

Lung Cancer Stigma across the Social Network: Patient and Caregiver Perspectives



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ABSTRACT

Objective: To examine the personal experiences of people with lung cancer and their caregivers and how stigma is manifested throughout a patient's social network.

Methods: A qualitative thematic analysis of interviews with 28 patients with lung cancer and their caregivers was conducted. Telephone interviews were conducted and transcribed verbatim. Data analysis was guided by contemporary stigma theory.

Results: Patients and caregivers reported feeling high levels of felt stigma and concomitant psychological distress in response to the diagnosis of lung cancer. Three overarching themes emerged: the nexus of lung cancer and smoking, moralization, and attacking the link between lung cancer and smoking. Stigma was inevitably linked to smoking, and this formed the hub around which the other themes were organized. Caregivers reported feeling invisible and noted a lack of support systems for families and caregivers. In addition, there was evidence that caregivers experienced stigma by association as members of the patients' close networks. Both groups responded ambivalently to stigmatizing antismoking advertisements.

Conclusions: The qualitative analysis demonstrated the complex interplay of the social and personal domains in the experience and outcomes of stigma in lung cancer. There

is a significant potential for caregivers of patients with lung cancer to experience exacerbations of psychosocial distress as a consequence of widely shared negative views about lung cancer and its prognosis. It remains for researchers and practitioners to incorporate such complexity in addressing stigma and psychosocial distress in both patients and caregivers.

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Keywords: Lung cancer; Oncology; Stigma; Psychological distress; Patients; Caregivers

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Introduction

In Australia lung cancer is the fifth most commonly diagnosed cancer, with an estimated 12,434 new cases in 2017,¹ and the prevalence projected to rise in the future.² Although age-standardized incidence and mortality rates have decreased steadily for men, they have increased for women, who will represent 40% of new cases in 2017.¹ The increase of lung cancer in women has seen it overtake breast cancer as the most significant cancer, yet the advocacy and support for lung cancer has yet to catch up. Contrary to the improved survival outcomes for many cancers, the prognosis for people in whom lung cancer has been diagnosed remains poor, with 5-year relative survival rates of 14% for men and 19% for women for the period 2009–2013.¹ The most common cause of lung cancer is smoking, with occupational carcinogens also implicated.³ People with lung cancer report higher levels of psychological distress, greater unmet needs, and a greater risk of suicide than do other patient groups. Up to 62% of patients with lung cancer report significant psychological distress⁴; for many, this distress does not ameliorate over time, and indeed, it may worsen.⁵ Patients with lung cancer have a rate of suicide (81.7 per 100,000 person-years) that is up to eight times higher than the rates of those with other cancers such as breast, prostate, and colorectal cancer and almost five times the rate of the general population.⁶ Adding to this picture, patients with lung cancer, more so than patients with other cancers, feel stigmatized owing to their disease, and this feeling of stigmatization increases their psychological distress.⁷

Stigma may be an unintended outcome of public health programs concentrating on reducing rates of smoking to combat the incidence of lung cancer. Mass media advertising emphasizes smoking's health risks, including the risk of lung cancer. The ensuing stigmatization of smokers is regarded as a motivator for behavior change.^{8–10} In Australia, federal and state governments have mandated increasing levels of graphic and potentially stigmatizing health warnings on cigarette packets, culminating in 2012 with plain packaging of cigarettes and a large proportion of the packet covered by a graphic image, such as that of a diseased lung. Smoke-free workplace laws have further marginalized smokers. Thus, researchers argue that an ethical burden exists to address the disproportionate experience of stigma among patients with lung cancer that is associated with negative sequelae, such as treatment deferral and increased distress.^{11,12} A deeper examination of the stigma construct is required to understand the complex associations between the stigma of lung cancer and psychosocial outcomes.

