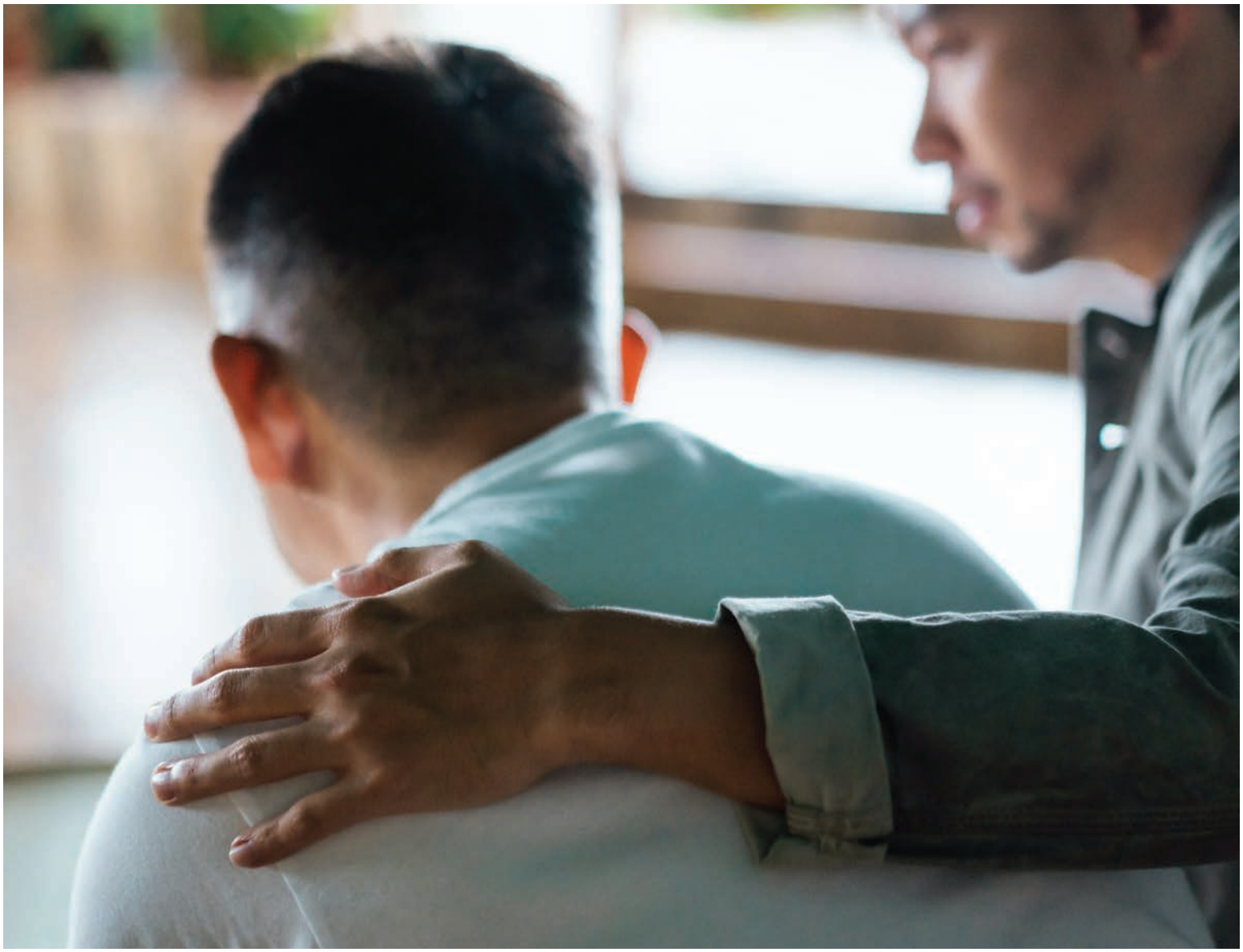
American Lung Association.

