
Zulfiqer Otty (zulfiqer.otty@health.qld.gov.au)  
Townsville Hospital

Rebecca Evans  
James Cook University

Sarah Larkins  
James Cook University

Sabe Sabesan  
Townsville Hospital

Amy Brown  
James Cook University

Research Article

Keywords: Lung cancer, referral pathway, qualitative study

Posted Date: May 17th, 2022

DOI: https://doi.org/10.21203/rs.3.rs-1619267/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License
Abstract

Background: Lung cancer referral pathways aim to reduce delays and improve referral patterns of people with suspected lung cancer. As part of implementing lung cancer referral pathway at a regional Australian hospital, this study aimed to explore the experiences and perceptions of people with lung cancer and their carers.

Methods: In-depth interviews were used to elicit data for thematic analysis in this cross-sectional qualitative study. Newly diagnosed lung cancer patients and their carers at an academic cancer centre were invited to participate in interviews. Five interviews were conducted face-to-face, and fourteen interviews were conducted by telephone (as per interviewee preference). Interviews were audio-recorded, transcribed, and qualitatively analysed. Descriptive phrases were used to generate initial inductive codes and themes.

Results: Nineteen out of 36 participants approached agreed to take part in the study. Important aspects for participants identified were: quality of communication from clinicians, timeliness of investigations and specialist referrals, patient advocacy, psycho-social support, and co-ordination of care. Various difficulties experienced which reduced their perception of quality of care were reported by some patients and their carers. Tele-health consultations, including telephone consultations, were being used widely due to the COVID 19 pandemic. Factors which positively impacted the care experience were good communication, timeliness and patient advocacy and support. Improper communication, long waiting times for investigations and appointments, uncertainty about the process and inconsistent providers negatively impacted the care experience. Participants preferred face to face or video-linked consultations over telephone consultations.

Conclusions: Proper communication, timeliness and adequate psycho-social support were perceived as important factors in improving satisfaction of lung cancer patients and their carers during the referral pathway. Methods to improve communication by clinicians, reduce delays and provide support care during the referral pathway should be explored further.

Introduction

Lung cancer is a significant cause of morbidity and a leading cause of cancer mortality in the world (1). Studies done internationally show significant variations in pathways to lung cancer diagnosis and treatment between countries and health services (2–5). Limited access to cancer diagnosis and management is an issue faced by patients in rural and regional communities (6–9). Lung cancer care spans both hospital and community-based health care settings (10, 11). Most lung cancer patients initially present to their general practitioner (GP) with symptoms (10, 12). Although most such patients are referred promptly for specialist assessment, some experience multiple medical consultations, which lead to delay in diagnosis (9, 13). Increased uptake of lung cancer screening may also result in increased
use of lung cancer referral pathway (14). A simplified referral pathway of people suspected with lung
cancer is depicted in Fig. 1.

To reduce variations in management approaches and delays, many organizations have established
health pathways and optimal care pathways (15–17). Our hospital, a tertiary regional health service in
North Queensland, Australia, has begun implementing an Optimal Lung Cancer Referral Pathway to
improve referral patterns and reduce delays in diagnosis of people with suspected lung cancer. Despite
the disruption caused by COVID 19, there was minimal impact on the structure of the lung cancer referral
pathway, with the main change being the widespread use of telehealth for consultations.

As part of improving the referral pathway, we conducted a qualitative study with the aim of exploring the
experiences and perceptions of lung cancer patients and their carers about their pathway from initial
presentation with symptoms to being diagnosed with lung cancer.

Methods

Study design

The study was conducted in a regional tertiary hospital in Australia, which has a large catchment area,
with a significant number of geographically dispersed rural and remote communities. A
phenomenological approach was undertaken in order to understand the experiences of lung cancer
patients and their carers in this descriptive cross-sectional qualitative study, we used in-depth interview
technique to elicit data for thematic analysis (18).

We developed a semi-structured qualitative interview guide, focusing on patients’ and carers’ experiences
of the lung cancer referral pathway and their perspectives on appropriateness and acceptability of the
care provided (interview guide is provided in the appendix). The interview questions were designed to be
open-ended, while not leading participants and allowed for follow-up probing questions to elicit deeper
responses. Interview questions were piloted with two volunteers (one lung cancer patient and the other a
junior doctor) and relevant changes made prior to use to ensure appropriateness and clarity of the
questions.

