

Stigma and lung disease

What we can do

CHRISTINE JENKINS AM, MB BS(Hons II), MD, FRACP

Stigma towards people with lung disease makes a major contribution to delay in diagnosis and affects the psychological health and level of care received by patients. Making assumptions about a diagnosis based on smoking as the only risk factor affects the health and wellbeing of patients.

Lung disease affects one in three Australians and one in seven deaths is a result of lung disease.^{1,2} Health professionals need to be aware of the symptoms of lung disease and the incidence of people presenting both with and without risk factors. About one-fifth (21%) of people with lung cancer are lifelong nonsmokers (Box 1).³ To this end, Lung Foundation Australia offers training and resources for health professionals to ensure best-practice diagnosis, treatment and care for their patients (Box 2). Lung disease has never been a simple issue, and it is Lung Foundation Australia's belief that widespread negative attitudes and social stigma surrounding people with lung disease are significant barriers to improving outcomes.

In 2017, Lung Foundation Australia commissioned a nationally-representative survey to learn more about the stigma associated with lung cancer in particular, as well as lung disease generally, and to gain a deeper understanding of the key issues facing the patient and carer communities.⁴

RESPIRATORY MEDICINE TODAY 2018; 3(2): 26-29

Professor Jenkins is the Chair of Lung Foundation Australia, Sydney; Head of the Respiratory Group, The George Institute for Global Health, Sydney; Professor of Respiratory Medicine, UNSW Sydney, Sydney; Senior Staff Specialist in the Department of Thoracic Medicine, Concord Hospital, Sydney; and Head of the Respiratory Discipline at The University of Sydney, Sydney, NSW.



Key points

- Stigma affects the psychological health of people with lung disease.
- Early diagnosis is key: GPs need to be alert to symptoms of lung disease to ensure timely referrals are made.
- Making assumptions based only on the presence or absence of smoking is a risk for delaying diagnosis or making an incorrect diagnosis.

Stigma and lung cancer

The survey results showed that more than one-third of Australians (35%) consider that people living with lung cancer are 'their own worst enemy' and 'have only themselves to blame'. One in 10 Australians believe that those with lung cancer 'got what they deserved', were 'disgusting' and 'filthy'. Further, despite one in three women and one in 10 men diagnosed with lung cancer having no history of smoking, the first question almost 40% of Australians would ask someone diagnosed with lung cancer – without first expressing concern – is whether they were a smoker.^{4,5} Almost 90% of Australians believe smoking is the only lung cancer risk factor, despite other proven links including genetics, pollution and occupational exposure, for example.⁴ The survey also revealed that 35% of Australians would not speak out if they were diagnosed with lung cancer because of fear of judgement, or at least were uncertain about whether they would disclose their diagnosis. These findings mirrored results found in a global survey conducted in 15 developed

1. Lung cancer symptoms³

Lung cancer symptoms can be vague and the disease is often found when it is in an advanced stage. Symptoms include:

- cough (new, persistent or changed)
- coughing up blood
- breathlessness
- fatigue
- chest pain
- weight loss
- hoarse voice
- recurrent or slowly resolving lower respiratory tract infections

countries. Of all populations measured, Australians had the least sympathy for someone diagnosed with lung cancer compared with other cancers, based on its association with tobacco smoking (Figures 1 and 2).⁴⁻⁶

The individual impact of these prevailing negative attitudes is well documented. Patients with lung cancer delay seeking help, stop treatment early and experience significant psychological and social consequences.⁷ Lung cancer patients, more so than patients with other cancers, feel stigmatised by their disease, increasing their subjective distress and negatively influencing help-seeking behaviours and overall patient outcomes (Box 3).⁵

2. Lung Foundation Australia – who we are

Lung Foundation Australia is a peak body and first point of call working to support anyone living with a lung disease. Our mission is to improve lung health and reduce the impact of lung disease for all Australians by:

- driving community awareness about lung health
- funding world class, life-changing research
- advocating for patients to have equitable access to care and treatment
- providing information and support for patients
- facilitating best-practice training and education for health professionals.

