

# 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.

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**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.<sup>1-6</sup> Low-dose computed tomography (LDCT) screening has demonstrated effectiveness in increasing early detection of localized, resectable thoracic tumors.<sup>5</sup> 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.<sup>2,6</sup> Simultaneously, a growing global community of lung cancer advocates are highlighting survivorship stories, promoting research and evidence-based care, and focusing on policy needs.<sup>7</sup> 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.<sup>8-10</sup> 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<sup>11</sup>) 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).<sup>12-14</sup> 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).<sup>15</sup> 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.<sup>16-18</sup> Although there may be subtle positive effects of stigma that foster advocacy and social cohesion for some patients,<sup>11</sup> 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<sup>19</sup> 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).<sup>20</sup>

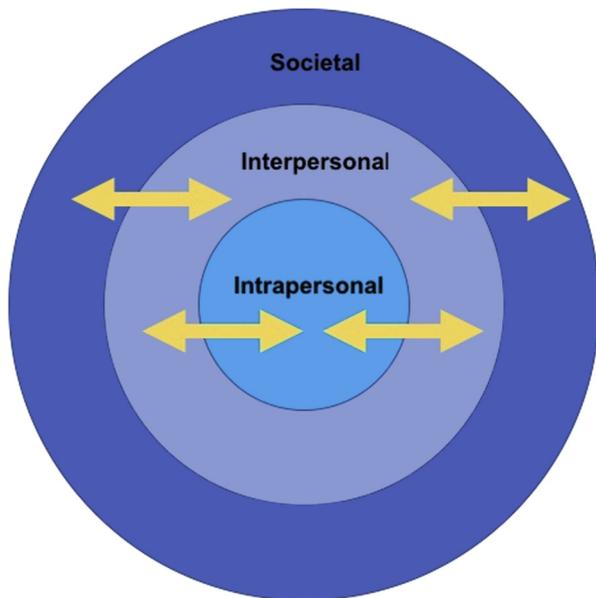
A second important consideration of lung cancer stigma is its impact across the entire *continuum* of care and control, including prevention (e.g., smoking cessation interventions), screening and early detection, diagnosis, treatment, and survivorship (Fig. 2).<sup>21</sup> At each phase of the continuum, 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<sup>22</sup> 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<sup>20</sup> (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.<sup>20</sup>

### Prevention

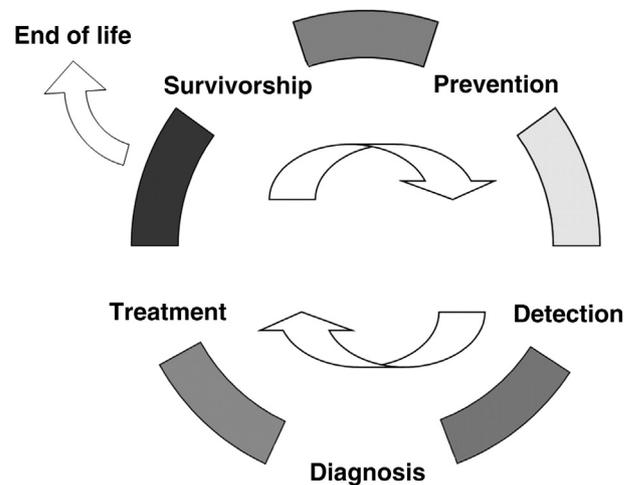
Rates of smoking in both adults and youths in the United States have been near an all-time low since the popularization of smoking in the 1940s. In the 50 years since the 1964 Surgeon General's report *Smoking and Health*, rates of smoking among U.S. adults have fallen from a high of 43% to a national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



**Figure 1.** Socioecological model to understand multilevel processes of lung cancer stigma. In the context of lung cancer stigma, the *intrapersonal level* centers on thoughts, feelings, and actions of the affected person. The *interpersonal level* centers on the social relationships and perceptions of others. The *societal level* addresses social conditions, structural components, and public attitudes. Adapted from Bronfenbrenner<sup>19</sup> and Cook et al<sup>20</sup> with permission from Elsevier.

have not benefited all individuals equally, such that the rate of cigarette smoking remains high among individuals with low income and education, certain racial and ethnic minorities, those with serious mental illness, those with physical disabilities, sexual and gender minorities, residents of rural communities, and other vulnerable subpopulations.<sup>25</sup> Not only have some communities not benefited as substantially as others but aggressive tobacco control messages may also be engendering harm as an unintended consequence, reducing empathy for dependent tobacco users, and creating an oppositional and contentious environment between tobacco users and non-tobacco users.<sup>26</sup>

