

# Personal responsibility, regret, and medical stigma among individuals living with lung cancer

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**Abstract** Understanding the degree to which adults with lung cancer perceive personal responsibility for their disease, personal regret for actions that may have contributed to lung cancer, and potential stigmatization from others is important, because these perceptions and experiences may be linked with treatment nonadherence, feelings of isolation, avoidance of healthcare providers, and poor quality of life. The purpose of this study was to evaluate rates and intensity of these types of experiences and to characterize the extent to which they are linked with smoking status and psychological adjustment in those living with lung cancer. Adults with lung cancer ( $N = 213$ ) were recruited from two major cancer centers to complete a mail survey. Perceived responsibility was frequent in those who had ever smoked (74–80 %), whereas regret and feelings of stigmatization were less frequent. When present, however, personal regret and stigmatization were associated with adverse psychological outcomes, particularly for never smokers. These results are consistent with the theory of stereotype threat and have clinical implications for management of people with lung cancer.

**Keywords** Lung cancer · Stigma · Smoking · Mental health · Distress

## Introduction

The psychosocial needs and experiences of adults living with lung cancer have received relatively little attention compared with other cancer types, yet the available data suggest that those with lung cancer suffer disproportionately from depression, anxiety, and other symptoms (Else-Quest et al., 2009; Lebel et al., 2013; LoConte et al., 2008; Zabora et al., 2001). Additionally, lung cancer is considered a stigmatizing disease (Cataldo et al., 2011; Chapple et al., 2004; Gonzalez & Jacobsen, 2010), in part because 90 % of cases of lung cancer are attributable to cigarette smoking, a personally controllable health behavior (Alberg et al., 2007). Understanding the degree to which adults with lung cancer experience regret, take personal responsibility for their disease, and experience stigmatization from others is important, because these experiences may be linked with treatment nonadherence, feelings of isolation, avoidance of healthcare providers (Chapple et al., 2004), and poor quality of life (Gonzalez & Jacobsen, 2010). The goals of the current study are to characterize how levels of regret, personal responsibility, and perceived stigma from medical staff vary across current, former, and never smokers and are associated with psychosocial outcomes.

Cancer in general has long been stigmatized (Abrams & Finesinger, 1953), and only in the recent past have societal attitudes begun to shift (Holland, 2002). However, attitudes may not have changed as much for lung cancer as for other cancers. Smoking is considered by most people to be a controllable behavior, and people often associate lung cancer with previous smoking behavior, regardless of

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whether the person with lung cancer was a smoker, exposed to secondhand smoke from a family member, or had no smoking history.

In qualitative studies, perceived stigma, assumption of personal responsibility, and regret are common themes that emerge from the experiences of those living with lung cancer (Chapple et al., 2004; Tod et al., 2011). Although these constructs are related conceptually, it is important to distinguish between them. Stigma occurs when others consider one to be undesirable due to possessing a certain attribute (Goffman, 1963). Perceived responsibility refers to a sense of acceptance that one is responsible for causing something to happen (e.g., a lung cancer diagnosis). Finally, regret involves the presence of ruminative thoughts regarding past behavior and negative emotions (Wrosch et al., 2007). These constructs have been conceptualized in relationship to internalized and perceived stigma by Hamann et al. (2014). More specifically, self-blame and regret are included as sub-constructs within internalized stigma; and externalized stigma includes a negative appraisal from multiple sources, such as family and friends, medical providers, and society in general.

Many patients are reluctant to disclose their diagnosis, in part because the most common response from others is, “Did you smoke?”, implying that the patient is responsible for his or her disease (Chapple et al., 2004). Many patients view such questions about their smoking history as inherently judgmental and stigmatizing, in part because they ignore nuances in behavioral risk factors for lung cancer, such as exposure to primary or secondhand smoke, length of smoking history, quantity of smoking, exposure to other carcinogens, engagement in other cancer prevention behaviors, and individual susceptibility to environmental exposures. The stigma associated with lung cancer may manifest in a number of ways, including being blamed for causing one’s illness (Chambers et al., 2012), being treated differently by healthcare providers (Wassenaar et al., 2007), or being given less scientific attention compared to other cancer types (Chapple et al., 2004; Parker-Pope, 2008).

Feelings of regret and personal responsibility may derive from internalized feelings or exposure to stigma in the environment (Earnshaw & Chaudoir, 2009; Hamann et al., 2014). At least one cross-sectional study revealed associations between stigma, self-esteem, anxiety, and personal responsibility in lung cancer survivors (Else-Quest et al., 2009). An important question is whether current, former, and never smokers experience such feelings in different ways. Because lung cancer and smoking behaviors are so tightly linked in the public imagination, it is possible that even never smokers experience stigma, personal responsibility, and regret. Smoking behaviors are linked with caregivers’ attitudes and feelings about their

loved one with lung cancer (Lobchuk et al., 2008), but no studies to date have evaluated the effect of smoking history on personal experiences of perceived stigma, personal responsibility, and regret in lung cancer survivors.

Similarly, little is known about how feelings of personal responsibility, regret, and perceived stigma might influence psychological outcomes differently for those with distinct smoking histories. Understanding the nature of the relationships that exist between these constructs and psychological outcomes is important given that adults living with lung cancer are at high risk for experiencing depressive symptoms (Gonzalez & Jacobsen, 2010), anxiety (Myrdal et al., 2003), and considerable distress (Graves et al., 2007). How personal responsibility and regret might influence psychological outcomes in those with lung cancer has not previously been addressed in the literature, and only a handful of studies have evaluated links between stigma and psychological outcomes. Specifically, the experience of stigma is linked with higher depression (Gonzalez & Jacobsen, 2010), worse quality of life (Cataldo et al., 2012), and greater feelings of personal responsibility and regret (LoConte et al., 2008). In at least two studies involving samples of lung cancer survivors, having a smoking history was not associated with levels of perceived stigma (Carter-Harris, 2015; Cataldo et al., 2012), whereas smoking was linked with greater perceived stigma in another study (LoConte et al., 2008). Several studies have also reported that higher levels of stigma have been associated with worse physical functioning in individuals with neuromuscular disease (van der Beek et al., 2013), HIV (Shah et al., 2015), and lung cancer (Cataldo & Brodsky, 2013). Further, it is unclear whether smoking history in lung cancer survivors has an effect on perceived stigma from medical providers (i.e., “medical stigma”).