Addressing the Stigma of Lung Cancer:

Examining a Decade of Progress and Challenges

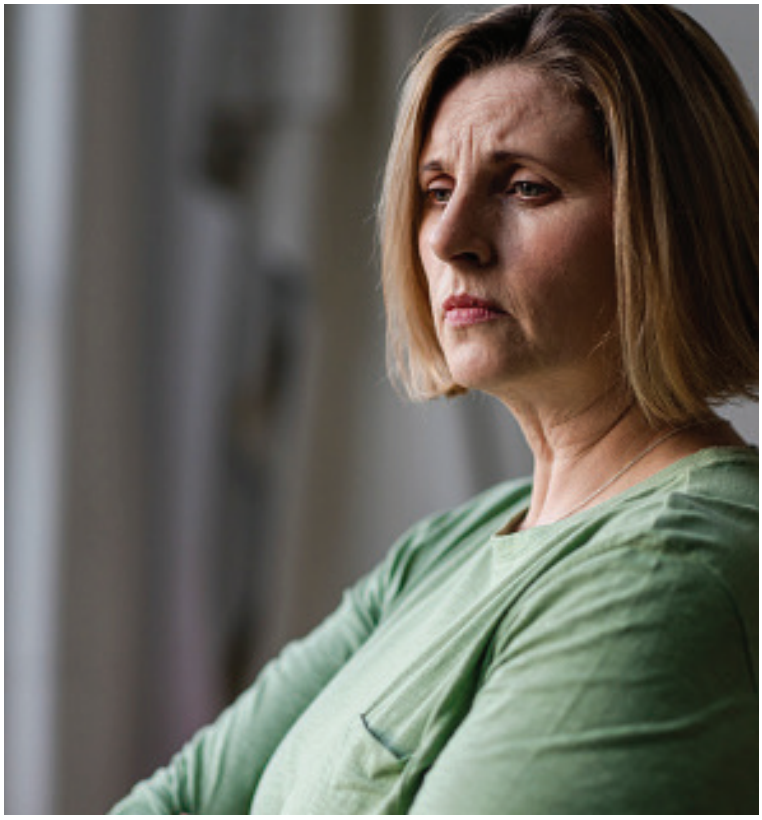


It is estimated that about 235,000 Americans will be diagnosed with lung cancer this year.[1] And it is likely that each person receiving this diagnosis will confront stigma at some point in their journey. Whether they find themselves subscribing to the belief that the disease is untreatable or they are experiencing lack of empathy from the community (or from one's own self), stigma continues to plague lung cancer.

What is lung cancer stigma? There are many ways to define lung cancer stigma. The literature previously discussed internal (i.e., perceived or felt stigma) and external or enacted stigma (i.e., discrimination, intentional or not, directed at the patient and the disease by an outside source).[2] However, current research acknowledges a third type of stigma: internalized feelings of guilt or shame. The different types of stigma often interact, with perceived and external stigma intensifying internal stigma. A common example is an individual with lung cancer who has a history of smoking. This individual may experience self-blame due to perceived and actual judgment from others because of the disease's widely recognized connection to tobacco use.[3]

Lung cancer stigma has wide-ranging negative impacts at the personal, interpersonal and societal levels.[4] Stigma can result in patients delaying treatment and increased rates of depression and isolation.[4,5] Due to the harmful effects of lung cancer stigma, advocates and researchers are interested in better understanding stigma and how to address it.

From 2012-2014, the American Lung Association conducted several opinion research projects, including an online survey, focus groups and stakeholder interviews. The research aimed to assess the public's knowledge, attitudes, underlying motivations, perceptions and experiences with the issue. The



research revealed that the low awareness of lung cancer, the high lung cancer mortality rate and the disease's connection to tobacco use were main factors contributing to stigma. [6]

In the decade since the Lung Association's initial stigma report was published, there's been improvement in certain areas, but some stagnation as well, as discussed below.

Survival Rate and Awareness

Several factors which contribute to lung cancer stigma, specifically low disease awareness and high mortality, have improved over time, due to treatment advances, early detection and large awareness campaigns.[1] Despite progress in reducing stigma triggers, lung cancer stigma still continues to impact those facing the disease. A Rigney et al. (2018) decade-long analysis of public, oncologist and patient attitudes about lung cancer and stigma showed a significant increase in lung cancer awareness and stigma awareness and an

increase in treatment options. However, the study found no change in the percentage of the public reporting that patients with lung cancer are at least partially to blame for their illness (60.3% in 2018).[7] This suggests that future efforts may need to focus specifically on blame-reduction interventions to address the root of stigma.

Body of Literature

Although there has been little progress in reducing lung cancer stigma, the phenomenon is much better understood than it was a decade ago, as there has been a consistent increase in the number of professional publications addressing lung cancer stigma.[8] The number of journal articles containing the terms "lung cancer" and "stigma" increased over 20% between 2014 and 2024.