Current disparities in smoking prevalence, particularly among various subpopulations, are likely contributing to the declining social acceptance and stigmatization of current smoking. The tobacco industry's practice of targeting marketing to certain racial and ethnic groups is thought to further contribute to social discrimination and stigmatization of smokers.<sup>25</sup> International evidence suggests that smokers' perceived and internalized stigma is universal and that it not only has a negative impact on mood and self-esteem but also might inhibit smoking cessation efforts through concealment and social withdrawal.<sup>14,26-30</sup> Smokers often report self-blame, guilt, and awareness of their marginalization as smokers. In a recent intervention trial, low-income smokers who reported higher levels of baseline stigma



**Figure 2.** Continuum of cancer care. The stages of the cancer continuum include prevention, detection, diagnosis, treatment, and survivorship. At each stage of the continuum, the stigma of lung cancer may be a barrier to the successful application of research advances to reduce the burden of lung cancer. Therefore, it is crucial that interventions focused on stigma acknowledge and address *each* element of this extended lung cancer care continuum. Reprinted with permission from J.H. Rowland.<sup>21</sup>

were less likely to engage in a smoking cessation intervention.<sup>31</sup> Stigma has been associated with misreporting of smoking status to health care providers, particularly in hospitalized smokers and those with chronic medical conditions.<sup>30,32</sup> These findings highlight the importance of gaining a greater understanding of the role of stigma as a barrier for smoking cessation, including a focus on tailoring cessation interventions to optimize engagement and cessation outcomes.

### Screening

In the context of lung cancer screening, evidence suggests that stigma is a powerful barrier to effective early detection with LDCT of the chest.<sup>33</sup> Compared with uptake of other types of cancer screening at the same implementation stage, the rate of LDCT screening of eligible patients remains very low (approximately 4%).<sup>8,34</sup> Of equal importance is the fact that only 10% of screening-eligible patients have engaged in a discussion about the option of screening with their health care clinician.<sup>35</sup> In qualitative interviews of screening-eligible individuals, Carter-Harris et al.<sup>33</sup> identified patient-reported stigma as a significant hindrance to lung cancer screening; patients described concerns about being judged and blamed by health care clinicians as limiting their engaging in screening. In terms of intrapersonal interventions, recent work has focused on developing patient-focused lung cancer screening decision aids,<sup>36,37</sup> including those that address the role of stigma.<sup>38</sup> In particular, tailoring screening messages by smoking

status has the potential to decrease stigma in former smokers who are eligible for lung cancer screening and are engaging with such a decision aid.<sup>38</sup> Although more work is needed, targeted empathic messages and tailored decision aids hold the promise to reduce stigma and increase informed uptake of lung cancer screening.

### Diagnosis and Treatment

Stigma-related fears are associated with patient-initiated delays in seeking medical help that may result in more late-stage diagnoses.<sup>18,39</sup> Early screening and recognition of lung cancer symptoms combined with timely medical help-seeking behavior can facilitate earlier-stage diagnoses and increased survival; however, too few lung cancer diagnoses are made in these early stages.<sup>40</sup> A cross-sectional, quantitative study reported significant associations between patient-reported stigma and increased time from onset of symptoms to medical help seeking.<sup>18</sup> Other qualitative reports<sup>39,41–43</sup> have supported this theme, noting a reluctance of patients to seek medical care for symptoms owing to fear of being blamed by their clinicians. Results suggest that efforts aimed to educate patients about lung cancer symptoms should also address the role of stigma as a barrier to earlier diagnosis. Reducing stigma in this context could have powerful effects on symptom recognition, earlier diagnosis, and enhanced survival outcomes.

