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A Longitudinal Investigation of Internalized Stigma, Constrained Disclosure, and Quality of Life Across 12 Weeks in Lung Cancer Patients on Active Oncologic Treatment

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ABSTRACT

Introduction: Internalized lung cancer stigma (i.e., feelings of regret, shame, and self-blame about one's lung cancer) is related to poorer psychological outcomes. Less is known about how internalized stigma relates to physical and functional outcomes or how constrained disclosure (i.e., avoidance of or discomfort about disclosing one's lung cancer status to others) relates to well-being. Furthermore, no study has examined whether internalized stigma and constrained disclosure predict changes in well-being for lung cancer patients. This longitudinal study characterized relationships of internalized stigma and constrained disclosure with emotional and physical/functional outcomes.

Methods: Participants (N = 101, 52.4% male, 63.4% currently/formerly smoked) were lung cancer patients on active medical treatment who completed questionnaires on stigma and well-being at study entry and at 6- and 12-week follow-up. Multivariable linear regressions characterized relationships of internalized stigma and constrained disclosure with emotional and physical/functional well-being at study entry and across time.

Results: Participants who currently or formerly smoked reported higher levels of internalized stigma (but not constrained disclosure), compared to never smokers ($p < 0.001$). Higher internalized stigma and constrained disclosure were uniquely associated with poorer emotional and physical/functional well-being at study entry (all $p < 0.05$), beyond sociodemographic characteristics, time elapsed since diagnosis, and smoking status. Higher internalized stigma predicted significant declines in emotional well-being across 6 and 12 weeks (all $p < 0.01$) and declines in physical/functional well-being across 6 weeks ($p < 0.05$).

Conclusions: Internalized lung cancer stigma and constrained disclosure relate to emotional and physical/functional maladjustment. Findings carry implications for provider- and patient-focused interventions to reduce internalized stigma and promote well-being.

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Keywords: Lung cancer; Stigma; Disclosure; Quality of life; Well-being; Longitudinal

Introduction

In 2018, an estimated 234,030 new cases of lung cancer will be diagnosed in the United States.[1] Lung cancer is the leading cause of cancer-related mortality, accounting for an estimated 25% of cancer-related deaths in 2018.[1] However, lung cancer mortality has declined by 45% for men and 19% for women over several decades due to reductions in smoking, advances in screening, and newly developed oncologic treatments.[2-4] An estimated 415,000 men and women in the United States are living with lung cancer.[5] A substantial proportion of adults with lung cancer report bothersome physical symptoms and evidence significant impairments in physical and emotional well-being as well as impairments in functional well-being, defined as the ability to perform usual tasks of daily living.[6-10] People with lung cancer also report worse quality of life and greater distress compared to age-matched controls and adults with other cancers.[11,12] It is crucial to understand and promote quality of life for this population, particularly because it may also relate to important clinical outcomes (e.g., disease progression, survival).[13,14] Sociodemographic and medical characteristics can be relevant for identifying patients most likely to experience physical and psychological morbidities.[15-17] However, these characteristics cannot be changed through intervention. Therefore, it is important to identify malleable psychosocial factors that predict well-being and can potentially be harnessed through intervention. Additionally, identifying such factors within a longitudinal perspective is needed to bolster causal inference of psychosocial factors influencing health-related outcomes, test theoretical models of adjustment to disease, and identify targets for intervention.

Stigma, defined as recognition and devaluation of a distinguishing characteristic, is an important psychosocial risk factor to study in this population because lung cancer is stigmatized due to its strong association with smoking, the perception of the disease as self-inflicted, and the lethality of the disease.[18,19] Perceptions of stigma are commonly reported by lung cancer patients.[20,21] Additionally, the general population and medical providers evidence negatively biased perceptions towards lung cancer patients.[22,23] Cross-sectional research shows that higher levels of lung cancer stigma are associated with poorer quality of life, higher levels of depressive symptoms, and higher distress.[24-27] However, the correlational nature of past research precludes causal inference, prompting calls for longitudinal research to examine temporal relationships between lung cancer stigma and health-related adjustment.[26,27] Accordingly, the aim of this longitudinal study was to test whether lung cancer stigma and the associated experience of constrained disclosure, defined as avoidance or discomfort about disclosing one's lung cancer status to others,[20] predicted emotional and physical/functional well-being across 12 weeks in lung cancer patients on active oncologic treatment.