In recent years, since Erving Goffman's¹³ preeminent contributions, the concept of stigma has undergone

considerable theoretical refinement¹⁴ from both sociological perspectives,¹⁵ emphasizing a stigmatized identity within a given social context and sociopsychological contexts,^{16,17} focusing on individual responses to stigmatized identities. Contemporary accounts of stigmatizing processes emphasize group identities and are based in the differential power relations accompanying stigma. From a contemporary perspective, stigma can accrue both to the person who is a member of a marked category (e.g., a patient with lung cancer) and to that person's immediate familial networks (i.e., stigma by association¹⁸). Stigma may be manifest in several experiential forms that are often grouped under the term *enacted* or *felt* stigma.^{14,19} Patients with lung cancer and their caregivers may perceive being devalued by others, may anticipate negative affect and discriminatory behavior, and may even endorse (or internalize) such stigma themselves. Not surprisingly, such stigma is associated with treatment delay and other maladaptive outcomes.^{7,20}

Although previous studies of stigma in lung cancer have provided valuable insights into experiences at the level of the individual patient,²¹ examinations of the stigma of lung cancer have yet to incorporate a genuinely multilevel perspective that considers multiple facets of the patient's familial and social networks. Researchers have increasingly recognized the important role that close family members (often, significant others) play in providing tangible and emotional support and in their connections with patients across the cancer journey, which although not clearly defined, is often termed *informal caregiving*.²² This work also highlights the high emotional and financial costs and notes the particular challenges of caregiving in lung cancer. Caregivers are recognized to be a vulnerable population that in providing crucial psychosocial support, are at risk of increased psychological distress and other unmet needs.²³

These phenomena require rigorous examination. However, existing quantitative measures of stigma may not be sufficiently sensitive for this purpose. Instead, qualitative analysis of fewer participants in great depth may allow stronger, more stable conclusions. Qualitative analysis gains rigor when it is performed, as in the present case, under the guidance of well-defined theory associated with a coherent body of empirical results. A recent review⁷ found that qualitative studies of lung cancer stigma had suffered from a lack of a clear theoretical model of stigma. To enhance rigor and stability, researchers first identify theoretically consistent patterns or themes that appear consistently across participants and then collect illustrative individual utterances, often comparing and adjusting classification iteratively.

To avoid excessive subjectivity, the members of the research team undertake different roles and provide independent validation of each other's perspectives. Qualitative analysis responds to the depth and richness of responses and plays an important role in advancing theory and models (see Fig. 1) and seeding later empirical work, such as by identifying the important themes that can be targeted by later interventions.

Accordingly, in the present study, the personal experiences of patients with lung cancer and their caregivers were examined to address the central research objective of examining the nature of the stigma experienced by patients with lung cancer and their caregivers. An integral aspect involves the extent of the role that beliefs about smoking play in stigmatizing processes. In turn, perceptions of the role of smoking as a visible mark of lung cancer are central to the integration of the different facets of analysis.

Material and Methods

The sample consisted of 28 participants (18 female and 10 male, including 16 patients with lung cancer and 12 caregivers) who were recruited from clinical and support group networks in Australia. Participants were interviewed individually in Queensland between April and June 2012. All gave written informed consent to participate in recorded, open-ended, in-depth interviews. Purposive maximum variation sampling was used to select participants to ensure a range across sex, age, and cultural groups. In keeping with standard approaches in thematic analysis, interviews ceased when saturation was evident and no new themes in the data could be discerned. At this point, it was considered unethical to continue to

prevail upon participants to take part in further interviews. Demographic characteristics are listed in Table 1. The time since diagnosis ranged from 5 to 60 months (median 40 months). Of those patients with a known disease stage, two had stage II lung cancer, three had stage IIIA, one had stage IIIB, and two had stage IV. Four patients had had an operation, two had received radiation, two had undergone chemotherapy, and eight had been given a combination of the three treatments. Smoking status was not collected, as it was accepted that asking a person with lung cancer whether they smoke is seen to be a stigmatizing question.

Two experienced female interviewers conducted the interviews, mostly by telephone, with three face-to-face interviews conducted in a public place of the participant's choosing. Interviewers were provided with an interview guide (see the Appendix). Interviews were largely unstructured in form, and all questions were open-ended to avoid leading participants to particular responses. Patients or caregivers were first prompted to tell their story from what they perceived as the beginning of their cancer journeys. Then, open questions not mentioning stigma were posed; these open questions focused on experiences with other people, physicians and the health system, and media advertisements. All interviews were digitally audio recorded and transcribed verbatim for analysis (the average patient interview lasted 53.09 minutes, and the average caregiver interview lasted 39.85 minutes). Ethical approval for the project was provided by Griffith University.