An expanding research base has also addressed the psychosocial and behavioral intrapersonal impact of stigma in the context of *treatment*. Despite advances in targeted therapies, a significant percentage of patients with lung cancer do not receive molecular testing and evidence-based anticancer treatment,<sup>10,44,45</sup> and they are less likely to engage in clinical trials,<sup>46</sup> participate in supportive care,<sup>47,9</sup> and seek rehabilitation services<sup>48</sup> despite high levels of distress and comparatively poor quality of life. Again, the role of patient-reported stigma in limited engagement and adherence to treatment is potentially significant. In a cross-sectional quantitative study of 231 patients with lung cancer, stigma was significantly associated with reduced patient-reported engagement in care.<sup>49,50</sup> In a qualitative study of 65 individuals with lung cancer, a salient theme involved highly stigmatized patients who questioned whether they deserved treatment and were less likely to seek out information about treatment options.<sup>11</sup> More research is needed to untangle the complex relationships between engagement in care, treatment decisions, adherence, and stigma. Establishing a clear relationship between stigma and measurable aspects of treatment adherence and positive health behaviors (e.g., smoking cessation, physical activity, and other beneficial health changes) is needed to guide stigma reduction interventions geared toward

enhancement of patient engagement, informed treatment decisions, adherence, and outcomes.

### Survivorship

In the context of survivorship, multiple cross-sectional studies have established relationships between patient-reported stigma and depression,<sup>51</sup> lower social functioning,<sup>52</sup> reduced quality of life,<sup>53</sup> and other psychosocial impairment.<sup>17,54–57</sup> Further studies are needed to establish causal connections between stigma, posttreatment surveillance, and other psychosocial/behavioral outcomes, but existing work suggests that stigma has significant *intrapersonal effects* for patients with lung cancer and lung cancer survivors. Two primary approaches—education and psychotherapy—have shown promise in reducing stigma and psychosocial distress. For example, Brown-Johnson et al.<sup>58</sup> developed an interactive mobile health tool to address stigma by coaching patients toward assertive communication with health care clinicians. Initial testing with eight patients supported its feasibility and acceptability in practice.<sup>58</sup> A single-arm, open trial tested an acceptance-focused cognitive behavioral intervention with 14 patients and demonstrated feasibility and initial efficacy with decreases in stigma, cancer distress, and depression.<sup>59</sup> It will be important for larger-scale studies to extend these pilot findings and demonstrate utility across multiple psychosocial and behavioral outcomes. Of additional utility will be a review of effective stigma reduction interventions in other health domains (e.g., human immunodeficiency virus [HIV]/acquired immunodeficiency syndrome, substance use, obesity, mental health) to apply a best practices approach to this work. For example, in addition to education and cognitive-behavioral counseling, Cook et al.<sup>20</sup> identified the utility of interventions that promote belonging and affirmation of values among stigmatized individuals. Such techniques and strategies may be useful supplements to existing evidence-based psychosocial interventions targeted toward patients with lung cancer.<sup>60</sup>

### An Interpersonal Perspective on Addressing Lung Cancer Stigma

Consistent with an interpersonal perspective,<sup>20</sup> lung cancer stigma is intricately tied to social relationships and perceptions of others. The lung cancer experience involves a complex array of interactions with health care providers, family members, friends, and other caregivers. Stigma has the potential to affect the nature of these social relationships, from content and quality of communication to clinician decision making about treatment, thus emphasizing the importance of addressing social processes in stigma reducing interventions.

## Prevention

As tobacco use has declined among the general population, smoking has shifted from once being viewed as conventional behavior to now being viewed as an aberrant behavior. In their population survey of New York residents, Stuber et al.<sup>26</sup> described the negative impact of nonsmoking family and friends' attitudes on smokers' perceived stigma. Recent evidence suggests that interpersonal-level stigma from health care providers may also have a negative impact on accurate disclosure of smoking status and other smoking-related discussion.<sup>30</sup> Critical and judgmental assumptions about personal responsibility and blame may diminish the effectiveness of health care providers' cessation advice, support, and provision of smoking cessation resources.<sup>61</sup> Browning et al.<sup>62</sup> reported that only 38% of smokers in their study received assistance with smoking cessation from their medical provider, and strong socioeconomic disparities existed among those offered cessation assistance.

Given the apparent biases of some primary health care providers,<sup>63</sup> clinician-focused interventions that promote best practices to provide empathic smoking cessation advice and support are needed. To date, there has also been little work focusing on how friends and family (smokers and nonsmokers) can best support smokers struggling with tobacco dependence, suggesting a clear need for further study and application.