We work across all areas of lung disease with a particular focus on lung cancer, chronic obstructive pulmonary disease, bronchiectasis, idiopathic pulmonary fibrosis, pulmonary arterial hypertension and rare lung disease in children.

We offer a range of support services and evidence-based resources that reinforce best practice and empower patients with lung disease to take an active role in their health.

For more information, go to our website (www.lungfoundation.com.au) or contact Lung Foundation Australia's Information and Support Line via freecall 1800 654 301.

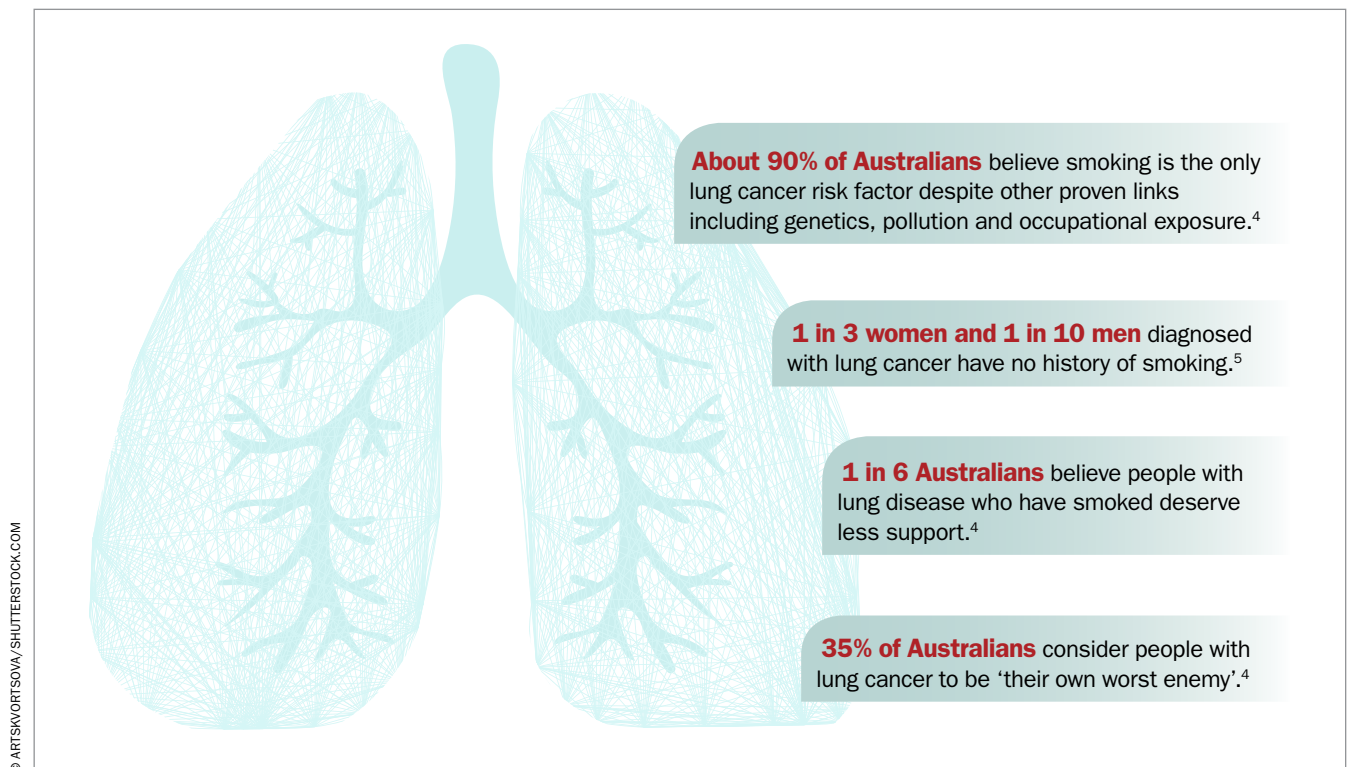


Figure 1. Lung disease in Australia: key statistics.^{4,5}

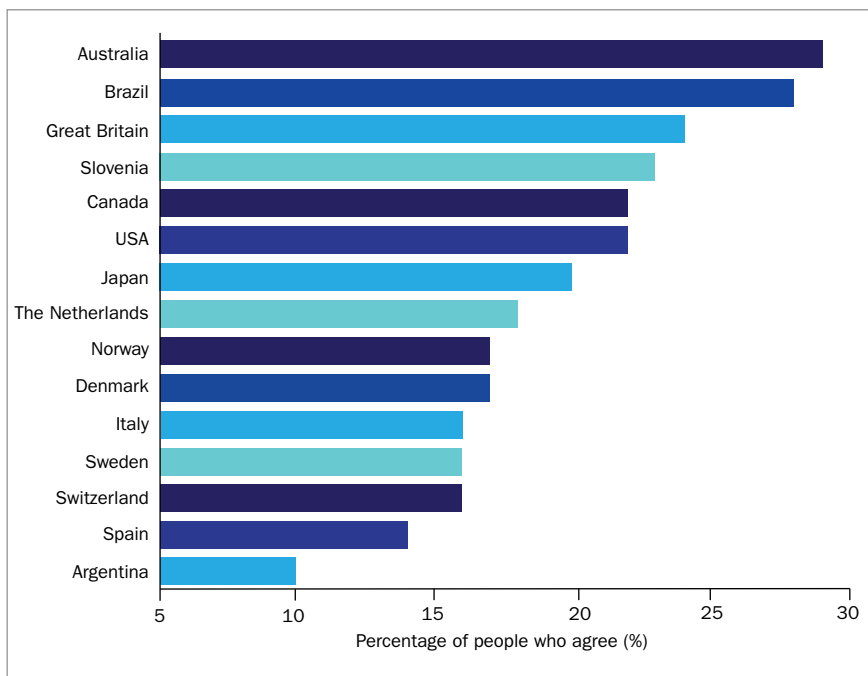


Figure 2. Proportions of populations in 15 developed countries who had less sympathy for people with lung cancer than people with other types of cancer, after being asked: ‘Lung cancer is mainly caused by smoking cigarettes and other tobacco products. Bearing this in mind, do you agree or disagree with the following statement: “I have less sympathy for people with lung cancer than people with other types of cancer”?’

Adapted from Global perceptions of lung cancer. An Ipsos MORI report for the Global Lung Cancer Coalition.⁶

Healthcare providers’ attitudes can be as negative as those of patients, caregivers and the general public.⁸ Clinicians tend to underestimate the survival rates for different stages of lung cancer and the likely benefits of chemotherapy.^{5,9} This is a rapidly evolving therapeutic area; in recent years highly effective treatments have become available and it can be difficult to stay up to date with the latest advancements. An Australian study showed 11% of patients diagnosed with lung cancer did not see a lung cancer specialist and as

many as 33% did not receive cancer-specific treatment after the initial diagnosis.¹⁰

A recent systematic review found that lung cancer patients consistently reported health-related stigma, and stigma was related to poorer psychological and quality of life outcomes as well as fears that medical treatment may be futile or even denied.⁷ To date there is little research exploring the barriers to optimal lung cancer care in Australia. However, one Australian study found beliefs among primary care physicians that

nonsmokers with lung cancer were more worthy of sympathy; that delays in treatment occur from the investigation of differential diagnoses; and that anti-tobacco messaging highlighting lung cancer deterred smokers from seeking medical advice.¹¹ In late October 2018, Lung Foundation Australia will release a comprehensive research report that delves further into the issues of stigma, equity of access and psychosocial support to reveal the true burden and impact of lung cancer in Australia.