With more publications, researchers are able to analyze the growing body of lung cancer stigma literature. In 2019, Webb et al. published a scoping literature review examining perspectives of survivors on the physical, psychological and social influences of stigma. The analysis of 30 peer-reviewed studies echoed much of what was already known about lung cancer stigma: stigma is a barrier that affects the physical, mental and social well-being of those with lung cancer and negatively impacts care. However, the review also noted that, despite stigma's connection to a history of tobacco use, patients with lung cancer experience negative changes to their quality of life and mental health regardless of their tobacco-use history. The review also highlighted the compelling evidence that strong patient–provider communication is associated with decreased lung cancer stigma.[3]

Since 2014, there has also been increased development, analysis and refinement of scales measuring lung cancer stigma, including Hamann et al.'s (2018) Lung Cancer Stigma Inventory (LCSI) scale. This scale has been studied extensively and proven to be a reliable and valid tool to measure lung cancer stigma.[9] As stigma has become better measured and understood by researchers, many seek to develop evidence-based interventions to reduce it.

Evaluating Interventions

Much of the stigma literature examines the role of healthcare providers in perpetuating stigma felt by many patients. Data show that stigma is commonly experienced by patients diagnosed with lung cancer during routine cancer care and is often triggered by the provider's assessment of tobacco-use history.[10] A study by Ostroff et al. (2022) recognizes some patients feel guilt and shame when discussing their tobacco-use history even if the provider conducts the assessment in a non-judgmental way. Based on a series of qualitative interviews, Ostroff et al., published a list of Do's and Don'ts for providers to reference when discussing tobacco-use history with patients. This comprehensive list recommends providers normalize tobacco use, acknowledge the challenges of quitting tobacco and communicate in a personal and empathetic manner, among other suggestions. Examples of actions providers should avoid include blaming language, making presumptions about tobacco-use history and withholding treatment based on tobacco use. Following the guidance outlined in the research is likely to facilitate empathic, supportive and

non-judgmental communication, which may improve patient-clinician communication about smoking and could reduce stigma in the context of lung cancer care.[10]

Patient-provider communication continues to be an area of study, with a national randomized control trial by Banerjee et al. (2024) currently in progress. This trial is evaluating how training providers in empathic communication skills (ECS) translates to a reduction in lung cancer stigma.[11] The results of this study will likely inform best-practices for reducing stigma felt by patients in a medical setting and also perhaps show how counseling from a provider may be able to address a patient's internalized stigma.

Researchers are also examining stigma-reducing interventions focused on using techniques like cognitive behavioral therapy[12] and Acceptance and Commitment Therapy (ACT) with patients who are experiencing internal stigma.[13] The promise of refined evidenced-based interventions is a significant advancement in the efforts to reduce lung cancer stigma. Currently, the literature points to coordinated, interdisciplinary and well-conceptualized interventions having the potential to make an impact on reducing stigma, but more research is needed.[14]

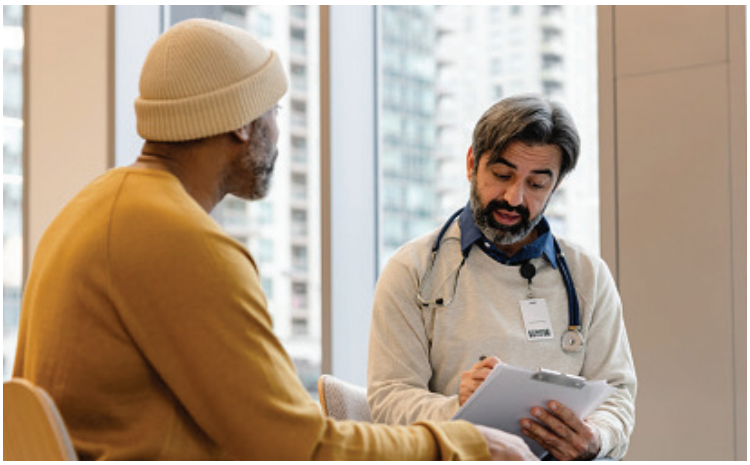
Interventions addressing societal stigma are notably absent from the literature. Considering there has been very little movement in society's view of the connection between lung cancer and personal responsibility, it may be worthwhile for researchers and organizations to collaborate on public awareness campaigns targeting the general public, like "The Wrong Question" campaign presented in Canada. This campaign addresses one of the most stigmatizing behaviors often described by people facing lung cancer, which is fielding the question: "Did you smoke?". Ideally, messaging campaigns addressing societal stigma should be evaluated in a formal manner so stakeholders have evidenced-based guidelines to follow for future messaging.