## Screening

Most studies addressing clinician-level barriers to lung cancer screening (LDCT) referrals have focused on awareness of guidelines, knowledge of survival benefits, and logistical concerns among primary care clinicians.<sup>64-67</sup> Collectively, this work highlights the connections between limited awareness and lower rates of referrals for lung cancer screening and also emphasizes the need for clinician education about lung cancer screening. However, it is also plausible that underlying stigma and biased attitudes toward screen-eligible patients and clinician *nihilism* (pessimistic views of individuals at high risk of lung cancer and patients with lung cancer) may bias perceptions of individual patients and limit clinician-initiated discussions and referral patterns for lung cancer screening.<sup>68</sup> Given the public health challenges associated with increasing lung cancer screening, it is important to fully elaborate this connection and use the information to tailor clinician-focused education toward engaging appropriate high-risk patients in a discussion about their options for lung cancer screening.

Relatively little research has evaluated direct interventions to address clinician nihilism, bias, and stigma about initiating discussions regarding lung cancer screening. However, recent efforts to educate clinicians

have integrated material to establish social norms regarding the significance and potential importance of lung cancer screening for individual and population health. One continuing education program that was developed and initially tested in Kentucky has demonstrated the preliminary value of direct training for clinicians regarding the benefits and challenges of lung cancer screening.<sup>69,70</sup> The data showed that clinicians were receptive to the information and benefited from reviewing the data alongside consideration of shared decision making as a platform to explore the option of lung cancer screening. In addition to continuing education efforts, community cancer control specialists from the Kentucky Cancer Program have conducted academic detailing visits as part of the Kentucky Lung Cancer Education, Awareness, Detection, and Survivorship (LEADS) Collaborative with more than 2500 clinicians in an effort to boost lung cancer screening efforts and provide support and tools.<sup>71</sup> Although these efforts hold promise for indirectly addressing barriers such as nihilism and bias, it may be beneficial to include more overt efforts to discuss and explore concerns related to these important variables. In addition to conducting longer-term evaluations of training programs, it may be important to identify and test training and implementation strategies that more directly address nihilism and bias as barriers both in academic training settings and with practicing clinicians. These interventions can support broader implementation of lung cancer screening and create opportunities to explore the promise of screening in reducing lung cancer nihilism and stigma.

## Diagnosis and Treatment

To what degree does clinician stigma affect the timing of diagnosis and treatment decisions for patients with lung cancer? In a qualitative study of reasons for delay in diagnosis of lung cancer, general practitioners had differential responses to patients with newly diagnosed lung cancer, reporting sympathy for patients who had never smoked but noting blame toward current smokers.<sup>72</sup> Innovative work from Wassenaar et al.<sup>63</sup> demonstrated that general practitioners were less likely to provide evidence-based specialty referrals to patients with lung cancer than to equally staged patients with breast cancer. In this study of primary care clinicians, the researchers compared responses to randomly assigned, identically staged case scenarios of breast and lung cancer. The results indicated that primary care physicians were less likely to refer the patient with advanced-stage lung cancer for further treatment and were also less likely to closely monitor her for uncontrolled pain.<sup>63</sup> It was suggested that these findings may have been driven by physician nihilism and biased perceptions of lung cancer. In particular, a nihilistic

perspective toward the prognosis of patients with lung cancer may result in both the underuse of potentially beneficial therapies and a delay in the widespread adoption of new therapies.<sup>73</sup> Although timely access to a cancer specialist after lung biopsy has significant treatment implications,<sup>10</sup> multiple studies have documented that a significant proportion of patients with advanced lung cancer are not receiving appropriate follow-up care.<sup>10,74</sup> One nationwide database study observed that 6% to 10% of patients with newly diagnosed metastatic lung cancer did not receive cancer-directed therapy after positive biopsy results.<sup>10</sup> Another study used the National Cancer Database and found an increasing rate of patients with advanced-stage NSCLC who are not receiving cancer treatment.<sup>74</sup>

In addition to its potential impact on decisions about anticancer treatments, stigma may also affect clinician guidance toward ancillary treatment, including advice regarding cessation and referral for evidence-based tobacco treatment. The National Comprehensive Cancer Network has recommended smoking cessation for all smokers who are undergoing treatment for cancer.<sup>75</sup> Despite the potential “teachable opportunity” associated with diagnosis and treatment, many patients with lung cancer do not receive sufficient support for smoking cessation during these times.<sup>76</sup> Although nihilism and pessimistic assumptions about patients’ motivation to quit may limit initiation of cessation-based discussions, clinicians may also be hesitant to address smoking cessation because of lack of training and concern about upsetting patients.<sup>77</sup> Further research is needed to understand how to best manage both the priority of identifying and referring tobacco-dependent patients with lung cancer<sup>78</sup> and the importance of maintaining supportive provider-patient relationships. As in clinician-based interventions in the context of screening, addressing clinician roles in timely diagnosis and evidence-based tobacco treatment and referrals will require a focus not only on awareness of the clinical importance of smoking cessation but also on the nature of patient-provider communication to reduce the negative impact of stigma and nihilism.