The process of stigmatization involves the devaluation of an individual based on a distinguishing characteristic and can prompt intrapersonal processes such as internalized stigma (i.e., directing negative societal attitudes toward oneself) and anticipated stigma (i.e., fear of negative evaluation or treatment from others).[18,28] These processes represent the two primary ways that stigma has been conceptualized as a psychosocial stressor that can be deleterious for well-being and are described below with regard to their relevance to lung cancer.[18,20,28]

Research on lung cancer stigma has focused primarily on internalized stigma. Consistent with theory, internalized stigma is indicated by feelings of regret, shame, and self-blame and is experienced by the majority of lung cancer patients.[20,28] Internalized stigma may be related to poor health through processes such as low self-esteem, maladaptive beliefs about oneself, or restricted use of social support resources.[18] Evidence suggests that internalized stigma is higher among adults who smoked.[20,26,29] However, relationships between nuanced smoking-related factors (e.g., time elapsed since smoking cessation) and internalized stigma have not been tested. Characterizing such relationships could identify particular subgroups of patients who may benefit from interventions designed to decrease internalized stigma.

Many people with lung cancer report experiences of anticipated stigma, which may be harmful for health through processes such as affective or physiological hypervigilance or perceived stress.[18,21,28,30] Feelings of anticipated stigma are also theorized to lead to constrained disclosure.[20] Constrained disclosure has been reliably characterized in a sample of more than 200 lung cancer patients and was related significantly to higher internalized stigma.[31] It is posited that constrained disclosure may be harmful for health by hindering patients' ability to recruit social support or process their thoughts and feelings about their cancer.[32] Few studies, however, have examined whether constrained disclosure is related to health outcomes. One study showed that higher self-reported social constraint, which includes constrained disclosure about one's lung cancer, mediated the relationships of shame with higher distress and worse quality of life.[32] Also, recently presented findings indicate that constrained disclosure is related to higher depressive symptoms in lung cancer patients.[33] Constrained disclosure and internalized lung cancer stigma are conceptually and statistically related, and no study

has evaluated their unique contributions to health-related adjustment.[31,33]

Research has predominantly focused on characterizing the relationship between lung cancer stigma and psychological health.[24-27,29,34,35] Only two studies to our knowledge have assessed whether stigma is related to greater physical symptom severity and/or functional impairments in lung cancer patients, and none has done so longitudinally.[26,35] Additional research is needed to assess whether internalized lung cancer stigma and constrained disclosure are related to physical and functional outcomes across time.

The primary aim of the current study was to test whether internalized lung cancer stigma and/or constrained disclosure were associated significantly with emotional and physical/functional quality of life across 12 weeks in a sample of lung cancer patients on active oncologic treatment. Theory and research led to the hypothesis that higher internalized stigma and constrained disclosure would be associated with poorer emotional and physical/functional well-being at study entry and would predict significant declines in well-being 6 and 12 weeks later.[20,26,35] We also explored whether smoking-related characteristics (e.g., months since smoking cessation) were associated with internalized stigma and constrained disclosure. Finally, we explored whether smoking status moderated relationships between internalized stigma and constrained disclosure with well-being.

Methods

Participants

Men and women with lung cancer were recruited to participate in the study through University of California–Los Angeles (UCLA) Hematology and Oncology clinics. Patients were eligible if they were: 1) diagnosed with lung cancer (any type and any diagnosis duration); 2) receiving active oncologic treatment; 3) at least 18 years of age; and 4) comfortable reading and responding to questions in English. Participants were ineligible if cognitive impairment was apparent. Consecutive patients were recruited to reduce potential bias. Eligible participants completed self-report questionnaires at study entry as well as at 6- and 12-week follow-up assessments. All participants provided written informed consent. All procedures were approved by the Institutional Review Board at UCLA.

Measures

At study entry, participants reported their age, sex, race/ethnicity, years of education, marital status, and smoking history. Current oncologic treatment, months since diagnosis, cancer stage and type, history of cancer-related surgery, and past receipt of chemotherapy were assessed via medical record review. Smoking status was separated into three categories: current, former, and never smoker (fewer than 100 cigarettes smoked in lifetime).[26] Participants who currently or formerly smoked provided age at smoking initiation, number of years smoked, number of packs smoked per day, and months since smoking cessation (scored as 0 for those currently smoking). Pack-years was computed by multiplying number of packs smoked per day by number of years smoked.