Perceived stigma from healthcare providers has been associated with delayed access to care in individuals infected with HIV (Kinsler et al., 2007), and perceived stigma (i.e., stigma perceived from multiple sources) has been associated with delaying medical help-seeking behavior in lung cancer survivors (Carter-Harris, 2015). One study found that the majority (82 %) of nurses that were surveyed attributed at least some blame to individuals with lung cancer (Wang et al., 2015), and another qualitative study reported that approximately half (48 %) of the lung cancer survivors in their sample reported perceived stigma from medical providers (Hamann et al., 2014). However, it is unclear as to whether perceived stigma specifically from healthcare providers differs across lung cancer survivors with different smoking histories, and whether said stigma is associated with worse psychosocial outcomes.

The first aim of the present study was to characterize differences in the rates and intensity of personal responsi-

bility, regret, and medical stigma in current, former, and never smokers with lung cancer. Given results of previous studies (e.g., Cataldo et al., 2012) and the strength of the association between smoking behaviors and risk for lung cancer, it was hypothesized that lung cancer survivors with a smoking history would report higher levels of personal responsibility, regret, and medical stigma compared to those without a smoking history. The second aim of the study was to evaluate the impact of personal responsibility, regret, and medical stigma on psychosocial and health-related outcomes. Hamann et al. (2014) used qualitative methods to identify a number of potentially significant consequences of perceived stigma (e.g., medical stigma) and internalized stigma (e.g., regret), such as increasing psychological distress and avoidance. In this study, we were able to test these hypotheses that higher levels of personal responsibility, regret, and medical stigma would be associated with worse psychological adjustment, poorer physical health-related outcomes, more use of avoidance-oriented coping, and more supportive care needs and to evaluate whether these associations differed for those with different smoking histories.

## Methods

### Participants

Participants were at least 18 years of age, English-speaking, diagnosed with nonsmall cell or small cell lung cancer, and recruited from Loma Linda University Medical Center (LLUMC) and City of Hope Medical Center (COH). Exclusion criteria included mesothelioma diagnosis, feeling too sick or physically incapable to take part, and not being fluent in reading and writing in English. All participants recruited from COH had received their lung cancer diagnosis no more than 6 months prior to joining the study, whereas participants recruited from LLUMC were not excluded on the basis of time since diagnosis.

### Procedures

All procedures were approved by institutional review boards of each of the institutions involved. At LLUMC, participants were recruited from the cancer registry. All those diagnosed with lung cancer in the past 12 months were mailed information about the study, and a research assistant attempted to contact each potential participant by telephone. Questionnaire packets were mailed to those who were interested in participating. Approximately 40 % of those who were mailed information about the study were successfully contacted, and of these, 63 % consented to participate in the study. Approximately 72 % of those who

were successfully contacted via the registry returned the baseline questionnaire. At COH, participants were identified by the project coordinator (PC) along with clinic staff and the attending physician before the patient's scheduled appointment. The study was explained to the participants by the PC during their visit to the cancer center, and informed consent was obtained. Questionnaires, a copy of the IRB-approved consent form, and a return envelope to the COH Department of Psychology were given to patients who consented. Study personnel successfully contacted 62 % of all eligible patients, and 98.4 % of these consented to participate. All participants who completed the questionnaire were provided with a gift card (\$20 at CoH, \$10 at LLUMC). Recruitment procedures described here are the same as those described by Sanders et al. (2010).

## Measures

### *Medical and demographic characteristics*

Demographic and medical characteristics were assessed via self-report paper-and-pencil questionnaires returned to the authors. The demographic (age, sex, years of education, ethnic background) and medical characteristics (cancer stage, type of lung cancer, weeks since diagnosis, smoking status) were reported by the participants according to categories and levels denoted in Table 1. Smoking status was separated into three categories: former smoker, current smoker, never smoker. Never smokers reported smoking <100 cigarettes in their lifetime. Current smokers reported having smoked at least 100 cigarettes in their lifetimes and still smoke. Former smokers reported having smoked at least 100 cigarettes in their lifetimes and quit smoking by the time of data collection.

### *Psychological adjustment*

**Intrusion symptoms** Intrusion symptoms were measured using the Impact of Event Scale-Revised (Horowitz et al., 1979), which assesses the frequency and severity of cancer-related thoughts and feelings associated with one's cancer experience. The scale is reliable and sensitive to psychological intervention (Edgar et al., 1992; Horowitz et al., 1979). The Intrusion scale showed good internal consistency in the current study (Cronbach's  $\alpha = .88$ ).

**Depressive symptoms** Depressive symptoms were measured using the 20-item Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977). The scale is valid for use in cancer populations (Baker et al., 2002; Hann et al., 1999) and was internally consistent in the current study,  $\alpha = .90$ .