Specific phases of thematic analysis²⁴ were followed (see the Consolidated Criteria for Reporting Qualitative Studies²⁵ checklist [Appendix Table 1]). Two coders (S. O. and S. C.) who had not conducted any interviews

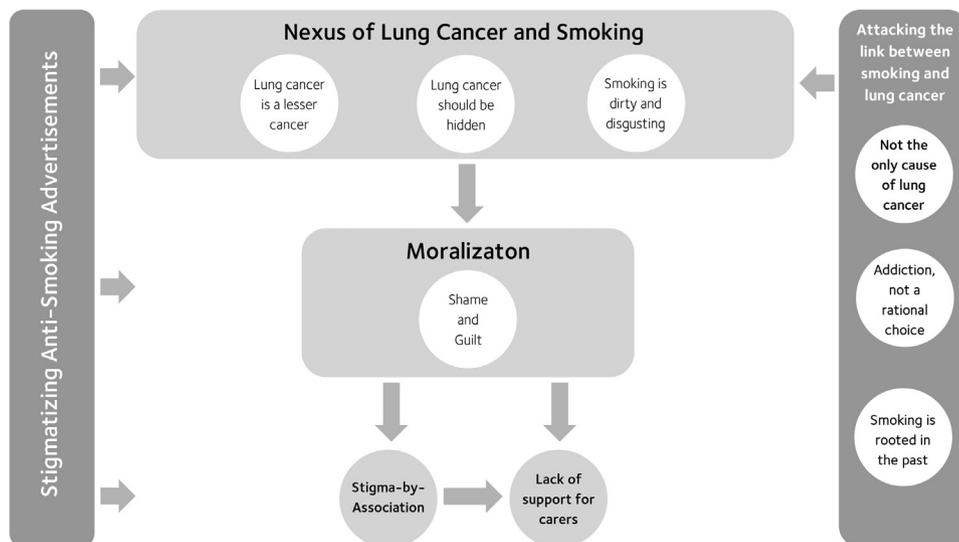


Figure 1. Model of themes underlying patients and carers transcripts.

Table 1. Demographic Characteristics of the Patients and Caregivers

Characteristics	Patients (n = 16)		Caregivers (n = 12)	
	n	%	n	%
State				
Queensland	10	62.5	7	58.3
New South Wales	6	37.5	4	33.3
Victoria	0	0.0	1	8.3
Sex				
Male	7	43.7	3	25.0
Female	9	56.3	9	75.0
Age group, y				
30-39	0	0.0	1	8.3
40-49	0	0.0	2	16.7
50-59	1	6.3	1	8.3
60-69	12	75.0	6	50.0
70-79	3	18.8	2	16.7
Indigenous status				
Yes	2	12.5	2	16.7
No	12	75.0	10	83.3
Unknown	2	12.5	0	0.0
Highest completed year of school education				
Year 12 or equivalent	7	43.7	4	33.3
Year 11 or equivalent	0	0.0	1	8.3
Year 10 or equivalent	3	18.8	6	50.0
Year 9 or equivalent	1	6.3	1	8.3
Year 8 or less	3	18.8	0	0.0
Missing	2	12.5	0	0.0
Highest level of education completed				
University or college degree	3	18.8	1	8.3
Postgraduate qualifications	2	12.5	4	33.3
Trade or technical certificate or diploma	2	12.5	2	16.7
No higher education qualifications	7	43.7	5	41.7
Missing	2	12.5	0	0.0

read all transcripts independently, and once they had become familiar with the data, they generated an initial codification of interesting features of the data. Another author (J. D.) independently validated the coding scheme. Separate lists of themes were then created by the two coders (S. O. and S. C.), compared, and modified when necessary to achieve consistency. A single set of themes was then applied to the transcripts by one of the coders (S.O). Analysis was done by marking up hard copies of the transcripts without the use of any computer software.

Data analysis was guided by contemporary stigma theory.^{14,15,17,26} Although there is no one single model that can be regarded as representing the sum of stigma theory, there is a broad core of overlapping constructs¹⁴ that cover the basis of stigma as defined by the original work of Goffman¹³ and Allport.²⁷ In this view, as already

described, the stigmatized person belongs to a class of people who are distinguished by a mark or taint that sets them apart from so-called normal people. The consequences of carrying the stigmatizing mark include devaluation and discrimination in different forms. As there is already evidence of the stigma felt by patients with lung cancer and its relationship to smoking⁷ and evidence that an inductive model of stigma based on Goffman's work can explain the experiences of patients with lung cancer,¹⁹ we expected to find reports of enacted stigma from our multilevel sample of patients with lung cancer and their caregivers. However, as the primary research question concerned the nature of the underlying components of stigma and the relationships between them, we did not use the definitions of enacted stigma to guide the development of the themes; rather, we proceeded inductively within the theoretical constraints already discussed.

