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Barriers to lung cancer care: health professionals' perspectives

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Abstract

Purpose Globally, lung cancer is the most common cancer and the leading cause of cancer death. Problematically, there is a wide variation in the management and survival for people with lung cancer and there is limited understanding of the reasons for these variations. To date, the views of health professionals across relevant disciplines who deliver such care are largely absent. The present study describes Australian health professionals' views about barriers to lung cancer care to help build a research and action agenda for improving lung cancer outcomes.

Methods Qualitative semi-structured interviews were undertaken with a multidisciplinary group of 31 Australian health professionals working in lung cancer care for an average of 16 years (range 1–35 yrs.; SD = 10.2) seeing a mean of 116 patients annually.

Results Three superordinate themes were identified: illness representations, cultural influences, and health system context. Illness representations included three themes: symptoms attributed as smoking-related but not cancer, health-related stigma, and therapeutic nihilism. Cultural influence themes included Indigenous health care preferences, language and

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communication, and sociodemographic factors. Health system context included lack of regional services and distance to treatment, poor care coordination, lack of effective screening methods, and health professional behaviours.

Conclusions Fractured and locally isolated approaches routinely confound responses to the social, cultural and health system complexities that surround a diagnosis of lung cancer and subsequent treatment. Improving outcomes for this disadvantaged patient group will require government, health agencies, and the community to take an aggressive, integrated approach balancing health policy, treatment priorities, and societal values.

Keywords Lung cancer · Stigma · Nihilism · Health professionals' attitudes

Introduction

Globally, lung cancer is the most common cancer, contributing one in five cancer deaths [1]. Due to poor survival, geographical patterns of lung cancer incidence and mortality are similar. A number of area-level and individual characteristics are associated with both treatment and survival. Internationally, where people live, how well educated they are, and their extent of socioeconomic disadvantage appear to consistently influence access to treatment for lung cancer. Specifically, lung cancer patients with lower education, low socioeconomic status, older age, and who are male are less likely to receive surgery, radiotherapy and chemotherapy, and indeed any lung cancer treatment [2–4]. A systematic review of the world-wide literature also found that area-level socioeconomic deprivation is associated with a lower likelihood of receiving surgery, chemotherapy or any type of treatment for lung cancer [5]. However, further research is needed to understand the causes of these disparities so that strategies to improve lung cancer outcomes equitably across communities can be developed.

Analysis of linked population-wide health data indicates that in Australia, as distance from specialist thoracic health services increases, people with lung cancer are less likely to receive surgery and are more likely to die from the disease [6]. This burden is even greater in the Indigenous population who experience poorer health than that in non-Indigenous Australians, including higher lung cancer mortality rates [7]. Indigenous Australians are less likely to receive surgery for their lung cancer, and the odds of receiving suboptimal treatment for non-small cell lung cancers are higher for Indigenous compared with those for non-Indigenous patients [8–10]. The reasons for these disparities are complex. However, Indigenous Australians are 2.5 times more likely to smoke [11]; live in geographically remote areas where access to health services is limited [11]; and are diagnosed at more

advanced stages of the disease in comparison with other Australians [12, 13].

In addition to sociodemographic and cultural issues, illness representations may be a barrier to early diagnosis of lung cancer and adhering to treatment. Illness representations refer to a person's beliefs and expectations about their illness (e.g., the cause of the cancer, likelihood of cure), and these beliefs influence responses to illness and health care [14]. In lung cancer, health-related stigma is closely connected to beliefs about lung cancer causation and prognosis. Stigma refers to a characteristic that connects to a negative stereotype that sets the stigmatised group apart as separate to the dominant group [15]. This may lead to discrimination and if internalised by the stigmatised person lead to feelings of shame or guilt and a fear of discrimination [16]. In lung cancer, stigma is health-related and conferred by a) the link between smoking and lung cancer and b) social representations of lung cancer as self-inflicted and as a disease with high mortality and a poor quality death [17]. Research from North America has found stigma and shame about lung cancer, social isolation and smoking-related stigma to be associated with delay in seeking medical help by lung cancer patients [18, 19]. Other researchers have found that lung cancer patients who have more internalised shame about their cancer are more likely to conceal their diagnosis from their social network [20] and that the negative effects of stigma and shame on lung cancer patients distress and quality of life were mediated by cancer threat and social constraints [21]. Hence, stigma influences the patient experience of lung cancer and although objective studies of actual discrimination in cancer treatment are not evident, stigma seems likely to influence the care pathway. Finally, therapeutic nihilism has been described as a barrier to lung cancer care where some patients and clinicians may believe cure is unlikely and that medical treatment for lung cancer is of little or no value [22, 23].