Internalized stigma was measured at study entry using an adapted version of the Cancer Responsibility and Regret Scale.[26] Specifically, we used the four items from the regret subscale (e.g., "When it comes to my cancer, I have nothing to be ashamed of" [reverse scored]) in addition to four new items adapted from HIV-related stigma scales that captured feelings of shame, guilt, and self-blame (e.g., "I feel guilty that I have lung cancer").[36,37] Constrained disclosure was assessed at study entry with two adapted items from an HIV stigma scale (e.g., "I hide my lung cancer status from others" and "It is difficult for me to tell people about my lung cancer").[37] Items were rated on a 7-point Likert scale (1 = strongly disagree, 7 = strongly agree). Higher scores indicate higher internalized stigma and constrained disclosure. Internal consistency reliability for both subscales was adequate (αs > .74; Spearman-Brown coefficients > .74).

Emotional and physical/functional well-being were measured at study entry and at 6- and 12-week follow-up with two subscales from the 35-item Functional Assessment of Cancer Therapy-Lung (FACT-L) scale.[38] The Trial Outcome Index, a subscale of the FACT-L, was computed as the sum of the 21 physical well-being (e.g., "I have nausea"), functional well-being (e.g., "I am able to work [including work at home]"), and lung cancer-specific symptom items (e.g., "I have been short of breath"). It is considered the best composite index of physical/functional well-being and lung cancer-specific symptoms.[38] Additionally, the emotional well-being subscale from the FACT-L was computed as the sum of the 6 emotional well-being items (e.g., "I feel sad"). The FACT-L Trial Outcome Index (referred to as physical/functional well-being from this point forward) and the FACT-L emotional well-being subscale were evaluated as outcomes. Both subscales had adequate internal consistency reliability at all assessments (αs > .68). Higher scores indicate higher well-being.[38] Total scores range from 0 to 24 and 0 to 84 for emotional and physical/functional well-being, respectively.

Statistical Analysis

First, descriptive statistics were derived for study variables. Next, between-subjects analysis of variance models were used to evaluate whether internalized stigma and constrained disclosure differed by smoking status. Among participants who currently or formerly

smoked, Pearson's correlations were used to examine relationships between smoking-related characteristics and internalized stigma and constrained disclosure. Multivariable linear regressions were conducted to explore whether smoking status moderated relationships between internalized stigma, constrained disclosure, and well-being.

Next, multivariable linear regression models using the SEM command in STATA v13 (StataCorp, College Station, TX) were conducted to evaluate internalized stigma and constrained disclosure as predictors of well-being at study entry and over time. Emotional and physical/functional well-being at study entry, 6-week follow-up, and 12-week follow-up were each entered as the dependent variable in six separate multivariable linear regression models. To evaluate change over time, emotional and physical/functional well-being at 6- and 12-week follow-up were evaluated with study entry well-being controlled statistically.

A priori based on evidence, age, sex, education, race/ethnicity, and marital status were selected as covariates.[17,15,39,40] Because findings on whether cancer- and treatment-related characteristics are related to quality of life in lung cancer patients are mixed, any medical factor associated with the outcome at $p < 0.10$ was also entered as a covariate.[15,40-42] Likelihood ratio tests assessed whether the full model produced significantly better model fit than the covariate-only model. Regressions were estimated with full information maximum likelihood to address missing data.[43] Two-tailed significance tests were used, and $p < 0.05$ was considered statistically significant.

Results

Of 211 patients screened, 25 were ineligible, 40 declined to participate, and 20 passively refused (e.g., indicated interest in being re-approached but attempts to do so were unsuccessful). Of 186 eligible patients, 126 provided informed consent and the 101 participants (53 men, 48 women) who completed the first survey were included in subsequent analyses. Of the 101 participants, 80 (79%) and 69 (68%) participants completed the 6- and 12-week follow-up assessments, respectively. Participants who completed all assessments did not differ significantly from participants who completed one or two assessments on internalized stigma, constrained disclosure, or study entry well-being (all $p > 0.35$).

The sample was comprised of eight participants who currently smoked, 56 who formerly smoked, and 37 who never smoked. On average, participants were 64.5 years old and had 15.7 years of education. The majority was married/living as married, non-Hispanic White, and had stage IV disease. Ninety participants were diagnosed with NSCLC (76.7% [n = 69 of 90] of which was

adenocarcinoma), eight with small cell lung cancer, and three with mesothelioma (Table 1). (Findings did not change if the three participants with mesothelioma were excluded from analyses.) Participant characteristics are presented in Table 1. Internalized stigma and constrained disclosure were correlated significantly ($r = .20$, $p = 0.048$) and did not interact significantly to predict the outcomes (all $p > 0.30$).