Societal stigma is often an unintended consequence of effective tobacco control policies and programs. Over 60 years ago, lung cancer became the first health risk to be conclusively linked to smoking. Since then, decades of tobacco control campaigns have been critical in saving and improving the lives of millions of people. They have also been highly successful in cementing the connection between smoking and lung cancer in the public's mind. Given the critical public health benefits of tobacco-use prevention and cessation, that link should not be minimized or downplayed. But it is important to recognize that lung cancer is often mislabeled by the general public as a disease that only impacts individuals with a smoking history. And sadly, many people think those with lung cancer have brought the diagnosis upon themselves.[6]

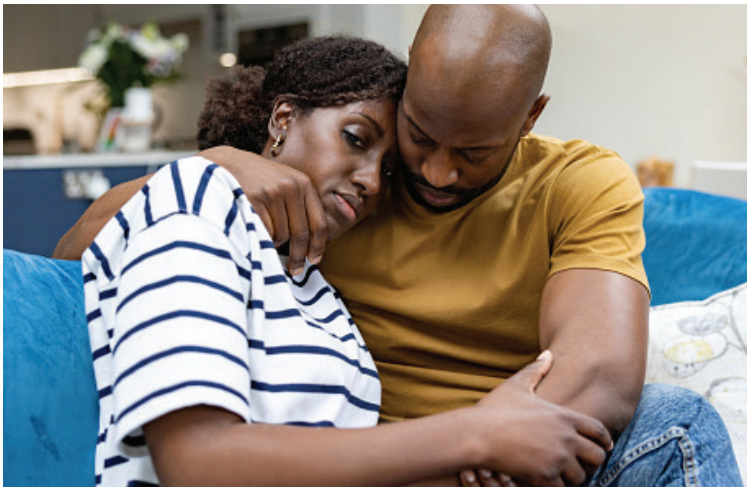
Many public health and patient advocacy organizations, including the Lung Association, are refining the way they speak about tobacco use and lung cancer. There is a need for a more concerted effort to educate the public about the risk factors of tobacco use without reinforcing blame, fear and shame.[8]

Representing a Diverse Population in Research

Although there's been an increase in lung cancer stigma literature in the past decade, certain subpopulations of patients with lung cancer are not fully represented. The literature review by Webb et al. (2019) found only 16% of



the studies they reviewed had adequate representation of patients with lung cancer who identified as Black and none featured adequate representation of those who identified as Pacific Islander or Native American.[3] Racial disparities are important to consider in stigma research, as populations not represented in research often face worse health outcomes compared to their white counterparts. One study found significant relationships between race and lung cancer stigma, specifically a higher degree of stigma among Black individuals compared to white individuals.[15]



Future studies should also include other populations often excluded in stigma research, like those with early-stage lung cancer and caregivers. Stigma studies typically focus on patients with advanced disease, whose experiences may differ from patients with earlier stage lung cancer. Because of the improved prognosis for early-stage versus advanced-stage lung cancer, one might assume patients with early-stage lung cancer do not experience as much stigma. However, one study examining a population of patients with predominantly early-stage lung cancer found that those individuals experienced lung cancer stigma at a high incidence and level similar to populations with more advanced disease.[16]

There is also significant potential for caregivers of patients with lung cancer to experience distress as a result of stigma and researchers and advocates should incorporate this into their studies and interventions.[17]

Treatment Stigma

While stigma is typically discussed in terms of a person or a disease being stigmatized, stigma may extend to perceptions of therapies used to treat lung cancer. Some lung cancer therapies may be stigmatized due to misconceptions held by certain populations. For example, the belief that "cutting" and "air" during surgery can cause cancer to spread is prevalent among some Black individuals. This belief may delay adherence to treatment and worsen health disparities.[18]

Clinical trials are another highly stigmatized part of cancer care. Many populations are not adequately represented in clinical trials, in part because clinical trial participation is often viewed as allowing oneself to be a "Guinea pig" or "test subject" for experiments. In 2021, the Lung Association launched a multi-year program called *Awareness Trust and Action (ATA)*, aimed at dispelling mistruths and misconceptions about clinical trials and providing guidance for communicating about clinical trials. Suggested interventions that emerged from the *ATA* research for addressing clinical trial stigma are similar to the emerging best practices for reducing other types of stigma and hinge on clear, empathetic and quality communication from stakeholders.