The primary method used to analyze the transcripts was qualitative thematic analysis,²⁴ in which researchers seek and interpret concepts and themes across responses. Although there are many approaches to thematic analysis, we focused on identifying themes occurring across the responses of all the participants collectively. We did so inductively but guided by stigma theory and previous evidence regarding stigmatization in lung cancer. Unlike in grounded theory,²⁸ themes were not completely emergent,²⁹ but neither were they simple reflections of the questions put to participants. The aim of the analysis was not to describe a set of themes but rather to draw them together into a coherent model of stigma in lung cancer survivors and caregivers, as represented across multiple levels of analysis.

Results

Overview of themes

The complete set of themes that were derived from the transcripts are presented in Table 2. Figure 1 shows a model of the process by which the emergent themes give rise to stigma and its consequences. In this model, three overarching themes, which are discussed in later in this article, connect perceptions of lung cancer and smoking: (1) the perceived nexus of lung cancer and smoking, (2) the moralization of lung cancer and smoking, and (3) attacking the links between lung cancer and smoking.

According to Figure 1, the nexus between lung cancer and smoking gives rise to emotions such as disgust, which produce moral responses to lung cancer such as shame and guilt. In turn, moralization of smoking and lung cancer cue stigma by association, incorporating both patients and caregivers and ultimately leading to perceptions of low support offered to caregivers as members

Table 2. Themes underlying patient and caregiver responses regarding the stigma of lung cancer

Theme/Subtheme	Illustrative Quotes
The nexus of lung cancer and smoking	<p>“I think that they think that anybody with anything like that, it’s either smoking or asbestos. That must be the general attitude of what people think ... a lot of people, as soon as I say that—were you a heavy smoker? And I haven’t had a smoke for 40 years.” (patient 112)</p> <p>“You’re a smoker. They think—yeah, I think the first thing came to mind is you are a heavy smoker.” (caregiver 143)</p>
Smoking per se is a dirty and disgusting act	<p>“Some people look at cigarette smoking as a dirty, filthy habit, which I agree, and others give up smoking and they think it’s disgusting to see anyone.” (patient 147)</p>
Lung cancer should be hidden from others	<p>“But I don’t make a point of telling anybody I’ve got lung cancer.” (patient 111)</p> <p>“But the lung cancer was—I think probably I was a little bit reticent about saying anything to anybody about it.” (patient 153)</p>
Lung cancer is a lesser cancer	<p>“There are always campaigns for say breast cancer, and or leukemia, or and so forth. But there really isn’t one to solve lung cancer that I know of.” (patient 005)</p> <p>“They get pink, warm, and fuzzy about breast cancer, but there is nothing pink and warm and fuzzy about lung cancer, and people tend to think of it as it’s a nasty cancer. Nasty because it’s from a—it has come from a nasty habit that you have.” (patient 153)</p>
Moralization	
Lung cancer is a source of shame and guilt	<p>“It makes me feel like, ashamed and probably, if I could go back and change my life, I would.” (patient 010)</p> <p>“But I don’t—I don’t change the channel, I look at it and I just think dear me, look what I’ve done. You know, because—see because they can’t get to it.” (patient 142)</p>
Stigma by association	<p>“It’s hard to have to carry that burden of people judging you as well.” (caregiver 013)</p>
Lack of support for caregivers	<p>“So it was probably about 4 months before I actually told him what I was doing. I never thought for 1 minute that he wouldn’t want me to be part of it, but I also didn’t want him to become emotional over the fact that I was having so much difficulty because I was really supposed to be supporting him, not falling apart myself. So I was hiding it a bit from him.” (caregiver 023)</p> <p>“No support for me at all. Zero, I would say. I don’t think anyone has ever in the whole process asked me how I was coping with it—not at the hospital, not even when mum goes to see her physician every 3 months or 5 months. No. ... Like we don’t count. Like people don’t think that we’re affected by it. That we don’t matter.” (caregiver 146)</p>
Attacking the link between smoking and lung cancer	
Smoking is not the only cause of lung cancer	<p>“But they still think, ‘Oh, smoking.’ And I don’t think mine was smoking, I think mine was through mold.” (patient 018)</p> <p>“Like all the ads on TV tell you that if you’re a smoker, you risk getting lung cancer. They don’t sort of come on the TV and say, ‘Well if you inhale fertilizer or chemical or something, then you could get lung cancer.’ The only thing we hear about is smoking.” (caregiver 021)</p>
Smoking is a reflection of addiction and is more like a powerful illicit drug than a rational choice-driven behavior	<p>“If you are a smoker and you have to have that next cigarette or whatever it is you’re having.... Because it’s your problem, it’s your addiction.” (caregiver 023)</p> <p>“They don’t stop, do they? Drugs, they don’t stop. They just keep going. Well, smoking is a drug, really.... Bad drug, really. And I find out, like even when you get off it, you still feel like it.” (patient 156)</p>
Smoking is an act rooted in the past, which, in turn, represents qualitatively distinct rules and norms from the present	<p>“Years ago, the warnings weren’t out like they are now.” (patient 147)</p> <p>“In his day when he... went to work at a young age.... The culture was to work hard and smoking was part of the culture then. They weren’t telling you that smoking was bad for your health, they were promoting it as being a cool thing.... Before that, people in World War II, they were all given cigarettes by the government, to help them, it was a means of helping them with stress.” (caregiver 013)</p> <p>“But, at the time, we didn’t know, did we?” (caregiver 145)</p>
Stigmatizing advertisements linked to lung cancer are welcomed by some but seen as harsh and unnecessarily distressing by others	<p>“I can’t watch them.... I just have to turn away.... I honestly don’t know whether they would do any good.” (patient 144)</p> <p>“I’m all for them.... The stronger the better. The message is getting across, although maybe it’s getting across to people like me and people I know that don’t smoke anyway, which isn’t all that useful.” (caregiver 004)</p>