**Table 1** Factor solution for the Cancer Responsibility and Regret Scale

Item	Factor loadings			$\bar{x}$ (SD)
	Personal responsibility	Regret	Medical stigma	
When it comes to my cancer I am to blame	<b>.84</b>	.13	.09	4.6 (2.2)
I accept personal responsibility for getting cancer	<b>.81</b>	.01	.04	4.7 (2.2)
If I had done things differently, I probably would not have developed lung cancer	<b>.66</b>	.32	.04	4.6 (2.1)
There is nothing I could have done to keep myself from getting cancer <sup>a</sup>	<b>.63</b>	.27	−.05	4.7 (2.2)
I have no regrets when it comes to choices I've made in life <sup>a</sup>	.13	<b>.78</b>	.02	3.5 (2.1)
I have no regrets about the way I've lived my life <sup>a</sup>	.18	<b>.76</b>	.06	3.2 (2.1)
When it comes to my cancer, I have nothing to be ashamed of <sup>a</sup>	.11	<b>.44</b>	.12	2.4 (2.0)
Nurses who have cared for me seem to blame me for my cancer <sup>a</sup>	.12	.16	<b>.74</b>	1.9 (1.6)
I feel that I have gotten worse medical care than other patients with cancer	−.02	.02	<b>.58</b>	1.6 (1.3)
Doctors have taken steps that have made my cancer worse than it would have been otherwise	−.15	.01	<b>.51</b>	1.6 (1.4)
My doctor acts as if I am to blame for my cancer	.24	.07	<b>.50</b>	2.3 (1.9)

Bold values indicate factor loadings above .40

<sup>a</sup> Item is reverse coded

**Distress** Distress was measured with the Distress Thermometer (DT; Roth et al., 1998). Respondents circle a number on a 0–10 Likert scale (visually represented as a thermometer) to indicate the severity of distress experienced over the previous week. The DT is sensitive and specific in identifying clinically significant distress in cancer survivors (Jacobsen et al., 2005).

#### Physical health-related adjustment

**Physical functioning** The Medical Outcomes Study Short Form (SF-36) 10-item Physical Functioning subscale (Ware & Sherbourne, 1992) assesses the effect of personal health on physical activity and engagement in instrumental activities of daily living (ADLs; Ware & Sherbourne, 1992). Participants indicate how much their physical activity and ADLs are limited by their health (does not limit the activity, limits the activity a little, limits the activity a lot). Reliability of this subscale in the current study was good ( $\alpha = .93$ ). Each participant also provided self-reported medical and cancer-related history (e.g., cancer type and stage of disease).

**Symptom bother** Physical symptom bother was assessed using the Memorial Symptom Assessment Scale-Short Form (MSAS-SF). Twelve symptoms from the MSAS-SF (Chang et al., 2000; Portenoy et al., 1994) were scored on a 5-point Likert scale to indicate the severity of bother for each symptom within the past week (0 = 'not at all/did not have' and 4 = 'very much'): pain, lack of energy, cough, dry mouth, nausea, shortness of breath, lack of appetite, difficulty swallowing, weight loss, distorted taste, consti-

pation, and insomnia. Those who did not experience a particular symptom in the past week were considered to have zero bother associated with that symptom. The MSAS-SF has good convergent validity in cancer populations (Chang et al., 2000). A total Symptom Bother scale was created by summing the item ratings and was internally consistent ( $\alpha = .84$ ).

#### Satisfaction with healthcare

Satisfaction with healthcare was measured using a 10-item author-constructed scale. On a 6-point Likert scale, patients rated their level of agreement to items, which included 'I have complete trust in my doctors and nurses' and 'I feel that my doctors and nurses listen to what I have to say.' Internal consistency was adequate ( $\alpha = .73$ ).

#### Supportive care needs

Supportive Care Needs were measured using the Supportive Care Needs Survey, Short Form (SCNS). The SCNS (Bonevski et al., 2000) is a 31-item scale, which measures the participant's level of need in four domains: psychological needs (e.g., fears about cancer returning), health system and information needs (e.g., opportunity to talk to someone who understands and has been through a similar experience), physical and daily living needs (e.g., feeling unwell), and patient care and support needs (e.g., hospital staff attending promptly to physical needs) (McElduff et al., 2004). Participants indicate 'no need' (1 'not applicable', 2 'satisfied') or some need (3 'low need', 4 'moderate need', 5 'high need'). Scores for the four subscales were generated by averaging the completed items. Con-

struct validity and internal reliability for the SCNS have been established (McElduff et al., 2004). The four scales were internally consistent in the current study, Cronbach's  $\alpha > .84$ .

### *Coping strategies*

Coping strategies were measured using items from the COPE (Carver et al., 1989; Thornton et al., 2012), which assesses how often individuals use specific strategies to manage stress. Each item was measured using Likert scales (1 = 'I don't do this at all'; 4 = 'I do this a lot') specific to the cancer experience. Problem-focused coping was derived from two COPE subscales: coping through planning and active coping efforts (4 items,  $\alpha = 0.81$ ). Avoidant coping was a composite derived from the mental disengagement, behavioral disengagement, and denial subscales (12 items;  $\alpha = 0.75$ ).

### *Personal responsibility, regret, and medical stigma*

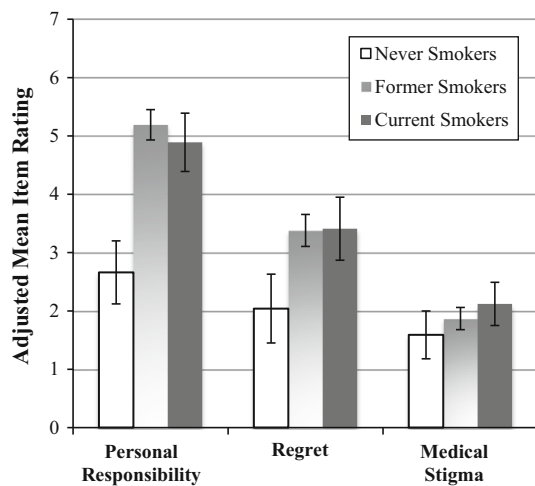
Personal responsibility, regret, and medical stigma were measured with the author-constructed Cancer Responsibility and Regret Scale (CRRS). When data collection occurred, no Personal Responsibility, Regret, or Medical Stigma scales for use in cancer survivors had appeared in the literature. Twenty-three items, based on clinical interactions with members of a lung cancer support group and existing items from relevant non-cancer-specific measures, were developed to measure four proposed dimensions of guilt and blame: (1) personal responsibility, (2) regret, (3) social or medical stigma, and (4) blaming others. Participants rated their agreement with each of the items using a 7-point Likert scale (1 = strongly disagree, 7 = strongly agree). The 23 items were factor analyzed, and factor extraction was conducted using parallel analysis (Horn, 1965). Parallel analysis involves the random generation of a data set with the same number of cases and variables; eigenvalues are averaged from multiple principal components analyses. Upon comparing the randomly-generated and observed eigenvalues, only observed eigenvalues greater than the averaged random eigenvalues were retained. This process led to the extraction of three factors, using Varimax rotation. Items were removed if they (a) did not load above .40 on any factor or (b) there was substantial cross-loading on a second factor (i.e., the difference between primary factor loading and secondary factor loading  $<.15$ ). As items were removed, the underlying factor structure did not change. The final three factors demonstrated simple structure (Thurstone, 1947), with each of the 11 final items loading strongly on only one factor (see Table 1).