Conclusion

While lung cancer stigma is better understood today than in the past, it remains a problem with far-reaching negative effects for patients, their families and the lung cancer community at large. The community is equipped to tackle stigma as stakeholders have already collaborated on a national scale. Examples include consortiums like the National Lung Cancer Roundtable's Campaign to End Lung Cancer Stigma, which has hosted summits and produced communications guidance material, as well as The White Ribbon Project, which uses large hand-made ribbons to promote awareness about lung cancer and change public perception of the disease.

The disease's connection to tobacco use is by far the most challenging factor to confront and the main cause of stigmatizing beliefs. Despite efforts from advocates, researchers and healthcare providers to adjust language to reduce stigma when discussing both tobacco and lung cancer, the internal biases of individuals and society remain a defining aspect of the lung cancer experience for many patients. The research points to the need for coordinated, multidisciplinary, large-scale efforts to reduce stigma throughout the care continuum.[14]

However, each person has a role to play in reducing lung cancer stigma. The biggest action any one person can take is to show empathy towards someone facing lung cancer. It is important to acknowledge that discussing tobacco use in the context of lung cancer can be a sensitive topic, which should be handled with thoughtfulness and care. Stakeholders should continue to share information raising awareness of lung cancer and its many treatment options, as well as partner with advocates to continue to gather and share patient stories. Providers should be ready to address myths and misconceptions about lung cancer risk factors and treatment and make every effort to communicate in a clear, accurate and understanding way with patients and their families.

No one deserves lung cancer and every patient deserves to be treated with respect. Through small changes at the interpersonal level and large, evidence-based interventions at the institutional level, lung cancer stigma will lessen, improving the quality of life and health outcomes for those facing lung cancer.

Learn more about lung cancer stigma, including guidance for communication at Lung.org/stigma.

For more information about lung cancer, visit Lung.org/lung-cancer.

[1]American Lung Association. (2024). 2024 Lung Health Barometer. https://www.lung.org/lung-force/lung-health-barometer

[2]Hamann, H. A., Ostroff, J. S., Marks, E. G., Gerber, D. E., Schiller, J. H., & Lee, S. J. C. (2013). Stigma among patients with lung cancer: a patient-reported measurement model. Psycho-Oncology, 23(1), 81–92. https://doi.org/10.1002/pon.3371

[3]Webb, L. A., McDonnell, K. K., Adams, S. A., Davis, R. E., & Felder, T. M. (2019). Exploring Stigma Among Lung Cancer Survivors: A Scoping Literature Review. Oncology Nursing Forum. https://doi.org/10.1188/19.onf.402-418

[4]Cataldo, J. K., Jahan, T. M., & Pongquan, V. L. (2012). Lung cancer stigma, depression, and quality of life among ever and never smokers. European Journal of Oncology Nursing, 16(3), 264–269. https://doi.org/10.1016/j.ejon.2011.06.008

[5]Carter-Harris L. (2015). Lung cancer stigma as a barrier to medical help-seeking behavior: Practice implications. Journal of the American Association of Nurse Practitioners, 27(5), 240–245. https://doi.org/10.1002/2327-6924.12227

[6]American Lung Association. (2014). Addressing the Stigma of Lung Cancer. https://www.lung.org/getmedia/54eb0979-4272-4f43-be79-9bef36fab30b/ala-stigma-of-lc-2020-v1.pdf

[7]Rigney, M., Rapsomaniki, E., Carter-Harris, L., & King, J. C. (2021). A 10-Year Cross-Sectional Analysis of Public, Oncologist, and Patient Attitudes About Lung Cancer and Associated Stigma. Journal of Thoracic Oncology, 16(1), 151–155. https://doi.org/10.1016/j.jtho.2020.09.011

[8]Hamann, H. A., Williamson, T. J., Studts, J. L., & Ostroff, J. S. (2021). Lung Cancer Stigma Then and Now: Continued Challenges Amid a Landscape of Progress. Journal of Thoracic Oncology, 16(1), 17–20. https://doi.org/10.1016/j.jtho.2020.10.017

[9]Hamann, H. A., Shen, M. J., Thomas, A. J., Lee, S. J. C., & Ostroff, J. S. (2018). Development and preliminary psychometric evaluation of a patient-reported outcome measure for lung cancer stigma: The Lung Cancer Stigma Inventory (LCSI). Stigma and Health, 3(3), 195–203. https://doi.org/10.1037/sah0000089