of the patients’ networks. In parallel, stigmatization also leads to beliefs that weaken the initial connection between lung cancer and smoking. The model itself is set against the context of stigmatizing antismoking advertisements that provide background for the expression of ideas regarding lung cancer and stigma.

Further to this model, an overarching idea is that the expression of stigma was very similar across patients themselves and caregivers. Many caregivers described being seamlessly connected with the lung cancer journey. Caregivers’ transcripts were certainly not lacking in examples of enacted stigma.

The Nexus of Lung Cancer and Smoking

The central hub around which most of the other themes radiated was that perceptions about lung cancer and smoking are powerfully intertwined. For example, caregiver 152 reported a stigmatizing communication between a patient and her brother as follows: “Even when mum told her brother, he said that she’d had lung cancer—he said, ‘Well, that’s all those smokes that you’ve smoked,’ and things like that.”

Many participants, unprompted, described laypeople instantly and inevitably associating lung cancer with current or prior smoking and stated further that this connection arose automatically, especially in those of more distant acquaintance, when the subject of the patient’s lung cancer first came up. For example, patient 144 stated, “Because, you can just feel it... Because it’s the very first thing people ever ask you, ‘Did you smoke?’”

Subthemes involved stigmatizing attributes of lung cancer as a lesser cancer and one that should be hidden and smoking as a dirty and disgusting act *per se*. Patient 153 was particularly specific about the connection between smoking and lung cancer: “It’s a nasty cancer. It has come from a nasty habit that you have.”

Participants often noted how lung cancer was routinely hidden from the knowledge of others, especially those who were not close to the participant. Patient 111 stated the following:

I don’t get around saying to everybody, “Oh, I’ve got lung cancer.” If I feel a bit puffed out and I’m walking up stairs, somebody might say “Are you okay?” and I say, “Oh, yeah, just a bit of an emphysema, I’m a bit puffed out here.” But I don’t go into any detail that I’ve got lung cancer, unless I get to know them.

Ironically, this participant substituted emphysema, another chronic lung disease associated with smoking, for lung cancer, illustrating the potency of its stigmatizing association with smoking.

Another example is provided by the contrasts drawn spontaneously between lung and breast cancers. Table 2 shows the vivid comparisons made by patient 153, one of several who had experienced first breast and then lung cancer. She added, “because nobody waves the flag for lung cancer. If you have got breast cancer you are a hero; but if you have got lung cancer—I had even had a son say, ‘Well, mum, it’s your own fault, you smoked.’”