Patient recruitment

Newly diagnosed lung cancer patients and/or their carers, seen in the university hospital Oncology clinic
from 1st October 2020 to 30th March 2021 were eligible to participate if they were aged over 18 years,
and able to provide informed consent. Patients were purposively sampled, (for gender, rurality, different
stages of lung cancer and treatment modalities) to ensure a range of perspectives and experiences were
captured. Interviewing continued until thematic saturation was reached. The principal researcher, an
oncologist, did not recruit participants nor conduct the interviews, to avoid coercion.

Data collection
A research assistant conducted semi-structured interviews with patients and/or their carers, after obtaining written consent. The interview was conducted face-to-face or by telephone, (as indicated by participant choice), at a time convenient to the patient/carer. All the interviews were audio-recorded and transcribed verbatim. The research assistant also took field notes during the interviews.

Analysis: An iterative thematic analysis was undertaken to derive key codes and themes regarding participant experiences (18). Concurrent analysis was done by three authors, including the principal investigator, who separately read through a proportion of transcripts to familiarize themselves with the data. NVivo 12 software (QSR international, Melbourne, Australia) was used to facilitate data analysis. The principal researcher generated initial inductive codes and grouped the codes into theme headings. The codes and themes were finalized during the group discussions. This process was employed to minimize biases of any one author in interpreting data sources and generating coding and themes (19).

**Ethics approval**

was obtained for the study from the local Hospital and Health Service Ethics Committee (HREC/2020/QTHS/58635). All participants provided written informed consent. The study was conducted according to Good Clinical Practice and the Australian Code for the Responsible Conduct of Research.

**Results**

Thirty-six potential participants were approached and 19 agreed to take part. Fourteen were phone interviews, and five were face-to-face. Participant characteristics are provided in Table 1. This sample is largely representative of the region’s lung cancer patient population and included patients with different stages of lung cancer as well as patients from urban, regional and rural areas.
Table 1
Patient characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age in years (range)</td>
<td>64 (52–82)</td>
</tr>
<tr>
<td>Gender Male</td>
<td>10</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
</tr>
<tr>
<td>Residence: Urban</td>
<td>12</td>
</tr>
<tr>
<td>Regional</td>
<td>4</td>
</tr>
<tr>
<td>Rural</td>
<td>3</td>
</tr>
<tr>
<td>Stage of cancer</td>
<td>9</td>
</tr>
<tr>
<td>Early stage (curative)</td>
<td>10</td>
</tr>
<tr>
<td>Late stage</td>
<td></td>
</tr>
<tr>
<td>Type of lung cancer</td>
<td>16</td>
</tr>
<tr>
<td>Non-small cell lung ca</td>
<td>3</td>
</tr>
<tr>
<td>Small cell lung ca</td>
<td></td>
</tr>
<tr>
<td>Present for Interview</td>
<td>12</td>
</tr>
<tr>
<td>Patient only</td>
<td>2</td>
</tr>
<tr>
<td>Carer only</td>
<td>5</td>
</tr>
<tr>
<td>Patient and carer</td>
<td></td>
</tr>
<tr>
<td>Initial presentation GP</td>
<td>8</td>
</tr>
<tr>
<td>Emergency Department</td>
<td>8</td>
</tr>
<tr>
<td>Other specialties</td>
<td>3</td>
</tr>
</tbody>
</table>

Data analysis identified four major themes and several sub-themes, which are depicted in Table 2. The themes were inter-connected (Fig. 2 as supplement).
Table 2
summary of codes, themes and sub-themes:

