REVIEW ARTICLE

Multilevel Opportunities to Address Lung Cancer Stigma across the Cancer Control Continuum

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ABSTRACT

The public health imperative to reduce the burden of lung cancer has seen unprecedented progress in recent years. Fully realizing the advances in lung cancer treatment and control requires attention to potential barriers in their momentum and implementation. In this analysis, we present and evaluate the argument that stigma is a highly significant barrier to fulfilling the clinical promise of advanced care and reduced lung cancer burden. This evaluation of the stigma of lung cancer is based on a multilevel perspective that incorporates the individual, persons in the individual's immediate environment, the health care system, and the larger societal structure that shapes perceptions and decisions. We also consider current interventions and interventional needs within and across aspects of the lung cancer continuum, including prevention, screening, diagnosis, treatment, and survivorship. Current evidence suggests that stigma detrimentally affects psychosocial, communication, and behavioral outcomes over the entire lung cancer control continuum and across multiple levels. Interventional efforts to alleviate stigma in the context of lung cancer show promise, yet more work is needed to evaluate their impact. Understanding and addressing the multilevel role of stigma is a crucial area for future study to realize the full benefits offered by lung cancer prevention, control, and treatment. Coordinated, interdisciplinary, and well-conceptualized efforts have the potential to reduce the barrier of stigma in the context of lung cancer and facilitate demonstrable improvements in clinical care and quality of life.

Keywords: Lung cancer; Stigma; Multilevel approach; Cancer control continuum

Introduction

Recent advances in prevention, screening, treatment, and management of symptoms have brought the promise of decreased lung cancer burden closer to reality.[1–6] Low-dose computed tomography (LDCT) screening has demonstrated effectiveness in increasing early detection of localized, resectable thoracic tumors.[5] Molecular testing now facilitates targeting and personalization of treatment and is increasingly being integrated into standard clinical practice. After decades of effort, immune checkpoint inhibitors have demonstrated promising results and have received U.S. Food and Drug Administration approval for treatment of metastatic NSCLC.[2,6] Simultaneously, a growing global community of lung cancer advocates are highlighting survivorship stories, promoting research and evidence-based care, and focusing on policy needs.[7] Despite these promising advances across many aspects of lung cancer care and control, low clinician adoption, limited patient uptake, and other implementation challenges have been observed.[8–10] Therefore, to fully realize the impact of the research and clinical advances, it is important to understand and address significant modifiable *barriers* to their successful implementation. In this article, we

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present and provide evidence supporting the argument that the *stigma of lung cancer* (the experience and internalization of negative appraisal and devaluation from others[11]) is a formidable barrier to fulfilling the clinical promise of high-quality care and reduced lung cancer burden. In addition to documenting the impact of lung cancer stigma, we focus on promising interventions and future research directions to address this stigma and improve the outcomes of lung cancer care.

Attention to the robust causal connection between smoking and lung cancer, although crucial for tobacco control, may have unintended consequences that generate blaming responses and biased negative perceptions toward patients with lung cancer and those at high risk for lung cancer (e.g., current smokers).[12–14] Our previous work has identified three primary elements of lung cancer stigma from the patient's perspective: (1) perceived stigma (how what others think and say is evaluated by the patient); (2) internalized stigma (how perceived stigma can affect patients through self-blame and guilt); and (3) constrained disclosure (how stigma limits discussions of lung cancer with others).[15] For many patients who are at high risk of or have received a diagnosis of lung cancer, the stigma can detrimentally affect willingness to engage in screening for early detection, cause patients to delay seeking medical evaluation for presenting symptoms, and limit their involvement in lung cancer treatment and survivorship care.[16–18] Although there may be subtle positive effects of stigma that foster advocacy and social cohesion for some patients,[11] most investigations have reported on the pervasive negative consequences of lung cancer stigma. Lung cancer stigma can have far-reaching deleterious effects that range from reduced involvement in prevention and early detection interventions, negative psychosocial impact, impaired patient-clinician communication, inadequate access to diagnosis and treatment, and limited funding and public support for lung cancer research and care. Developing and testing interventions to ameliorate lung cancer stigma requires comprehensive understanding of mechanisms and targeted approaches across the cancer care continuum.

To understand the full scope and impact of lung cancer stigma, a *multilevel framework* is needed. The multilevel perspective incorporates the individual (patient), persons in the patient's immediate environment (e.g., family, friends), persons in the health care system (e.g., oncologic and primary care providers), and the larger societal structure that shapes perceptions and decisions (e.g., public attitudes, policy, media campaigns, research funding). Stigma is largely social in nature in that it is commonly perceived and internalized with an interpersonally and behaviorally relevant impact. Socioecological system models[19] provide useful frameworks to understand multilevel processes and address connections both within and across levels (Fig. 1). Within this model, interventions to improve one level (e.g., interpersonal communication) can also improve outcomes at other levels (e.g., individual quality of life).[20]

A second important consideration of lung cancer stigma is its impact across the entire *continuum* of care and control, including prevention (e.g., smoking cessation interventions), screening and early detection, diagnosis, treatment, and survivorship (Fig. 2).[21] At each phase of the continuum, lung cancer stigma may be a barrier to the successful implementation of research advances to reduce the lung cancer burden. Therefore, it is crucial that interventions focused on stigma consider relevant patient and quality of care outcomes across the lung cancer care continuum. This review addresses our current understanding of lung cancer stigma within these *multilevel* and *cancer continuum* perspectives. Although we focus primarily on lung cancer care within the United States, we have aimed to summarize the literature and perspectives on stigma from around the world when possible. In particular, we have focused on the status of current interventions and interventional needs within and across levels and experiences in the cancer continuum. Organizing our understanding of lung cancer stigma within this multilevel, multiphase framework allows for the development of a road map to reduce inequities affecting patients with lung cancer[22] and promote efficient and effective implementation of innovations in delivery of lung cancer care.

An Intrapersonal (Individual) Perspective to Addressing Lung Cancer Stigma

An intrapersonal perspective in the context of lung cancer stigma emphasizes the thoughts, feelings, and actions of the affected individual[20] (see Fig. 1). Assessing the impact of lung cancer stigma at the intrapersonal level involves consideration of the patient's psychosocial (e.g., depression, distress, self-esteem) and behavioral (e.g., screening participation, treatment adherence) processes likely influenced by public perception and internalization of stigma.[20]

Prevention

Rates of smoking in both adults and youths in the United States have been near an all-time low since the popularization of smoking in the 1940s. In the 50 years since the 1964 Surgeon General's report *Smoking and Health*, rates of smoking among U.S. adults have fallen from a high of 43% to a national low of 15.5%.[23] In 2016, only 8% of high school students smoked cigarettes.[24] Unfortunately, these gains in tobacco control