However, these comparisons were also drawn by patients, including men, who had not experienced any other cancers. Patient 144 stated the following: “But it’s

certainly nothing like breast cancer. I mean there are breast cancer support groups everywhere. But there’s not much about lung cancer.”

Moralization

This theme gives rise to the moralization of lung cancer, which itself contains two subthemes (see Fig 1). First, lung cancer is a source of shame and guilt. Second, lung cancer crucially gives rise to stigma by association, involving family and close social network members. In the process of moralization,³⁰ a domain becomes the object of morally relevant values, especially those arousing contempt, rather than being morally neutral and governed by preferences. Moralization³¹ is related to perceptions of smoking in industrialized cultures such as the United States and Australia. In a moralized domain, the predominant emotional responses are shame and guilt. Patient 111 explicitly identifies themselves as to blame for their condition, stating “but then again I can only blame myself too because I smoked all my life.... You’re just slowly killing yourself with that sort of thing, so how can I blame anything or anybody for that?” This comment illustrates the way in which the idea of lung cancer as a necessary outcome of smoking is transformed into personal blame and distress, which in turn lies in perceptions of moral responsibility. A comment from caregiver 021 speaks to how widely these associations are perceived:

We’ve probably always thought of that ourselves, like you see people that have got emphysema or lung cancer and the first thing you do think is, “Oh well, I suppose they’ve been a smoker.” So you’re being judgmental yourself, so I guess you don’t expect anyone else to not be judgmental.

In contrast, patient 155, a nonsmoker, provides an example of how positive moral responses can be evoked in those who can separate themselves from the stigma of smoking: “So the first thing, of course, anyone thinks, ‘Oh, you’ve been smoking.’ So you feel proud to say, ‘Well, no, I wasn’t.’”

The seamless nature of the reports of stigma between patients and caregivers in the respective transcripts provided clear examples of stigma by association in caregivers. For example, caregiver 013 notes the way in which both she and her husband perceived others’ negative appraisals: “But we were—we felt judged and criticized a lot before they even knew what it was—and this is a bit hard.... I’m just trying to say it’s hard when people judge you.”

Caregivers Lack Support

Some caregivers expressed the perception that little formal support was forthcoming for caregivers of patients with lung cancer. Those who did report social support tended to provide examples of close family or professional support, such as a longtime family physician. Many participants pointed out that support programs for caregivers were not available or not visible. Caregiver 146 said, "No support for me at all. Zero, I would say. I don't think anyone has ever in the whole process asked me how I was coping with it... Like we don't count. Like people don't think that we're affected by it." With respect to supporting patients, caregivers often noted how their role was a given rather than an extraordinary act. According to caregiver 004, "Well it was just something that I needed to do for her. Part of the job..."

Attacking the Link between Smoking and Lung Cancer

Next, the moralization of lung cancer is associated with the third main theme of patients' and caregivers' reframing of smoking to reduce its connection to lung cancer. Not surprisingly, irrespective of smoking status, many participants pointed out that smoking was not the only cause of lung cancer. Asbestos exposure was presented as another scientifically validated cause, that is crucially distinct from smoking and has avoided its most negatively stigmatizing aspects. Caregiver 013 commented, "And my husband had been involved in the asbestos, working with asbestos... And we found out it was asbestos, it wasn't the smoking cancer."

Some patients were at pains to point out that their particular form of cancer was not related to smoking. Others simply noted that although smoking played a major role in lung cancer, it was not the sole cause of all lung cancers. Caregiver 157 said, "And I made the point of educating people that there's a proportion of people who never smoke, like my mother-in-law, who get lung cancer. And so it's not just a smoker's disease."

Another important aspect of the social context of smoking is that of an act rooted in the past, representing norms qualitatively distinct from the present. Such beliefs reflect the real progression of antismoking norms that has occurred in most industrialized societies in recent decades.¹⁰ For example, caregiver 023 said, "I'm not a smoker, but when he took up smoking in his late teens, he certainly wasn't thinking of his future was he?... It was socially acceptable, it was even cool." This response reflects how smoking was once regarded as a normative, socially appealing behavior marking entry to adulthood. Many such statements refer ruefully to youthful tendencies toward rebellious individualism.

Participants noted a strong belief that young people were particularly to be dissuaded from smoking. A common response was that the sight of young people smoking provoked an urge to intervene to prevent it.