Factor 1 was labeled Personal Responsibility and accounted for 21.2 % of the variance prior to rotation. The four items that comprise this factor reflect feelings of personal responsibility for being diagnosed with lung cancer. Internal consistency for the factor was high (Cronbach's  $\alpha = .84$ ). Factor 2 was labeled Regret and accounted for 14.5 % of the variance. The three items reflect a general sense of regret about one's life decisions and cancer-related shame. Internal consistency was acceptable, Cronbach's  $\alpha = .71$ . Factor 3 was labeled Medical Stigma and accounted for 12.5 % of the variance. The four items comprising the factor reflect perceptions of being blamed by medical care providers, as well as the feeling of having received less than adequate care. Internal consistency was Cronbach's  $\alpha = .64$ , slightly lower than optimal for research purposes. Average item responses above four were considered as "elevated" levels of each of the factors.

### **Data analysis**

Descriptive statistics were computed for demographic and medical characteristics as a function of participants' smoking status (former smoker, current smoker, never smoker). Tests of significant differences by smoking status groups on demographic and medical characteristics were one-way ANOVAs for continuous variables and Chi square goodness-of-fit tests for categorical variables. One-way ANOVAs were conducted to test for significant smoking group differences on personal responsibility, regret, and medical stigma scores. Significance was set at  $\alpha = .05$ , two-tailed, and Bonferroni corrections were applied for *t*-tests of post hoc pairwise differences between smoking groups. Demographic and medical characteristics that differed significantly between smoking groups were included as covariates in all subsequent tests of the effect of smoking status on personal responsibility, regret and medical stigma. Smoking status was dummy coded with never smokers as the reference group. Three multiple regression models (three separate models with personal responsibility, regret, and medical stigma as dependent variables in said variables' respective models) were run with the following steps: The above-mentioned demographic and medical covariates were added in step 1 of the two-step stepwise multiple regression models, followed by the addition of smoking status in step 2 so as to test the effect of smoking status on personal responsibility, regret, and medical stigma in the presence of the above-mentioned demographic and medical characteristics that differed significantly between smoking groups. Given a lack of differences between former and current smokers (see Fig. 1), these groups were collapsed into "ever smokers" for comparison with "never smokers" in subsequent univariate





**Fig. 1** Adjusted mean differences in personal responsibility, regret, and medical stigma levels between current, former, and never smokers. Means are adjusted according to the effects of the following covariates: age, years of education, ethnicity, and lung cancer type. Error bars represent 95 % CIs

correlations. Univariate correlations were performed within ever and never smokers between factor scores and psychosocial adjustment variables. Significant differences between univariate correlations for ever and never smokers on psychological adjustment variables were tested via  $z$ -scores.

## Results

Demographic characteristics ( $N = 213$ ) are shown in Table 2. Smoking groups differed significantly on ethnicity,  $\chi^2(2) = 8.2$ ,  $p = .02$ , years of education,  $F(2, 208) = 6.11$ ,  $p = .003$ , age,  $F(2, 210) = 3.63$ ,  $p = .03$ , and type of lung cancer,  $\chi^2(4) = 9.5$ ,  $p = .05$ . There was a higher proportion of Caucasians among current (73.7 %) and former (83.0 %) smokers than among never smokers (61.8 %). Post hoc pairwise comparisons showed that never smokers completed significantly more years of education than current,  $t(69) = -3.28$ ,  $p = .002$ , and former smokers,  $t(171) = -3.06$ ,  $p = .003$ , who did not significantly differ,  $p = .32$ . Former smokers were significantly older than current smokers,  $t(177) = 2.10$ ,  $p = .04$ , or never smokers,  $t(173) = 2.12$ ,  $p = .04$ . A lower proportion of never smokers (11.8 %) reported having small cell lung cancer than either former smokers (24.8 %) or current smokers (36.8 %). Smoking groups did not differ significantly on gender, cancer stage, and weeks since diagnosis. Age, ethnicity, years of education, and cancer type were treated as covariates in subsequent covariate-adjusted analyses. Although symptom bother,  $F(2, 210) = 3.20$ ,  $p < .05$ , and problem-focused coping,  $F(2, 202) = 3.84$ ,

$p < .03$ , were significantly different across smoking groups in unadjusted one-way ANOVAs, there were no covariate-adjusted differences between smoking groups on any of the psychological adjustment, physical health-related adjustment, supportive care needs, and coping strategies variables.

### Differences in personal responsibility, regret, and medical stigma across smoking groups

Elevated levels of Personal Responsibility (i.e., average item response above 4) were reported by 74 % of current smokers, 80 % of former smokers, and 27 % of never smokers,  $F(2, 207) = 43.50$ ,  $p < .001$ . After Bonferroni adjustment for Type I error, two of the three pairwise comparisons were significant. Never smokers reported lower Personal Responsibility than either current smokers,  $t(70) = 6.80$ ,  $p < .001$ , Cohen's  $d = 1.61$ , or former smokers,  $t(170) = 9.40$ ,  $p < .001$ ,  $d = 1.80$ , who did not differ from one another. In the full model [ $F(7, 192) = 12.47$ ,  $R^2 = .31$ ,  $p < .001$ ], education ( $p = .41$ ), ethnicity ( $p = .88$ ), and lung cancer type ( $p = .064$ ) were not associated significantly with Personal Responsibility, but older age was related to lower Personal Responsibility,  $t = -2.22$ ,  $\beta = -.14$ ,  $p = .03$ . After adjustment for those covariates, the main effect of smoking status on Personal Responsibility remained significant,  $\Delta F(2, 192) = 33.16$ ,  $\Delta R^2 = .24$ ,  $p < .001$  (see Fig. 1).