Internalized Stigma and Constrained Disclosure by Smoking-Related Factors

The three smoking groups differed significantly on internalized stigma ($F (2,95) = 14.40$, $p < 0.001$). Planned comparisons (Tukey's Honest Significant Difference tests) revealed that current smokers reported higher levels of internalized stigma than former ($p = 0.001$) and never smokers ($p < 0.001$). Former smokers also reported higher levels of internalized stigma than never smokers ($p = 0.013$). Smoking history groups did not differ significantly on constrained disclosure ($p = 0.809$). Findings are displayed in Figure 1. The three smoking history groups did not differ significantly by age, education, sex, and race/ethnicity (all $p > 0.10$), or on emotional or physical/functional well-being at study entry (all $p > 0.41$). Statistical significance of these findings was identical when smoking status was examined dichotomously (current/former versus never).

Among participants who currently/formerly smoked, a greater number of months since smoking cessation was related to lower levels of internalized stigma ($r = -.47$, $p < 0.001$) but not constrained disclosure ($r = -.06$, $p = 0.674$). Additionally, number of pack-years smoked and age at smoking initiation were not significantly related to internalized stigma (all $p > 0.12$) or constrained disclosure (all $p > 0.38$). Results were unchanged when excluding the eight participants who currently smoked.

Well-Being Outcomes Regressed on Internalized Stigma and Constrained Disclosure

Covariates. Emotional and physical/functional well-being at each assessment was not associated significantly with cancer type (NSCLC versus other type; all $p > 0.44$), current oncologic treatment (immunotherapy or targeted therapy, chemotherapy, and combination therapy; all $p > 0.16$), disease stage (stage IV versus I-III; all p values > 0.14), line of treatment (all $p > 0.35$), participation in an oncologic clinical trial (all $p > 0.17$), history of chemotherapy (all $p > 0.16$), or previous lung cancer-related surgery (e.g., lobectomy; all $p > 0.28$). Emotional well-being was not associated significantly with months since diagnosis (all $p > 0.25$). By contrast, poorer study entry physical/functional well-being was associated with fewer months since diagnosis ($r = .17$,

Table 1. Sample Characteristics and Demographics (N = 101)

	n	Mean	Standard Deviation
Age, y	101	64.54	11.60
Years of education	93	15.69	2.83
Age at smoking initiation	61	18.39	4.94
Pack-years smoked	54	33.95	28.08
Internalized stigma	98	2.42	1.17
Constrained disclosure	97	2.73	1.82
Emotional well-being at study entry	99	17.57	4.02
Physical/functional well-being at study entry	99	57.15	16.80

	n	Median	Interquartile range
Months since lung cancer diagnosis	101	9.97	17.38
Duration of smoking cessation, mo	57	180.00	342.00

	n	%
Sex		
Male	53	52.5
Female	48	47.5
Race/ethnicity		
Non-Hispanic white	72	71.3
Other race/ethnicity	29	28.7
Marital status		
Married/living as married	66	65.3
Not married	34	33.7
Did not report	1	1.0
Smoking status		
Current	8	7.9
Former	56	55.4
Never	37	36.6
Cancer type		
NSCLC	90	89.1
Other lung cancer type	11	10.9
Stage of disease		
I or II	7	7.0
III	18	17.8
IV	74	73.3
Missing	2	2.0
Current participation in oncologic clinical trial		
Yes	55	54.4
No	45	44.6
Missing	1	1.0
Current oncologic treatment		
Immunotherapy only	49	48.5
Chemotherapy only	24	23.8

(continued)

Table 1. Continued

	n	%
Targeted therapy only	8	7.9
Combination therapy	20	19.8
Line of current oncologic treatment		
First	48	47.4
Second	22	21.8
Third	16	15.8
Fourth or fifth	14	14.9
Missing	1	1.0
History of lung cancer-related surgery		
Yes	29	28.7
No	71	70.3
Missing	1	1.0
Past receipt of chemotherapy for lung cancer		
Yes	48	47.5
No	52	51.5
Missing	1	1.0

$p = 0.098$) at $p < 0.10$. As such, "months since diagnosis" was included as a covariate in analyses.