Stigmatizing Antismoking Advertisements

Finally, the impact of stigmatizing advertisements is an important part of the background context that is linked to each of the other themes, demonstrating the way in which stigmatizing aspect of the ads wove connections between the main themes. Patients and caregivers often commented on how smoking-related imagery and lung cancer were represented in public health advertisements and tended to accentuate stigma. Caregiver 143 stated the following: "I don't think that makes any difference, really.... I have seen it on TV and I remember at the time it kind of... hit you a little bit because you are one of those—your loved one is affected by it, but a little bit hard."

Although most participants echoed these negative perceptions, several were in favor of such advertisements even if some viewers would be upset. However, consistent with the related theme that the act of smoking represented an addiction, rather than being subject to rational choice, many of these participants also accepted the fact that current smokers might be the least persuaded by such messages.

Discussion

The results of the present qualitative study accord broadly with previous literature and underline the impact of stigma across the lung cancer context.¹² Significant stigma, the core of which was the automatic association of lung cancer and smoking perceived to be represented across society, was reported by both patients and caregivers. Its strength is such that even those who had never smoked felt affected by it.

Our findings are highly consistent with those of previous studies showing that the act of smoking has come to be part of the moral domain denoting whether a person is good or bad.³⁰ Moral judgments involve both personal and social identities, and relevant comparisons with studies examining multilevel stigma and prisoners suggest that a negative outcome may be intergenerational in nature.³² These results also present novel directions for future interventions that can address both the consequences (e.g., distress and maladjustment) and stigmatizing sources (i.e., moralization) of stigma. In particular, our findings suggest that treatment components ought to make use of the inherent tendency of patients and caregivers to reframe negative views of smoking (e.g., noting that in the past smoking was rarely prohibited and even encouraged).

The ways in which stigma is experienced by patients and caregivers are remarkably similar, suggesting stigma by association, and this finding itself is consistent with stigma by association among families in which a member has a psychiatric illness.¹⁸ By contrast, stigma does not emerge strongly in reports on the difficulties faced by caregivers of men with prostate cancer,^{33,34} and future quantitative studies need to examine the potential differences in prevalence of stigma by association across cancer types.

In addition, an interpretation of these results must address differences between patients and caregivers. It is likely that caregivers experience considerable distress that is associated with the stigma linked to lung cancer in their loved ones. Potential treatment approaches for caregivers of patients with lung cancer need to address both the adjustment-related consequences of stigma and the socially given sources of such stigma. For example, cognitive behavioral therapy could address unhelpful cognition related to perceptions of the moral basis of smoking-related stigma in lung cancer.

The negative prognosis for many patients with lung cancer also suggests that longitudinal studies are needed to examine the trajectories of stigma and adjustment in their caregivers. Kim et al.³⁵ found that there were differences between those caregivers caring for patients currently with cancer versus patients in remission and patients who had died. Recently, evidence suggests that depression in caregivers of patients with cancer prospectively predicts physical decline.³⁶ Our work suggests that caregivers of patients with lung cancer are potentially at an early disadvantage with regard to perceptions of low support and a sense of stigma, and it is important to establish whether this negative contrast ameliorates in time or remains stable.

Our approach is not without limitations. First, we sampled purposively from support groups rather than randomly, and this may have skewed the nature of the responses that we sought. Second, the inherent limitation of qualitative work is the reduced level of objectivity that it contains. Although we would argue that a careful, theoretically derived coding scheme and the high degree of saturation mitigate against this possibility, future studies could follow up on these results while addressing such issues. For example, quantitative work could use both probability sampling and valid and reliable quantitative measures of stigma-relevant adjustment and distress indices, as suggested by our findings.

In conclusion, the responses of patients and caregivers regarding their experience of lung cancer have demonstrated the complex, multilevel interplay of the social and the personal domains. It remains for researchers and practitioners to incorporate such complexity when addressing the evident issue of stigma

and psychosocial distress for both patients and caregivers. In particular, as most caregivers are significant others, an explicit couples focus would enhance the utility of future research. Such further research is urgently needed to clarify the scope and boundaries of such stigma and its impact on psychosocial distress for both patients and caregivers.

