics and processes. Behav Res Ther. 1983; 23:481–482. http://www.sciencedirect.com/science/journal/00057967. [PubMed: 4026778]

11. Lerman C, Schwartz MD, Lin TH, Hughes C, Narod S, Lynch HT. The influence of psychological distress on use of genetic testing for cancer risk. J Consult Clin Psychol. 1997; 65:414–420. http://www.sciencedirect.com/science. [PubMed: 9170764]

12. McCaul KD, Schroeder DM, Reid PA. Breast cancer worry and screening: some prospective data. Health Psychol. 1996; 15(6):430–433. http://psycnet.apa.org/journals/hea/15/6/. [PubMed: 8973922]

13. Mermelstein R, Weeks K, Turner L, Cobb J. When tailored feedback backfires: a skin cancer prevention intervention for adolescents. Canc Res Ther Contr. 1999; 8:69–79.

14. Schwartz M, Lerman C, Daly M, Audrain J, Masny A, Griffith K. Utilization of ovarian cancer screening by women at increased risk. Cancer Epidemiol Biomarkers Prev. 1995; 4(3):269–273. http://cebp.aacrjournals.org/content/4/3.toc. [PubMed: 7606202]

15. Miller SM, Shoda Y, Hurley K. Applying cognitive-social theory to health-protective behavior: Breast self-examination in cancer screening. Psychological Bulletin. 1996; 119:70–94. http://psycnet.apa.org/journals/bul/119/1/. [PubMed: 8559860]

16. Janz NK, Becker MH. The health belief model: a decade later. Health Educ Q. 1984; 11(1):1–47.10.1177/109019818401100101 [PubMed: 6392204]

17. Leventhal H, Cameron L. Behavioral theories and the problem of compliance. Patient Educ Couns. 1987; 10:117–138.10.1016/0738-3991(87)90093-0

18. Weinstein ND. Perceived probability, perceived severity, and health-protective behavior. Health Psychol. 2000; 19(1):65–74.10.KB7//0278-6133.19.1.65 [PubMed: 10711589]

19. Office of Management and Budget. Revisions to the standards for the classification of federal data on race and ethnicity. Federal Register. 1997; 62:58781–58790. http://www.whitehouse.gov/omb/rewrite/fedreg/ombdir15.html.

20. Research Triangle Institute. SUDAAN example manual: release 9.0. Research Triangle Institute; Research Triangle Park, NC: 2004.

Table 1

Sample characteristics

Sociodemographic characteristics by smoking status

	Never smoked *n*=918 (52.8%)	Former smoker *n*=524 (25.1%)	Current smoker *n*=323 (22.1%)	*p* Value
Gender				
Male	38.6	53.3	53.8	*p*<.01
Female	61.4	46.7	46.2	
Education				
Less than high school	9.3	13.2	19.4	
High school	61.8	58.9	70.3	*p*<.0001
College graduate	28.8	27.9	10.3	
Race				
Non-Hispanic white	70.6	73.2	67.5	*p*=.525
Hispanic	12.6	9.9	10.6	
Non-Hispanic black	10.2	8.6	10.5	
Other	6.6	8.3	11.4	
Age				
18–34	34.6	12.8	38.5	*p*<.0001
35–49	30.4	27.2	34.2	
50–64	20.9	34.4	19.2	
65 and older	14.1	25.6	8.2	
Annual household income				
Less than $25,000	23.7	17.4	38.4	*p*<.0001
$25,000 to less than $35,000	11.3	11.3	12.6	
$35,000 to less than $50,000	11.0	13.6	15.7	
$50,000 to less than $75,000	22.9	25.7	19.5	
$75,000 or more	31.0	31.8	13.9	

Table 2

Bivariate associations reflecting weighted percentages for perceived risk, cancer worry, and illness representations, by smoking status

Construct	HINTS item	Never smoked n=918 (52.8%)	Former smoker n=524 (25.1%)	Current smoker n=323 (22.1%)	p Value
Perceived risk	How likely do you think it is that you develop lung cancer in the future? Would you say your chance of getting lung cancer is… (% reporting *very high*).	1.6	1.9	15.2	<.0001
	Compared to the average person your age, would you say that you are….(% reporting *more likely to get lung cancer*)	2.2	9.0	34.3	<.0001
Cancer worry	How often do you worry about getting lung cancer? (% reporting *often or all the time*)	1.8	3.1	18.4	<.0001
	You are reluctant to get checked for lung cancer because fear you may have it (% agree)	9.8	13.3	23.4	<.001
Illness representation					
Identity	People with lung cancer would have pain or other symptoms prior to being diagnosed (% agree)	41.7	36.8	35.5	=.25
Cause	Lung cancer is most often caused by a person's behavior or lifestyle (% agree)	86.1	82.6	75.4	<.05
	It seems like everything causes lung cancer (% agree)	15.4	17.2	26.2	<.05
Timeline	Lung cancer develops over a period of several years (% agree)	84.7	86.8	82.5	=.53
	There are ways to slow down or disrupt the development of lung cancer (% agree)	84.6	84.3	79.5	=.46
Consequences/Controllability	There's not much you can do to lower your chances of getting lung cancer (% agree)	17.1	17.6	20.7	=.63
	There are so many different recommendations about preventing lung cancer that it's hard to know which ones to follow (% agree)	38.2	41.3	55.2	<.01
	Overall, how many people who develop lung cancer do you think survive at least 5 years? (% reporting less than 25%)	16.7	18.9	17.0	=.83

Table 3

Multinomial regression models predicting odds of cancer risk perceptions, worry, and illness representations, by smoking status

	Never smoker vs. current smoker OR (95% CI)	Former smoker vs. current smoker OR (95% CI)
Cancer risk perceptions		
How likely do you think it is that you will develop lung cancer in the future?[a]		
Very low to moderate	Ref	Ref
Somewhat high to very high	.07 (.03–.18)	.16 (.07–.34)
Compared to the average person your age, would you say that you are (more, less, or about as) likely to develop lung cancer?		
Less likely	Ref	Ref
About as likely	.20 (.11–.34)	.49 (.28–.86)
More likely	.08 (.03–.21)	.48 (.23–1.04)
Cancer Worry		
How often do you worry about getting lung cancer?[a]		
Never, rarely, or sometimes	Ref	Ref
Often or all the time	.21 (.05–.93)	.24 (.06–1.00)
Illness representations		
There are so many different recommendations about preventing lung cancer that it's hard to know which ones to follow.		
Disagree	Ref	Ref
Agree	.70 (.43–1.12)	70 (.37–1.32)
Lung cancer is most often caused by a person's behavior or lifestyle.		
Disagree	Ref	Ref
Agree	1.68 (.91–3.11)	1.19 (.57–2.50)
It seems like everything causes lung cancer.		
Disagree	Ref	Ref
Agree	.75 (.36–1.57)	.89 (.44–1.81)
You are reluctant to get checked for lung cancer because fear you may have it.		
Disagree	Ref	Ref
Agree	.75 (1.57)	.89 (.44–1.81)

All estimates are weighted

[a]Collapsed across variable levels where estimates were unstable due to small sample size