3. A patient’s perspective: Ms TN’s story*

‘I had many months of coughing leading to the diagnosis. Because it was in episodes triggered by cold and stress, it behaved very much like an asthma attack. For months I wrote it off as just something to do with postviral bronchitis. Then I saw a GP and my chest x-rays were completely normal, so that led to a little bit more of a delayed diagnosis for me. It wasn’t until three months later when I saw my specialist who, on hearing my story, didn’t think it was likely to be cancer either until he saw the cancer on chest CT scans. He too was shocked and phoned me straight away to arrange a biopsy. By that time, my cancer had spread to my lymph nodes, my bones and my liver. I had spent months thinking I had asthma when in fact I had this lung cancer growing in me. At the time of getting that chest x-ray, if I was more aware of how possible and plausible it is for someone who has never smoked to have a high risk of lung cancer, I probably would have pushed for my CT scan earlier.’

* Name has been changed.



© DIGITALSKILLET/ISTOCKPHOTO.COM · MODEL USED FOR ILLUSTRATIVE PURPOSES ONLY

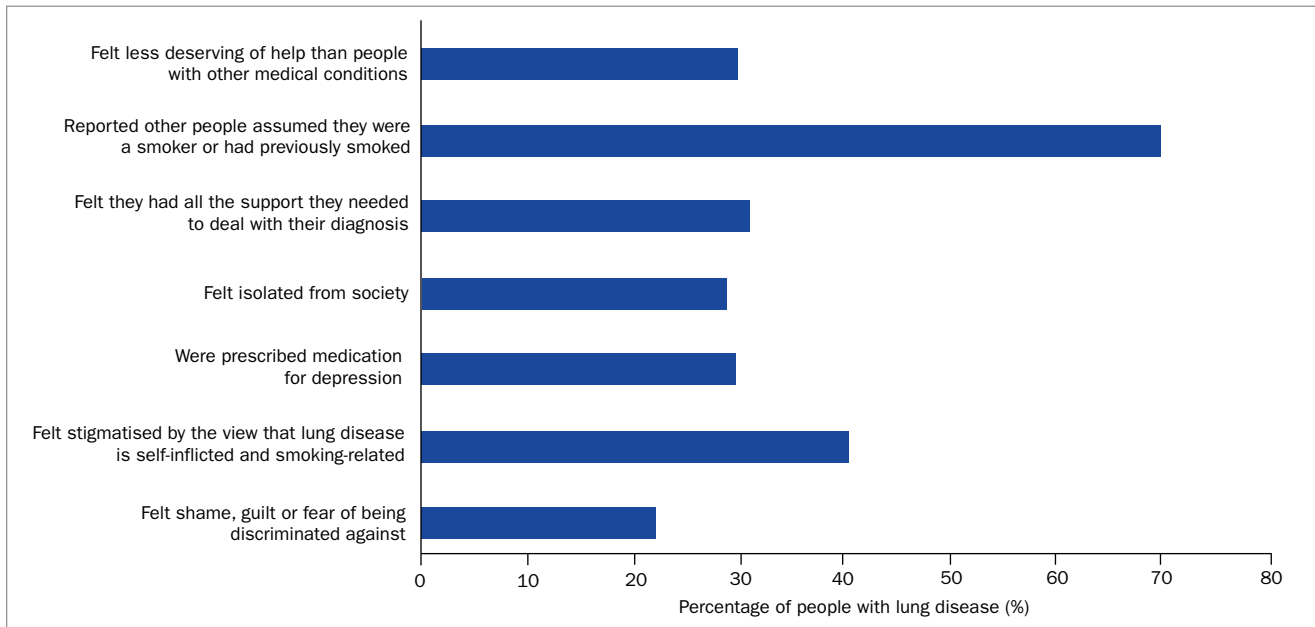


Figure 3. Lung Foundation Australia patient survey results 2017.⁴

Reproduced with permission from Lung Foundation Australia.