Elevated levels of Regret (i.e., average item response above 4) was reported by 32 % of current smokers, 35 % of former smokers, and 9 % of never smokers,  $F(2, 208) = 8.52$ ,  $p < .001$ . Never smokers reported lower feelings of Regret than either current smokers,  $t(170) = 3.94$ ,  $p < .001$ ,  $d = 0.93$ , or former smokers,  $t(171) = 3.88$ ,  $p < .001$ ,  $d = 0.74$ , who did not differ significantly from each other. In the full model [ $F(7, 193) = 3.14$ ,  $R^2 = .10$ ,  $p < .004$ ], education ( $p = .82$ ), ethnicity ( $p = .65$ ), lung cancer type ( $p = .34$ ), and age ( $p = .14$ ) were not associated with Regret (see Table 3). After adjustment for those factors, the main effect of smoking group on Regret remained significant,  $\Delta F(2, 193) = 8.22$ ,  $\Delta R^2 = .08$ ,  $p < .001$  (see Fig. 1).

Elevated levels of Medical Stigma (i.e., average item response above 4) were reported by 5 % of current smokers, 10 % of former smokers, and 9 % of never smokers. In the full model [ $F(7, 192) = 1.35$ ,  $R^2 = .05$ ,  $p = .23$ ], education ( $p = .37$ ), ethnicity ( $p = .067$ ), lung cancer type ( $p = .47$ ), and age ( $p = .57$ ) were not associated with Medical Stigma (see Table 3). Levels of Medical Stigma did not differ across smoking groups in either unadjusted,  $F(2, 206) = 1.27$ ,  $p = .28$ , or adjusted,  $\Delta F(2, 192) = 1.77$ ,  $\Delta R^2 = .02$ ,  $p = .17$ , analyses (see Fig. 1).

**Table 2** Demographic and medical characteristics of the sample

	Current smokers ( <i>n</i> = 38)		Former smokers ( <i>n</i> = 141)		Never smokers ( <i>n</i> = 34)		<i>p</i>
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	
Gender							>.05
Male	17	44.7	68	48.2	9	26.5	
Female	21	55.3	73	51.8	25	73.5	
Ethnicity							<b>.02</b>
Caucasian	28	73.7	117	83.0	21	61.8	
Other	7	18.4	20	14.2	12	35.3	
Unreported	3	7.9	4	2.8	1	2.9	
Cancer stage							>.05
I	6	15.8	21	14.9	2	5.9	
II	2	5.3	15	10.6	3	8.8	
III	5	13.2	24	17.0	5	14.7	
IV	9	23.7	38	27.0	17	50.0	
Not sure	16	42.1	43	30.5	7	20.6	
Type of lung cancer							<b>.05</b>
Small cell	14	36.8	35	24.8	4	11.8	
Nonsmall cell	12	31.6	74	52.5	18	52.9	
Other/don't know	12	31.6	32	22.7	12	35.3	
	$\bar{x}$	( <i>SD</i> )	$\bar{x}$	( <i>SD</i> )	$\bar{x}$	( <i>SD</i> )	<i>p</i>
Education (years)	12.8	2.5	13.3	2.6	14.9	2.7	<b>.003</b>
Age (years)	64.4	9.8	68.2	10.2	63.9	12.2	<b>.03</b>
Weeks since diagnosis	65.3	95.9	48.7	66.5	50.0	74.1	>.05

**Associations of personal responsibility, regret, and medical stigma with psychosocial adjustment by smoking group**

Associations between Personal Responsibility, Regret, and Medical Stigma and psychosocial outcomes were explored in all lung cancer patients and those who had ever (*n* = 179) and never (*n* = 34) smoked. For ever smokers, no significant relationships were found between Personal Responsibility and psychosocial outcomes. However, for never smokers, Personal Responsibility demonstrated moderate associations with depressive symptoms (*r* = .49), satisfaction with healthcare (*r* = −.57), psychological needs (*r* = .41), and use of avoidance coping strategies (*r* = .37, *p*'s < .032). The associations between Personal Responsibility and depressive symptoms (*z* = −2.39, *p* = .01), satisfaction with healthcare (*z* = 4.05, *p* = .001), and psychological needs (*z* = −2.13, *p* = .02) for never smokers were significantly higher than those in ever smokers. A complete list of correlations is provided in Table 4.

Regret demonstrated small but significant associations (*r* = .15–.22) with higher intrusion symptoms, depressive

symptoms, avoidance coping, and psychological needs in ever smokers. However, for never smokers, Regret demonstrated moderate to strong associations with depressive symptoms (*r* = .67), distress (*r* = .47), symptom bother (*r* = .47), psychological needs (*r* = .50), physical and daily living needs (*r* = .36), total supportive care needs (*r* = .39), and avoidance coping strategies (*r* = .36, *p*'s < .038). The associations between Regret and depressive symptoms (*z* = −3.33, *p* = .001), distress (*z* = −2.72, *p* = .001), symptom bother (*z* = 2.67, *p* = .001), and psychological needs (*z* = −2.13, *p* = .02) for never smokers were significantly greater than said associations in ever smokers.