<table>
<thead>
<tr>
<th>codes</th>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>communication</td>
<td>Quality of Communication from HCPs affect patient and carer satisfaction</td>
<td>Information needs vary between patients</td>
</tr>
<tr>
<td>Information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>comprehension</td>
<td></td>
<td>Both content and type of information from HCPs are important</td>
</tr>
<tr>
<td>Initial consultation</td>
<td></td>
<td>Improper communication causes distress</td>
</tr>
<tr>
<td>Delays</td>
<td>Delays cause significant anxiety and distress</td>
<td>Variation in presentations, referral pathways and timeliness</td>
</tr>
<tr>
<td>Timeliness</td>
<td></td>
<td>Perceptions, causes and impacts of delays</td>
</tr>
<tr>
<td>Investigations</td>
<td></td>
<td>Uncertainty about is a cause of anxiety</td>
</tr>
<tr>
<td>Distress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>family</td>
<td>Advocacy, Support and Coordination improves patient/ carer experience</td>
<td>Patient advocacy by HCPs, family and friends</td>
</tr>
<tr>
<td>support</td>
<td></td>
<td>psychosocial support for patients and carers</td>
</tr>
<tr>
<td>System issues</td>
<td></td>
<td>Co-ordination of care</td>
</tr>
<tr>
<td>satisfaction</td>
<td>Multiple factors influence overall satisfaction with care</td>
<td>Participants’ impression of referral pathway</td>
</tr>
<tr>
<td>difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td>comments</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Quality of communication from the health care providers (HCPs):

When participants were asked about the quality of communication, they commented on various aspects like the clarity of information, willingness to answer any questions, being knowledgeable, and using pictures and diagrams.

‘It has been quick; it has been easy, it has been... lots of communication. Communication has been great.... Yeah, like every doctor we've ever had has always been willing to answer anything I've wanted to know, like even if it's just the tiniest little question...” (58, female, urban).
“He was pretty upfront, he said it me that it was um... that they had found a mass. He said a picture paints a thousand words, so he actually showed me my x-rays, and showed me how one third of my left lung had collapsed, and showed me the mass that was on my lung.” (52, female, urban)

Having other family members accompanying them during medical consultations general improved patients’ feelings about comprehension. One elderly indigenous patient did not understand English very well and had help from family in translating all the information.

Information needs varied among the participants, with some of them expecting detailed information, while others were satisfied with minimal information. One patient explained how he used the internet to learn more about the cancer and treatments. Many patients and their carers were happy with whatever decisions their GP or specialist recommended to them, as they felt that the professionals knew what they were doing. But, one carer felt overwhelmed with information provided by the specialist. The main concern of many patients was knowing prognosis and how long they potentially have left to live.

“I suppose because I don’t know anything medical, ........ I don’t wanna see pictures, I just wanna get on with it. I just wanna get told what I have to do to get this over and done with.” (55, female, urban)

Improper communication from clinicians caused distress to some participants. Few patients were informed of the lung cancer diagnosis and prognosis over the phone by specialists. One of them had not seen the patient previously, had a difficult accent and did not offer any time for the patient or his wife to ask any questions. Another patient felt that the specialist was not aware of all the results before the consultation.

“All of a sudden it went from I’m getting no information; I’m getting information that is unexpected, uncontextualized and not given in a format where I have the opportunity to understand or ask questions.” (61, male, urban)

**Timeliness was an important factor for patients and their carers:**

Eight participants reported that all stages of their referral pathways took place in a timely manner. But, nine participants expressed that it took too long for the GP to acknowledge their condition and arrange for necessary investigations. Out of these, five participants had pre-existing chronic lung disease and two participants were mistakenly diagnosed with benign conditions. Many patients felt that since their GPs did not take their symptoms seriously during initial consultations, their diagnosis and treatment were delayed.

“But I’m a bit annoyed about the practice I went to in (a regional town) that wasn’t followed up earlier. Back to my GP was all different doctors, and I think in the beginning I think that they should have investigated it further”. (75, female, regional town)
Five patients had to present to the emergency department with severe symptoms and hence were referred directly to respiratory specialist. Two patients felt that their diagnosis was delayed because they lived in a regional/rural area. They reported that they did not have a regular GP as there was a frequent turnover of GPs. Some regional towns had specialists but waiting times for a specialist appointment was much longer than metropolitan areas.

“I mean my tumour was 6cm when it was eventually diagnosed at the [metropolitan hospital] a week later. And um, it couldn’t grow just in a minute, it had to have been there for a least a long, quite a good time...”. (72, female, regional town)

In contrast to those with perceived delays, one participant reported that everything was too rushed, and they did not have time to comprehend what was going on.

