The Psychosocial Impact of Lung Cancer-Related Stigma: Findings from the Cancer Experience Registry

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Background

- Patients with lung cancer (LC) report greater psychosocial distress and depression than people with other types of cancers.

- Patients with LC also report experiencing stigmatization because the disease is associated with smoking.

Aims

- The objectives of this study were to 1) characterize patients' experience of lung cancer stigma, and 2) examine the relationships between distress, depression, and lung cancer stigma.

Methods

- 47 LC patients enrolled in the online Cancer Experience Registry answered questions about their cancer history, 13 LC stigma-related statements (0 = *strongly disagree* to 4 = *strongly agree*), and 27 cancer-related distress items (0 = *not at all concerned* to 4 = *very seriously concerned*) based on CancerSupportSource®. Distress questions included a 4-item depression risk subscale.

- Analytic procedures included: descriptive statistics, independent samples t-tests and bivariate correlations between stigma-related statements and clinical and demographic variables (age, gender, and LC type), multivariate linear regression with stigma statements predicting distress (square root of sum of 27 items), and logistic regression with stigma statements predicting risk for depression (score ≥ 6). Regressions were adjusted for potentially confounding variables (LC type, age, gender).

Participants

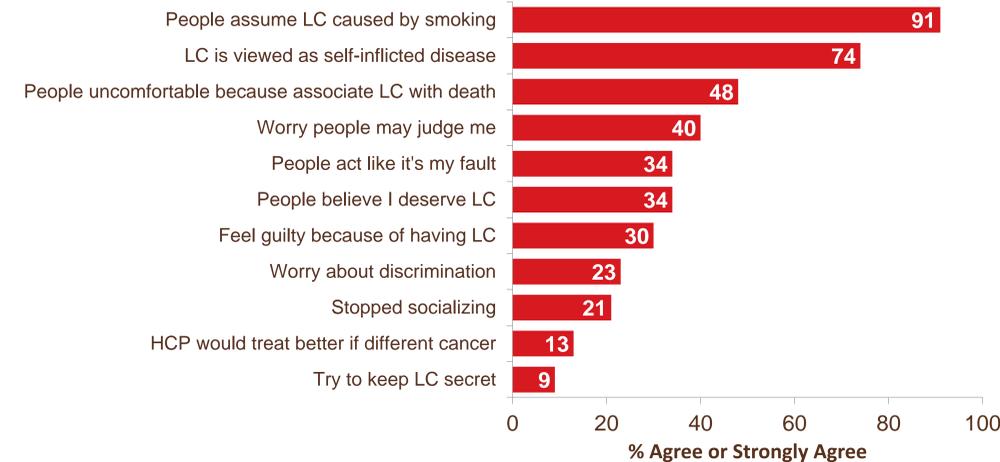| N = 47	Median / n	SD / %
Age	64 *Range: 39 - 79*	
Non-Hispanic White	40	85%
Time since diagnosis (years)	2 *Range: <1 - 13*	
Lung cancer type		
Non-small cell (NSCLC)	38	84%
Small cell (SCLC)	7	16%
Experienced recurrence	16	34%
History of metastatic disease	25	53%

Results

Proportion of Patients Agreeing with Lung Cancer Stigma Statements

Statement	% Agree or Strongly Agree
People assume LC caused by smoking	91
LC is viewed as self-inflicted disease	74
People uncomfortable because associate LC with death	48
Worry people may judge me	40
People act like it's my fault	34
People believe I deserve LC	34
Feel guilty because of having LC	30
Worry about discrimination	23
Stopped socializing	21
HCP would treat better if different cancer	13
Try to keep LC secret	9

- Most participants agreed that some people assume LC is caused by smoking even if the person with cancer never smoked (91%), and that lung cancer is viewed as a self-inflicted disease (74%).

- Of note, 81% reported being open to speaking with people about their lung cancer diagnosis, and 83% believed their health care team treated them as well as people with other cancer diagnoses.

Lung Cancer Stigma Experience Differs by Cancer Type, Gender, and Age

	Mean		t	p
Lung Cancer Type	NSCLC	SCLC		
LC is viewed as self-inflicted disease	3.1	1.9	2.60	.013*
Open to speaking about LC	3.4	2.6	2.11	.041*
People uncomfortable b/c associate LC with death	2.5	1.6	2.04	.048*
Feel guilty because of having LC	1.5	2.7	-2.15	.037*
Try to keep LC a secret	0.7	1.7	-2.54	.015*
Gender				
LC is viewed as self-inflicted disease	2.3	3.2	-2.46	.018*
Worry about people discriminating against me	0.8	1.7	-2.43	.019*
Open to speaking about LC	2.8	3.4	-2.09	.042*
			r	p
Age				
Worry about people discriminating against me			-.36	.026*
LC is viewed as self-inflicted disease			-.33	.045*

Note: *p < .05

- **Patients with NSCLC** were more likely to believe that lung cancer is viewed as a self-inflicted disease and that some people are uncomfortable around them because they associate lung cancer with death. They were also more open to speaking with people about their lung cancer diagnosis.

- **Patients with SCLC** felt more guilt because of having lung cancer and tried harder to keep their diagnosis a secret.

- **Younger patients and females** worried more about people discriminating against them and agreed more strongly that lung cancer is viewed as a self-inflicted disease. Females were also more open than males to speaking with people about their lung cancer diagnosis.

Lung Cancer Stigma is Associated with Elevated Distress

Stigma–related statement	β (SE)*	p
I feel guilty because of having LC	0.46 (0.19)	.004
I am open to speaking about LC	-0.37 (0.32)	.031
I try to keep LC a secret	0.49 (0.29)	.004
I worry people may judge me	0.43 (0.21)	.007
I stopped socializing because of reactions	0.40 (0.21)	.012

*Note: The square root of the overall summary score for distress was used to normalize the distribution. *Adjusted for LC type, age, and gender*

- Patients with greater distress tended to feel more guilt because of having lung cancer, tried harder to keep lung cancer a secret, worried more that people may judge them, and reported socializing less due to reactions people had to their lung cancer diagnosis.

- Patients with lower levels of distress were more open to speaking with people about their lung cancer diagnosis.

Lung Cancer Stigma is Associated with Risk for Depression

Stigma–related statement	Adjusted odds ratio (95% CI)*	p
I feel guilty because of having LC	2.28 (1.12, 4.67)	.024

*Note: Risk for depression defined as score ≥6 on the depression subscale (37% of the sample). *Adjusted for LC type, age, and gender*

- Patients who reported more guilt about having lung cancer were at greater risk for clinical levels of depression.

Implications and Conclusions

- As advances in lung cancer treatment emerge and people living with LC live longer, the short- and long-term implications of living with stigma become increasingly important.

- This study adds to the evidence that stigma is associated with greater distress and greater risk for clinically-significant depression in lung cancer patients.

- Our findings suggest that the type of lung cancer (NSCLC vs. SCLC) is related to the kinds of feelings patients experience related to stigma. Additionally, younger age and female gender are specifically associated with greater endorsement of stigma.

- These results support the development and evaluation of interventions to reduce the impact of lung-cancer related stigma, especially guilt, and the risks it confers for cancer-related distress and depression.

References
1. Zabora et al. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology, 10:* 19-28.
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3. Miller et al. (2014). Discriminatory power of a 25-item distress screening tool: A cross-sectional survey of 251 cancer survivors. *Qual Life Res, 23*(10): 2855-63.

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The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.
- The Registry is for all cancer survivors and caregivers, but also includes 11 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 11,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org