For ever smokers, Medical Stigma showed significant small to moderate associations (*r* = .16–.42) with intrusion symptoms, depressive symptoms, symptom bother, psychological needs, health system and information needs, physical and daily living needs, patient care and support needs, total supportive care needs, and avoidance coping. Medical Stigma also was negatively associated with satisfaction with healthcare (*r* = −.42). For never smokers, Medical Stigma showed moderate to strong associations with depressive symptoms (*r* = .67), distress (*r* = .52),

**Table 3** Stepwise multiple regression models testing the effect of smoking status on levels of personal responsibility, regret, and medical stigma in the presence of demographic variables

Variable	Personal responsibility <sup>a</sup>						Regret <sup>b</sup>						Medical stigma <sup>c</sup>					
	<i>B</i>	<i>t</i>	<i>p</i>	$\Delta F(df)$	$\Delta R^2$	<i>p</i> <sup>d</sup>	<i>B</i>	<i>t</i>	<i>p</i>	$\Delta F(df)$	$\Delta R^2$	<i>p</i> <sup>d</sup>	<i>B</i>	<i>t</i>	<i>p</i>	$\Delta F(df)$	$\Delta R^2$	<i>p</i> <sup>d</sup>
Step 1				3.15(5,194)	.08	<b>.009</b>				1.03(5,195)	.03	.40				1.09(5,194)	.029	.33
Age	-.071	-1.01	.31				-.073	-1.32	.19				.041	.57	.57			
Education	-.174	-2.51	<b>.01</b>				-.056	-.52	.60				-.095	-1.34	.18			
Ethnicity	-.111	-1.57	.12				-.090	-1.61	.11				.115	1.59	.11			
Lung cancer type dummy code 1 <sup>e</sup>	.190	2.19	<b>.03</b>				-.084	-.11	.91				-.111	-1.26	.21			
Lung cancer type dummy code 2 <sup>f</sup>	-.007	-.08	.94				-.132	-.93	.35				.002	.02	.98			
Step 2				33.16(2,192)	.24	<b>&lt;.01</b>				8.22(2,193)	.08	<b>&lt;.01</b>				1.76(2,192)	.018	.17
Age	-.139	-2.22	<b>.03</b>				-.105	-1.67	.051				.042	.57	.57			
Education	-.051	-.82	.41				.016	.40	.61				-.066	-.90	.37			
Ethnicity	-.010	-.15	.88				-.032	-.74	.97				.136	1.84	.07			
Lung cancer type dummy code 1 <sup>e</sup>	.116	1.53	.13				-.130	-.69	.07				-.136	-1.52	.13			
Lung cancer type dummy code 2 <sup>f</sup>	-.031	-.42	.68				-.142	-1.01	.45				.006	.07	.95			
Smoking status dummy code 1 <sup>g</sup>	.484	5.84	<b>&lt;.01</b>				.312	3.27	<b>&lt;.01</b>				.183	1.88	.06			
Smoking status dummy code 2 <sup>h</sup>	.683	8.13	<b>&lt;.01</b>				.379	3.90	<b>&lt;.01</b>				.121	1.22	.22			

$p < .05 = \text{bold}$

<sup>a</sup> Dependent variable = Personal responsibility. Full model  $F(7, 192) = 12.47$ ,  $R^2 = .31$ ,  $p < .001$

<sup>b</sup> Dependent variable = Regret. Full model  $F(7, 193) = 3.14$ ,  $R^2 = .10$ ,  $p < .004$

<sup>c</sup> Dependent variable = Medical stigma. Full model  $F(7, 192) = 1.35$ ,  $R^2 = .05$ ,  $p = .23$

<sup>d</sup> Significance level of  $\Delta F$

<sup>e</sup> Represents the mean difference between those with small cell lung cancer and those who did not know or reported having “other” lung cancer

<sup>f</sup> Represents the mean difference between those with non-small cell lung cancer and those who did not know or reported having “other” lung cancer

<sup>g</sup> Represents the mean difference between current and never smokers

<sup>h</sup> Represents the mean difference between former and never smokers

symptom bother ( $r = .46$ ), satisfaction with healthcare ( $r = -.68$ ), psychological needs ( $r = .44$ ), patient care support needs ( $r = .41$ ), total supportive care needs ( $r = .41$ ), and avoidance coping ( $r = .59$ ,  $p$ 's  $< .017$ ). As before, the associations between Medical Stigma and depressive symptoms ( $z = -3.12$ ,  $p = .001$ ), distress ( $z = -2.39$ ,  $p = .001$ ), satisfaction with healthcare ( $z = 1.96$ ,  $p = .03$ ), and avoidance coping ( $z = -2.49$ ,  $p = .01$ ) were significantly greater in never smokers than ever smokers.

## Discussion

Our findings suggest that feelings of personal responsibility are common in lung cancer survivors, particularly those with a history of smoking (74–80 %). Even 27 % of never smokers report strong feelings of personal responsibility, perhaps due to past exposures to second-hand smoke (e.g., from a parent or spouse), other environmental risk factors for lung cancer (e.g., asbestos, radon; Salander, 2007; Faller et al., 1995), or psychosocial factors (e.g., stress).



**Table 4** Univariate correlations between Cancer Responsibility and Regret Scale factors and psychosocial outcomes in ever smokers and never smokers