To date, research exploring barriers to lung cancer care in Australia is still emergent and the views of health professionals across relevant disciplines who deliver such care are largely absent from this discourse. One Australian study found beliefs amongst primary care physicians that non-smokers 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 deaths deterred smokers from seeking medical advice [24]. However, this research was limited by considering the views of only ten primary care physicians in one Australian state and the extent of previous clinical experience in lung cancer care of participants was not described, nor were broader sociodemographic or geographic issues explored. Hence, the experiences of specialised health professionals across disciplines who deliver lung cancer care in the broader Australian context remain unexplored. An understanding of these experiences is a key step towards improving care.

Accordingly, the aim of the present study was to explore the views of Australian health professionals about which factors they believe influence clinical care and outcomes for people with lung cancer. In doing so, we sought to clarify policy and practice priorities from the view point of health institutional stakeholders towards the setting of an action agenda.

Method

Recruitment

Ethical approval was obtained from Griffith University Human Research and Ethics Committee (HREC). Health professionals experienced in managing lung cancer were identified through existing professional networks and were sent a letter of invitation and information and consent form. Networks such as the Australian and New Zealand Lung Cancer Nurses Forum and Lung Foundation Australia¹ were selected to enable purposive sampling of health professionals from a range of professional backgrounds involved in lung cancer care. Not all possible professional backgrounds or characteristics were represented, and therefore this is a non-probability purposive sample. Of 91 health professionals contacted, 54 did not respond, three refused to participate, and three withdrew due to time constraints, leaving 31 (34 % response) participants. The majority of non-responders were primary care physicians (38 %) and medical/radiation oncologists (28 %); over 80 % of non-responders were male.

Participants

Of the 31 participating health professionals, 52 % were female (see Table 1). Most were from Queensland (61.3 %), 12.9 % from South Australia, 9.7 % from Victoria, 6.5 % from New South Wales, and 3.2 % each from the Australian Capital Territory, Western Australia, and Tasmania; 27 (87 %) were in urban locations and the remainder ($n = 4$) in regional areas. They had managed patients with lung cancer for a mean of 16 years (range 1–35 years; SD = 10.2) and saw a mean number of 116 patients (range 1–500; SD = 122.6).

Qualitative interviews

Qualitative semi-structured interviews were undertaken. Participants answered open-ended and broadly focussed questions about what factors they thought influenced 1) clinical care and outcomes and 2) support for people with lung cancer.

¹ At the time of the study Lung Foundation Australia was known as Australian Lung Foundation

Table 1 Participants' professional group ($n = 31$)

Professional group	<i>n</i>	%
Registered nurse	9	29.0
Cardiothoracic surgeon	3	9.7
Respiratory physician	3	9.7
General practitioner	3	9.7
Medical/radiation oncologist	5	16.1
Aboriginal and Torres Strait Islander health worker	2	6.5
Allied health*	5	16.1
Palliative care physician	1	3.2

*Allied health included physiotherapy, occupational therapy, social work, and psychology

Specific prompts about stigma and nihilism and the influence of health policy or anti-smoking campaigns were then introduced (See [Appendix A](#)). Participants were also prompted about health professional, patient, carer, and Aboriginal and Torres Strait Islander peoples' perspectives to ensure an in-depth consideration of at risk groups. The interview was semi-guided with participants free to speak at length with minimal interruption.

Data preparation and analyses

Interviews were digitally recorded. Of the 31 interviews conducted, two were not able to be transcribed due to technical difficulties; however, interviewer notes ensured no unique data were missed. The interviews took on average 33 min (min. 11 min; max. 57 min). Interviews were transcribed verbatim with transcripts de-identified and checked for accuracy. Each transcript was independently read by two qualitative data coders. Major themes were identified through an iterative process and examples documented separately by each coder. Denzin and Lincoln's [25] Interpretative Perspective framework was applied to the qualitative data analysis. This framework is concerned with identifying meaning and how it informs subjective understanding. Analysis through the Interpretative Perspective acknowledges that multiple perspectives of the human experience exist, and the aim of the current study was to enrich our understanding of health professionals' views on the lung cancer patient's experience.