Smoking status did not interact significantly with internalized stigma or constrained disclosure on emotional well-being, physical/functional well-being, or changes in well-being over time (all $p > 0.16$), although power to test interactions was limited. As such, smoking status (current/former versus never) was included along
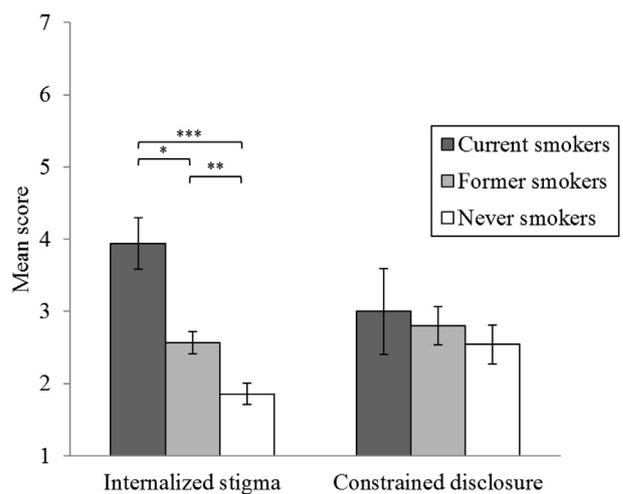
Figure 1. Mean scores of internalized stigma and constrained disclosure by smoking status * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; Error bars represent standard errors.

with months since diagnosis and a priori covariates (i.e., age, sex, education, race/ethnicity, and marital status) in analyses.

Study entry. First, we evaluated associations of internalized stigma and constrained disclosure with emotional well-being (Table 2) and physical/functional well-being (Table 3) at study entry, controlling for smoking status, sociodemographic factors, and months since diagnosis. Regarding covariates, women reported significantly poorer emotional and physical/functional well-being. Additionally, less time elapsed since diagnosis was associated significantly with poorer physical/functional well-being. No other covariate was associated significantly with the outcomes (all $p > 0.07$). Higher internalized stigma and higher constrained disclosure were associated significantly with poorer emotional and physical/functional well-being (Tables 2 and 3). The model with internalized stigma and constrained disclosure produced a significantly better fit than the covariate-only model for both emotional (χ^2 (2) = 12.19, $p = 0.002$) and physical/functional well-being (χ^2 (2) = 25.29, $p < 0.001$).

Changes in well-being across 6 weeks. Next, we assessed internalized stigma and constrained disclosure as predictors of 6-week well-being, controlling for covariates and well-being at study entry (Tables 2 and 3). Study entry emotional and physical/functional well-being, respectively, significantly predicted 6-week emotional and physical/functional well-being. Being married was associated significantly with declining emotional and physical/functional well-being across 6 weeks. Additionally, non-Hispanic white race/ethnicity was associated significantly with declining physical/functional well-being across 6 weeks. No other covariates were associated significantly with the outcomes (all $p > 0.05$).

Higher internalized stigma was associated significantly with declining emotional and physical/functional well-being (Tables 2 and 3). Constrained disclosure was not significantly associated with changes in emotional or physical/functional well-being (all $p > 0.10$). The model with internalized stigma and constrained disclosure produced a significantly better fit than the covariate-only model for both emotional (χ^2 (2) = 9.77, $p = 0.008$) and physical/functional well-being (χ^2 (2) = 6.59, $p = 0.037$).

Changes in well-being across 12 weeks. Finally, we assessed internalized stigma and constrained disclosure as predictors of 12-week well-being, controlling for covariates and well-being at study entry (Tables 2 and 3). Well-being at study entry significantly predicted 12-

Table 2. Internalized Stigma and Constrained Disclosure as Predictors of Emotional Well-Being at Study Entry, 6-Week Follow-Up, and 12-Week Follow-Up Using Multivariable Linear Regression Models (N = 101)

