ORIGINAL ARTICLE

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.

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

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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