Data analysis involved becoming thoroughly familiar with the transcripts and examining similarities and contrasts in themes [26]. Concepts were noted in each case, and emergent themes were identified by grouping similar concepts. Prior theory (illness representations) served as a resource for the interpretation of themes; however, the interpretative framework also promotes the uncovering of novel themes [27]. Themes that were identified later

in the process were coded in earlier narratives through a continual reviewing process.

Upon completion of analysis of all transcripts, the coders met to verify and discuss the thematic analysis. A small number of interpretive discrepancies were discussed and resolved. Then, in-text examples were identified across transcripts and documented to illustrate and verify the labelling of each major theme. Identified themes were verified by a third independent coder. Data coders had social and behavioural science backgrounds.

Results

Three superordinate themes were identified: illness representations; cultural influences; and health system context. Illness representations included three themes: symptoms attributed as smoking-related but not cancer, health-related stigma, and therapeutic nihilism. Cultural influence themes included Indigenous health care preferences and relationship to country, language and communication, and sociodemographic factors. Health system context included distance to treatment, lack of regional services, poor care coordination, and lack of effective screening methods. Exemplar quotes for each superordinate theme and most themes are presented below.

Illness representations

Across the illness journey from the point of symptoms to diagnosis and treatments, three themes were described as barriers to care: symptoms attributed as smoking-related but not cancer, health-related stigma, and therapeutic nihilism.

Symptoms attributed as smoking-related but not cancer

At the pre-diagnosis stage, delays in treatment were related to illness or somatic symptoms being interpreted by the patients and by primary care physicians as smoking-related but not indicative of cancer. These symptoms were also described as being vague and non-specific and on this basis again not being recognised or interpreted by the patient or clinicians as possible cancer. For example:

Well most of them are smokers, and most of – many of them will have chronic symptoms and therefore they will put down their symptoms simply to their smoking effect rather than the possibility that he or she has a new problem like lung cancer.

Health-related stigma

For health-related stigma, awareness of the causative link between lung cancer and smoking created a barrier for

patients to seeking treatment and cancer help, as well as causing patient distress. Participants expressed the views that smokers may feel shame at causing their own cancer and may avoid diagnosis and feel treatment is not deserved; that health professionals assume lung cancer patients are smokers; and that non-smokers may feel stigma more acutely because they are automatically assumed to be at blame for their cancer. It was also expressed that some patients keep smoking because they think the damage is done. A minority view was that there was no stigma associated with lung cancer.

I've had patients who have had lung cancer from a non-smoking cause, they've been a non-smoker and they've been diagnosed with lung cancer and I think they feel that stigma even more acutely because they are lumped in that category and regarded as people who have some blame, some fault, in the illness that they have and it's very, I guess, invalidating and distressing to them to have that sort of stigma.

Anti-smoking campaigns were described as contributing to stigma in lung cancer with lung cancer patients being more stigmatised by comparison to other cancers.

...like people who are diagnosed with lung cancer, they have feelings that it's their fault or feelings that people will think that they're using up their health resources and they don't somehow deserve them as much. I have a real problem with the current – some of the current anti-smoking things in that when they show someone who – the parent and the kids are in the background, and I'm not going to be around – it's almost inducing, inciting a degree of shame on behalf of the person with the condition.

In response to this, participants felt there was a need for more positive messages about early detection and treatment for lung cancer.

...another way of approaching the public health campaign would be to say giving up smoking reduces your risk of lung cancer and if you do get lung cancer it is potentially treatable in some people.

Therapeutic nihilism

Therapeutic nihilism also emerged in the interviews, alongside the view that treatment for lung cancer was futile and this was seen as affecting not only attendance for treatment but also other health behaviours such as smoking cessation.

I think in every hospital, you can always think of at least one or two of the clinicians that have that opinion, like that nihilistic, what's the point of doing anything, they're just going to die.

I think certainly if they are still a smoker at that point of diagnosis for some it will be an opportunity to give up, but for others they may take the view, well, the damage is done, I've got lung cancer so what's the point in giving up now?