Predictor	Emotional Well-Being at Study Entry				Emotional Well-Being at 6-Week Follow-Up				Emotional Well-Being at 12-Week Follow-Up			
	b	z	p	95% CI	b	z	p	95% CI	b	z	p	95% CI
Intercept	15.88[a]	3.85[a]	<0.001[a]	7.80 to 23.96[a]	11.81[a]	2.97[a]	0.003[a]	4.03 to 19.60[a]	12.26[a]	2.27[a]	0.023[a]	1.68 to 22.83[a]
Study entry emotional well-being	—	—	—	—	0.64[a]	6.65[a]	<0.001[a]	0.45 to 0.83[a]	0.75[a]	5.40[a]	<0.001[a]	0.47 to 1.02[a]
Age, y	0.03	0.96	0.337	-0.04 to 0.10	-0.03	-0.93	0.353	-0.09 to 0.03	-0.05	-1.11	0.266	-0.14 to 0.04
Sex (female vs. male)	-1.83[a]	-2.45[a]	0.014[a]	-3.30 to -0.37[a]	-1.34	-1.89	0.059	-2.72 to 0.05	-1.45	-1.52	0.129	-3.32 to 0.42
Education, y	0.16	1.10	0.272	-0.13 to 0.45	0.01	0.06	0.955	-0.24 to 0.26	-0.05	-0.27	0.786	-0.39 to 0.29
Race/ethnicity (other race/ethnicity vs. non-Hispanic white)	0.73	0.91	0.363	-0.84 to 2.30	0.99	1.35	0.178	-0.45 to 2.42	1.38	1.41	0.160	-0.55 to 3.32
Marital status (married vs. unmarried)	-0.61	-0.74	0.459	-2.22 to 1.00	-2.04[a]	-2.65[a]	0.008[a]	-3.55 to -0.53[a]	-0.96	-0.90	0.367	-3.05 to 1.13
Smoking history (current/former vs. never)	1.53	1.80	0.071	-0.13 to 3.19	0.38	0.51	0.612	-1.10 to 1.87	1.58	1.51	0.132	-0.48 to 3.64
Months since diagnosis	0.02	1.53	0.127	-0.01 to 0.05	0.02	1.53	0.125	-0.01 to 0.05	-0.02	-0.97	0.333	-0.05 to 0.02
Internalized stigma	-0.85[a]	-2.33[a]	0.020[a]	-1.56 to -0.14[a]	-1.03[a]	-3.06[a]	0.002[a]	-1.68 to -0.37[a]	-1.22[a]	-2.88[a]	0.004[a]	-2.05 to -0.39[a]
Constrained disclosure	-0.50[a]	-2.39[a]	0.017[a]	-0.92 to -0.09[a]	0.24	1.13	0.259	-0.17 to 0.65	-0.05	-0.18	0.858	-0.56 to 0.47

[a]Regression coefficients significant at $p < 0.05$.
Emotional well-being at study entry, 6-week follow-up, and 12-week follow-up were each entered as the dependent variable in three separate multivariable linear regression models. To evaluate change over time, emotional well-being at 6- and 12-week follow-up were evaluated with study entry emotional well-being controlled statistically. b, unstandardized coefficient estimate; z, z-score test statistic; CI, confidence interval.

Table 3. Internalized Stigma and Constrained Disclosure as Predictors of Physical/Functional Well-Being at Study Entry, 6-Week Follow-Up, and 12-Week Follow-Up Using Multivariable Linear Regression Models (N = 101)

Predictor	Physical/functional Well-Being at Study Entry				Physical/Functional Well-Being at 6-Week Follow-Up				Physical/Functional Well-Being at 12-Week Follow-Up			
	b	z	p	95% CI	b	z	p	95% CI	b	z	p	95% CI
Intercept	51.37[a]	3.22[a]	0.001[a]	20.08 to 82.66[a]	33.17[a]	2.65[a]	0.008[a]	8.60 to 57.74[a]	44.55[a]	2.37[a]	0.018[a]	7.72 to 81.38[a]
Physical/functional well-being at study entry	—	—	—	—	0.65[a]	8.85[a]	<0.001[a]	0.50 to 0.79[a]	0.70[a]	5.89[a]	<0.001[a]	0.47 to 0.93[a]
Age, y	0.15	1.07	0.284	-0.12 to 0.42	-0.08	-0.88	0.379	-0.27 to 0.10	-0.22	-1.41	0.158	-0.52 to 0.08
Sex (female vs. male)	-6.44[a]	-2.22[a]	0.026[a]	-12.11 to -0.76[a]	1.11	0.51	0.613	-3.21 to 5.44	1.93	0.59	0.553	-4.45 to 8.31
Education, y	0.80	1.39	0.166	-0.33 to 1.92	-0.06	-0.16	0.876	-0.82 to 0.70	-0.49	-0.80	0.426	-1.70 to 0.72
Race/ethnicity (other race/ethnicity vs. non-Hispanic white)	0.97	0.31	0.755	-5.10 to 7.04	6.78[a]	2.90[a]	0.004[a]	2.20 to 11.36[a]	5.27	1.57	0.117	-1.33 to 11.87
Marital status (married vs. unmarried)	-2.07	-0.65	0.514	-8.27 to 4.14	-6.12[a]	-2.39[a]	0.017[a]	-11.14 to -1.10[a]	-4.78	-1.31	0.190	-11.94 to 2.37
Smoking history (current/former vs. never)	4.45	1.36	0.175	-1.99 to 10.89	-1.10	-0.45	0.649	-5.84 to 3.64	1.00	0.28	0.781	-6.09 to 8.10
Months since diagnosis	0.14[a]	2.48[a]	0.013[a]	0.03 to 0.24[a]	-0.02	-0.50	0.620	-0.11 to 0.06	-0.05	-0.86	0.388	-0.18 to 0.07
Internalized stigma	-3.29[a]	-2.38[a]	0.018[a]	-6.01 to -0.58[a]	-2.15[a]	-2.00[a]	0.045[a]	-4.25 to -0.05[a]	-2.46	-1.69	0.091	-5.32 to 0.40
Constrained disclosure	-3.60[a]	-4.47[a]	<0.001[a]	-5.18 to -2.02[a]	1.12	1.64	0.100	-0.22 to 2.46	0.95	0.97	0.333	-0.97 to 2.86