### Survivorship

The interpersonal effects of stigma for *survivorship*, including communication and clinician perceptions, are highly salient and well studied, with important consequences for clinician- and family-focused interventions. In one qualitative study, 48% of patients with lung cancer discussed feeling stigmatized by at least a subset of their medical clinicians.<sup>11</sup> In an investigation of clinician perceptions for more than 3000 patients with solid tumors, researchers found that after adjustment for disease-relevant covariates, clinicians were three times

more likely to perceive lower quality of life for their patients with lung cancer.<sup>68</sup> These data suggest that perception biases about patients with lung cancer may be related to clinician stigma and nihilism, potentially influencing communication with patients and survivors. Other studies have supported the connection between stigma and interpersonal communication. For example, a large questionnaire study conducted in China revealed that 82% of oncology nurses attributed at least some blame to patients with lung cancer.<sup>79</sup> In a cross-sectional quantitative study, Shen et al.<sup>80</sup> reported that higher levels of patient-reported stigma were associated with poorer patient-clinician communication. Taken together, these studies support the need for stigma reduction interventions to address patient-clinician communication and clinician decision making.

Physicians and other clinicians who treat patients with lung cancer face numerous communication challenges, including how to communicate effectively in a nonjudgmental and empathic way that empowers patients without exacerbating feelings of self-blame and guilt. In particular, physicians note the challenges of discussing quitting smoking with patients with lung cancer while concurrently managing patients’ emotional distress after diagnosis of cancer and treatment.<sup>76–78</sup> Although empathic patient-clinician communication has been associated with lower levels of stigma, health care clinicians may frequently miss opportunities for empathy in lung cancer care.<sup>81</sup> To this end, in a current study on clinician-patient communication in lung cancer care,<sup>82</sup> Ostroff, Banerjee, and their colleagues are testing the impact of empathy-based training for thoracic oncology care physicians and have hypothesized that responding empathically to patients’ discussion of their smoking history may be instrumental to reducing patients’ perceived stigma and may be an effective way to improve disclosure of current smoking status and improve engagement with specialists in tobacco treatment. Current testing focuses on the feasibility and effectiveness of providing training in the skills of empathic communication to oncology care physicians and other health care providers who are treating patients with newly diagnosed lung cancer. The didactic-experiential empathic communication skills module focuses on taking a detailed tobacco history, advising current smokers to quit, and making a reliable referral for tobacco treatment services, all within the context of empathic nonjudgmental interactions with patients. The overall premise is that empathic assessment of smoking status and advising current smokers to quit will reduce perceived and internalized stigma and ultimately improve engagement with evidence-based tobacco treatment and psychosocial support services both during and after treatment of lung cancer.

The experience of lung cancer can have an overwhelming impact on patients' relationships with their partners or caregivers, and recent evidence suggests that stigma may play a role in the quality of these relationships. For example, Dirkse et al.<sup>83</sup> reported that patient-reported shame (a component of internalized stigma) was associated with patients' decreased satisfaction with their relationship with significant others. Similarly, patient-focused blame among lung cancer caregivers is associated with higher depressive symptom scores.<sup>84</sup> Findings suggest that caregiver-focused interventions in the context of lung cancer should address the impact of stigma and its effects on the caregiving process. A family-centered therapy approach may also be important for families who are struggling with lung cancer blame, guilt, and stigma. In fact, the National Cancer Institute has recently established new research funding opportunities that acknowledge the importance of generating more data to inform clinical practice with regard to supporting cancer caregivers.<sup>85</sup> In the context of lung cancer caregiving, the Kentucky Lung Cancer Education, Awareness, Detection, and Survivorship Collaborative has developed multiple modules that include attention to lung cancer stigma and blame among lung cancer caregivers.<sup>86,87</sup> The modules, which are designed to address lung cancer-specific stress and social support for survivors and caregivers, include activities that explore efforts to respond to stigmatizing comments and behaviors built on work originally developed by the Lung Cancer Alliance.<sup>88</sup> Additionally, the caregiving modules, which are designed to be delivered directly to caregivers in the absence of the lung cancer survivor, involve activities that include attention to stigma as it relates to being an effective caregiver and self-management for caregivers. Outcomes data regarding the impact of these efforts are being collected and will hopefully contribute to the foundation of data that address the challenges presented by stigma and bias for optimal caregiving to individuals with lung cancer and survivor outcomes.