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Appendix. Interview Guide

Patient and Caregiver Qualitative Interview Guide

Introduction. As outlined in the project information sheets, we are seeking to better understand people's experiences with lung cancer and how different views about lung cancer might influence this. To do this, we would like to ask you about your journey with lung cancer and which factors influenced your and/or your family member's care and treatment

1. A good place to start is to think back to the time when you first thought that you or your family member had a lung cancer worry. Can you tell me about what was happening at that time and what you remember thinking and feeling? (*Prompt then for And when you found out about the lung cancer? Deciding about treatment? The experience of treatment? Seeking support? At present.*)
2. Next, we would like to ask about how you think that lung cancer is thought about in our community and your experiences of this.
3. What do you think that most people think of when they think about lung cancer? (*Prompt for With family? Friends? Health professionals? Just your own feelings? For Indigenous people, prompt for community.*) How does this affect you as a patient with lung cancer or as a caregiver?
4. Can you tell me about your experiences with doctors or other health professionals (such as nurses) as a person with lung cancer or a caregiver?
5. As a person with lung cancer or partner and/or caregiver, what are your thoughts about television advertisements or stories in the media about smoking and lung cancer?

Note

- Interviewer is to ask for participants smoking status if it has not become apparent during the interview.
- Interviewer is to ask for patient diagnosis date if not already been obtained.
- Interviewer is to check that all demographic survey questions have been completed.

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Appendix Table 1. Consolidated Criteria for Reporting Qualitative Studies: 32-Item Checklist

Item No.	Guide Questions/Description	Response/Page No.
Domain 1: research team and reflexivity		
Personal characteristics		
1. Interviewer/facilitator	Which autho(s) conducted the interview or focus group?	Interviews were conducted by graduate student research assistants who were experienced interviewers. Supervision and assessment of interviews provided by S. O., S. C., and J. D.
2. Credentials	What were the researcher's credentials? (e.g., PhD, MD)	S. O., S. C., and J. D. have a PhD
3. Occupation	What was their occupation at the time of the study?	S. O. and S. C. were faculty members at Griffith University. At the time of the study, J. D. was chief executive officer of the Cancer Council Queensland
4. Sex	Was the researcher male or female?	The interviewers were both female (see the Materials and Methods) and the researchers were male (S. O. and J. D.) and female (S. C.)
5. Experience and training	What experience or training did the researcher have?	
Relationship with participants		
6. Relationship established	Was a relationship established before commencement of the study?	No relationship between the specific researchers and the participants
7. Participant knowledge of the interviewer	What did the participants know about the researcher? (e.g., personal goals, reasons for doing the research)	Participants knew that the researchers were interested in the perspectives of people with lung cancer and their caregivers
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? (e.g., bias, assumptions, reasons, and interests in the research topic)	Sex is reported
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? (e.g., grounded theory, discourse analysis, ethnography, phenomenology, content analysis)	Qualitative thematic analysis
Participant selection		
10. Sampling	How were participants selected? (e.g., purposive, convenience, consecutive, snowbal)	Purposive
11. Method of approach	How were participants approached? (e.g., face-to-face, telephone, mail, e-mail)	Telephone
12. Sample size	How many participants were in the study?	28
13. Nonparticipation	How many people refused to participate or dropped out? What were the reasons?	No dropouts occurred. No refusals recorded
Setting		
14. Setting of data collection	Where was the data collected? (e.g., home, clinic, workplace)	Telephone (n = 25); public place of participants' choosing (n = 3)
15. Presence of nonparticipants	Was anyone else present besides the participants and researchers?	No
16. Description of sample	What are the important characteristics of the sample? (e.g., demographic data, date)	These are presented in the Results and in Table 1
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	An interview guide with open-ended questions was provided
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audiovisual recording	Did the research use audio or visual recording to collect the data?	Interviews were digitally audio recorded

(continued)

Appendix Table 1. Continued

Item No.	Guide Questions/Description	Response/Page No.
20. Field notes	Were field notes made during and/or after the interview or focus group?	No field notes, but interviews were digitally transcribed verbatim
21. Duration	What was the duration of the interviews or focus group?	
22. Data saturation	Was data saturation discussed?	Data saturation was discussed with the broader research team at regular team meetings and informed an eventual decision to cease interviewing.
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	2
25. Description of the coding tree	Did authors provide a description of the coding tree?	Yes
26. Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data but were guided by stigma theory
27. Software	What software, if applicable, was used to manage the data?	Not applicable
28. Participant checking	Did participants provide feedback on the findings?	No
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes and/or findings? Was each quotation identified? (e.g., participant number)	Participant quotations (participant numbers) were used extensively in the body of the article, and more were presented for illustration in Table 2
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, results
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, results
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, results