[a]Regression coefficients significant at p < 0.05.
Physical/functional well-being at study entry, 6-week follow-up, and 12-week follow-up were each entered as the dependent variable in three separate multivariable linear regression models. To evaluate change over time, physical/functional well-being at 6- and 12-week follow-up were evaluated with study entry physical/functional well-being controlled statistically. b, unstandardized coefficient estimate; z, z-score test statistic; CI, confidence interval.

week emotional and physical/functional well-being, respectively. Covariates were not associated significantly with changes in well-being across 12 weeks (all p > 0.11). Higher internalized stigma was associated significantly with declining emotional but not physical/functional well-being across 12 weeks. Constrained disclosure was not associated significantly with changes in emotional or physical/functional well-being (all p > 0.33). The model with internalized stigma and constrained disclosure produced a significantly better fit than the covariate-only model for emotional (χ^2 (2) = 7.86, p = 0.020) but not physical/functional well-being (χ^2 (2) = 3.45, p = 0.178).

Discussion

In this 12-week study of 101 adults in treatment for lung cancer, higher internalized stigma (i.e., feelings of regret, shame, and self-blame about one's lung cancer) and constrained disclosure (i.e., avoidance or discomfort about disclosing one's lung cancer status to others) were uniquely associated with poorer emotional and physical/functional well-being at study entry, beyond sociodemographic, medical, and smoking-related characteristics, as hypothesized. Findings are consistent with cross-sectional research that higher levels of overall lung cancer stigma and feelings of regret, guilt, and shame specifically are associated with poorer psychological outcomes.[24-27,29,34,35] Internalized lung cancer stigma was also related to poorer physical/functional well-being, consistent with some cross-sectional research.[26,35]

The present study also showed that constrained disclosure is associated with adverse psychological and physical/functional well-being, independent of internalized stigma, which is a novel finding. These results are consistent with recently presented results that constrained disclosure about one's lung cancer is associated with higher depressive symptoms.[33] Constrained disclosure may contribute to poorer health outcomes by preventing patients from seeking social support or processing their thoughts and feelings with others, which can be adaptive strategies for coping with cancer.[32,44] Alternatively, feeling unwell may lead to constrained disclosure, and additional longitudinal research is needed to clarify temporal precedence.

This is the first longitudinal study to demonstrate significant relationships between stigma processes and changes in health-related outcomes among lung cancer patients, extending previous cross-sectional research.[24-27,29,34,35] Findings showed that internalized stigma was uniquely associated with changes in emotional and physical/functional well-being. Specifically, higher internalized stigma predicted significant declines in emotional well-being across 6 and 12 weeks as well as declines in physical/functional well-being

across 6 weeks. Constrained disclosure was not associated with changes in well-being. Future research should examine whether individual differences, such as extraversion or use of particular coping strategies, moderate relationships between constrained disclosure and health-related adjustment. The well-being of lung cancer patients fluctuates throughout the cancer trajectory, and these findings highlight the utility of internalized stigma in explaining such changes, beyond sociodemographic, medical, and smoking-related factors.[14,42]

Internalized stigma and constrained disclosure were correlated significantly, consistent with prior research.[31] Notably, overall levels of internalized stigma and constrained disclosure were low, also consistent with prior research.[26,34] On average, patients reported slight disagreement with stigma items, although scores spanned the range of the scales with some patients endorsing moderate or strong agreement with stigma items. The proportion of participants who never smoked (37%) in the current sample was higher than in the lung cancer population (10%), which may explain the low levels of stigma.[45] Despite low endorsement of stigma, robust relationships between internalized stigma, constrained disclosure, and well-being were apparent.

At study entry, women reported worse emotional and physical/functional well-being than men, which is consistent with prior research.[15] Years of education and smoking status were not related significantly to well-being, consistent with other studies of lung cancer patients.[9,40,46] Shorter time elapsed since diagnosis was related to poorer physical/functional well-being at study entry, which is inconsistent with previous opposite or null findings.[9,15] Previous studies assessed lung cancer patients during long-term survivorship or post-surgery rather than on active oncologic treatment, however, which may explain the disparate findings. Age and cancer stage were not related significantly to well-being, which also contradicts others' findings.[8,15,39] Finally, it is unclear why being married and non-Hispanic white race/ethnicity were associated with declining well-being across 6 weeks, given that these factors have previously been related to better functioning.[17] Notably, marital status and race/ethnicity did not differentiate patients on study entry well-being.