## A Societal Perspective on Addressing Lung Cancer Stigma

At a societal level, the correlates of stigma relate to understanding and adjusting social conditions, structural components, and public attitudes.<sup>20</sup> In the context of lung cancer, stigma can affect the societal level through social attitudes and stereotypes, systems of health care, public health campaigns, funding priorities, and other policy decisions.

### Prevention

Heralded as one of the leading modern day public health success stories, comprehensive tobacco control

efforts, including restrictions on indoor smoking, increased tobacco taxation, and public health national media campaigns<sup>89</sup> have decreased social acceptance of smoking and collectively contributed to tremendous headway in reducing tobacco use.<sup>90</sup> A number of studies have documented substantial societal stigma toward smoking and smokers. Many health initiatives (e.g., smoking bans) have been crucial components of successful population-level tobacco control.<sup>89</sup> However, some evidence suggests that certain elements of smoking stigma may actually deter individual cessation efforts.<sup>91</sup> For example, social isolation, blaming, and devaluation of smokers may encourage nondisclosure and clandestine smoking and may also limit access to evidence-based tobacco treatment.<sup>92</sup> In an effort to target tobacco cessation at a societal level, large-scale antitobacco campaigns have focused on hard-hitting messages.<sup>93</sup> Although these antitobacco campaigns are effective at reducing smoking, they may also unintentionally increase societal stigma toward smokers and patients with lung cancer.<sup>91</sup> There is a growing dialogue as to whether the public health benefits of large-scale antitobacco media campaigns are fully justified in light of the potential for exacerbating stigma toward smokers and patients with lung cancer and other tobacco-related diseases.<sup>94</sup> For instance, although there is strong evidence for the smoking reduction benefits of U.S. Centers for Disease Control and Prevention's Tips from Former Smokers campaign, which features highly evocative stories of people living with smoking-related diseases, there is also a growing appreciation for the need to better understand the side effects of these interventions and whether these antitobacco campaigns also increase societal stigma toward smokers and, by extension, patients with lung cancer.<sup>91,94</sup> Developers of public health media campaigns should consider lung cancer stigma in the development and dissemination of hard-hitting antitobacco media campaigns in a manner akin to how clinician-scientists must monitor for unexpected and undesirable side effects of all our well-intended interventions. Along these lines, the U.S. Food and Drug Administration's public education campaign Every Try Counts was designed to encourage cigarette smokers to quit by including nonjudgmental messages of support for repeating quitting efforts, with emphasis on the health benefits of quitting and lessons learned from prior quit attempts.<sup>95</sup>

### Screening

Stigma may be closely intertwined with societal perspectives on lung cancer screening.<sup>96</sup> Despite the strong and influential data supporting a relative reduction in lung cancer mortality among individuals randomized to the LDCT arm of the National Lung Screening

Trial,<sup>97</sup> there has been substantial and vocal public debate as well as considerable opposition to the implementation of lung cancer screening, despite it being a grade B recommendation of the U.S. Preventive Services Task Force.<sup>98,99</sup> On the basis of these lessons from other cancer screening modalities, there is an understandably greater amount of societal attention being paid to the potential harm of lung cancer screening,<sup>100</sup> including false-positive results,<sup>101</sup> cost-effectiveness concerns,<sup>102</sup> and other translational challenges.<sup>103</sup> In understanding discussions about lung cancer screening, it may also be important to address the subtle and often unintended impact of societal stigma and nihilism that could accompany these considerations and concerns. More research is needed to fully understand whether and how societal stigma and nihilism may be affecting public responses to lung cancer screening, and what can be done to address it.