Tobacco control programs that used fear appeals to encourage smoking cessation were described as promoting nihilism and stigma with resultant unintended negative effects on people with or at risk of lung cancer.

I think patients get very scared by the television programs, the television ads, and so therefore don't necessarily seek medical attention or delay. And then patients are quite reluctant to push themselves forward.

Cultural differences

A number of specific cultural issues were identified as barriers to lung cancer care for Aboriginal and Torres Strait Islander people, and these were represented by the themes Indigenous health care preferences and relationship to country, language and communication, and sociodemographic factors.

Indigenous health care preferences and relationship to country

Within this theme, participants described a preference by Aboriginal and Torres Strait Islander people for traditional medicine over “white man’s” medicine; a lack of knowledge about cancer and cancer treatment; fear of hospitals; and counselling services not being culturally accepted. For example:

(They) are very unlikely to approach white man's medicine. They like to use traditional medicine.

A lot of people don't want to travel to that; they've never been out of their community. They don't know what they're going into. And hospital to them means that if I go to hospital, I don't come home.

Other issues raised that were representatives of this theme were: the patient’s kinship group not being supportive of treatment; fear of dying away from their country; and being away from home/country support.

But it was like everyone in his family group just closed ranks and they wanted to look after him their way. So, yes, he did comply with some of the treatment, but only when he wanted to with his mob.

Language and communication and sociodemographic differences

Language and communication were important barriers for not only Aboriginal and Torres Strait Islander people but also for non-English speaking and other patients where the use of medical jargon in particular was noted as problematic. Sociodemographic differences described that relate to cultural background were male gender and rurality and that were seen as linked to stoic and avoidant illness behaviours.

I'm thinking mainly men. For the whole reason often men are, 'No, I'm okay.' The coping, they're big boys, they don't need any help and a lot of people just don't seek help because they are trying to stick their head in the sand.

It's just the general rule of people who are in the rural and remote areas tend to wait to see whether things are getting worse before they go to the doctor; more than they do in the urban areas.

Health services context

Health care context was described as contributing to delays, and themes included lack of multidisciplinary and palliative care services in rural and regional areas and resultant distance to treatment centres; poor care coordination; and the lack of a screening tool for early detections.

Lack of regional services and distance to treatment

Rurality impacted access to treatment and services and also led to financial blocks in accessing health services and not being able to take time off work for tests or treatment. For example:

The more remote people are the harder it is for them to access services, so therefore it becomes a bit of a self-fulfilling prophecy that they become very negative about the prospect of doing anything about their lung cancer because they are so far away and they can't access oncology services for chemotherapy for example.

Poor care coordination and lack of effective screening methods

Other health care settings issues included lack of care coordination, under-staffed hospitals, and lack of effective screening tools for early detection of lung cancer. For instance:

All those patients often find themselves lost in a very disjointed medical system. ... they get the information, they're shocked, they don't know where to go to next... So I'd say a lack of infrastructure within the system to follow people through is – lets the individual patients down.

Health professional behaviours were also described as blocking support, and this included gaps in services, lack of appropriate referral points, poor knowledge about lung cancer, and lack of responsiveness to patients' and carers' needs. For instance:

It's very clear that there are very little organised resources available to carers of people with advanced cancer, lung cancer or any other cancer. And so there is a real issue there of how to deal with that.