Variables	Personal responsibility				Regret			
	All patients	Ever smokers	Never smokers	<i>z</i> ( <i>p</i> )	All patients	Ever smokers	Never smokers	<i>z</i> ( <i>p</i> )
<b>Factors</b>								
Personal responsibility	–	–	–	–	–	–	–	–
Regret	<b>.33</b>	<b>.18</b>	<b>.41</b>	–1.30(.19)	–	–	–	–
Medical Stigma	.11	.04	<b>.42</b>	<b>–2.09(.04)</b>	<b>.17</b>	.12	<b>.36</b>	–1.32(.19)
<b>Psychological adjustment</b>								
Intrusion symptoms	.07	.02	.25	–1.21(.11)	<b>.24</b>	<b>.22</b>	.29	–.38(.35)
Depressive symptoms	<b>.15</b>	.07	<b>.49</b>	<b>–2.39(.01)</b>	.24	<b>.16</b>	<b>.67</b>	<b>–3.33(.00)</b>
Distress	.07	.01	.27	–1.37(.08)	.13	.06	<b>.53</b>	<b>–2.72(.00)</b>
<b>Physical health-related adjustment</b>								
Physical functioning	–.07	–.05	.09	–.72(.23)	–.13	–.09	–.18	.47(.32)
Symptom bother	.07	–.01	.27	–1.47(.07)	.09	–.01	<b>.47</b>	<b>–2.67(.00)</b>
Satisfaction with healthcare	.001	.14	<b>–.57</b>	<b>–4.05(.00)</b>	<b>–.18</b>	–.15	–.31	.87(.19)
<b>Supportive care needs</b>								
Psychological needs	<b>.14</b>	.02	<b>.41</b>	<b>–2.13(.02)</b>	<b>.22</b>	<b>.15</b>	<b>.50</b>	<b>–2.13(.02)</b>
Health system and information needs	–.05	–.06	.08	–.72(.24)	.06	.07	.10	–.16(.44)
Physical and daily living needs	.08	–.03	.10	–.67(.25)	<b>.20</b>	.13	<b>.36</b>	–1.26(.10)
Patient care and support needs	.05	.03	.17	–.73(.23)	.10	.07	.27	–1.06(.14)
Total supportive care needs	.08	–.01	.24	–1.31(.10)	<b>.20</b>	.14	<b>.39</b>	–1.39(.08)
<b>Coping strategies</b>								
Problem-focused coping	–.01	.10	.08	.10(.46)	–.06	.03	–.21	1.25(.11)
Avoidance coping	.10	.11	<b>.37</b>	–1.43(.08)	<b>.15</b>	<b>.16</b>	<b>.36</b>	–1.11(.13)
Variables		Medical stigma						
	All patients	Ever smokers	Never smokers	<i>z</i> ( <i>p</i> )	<i>M</i> ( <i>SD</i> )	Range		
<b>Factors</b>								
Personal responsibility	–	–	–	–	–	1–7		
Regret	–	–	–	–	–	1–7		
Medical Stigma	–	–	–	–	–	1–7		
<b>Psychological adjustment</b>								
Intrusion symptoms	<b>.15</b>	<b>.19</b>	.17	.11(.46)	8.7 (8.3)	0–35		
Depressive symptoms	<b>.28</b>	<b>.20</b>	<b>.67</b>	<b>–3.12(.00)</b>	14.4 (10.6)	0–53		
Distress	<b>.17</b>	.11	<b>.52</b>	<b>–2.39(.01)</b>	3.3 (2.9)	0–10		
<b>Physical health-related adjustment</b>								
Physical functioning	–.11	–.13	–.10	–.16(.44)	43.7 (28.2)	0–100		
Symptom bother	<b>.26</b>	<b>.24</b>	<b>.46</b>	–1.30(.10)	1.3 (.8)	0–3.25		
Satisfaction with healthcare	<b>–.44</b>	<b>–.42</b>	<b>–.68</b>	<b>1.96(.03)</b>	52.5 (10.3)	18–60		
<b>Supportive care needs</b>								
Psychological needs	<b>.26</b>	<b>.23</b>	<b>.44</b>	–1.22(.11)	2.7 (1.0)	1–5		
Health system and information needs	<b>.31</b>	<b>.32</b>	.32	.00(.50)	2.3 (.8)	1–5		
Physical and daily living needs	<b>.17</b>	<b>.16</b>	.24	–.43(.33)	3.3 (1.1)	1–5		
Patient care and support needs	<b>.30</b>	<b>.29</b>	<b>.41</b>	–.70(.24)	2.1 (.6)	1–5		
Total supportive care needs	<b>.31</b>	<b>.30</b>	<b>.41</b>	–.65(.26)	2.6 (.7)	1–5		

**Table 4** continued

Variables	Medical stigma			$z(p)$	$M (SD)$	Range
	All patients	Ever smokers	Never smokers			
Coping strategies						
Problem-focused coping	.04	.09	-.09	.93(.18)	2.7 (.8)	1–4
Avoidance coping	<b>.24</b>	<b>.19</b>	<b>.59</b>	<b>-2.49(.01)</b>	1.6 (.4)	1–3.08

$z(p)$  = significance test of difference between ever and never smoker correlations.  $p < 0.05$  = bold

Hypothesis 1, that personal responsibility would be higher in those with a smoking history, was supported. Additionally, being younger was associated with a greater sense of responsibility. Given increases in awareness about the health consequences of smoking and erosion in social acceptance of smoking, it is not surprising that younger lung cancer survivors feel a stronger sense of personal responsibility than do older survivors. The second hypothesis that personal responsibility would be associated with psychosocial and health-related outcomes was only partially supported. For those with a smoking history, feelings of personal responsibility appear to be benign and have little association with overall psychological functioning. In endorsing the Personal Responsibility items, it is likely that ever smokers were acknowledging the reality of their smoking's contribution to lung cancer without experiencing the negative affective consequences that can accompany self-blame (Shaver & Drown, 1986). Although endorsement of Personal Responsibility was relatively low in never smokers, when it was endorsed, Personal Responsibility was associated with poorer adjustment. Perhaps those never smokers attribute cancer causation to some other internal (e.g., negative character traits) or external (e.g., partner smoking) factors, which in turn are linked to poor adjustment, or perhaps depressed never smokers are likely to assume personal responsibility for bad outcomes.