### Diagnosis and Treatment

How might societal stigma toward lung cancer affect the structural environment of lung cancer diagnosis and treatment? Although this direct relationship is difficult to connect, it is clear that there are significant disparities in treatment access and treatment research funding for lung cancer.<sup>104</sup> Progress in the diagnosis and treatment of lung cancer is largely spurred by research funding, but recent discussions have highlighted major disparities for opportunities to address lung cancer in this capacity.<sup>105</sup> In fiscal year 2016, the National Cancer Institute spent \$519.9 million for research on breast cancer compared with \$283.8 million for research on lung cancer.<sup>106</sup> This difference in funding likely limits research advances and productivity. A recent worldwide analysis of articles in lung cancer journals concluded that the research base in most countries severely lags behind other cancers.<sup>107,108</sup> On a policy and legislative level, attention to lung cancer diagnosis and treatment is also limited. Although connective empirical data are scarce, patients, clinicians, and advocates have all argued that these policy and funding discrepancies are the result of societal-level stigma and nihilism, creating a self-fulfilling cycle in which lung cancer is viewed as untreatable and patients with lung cancer are not prioritized as deserving to receive the resources needed to advance treatment goals. For example, in an interview-based study of clinicians, most respondents endorsed the belief that societal stigma directly affects funding for lung cancer research.<sup>109</sup>

More research using varied methodologies (e.g., vignette-based studies, policy-level analyses) is needed to better understand the connection between research and treatment funding and societal stigma. Addressing these funding and policy discrepancies has been a major focus of lung cancer advocates, who have been

promoting legislative action<sup>110</sup> and other policy initiatives that address treatment successes and needs of patients.<sup>111</sup> Of interest, the emergence of new treatments and communication about their potential benefit may be one way to reduce lung cancer stigma on the societal level.<sup>112,113</sup> Although further research is needed, it may be the case that attention to anticancer agents helps to normalize lung cancer as a treatable illness and reduce the associated stigma. In the emerging landscape of alternative communication platforms, it may also be plausible to leverage social media to change the public perception of lung cancer and the associated stigma.<sup>114</sup>

### Survivorship

Studies of societal attitudes toward lung cancer survivors underscore the impact that social stigma has on structural forces shaping lung cancer care. A large-scale (N = 1778) general population study of explicit and implicit attitudes (beliefs that may exist outside of conscious awareness) found that participants were more likely to agree with negative descriptive and normative statements about lung cancer than about breast cancer; participants also had significantly stronger implicit negative associations with lung cancer than with breast cancer.<sup>115</sup> Marlow et al.<sup>116</sup> randomized a sample of online survey participants to complete a cancer stigma scale related to lung, colorectal, skin, breast, or cervical cancer and found that participants reported the greatest levels of stigma related to lung cancer, with increased perceptions of patients' responsibility for their disease. In another unique study, Luberto et al.<sup>117</sup> used grounded theory to analyze online comments about a study detailing smoking among patients with lung cancer and patients with colorectal cancer. Stigma-based comments were common, with discussions centering on blame and personal responsibility for lung cancer.<sup>117</sup> In terms of public attention and action, Weiss et al.<sup>118</sup> conducted a phone survey of 1071 people and asked about the likelihood of their donating money or volunteering time for a cancer organization; 29% of respondents stated that they would likely or very likely donate time and/or money to a breast cancer organization compared with 18% of respondents stating that they would likely or very likely donate time and/or money to a lung cancer organization. Similarly, 25% of respondents selected breast cancer organizations to hypothetically support compared to 12% of respondents who chose lung cancer organizations.<sup>118</sup> With emerging improvements in lung cancer outcomes, a larger community of lung cancer survivors may emerge and play a larger role in terms of advocacy. As lung cancer survivorship increases and advocacy grows, public support is also expected to increase. However, there is likely to be a continuing need to address societal stigma and its effects on lung cancer

survivorship. Advocacy groups have raised awareness of stigma-related concerns in public forums<sup>119</sup> and conferences. Organizations have also launched public awareness campaigns that overtly address the stigma of lung cancer through direct contrasts.<sup>120</sup> Future work is needed to establish the impact of such media campaigns on societal attitudes and behaviors. Interventional activity could also heed lessons from efforts to reduce the social stigma of HIV, which focused on promotion of the disease as treatable, along with emphasis on institutional education, community engagement, and presentation of the disease with a human face.<sup>121</sup>