Consistent with prior research, those who currently or formerly smoked (versus never smokers) reported higher levels of internalized stigma.[26,29] Feelings of self-blame, guilt, shame, and regret surrounding one's lung cancer diagnosis are closely linked to one's past experiences of smoking.[19] Levels of constrained disclosure were comparable across all smoking groups, consistent with recently presented findings from a separate sample of lung cancer patients.[33] People may not share their lung cancer status, regardless of smoking history, for several reasons. Some may limit their disclosure to avoid others' automatic reactions, which often imply that the cancer is their fault, and others may want to avoid pity or burdening others.[20,21,47] This is the first quantitative study to show that current smokers report significantly higher levels of internalized stigma than former smokers, which is consistent with qualitative findings.[20] Current and former smokers did not differ significantly on feelings of regret in one study, and other studies combined current and former smokers into one group when assessing internalized stigma.[24,26,29] Current smokers may face stigma not only about their past but also about their current smoking, perhaps from their medical team, family, or friends. However, these findings should be cautiously interpreted, given that only eight participants currently smoked.

Among participants who currently or formerly smoked, we explored whether smoking-related factors were associated with internalized stigma and constrained disclosure. A greater number of months since smoking cessation was associated significantly with lower levels of internalized stigma, but not constrained disclosure. Qualitative findings also suggest that feelings of internalized stigma are expressed more by lung cancer patients who currently smoke or recently quit, compared to long-term quitters.[20] Adults who have quit smoking for a longer time may have developed an identity as a former (rather than current) smoker, which may mitigate feelings of shame. Thus, early smoking cessation efforts may have implications for preventing or reducing internalized stigma. Age at smoking initiation and pack-years smoked were not associated with internalized stigma or constrained disclosure, consistent with recently presented findings.[33]

Limitations and Strengths

A strength of the study is its longitudinal design, which informs theory and strengthens causal inference about the influence of lung cancer stigma on well-being.[20] However, causality cannot be directly inferred. Interventions that aim to reduce lung cancer stigma and subsequently facilitate positive adjustment would further bolster causal inference. Although some attrition occurred, the retention rate (68%) was comparable to another 12-week longitudinal study of lung cancer patients (67%).[48] Additionally, using separate measures of internalized stigma and constrained disclosure allowed for evaluation of independent contributions of these constructs for both emotional and physical/functional health outcomes.[31] However, the constrained disclosure subscale contained only two items, and assessing this construct with additional items may provide a more reliable estimate of constrained disclosure. Future research should quantify lung cancer stigma and

constrained disclosure with the recently developed Lung Cancer Stigma Inventory, which uses a 6-item constrained disclosure subscale and was established through a multiphase psychometric evaluation process.[31] Most participants were non-Hispanic white and caution is warranted in generalizing these findings broadly. However, race/ethnicity was not associated with internalized stigma, constrained disclosure, or well-being.

Conclusions

Although internalized stigma and constrained disclosure were not high, they contributed significantly and uniquely to emotional and physical/functional well-being in lung cancer patients during active oncologic treatment. Additionally, internalized stigma may be especially important for explaining changes in well-being across time, and adults who currently smoke or have recently quit may be at particular risk for experiencing internalized stigma.

There is a need for interventions to reduce the negative influence of stigma and improve well-being for lung cancer patients, and the longitudinal findings in the current study can inform such interventions. Specifically, feelings of self-blame and shame may be candidate intervention targets for mindfulness- or acceptance-based therapies.[49] Additionally, affective or physiological hypervigilance associated with anticipated stigma should also be considered as potential targets for such interventions. Finally, feelings of avoidance or discomfort about disclosing one's lung cancer status may be targeted through provider-focused interventions that encourage oncologists and medical teams to use empathic communication skills in their discussions with lung cancer patients and couple- or family-based interventions that aim to bolster socially supportive exchanges. Future research should examine whether lung cancer stigma varies or relates to health outcomes differently across various phases of the cancer trajectory (e.g., at diagnosis, during long-term survivorship, or at the end-of-life). These findings highlight the importance of internalized lung cancer stigma and constrained disclosure for health-related adjustment and emphasize the need for intervention development.

Acknowledgments

This research complied with laws of the country in which it was performed. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants in the study.

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