Discussion

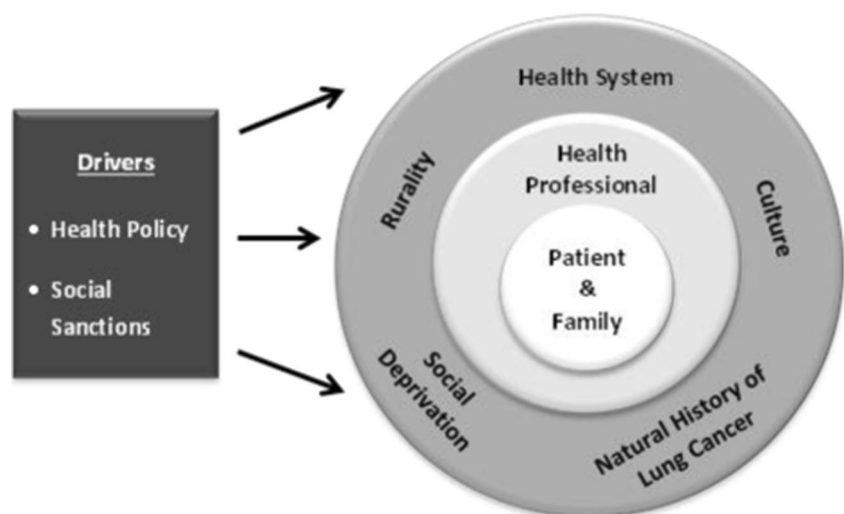
The present study presents a multi-faceted picture of disadvantage for lung cancer patients. Conceptually and practically, the experiences of the patient, their family, and the health professionals who care for them appear to be nested within the health system and society with a network of influences leading to systematic disadvantage. Broadly speaking, these influences include geography or rurality, social deprivation, culture, and the natural history and epidemiology of lung cancer (see Fig. 1). The dynamic of disadvantage is powered by health policy and how this is expressed in the health system and by the social sanctions that arise for people whose illness is seen as self-inflicted (tobacco-related illness as self-harm) and where the behaviour that leads to this illness (i.e., smoking) is socially sanctioned [28]. This means that serious

efforts to improving lung cancer outcomes will require a complex and multi-focussed strategy across all these influences if substantive change is to occur. In particular, addressing how health systems are organised to respond to lung cancer, especially in rural and regional areas and conditions of socioeconomic deprivation and cultural diversity, will be crucial.

As in previous research, stigma was described as a reason why some patients may not seek care or support and why treatments and support might not be offered to lung cancer patients [18–20]. Nihilism was repeatedly reported as a reason why clinicians may not offer treatment and why patients and carers themselves may not accept or seek treatment. Hence, despite early attention to this issue [22], it seems much has not changed. Anti-tobacco campaigns were seen as a contributor to lung cancer stigma by most participants, with the view expressed that more positive media about lung cancer to inspire hope was needed. Tobacco control communications that apply highly emotive and negative messages about smoking-related illnesses in an effort to dissuade people from smoking or encourage cessation can be expected to have an impact on those who have these illnesses. Specifically, negative media images about lung cancer are likely to be distressing for a person who has a lung cancer diagnosis; however, a shift to more positive messaging may be inconsistent with current tobacco control messages. The balancing of policy, priorities, and values for government, health agencies, and the community is a key future question for discussion by health care providers and researchers [29].

For Indigenous patients, disadvantage was overlaid with complex language and cultural barriers that contribute to the gap between Indigenous and non-Indigenous lung cancer outcomes [12, 13]. Consistent with previous research, feelings of disconnect with health care services, and fears about absence from home during treatment with competing social, cultural, and family demands were described [30]. From the Indigenous health workers

Fig. 1 Network of influencers on lung cancer care



and community members' point of view, the main barriers impacting on quality health care of Indigenous Australians with lung cancer are communication and follow-up processes [31]. One study reporting community and allied health service use by Indigenous people diagnosed with a mix of cancer types has shown that while patients access multiple services, the most frequent services used were Indigenous health services [32]. A range of culturally appropriate hospital and community-based services is needed for these patients (e.g. psychological counselling, assistance with travel, and accommodation) from diagnosis and through the patient's journey, ideally with a specific Indigenous staff member as the care provider [33]. This need also extends to the development of well-targeted smoking cessation and prevention interventions for this population [34].

Strengths of this study include representation of a range of views of both male and female health professionals with extensive experience in lung cancer patient care across a variety of geographic and health care settings and disciplines. However, the nature of purposive sampling adopted limits, at least in part, transferability of these perspectives to all health professionals working in cancer care.

In conclusion, a profound reflection is needed on how our society has, and continues to, responded to the community and individual burden of lung cancer. As chronic diseases escalate not only in Australia but globally, health organisations have increasingly moved towards a focus on personal responsibility for health and the self-management of disease. This approach implies that given enough effort, good health is possible for all. However, assuming this fails to consider what matters most to individuals and what is relevant in the context in which they live and in which their health status evolves.

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Compliance with ethical standards

Conflicts of interest The authors declare that they have no conflict of interest.

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