## Discussion and Future Directions

In this analysis, we have comprehensively evaluated the evidence that stigma is an important barrier to achieving the clinical promise of advanced lung cancer care. Our overall findings both extend the analysis of the review by Chambers et al.<sup>17</sup> and highlight the detrimental role of lung cancer stigma across multiple levels (individual, interpersonal, and societal) and across the entire cancer care continuum (prevention, screening, diagnosis, treatment, and survivorship). Existing research has generally established the connection between lung cancer stigma and outcomes related to treatment and survivorship at both the individual and interpersonal (clinician) levels. It is clear that stigma is

associated with increased psychosocial burden for patients with lung cancer and survivors, although the causal mechanisms and potential moderators have not been fully established. Furthermore, the role of stigma and nihilism in clinician communication and perceptions is gaining clarity. Therefore, it is not surprising that both patient-focused<sup>58,59</sup> and clinician-focused interventions targeting both individual stigma and relevant communication processes have begun to be developed and tested. Expanded attention to these promising interventions, including a focus on behavioral and clinical care outcomes along with the potential for scalability, is an important future goal (Table 1). Successful sustainability will require further effort to translate evidence-based interventions into clinical care settings and provide useful stigma reduction resources to lung cancer care clinicians.

Understanding the multilevel role of stigma in the context of prevention, screening, and early detection is a crucial area for future study to realize the full benefits offered by cancer prevention and control in these areas. Existing research has documented stigma as a barrier to patient-clinician discussions about smoking, the decision to screen (or not screen) for lung cancer, and actual screening behavior. There is a distinct and exceptional opportunity at this relatively early stage of implementation of lung cancer screening to design

**Table 1.** Key interventional needs to address lung cancer stigma across socioecological levels and the cancer care continuum

Interventional Need	Intrapersonal (Individual/Patient)	Interpersonal (Clinician/Family)	Societal (Social Attitudes/Policy)
Prevention	Tailor smoking cessation interventions for stigmatized smokers Acknowledge youth experimentation and nicotine addiction as drivers of persistent smoking	Address social support techniques for family/friends to adaptively encourage smoking cessation Improve strategies for clinician communication and patient engagement in tobacco treatment	Consider lung cancer stigma in the development of messaging for antitobacco media campaigns
Screening	Address stigma in developing patient decision aids for lung cancer screening Consider messaging in screening decision aids and tailor by smoking status in efforts to decrease stigma	Expand clinician-level information about lung cancer screening Overtly discuss stigma and nihilism with clinicians in training and practice	Consider addressing stigma in development of public campaigns and materials focused on lung cancer screening Work with advocacy groups to change the public conversation about stigma related to those at risk for lung cancer
Diagnosis/treatment	Develop patient-focused stigma reduction modules/interventions to facilitate timely diagnosis, treatment adherence, and other positive health behaviors (e.g., smoking cessation)	Directly address clinician nihilism in education that promotes evidence-based referral and treatment information	Promote societal understanding of lung cancer by highlighting diagnosis and treatment options, including the benefits of tobacco cessation on cancer treatment outcomes
Survivorship	Continue establishing the effectiveness of patient-focused education and counseling on reducing stigma, psychosocial distress, and adherence to survivorship guidelines	Continue training focused on clinician empathy and communication with patients with lung cancer Expand efforts to support caregivers of patients with lung cancer	Expand advocacy efforts that highlight experiences of lung cancer survivors and promote policy change

interventions that both leverage the ability to identify stigma and intervene in this vulnerable patient population (see Table 1). Across all phases of the cancer control continuum, it will be important to further understand the impact of societal-level stigma (related to both smoking and lung cancer) on discrepancies in policy, legislation, and funding. Partnerships between patient advocates and lung cancer researchers can help elucidate and address these issues through discussions about evidence-based messaging and measurement of message impact, along with greater exposure to legislative strategies (see Table 1). Progress has already been made, with changes to anti-smoking media campaigns that emphasize empathy and positive behavioral support along with introduction of lung cancer-focused legislative efforts. As cancer control moves forward in lung cancer specifically, it is imperative to realize that stigma is a multilevel phenomenon that can be addressed only by multilevel approaches involving elements of a socio-ecological framework as guides to study and implementation.

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. The understanding of stigma as it relates to lung cancer is relatively recent, but the focus on stigma in other disease domains, including HIV/acquired immunodeficiency syndrome, has a robust literature and history. Although it will be important to understand issues and needs specific to lung cancer, attention to successful stigma reduction interventions and lessons learned in other domains will also be an important element to consider and integrate. There is a unique opportunity to be proactive rather than reactive in this arena. Successfully addressing stigma is an important step in fulfilling the promise to reduce the burden of lung cancer.

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