Stigma is a broader issue in lung disease

The issue of stigma is not isolated to lung cancer; it is felt by patients with all lung diseases. The 2017 Lung Foundation Australia survey found that 30% of patients with lung disease felt less deserving of help than people with other medical conditions and 70% said other people assumed they were a smoker or had previously smoked (Figure 3).⁴

Stigma in lung disease does not only affect patients and hinder the efforts of clinicians; it translates into a lack of action in public policy, research and advocacy. For example, on the basis of the level of research funding directed to specific tumour types, lung cancer is clearly underfunded. Despite causing almost 20% of all cancer deaths in Australia (more than breast, prostate and ovarian cancer combined) lung cancer received only 5% of the total funding measured by the Australian Institute of Health and Welfare from 2009 to 2011. This compared with 14% for colorectal cancer, 13% for prostate cancer and 26% for breast cancer.⁵

Conclusion: what we can do

Early diagnosis is key to improving survival rates for people with lung disease, and GPs

play a central role in ensuring all Australians, despite their smoking history, receive equitable care and treatment. GPs should be alert to symptoms of lung disease to ensure timely referrals are made for diagnosis and treatment services.

RMT

References

1. Poulos LM, Correll PK, Toelle BG, Reddel HK, Marks GB. Lung disease in Australia. Sydney: Woolcock Institute of Medical Research; 2014. Available online at: https://lungfoundation.com.au/wp-content/uploads/2014/10/LUNG-DISEASE-IN-AUSTRALIA-REPORT_Final_22October14.pdf (accessed September 2018).
2. Australian Institute of Health and Welfare (AIHW). Chronic respiratory conditions. Canberra: AIHW; 2016. Available online at: www.aihw.gov.au/chronic-respiratory-conditions (accessed September 2018).
3. Cancer Australia. Risk factors for lung cancer: an overview of the evidence. Sydney: Cancer Australia; 2014. Available online at: https://canceraustralia.gov.au/system/tdf/publications/risk-factors-lung-cancer-overview-evidence/pdf/2014-risk_factors_for_lung_cancer_an_overview_final_lr.pdf?file=1&type=node&id=4062 (accessed September 2018).
4. Lung Foundation Australia (LFA). PureProfile consumer survey. Brisbane: LFA; 2017.
5. Lung Foundation Australia (LFA). Improving outcomes for Australians with lung cancer: a call to action. Brisbane: LFA; 2016. Available online at: <https://lungfoundation.com.au/wp-content/uploads/2016/08/LFA-improving-outcomes-report-0816-proof10.pdf> (accessed September 2018).

6. Ipsos MORI. Global perceptions of lung cancer. An Ipsos MORI report for the Global Lung Cancer Coalition. London: Ipsos MORI; 2011.
7. Chambers SK, Dunn J, Occhipinti S, et al. A systematic review of the impact of stigma and nihilism on lung cancer outcomes. *BMC Cancer* 2012; 12: 184.
8. Sriram N, Mills J, Lang E, et al. Attitudes and stereotypes in lung cancer versus breast cancer. *PLoS ONE* 2015; 10: e0145715.
9. Jennens RR, de Boer R, Irving L, Ball DL, Rosenthal MA. Differences of opinion: a survey of knowledge and bias among clinicians regarding the role of chemotherapy in metastatic non-small cell lung cancer. *Chest* 2004; 126: 1985-1993.
10. Vinod SK, O'Connell DL, Simonella L, et al. Gaps in optimal care for lung cancer. *J Thorac Oncol* 2008; 3: 871-879.
11. Scott N, Crane M, Lafontaine M, Seale H, Currow D. Stigma as a barrier to diagnosis of lung cancer: patient and general practitioner perspectives. *Prim Health Care Res Dev* 2015; 16: 618-622.

COMPETING INTERESTS: None.

Don't miss

Complexities in managing obesity in COPD on page 15