Consistent with the first hypothesis, Regret was more prevalent in lung cancer survivors with a smoking history than those who never smoked. Endorsement of Regret was much less prevalent than Personal Responsibility (32–35 % of ever smokers; 9 % of never smokers). The second hypothesis was also partially supported. Regret was associated with greater intrusive thoughts/feelings, unmet psychological needs, and use of avoidance-oriented coping strategies. Perhaps regret represents an internalized experience of intrusive thoughts regarding past decisions that led to one's cancer, and those who experience significant levels of regret may spend more time dwelling on past decisions than in actively confronting current stressors. Fortunately, regret may be modifiable. Wrosch et al. (2007), in a study of older adults not specific to those with

lung cancer, found that a regret-focused writing intervention significantly reduced feelings of regret intensity. In those with cancer, studies have suggested that simply audio taping clinical encounters can reduce regret associated with cancer-related treatment decisions (Good et al., 2015). Accordingly, it may be possible to intervene with those lung cancer survivors who experience intense feelings of regret to decrease intensity of regret and concomitant negative symptoms (e.g., intrusive thoughts/feelings).

In contrast to at least one other study of stigma in lung cancer, participants did not, on average, report feeling stigmatized from medical providers. A much higher rate of perceived stigma from medical providers was reported in another study (48 %; Hamann et al., 2014), which may be due, in part, to differences in measurement (i.e., thematic content analysis vs. a midpoint cutoff on scale). Although an uncommon experience across smoking groups, greater Medical Stigma was associated with worse psychosocial functioning and specifically with worse satisfaction with healthcare, greater health system and information needs, and greater total supportive care needs, providing additional support to our second hypothesis. However, contrary to our first hypothesis, Medical Stigma was reported as often for never smokers as those with a smoking history, which corroborates Chapple et al.'s (2004) qualitative findings, suggesting lung cancer survivors felt blamed for their disease by hospital staff, regardless of whether they had ever smoked. It is possible that the stigma experience (i.e., feeling blamed by medical staff) hinders meeting health system and information needs because it contributes to avoidance of healthcare providers and treatment non-compliance (Carter-Harris, 2015; Chapple et al., 2004).

Ever and never smokers significantly differed in several of their associations between CRRS factors and adjustment variables. More specifically, never smokers demonstrated stronger associations between factors and adjustment variables. Of note, never smokers demonstrated stronger associations between every factor score and depressive symptoms when compared to ever smokers. These findings suggest that the presence of perceived personal responsibility, regret, and perceived stigma may have particularly adverse effects on the psychological adjustment of never

smokers relative to current and former smokers, although reciprocal causation cannot be ruled out.

Our findings are consistent with theory and evidence regarding stereotype threat (Aronson et al., 2013; Steele & Aronson, 1995), which may be present in interactions between lung cancer survivors and medical staff as well as the larger social network. As lung cancer patients seek to make causal attributions for their disease (Faller et al., 1995), they may be simultaneously vigilant of others' verbal and nonverbal cues to confirm any negative stereotypes associated with being a lung cancer survivor. It is possible that smokers who assume personal responsibility for their lung cancer are less vigilant to stereotype cues and experience less impact with respect to negative psychosocial outcomes. Regret, however, may be accompanied by rumination regarding past decisions (e.g., "How could I have smoked?...that was the worst decision I could have made"), which could intensify identification with the negative stereotype, increase use of avoidant coping strategies, and increase depressive symptoms. Our results also overlap with the model of lung cancer stigma proposed by Hamann et al. (2014), which identifies two main factors associated with stigma: perceived/felt stigma (which includes medical stigma) and internalized/self stigma (which includes regret and self-blame/guilt).

Several limitations of the current study should be noted. Because the present results are cross-sectional, we are unable to estimate the extent to which personal responsibility, regret, and medical stigma might causally influence psychological adjustment. Longitudinal and experimental research is needed to evaluate contributors to and consequences of personal responsibility, regret, and medical stigma, as well as their malleability through intervention. Second, this study was conducted among lung cancer survivors who were sufficiently healthy to complete questionnaires, and those with worse disease or functional status may be under-represented in the current sample relative to the general population of those with lung cancer. Given the high mortality rate in this population, obtaining large, representative samples is challenging, and the present study provides one of the largest samples to date to yield high-quality psychosocial data. Third, subsample sizes were low for current and never smokers compared to former smokers, but the distribution is comparable to other samples of lung cancer survivors who reported smoking history (Gonzalez & Jacobsen, 2010; LoConte et al., 2008). Additionally, internal consistency of the Medical Stigma factor could be improved in future studies by adding additional items. Finally, none of the items retained for use in the CRRS provided a measure of perceived non-medical social stigma or blame (e.g., from friends, family members, and others). Although the original item pool included several lung-cancer specific social stigma items, none were

retained in the final measure due to lack of internal consistency. There are current efforts underway to develop comprehensive measures of stigma that will likely include items specific to social stigma, medical stigma, self-blame, guilt/shame, anger, regret, and consequences of stigma (Hamann et al., 2014).

Given the associations between medical stigma and psychological adjustment, satisfaction with healthcare, and avoidance coping, there is a need to better understand how and when feelings of personal responsibility, regret, and medical stigma arise and how they might predict psychosocial and health-related outcomes. As those with lung cancer present for treatment, they may feel vulnerable and vigilant to unfair treatment, and even well-intentioned interactions can activate socially-shared beliefs, such as the belief that smokers can be refused treatment (Chapple et al., 2004). However, given the low levels of perceived stigma from healthcare staff reported in the study sample, further research is needed to corroborate or flesh out rates of lung cancer survivors who perceive stigma from medical providers. As mentioned above, other studies have reported much higher rates of perceived stigma from medical providers (e.g., Hamann et al., 2014). Finally, many unanswered questions remain, such as the extent to which regret, blame, and stigma are associated with other key aspects of treatment for lung cancer, such as physician-patient communication patterns, adherence to difficult treatments, adoption of recovery-oriented health behaviors, and appropriate healthcare utilization.

#### Compliance with ethical standards

**Conflict of interest** Kevin R. Criswell, Jason E. Owen, Andrea A. Thornton and Annette L. Stanton declare that they have no conflict of interest.

**Human and animal rights and Informed consent** All procedures followed were in accordance with ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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