[10]Ostroff, J. S., Banerjee, S. C., Lynch, K., Shen, M. J., Williamson, T. J., Haque, N., Riley, K., Hamann, H. A., Rigney, M., & Park, B. (2022). Reducing stigma triggered by assessing smoking status among patients diagnosed with lung cancer: De-stigmatizing do and don't lessons learned from qualitative interviews. PEC Innovation, 1, 100025. https://doi.org/10.1016/j.pecinn.2022.100025

[11]Banerjee, S. C., Malling, C. D., Schofield, E. A., Carter-Bawa, L., Bylund, C. L., Hamann, H. A., Parker, P. A., Shen, M. J., Studts, J. L., Williamson, T. J., & Ostroff, J. S. (2024). Empathic communication skills training to reduce lung cancer stigma: Study protocol of a cluster randomized control trial. Contemporary Clinical Trials, 145, 107669. https://doi.org/10.1016/j.cct.2024.107669

[12]Chambers, S. K., Morris, B. A., Clutton, S., Foley, E., Giles, L., Schofield, P., O'Connell, D., & Dunn, J. (2014). Psychological wellness and health-related stigma: a pilot study of an acceptance-focused cognitive behavioural intervention for people with lung cancer. European Journal of Cancer Care, 24(1), 60–70. https://doi.org/10.1111/ecc.12221

[13]Kaplan, D. M., Hamann, H., Price, S. N., Williamson, T. J., Ver, E. S., McConnell, M. H., Duchschere, J. E., Garland, L. L., & Ostroff, J. S. (2022). Developing an ACT-based intervention to address lung cancer stigma: Stakeholder recommendations and feasibility testing in two NCI-designated cancer centers. Journal of Psychosocial Oncology, 41(1), 59–75. https://doi.org/10.1080/07347332.2022.2033377

[14]Hamann, H. A., Ver Hoeve, E. S., Carter-Harris, L., Studts, J. L., & Ostroff, J. S. (2018). Multilevel Opportunities to Address Lung Cancer Stigma across the Cancer Control Continuum. Journal of Thoracic Oncology, 13(8), 1062–1075. https://doi.org/10.1016/j.jtho.2018.05.014

[15]McDonnell, K. K., Webb, L. A., Adams, S. A., Felder, T. M., & Davis, R. E. (2022). The association between lung cancer stigma and race: A descriptive correlational study. Health Expectations, 25(4). https://doi.org/10.1111/hex.13495

[16]Bédard, S., Sasewich, H., Culling, J., Turner, S. R., Pellizzari, J., Johnson, S., & Bédard, E. L. R. (2022). Stigma in Early-Stage Lung Cancer. Annals of Behavioral Medicine. https://doi.org/10.1093/abm/kaac021

[17]Occhipinti, S., Dunn, J., O'Connell, D. L., Garvey, G., Valery, P. C., Ball, D., Fong, K. M., Vinod, S., & Chambers, S. (2018). Lung Cancer Stigma across the Social Network: Patient and Caregiver Perspectives. Journal of Thoracic Oncology: Official Publication of the International Association for the Study of Lung Cancer, 13(10), 1443–1453. https://doi.org/10.1016/j.jtho.2018.06.015

[18]DeLisser, H. M., Keirns, C. C., Clinton, E. A., & Margolis, M. L. (2016). "The Air Got to It:" Exploring a Belief About Surgery for Lung Cancer. Journal of the National Medical Association, 101(8), 765–771. https://doi.org/10.1016/S0027-9684(15)31004-X

About the American Lung Association

The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research. The work of the American Lung Association is focused on four strategic imperatives: to defeat lung cancer; to champion clean air for all; to improve the quality of life for those with lung disease and their families; and to create a tobacco-free future. For more information about the American Lung Association, which has a 4-star rating from Charity Navigator and is a Platinum-Level GuideStar Member, call 1-800-LUNGUSA (1-800-586-4872) or visit: Lung.org. To support the work of the American Lung Association, find a local event at Lung.org/events.

The report was authored by Carly Ornstein, MPH.

American Lung Association.

National Office | 55 W. Wacker Drive, Suite 1150 | Chicago, IL 60601
Ph: 312-801-7630 | Lung HelpLine 1-800-LUNGUSA | Lung.org