Participants expressed that the experience of uncertainty was hard to handle and was a cause of distress. Many patients/carers reported that they lived in fear while waiting for diagnosis. A few patients felt that the delays caused their tumours to grow while they were waiting, which led to worse outcomes. One patient reported contemplating not having any further investigations as he was frustrated with the perceived delays.

“And it was just near the end that I felt like oh my god please can we get something going, because I was really well aware of the fact there was really something there then, and I just wanted something to start”. (63, female, regional town)

**Patient advocacy, psychosocial support, and care coordination during the referral process:**

Although most participants were content with the management advised by their GPs, some of them demanded investigations and specialist referrals. One of the carers, who was a retired nurse, requested an urgent chest x-ray for her husband who was being treated for pneumonia. Participants also spoke positively about experiences where they perceived that their HCPs advocated for them to access a needed resource or to connect them with another HCP.

“It wasn’t severe, just in the back of my mind being a nurse, I thought no let’s clarify that. And it was me that persevered with our GP to say look he needs an x ray, the second time I went with him and insisted. And he had one and obviously I’m very glad he did.” (carer, female, urban)

Although most of the patients did not have access to cancer care coordinators, one patient reflected that her appointments were made quicker with the help of a care coordinator. Two participants who live in regional areas would have preferred all their appointments early in the morning, so that they could drive back home on the same day. Sometimes, a breach in continuity of care happened when patient was transferred from one hospital to another.
“Then I got handed over to a number of other doctors. And um... yeah so come November when it all finished, there was no indication of appointment follow-ups or scan or anything. And that’s where they fell down there a little bit.” (62, male, urban)

Many patients and carers received good support from next of kin and friends. They received valuable emotional, financial, and practical support at home and while accessing health care. Although we did not explicitly ask the participants about referral for psycho-social services, one carer mentioned receiving help from a support worker in taking the patient to appointments.

“I’m his carer, but we do have a support worker that started in the last few years, because things were getting a bit much for me in the way of heavy work and things. I’ll go to the doctors’ meetings in the morning, and then I go and do what I need to do while [name] stays with him.” (carer, female, urban)

Satisfaction with the referral pathway depended on multiple factors:

Nine of the participants reported that they were very satisfied with their referral process. Despite being a difficult time, they felt that they had the best possible care and could not suggest any improvements. Three participants and their carers were not satisfied with the referral process and suggested improvements. One of them felt that it was important to have continuity of their management and one specialist who will communicate with them all the time and who can be trusted and understood. Although most patients were satisfied with how the public health system works, one patient mentioned that she had bad experiences in public hospitals previously. Using telehealth consultations improved satisfaction for regional/rural patients, with a preference for video link rather than telephone expressed.

“The whole hospital has been great. The nurses at the CT scan and the radiology and everything like that, they’re all lovely people.” (67, male, urban)

“Unless it’s like remote telemedicine or whatever, and then do it on a video link, do not do it just on a god damn mobile phone” (61, male, urban).

Discussion

Patient feedback and patient-reported outcomes are important factors in determining the quality and overall value of health care initiatives(32). Although qualitative studies have been published exploring various aspects of patient experiences during the lung cancer referral pathway (20–28), only few studies have been done in regional health service(29, 30). This study was done in a regional cancer Centre in northern Australia, which has large rural and remote catchment area. Another unique aspect of this study is that many carers participated in the interview and we were able to obtain their experiences as well. Most of the studies did not include carers (27, 31).

Few studies have considered the significance of communication from health care practitioners (HCPs) during the lung cancer referral process and the psychological impact of delays(21, 30, 31). Although most
participants in this study expressed satisfaction about the overall experience, some of them faced difficulties due to improper communication and delays. Many patients and carers experienced significant anxiety while waiting for their results or doctors’ appointments. Participants reported negative experiences when an appointment or procedure occurred later than when the patient perceived it was needed. Maliski et al. reported that the family was an important source of support, both emotionally and through supplying financial and physical aid(42). We also found that many patients received adequate support from family and friends during their referral process.

A qualitative study in lung cancer patients in New Zealand found that there were significant barriers for GPs to refer to specialists and these delayed treatment(31). New Zealand has a health system similar to Australia. Most of the delays in this study occurred prior to specialist appointment, which is similar to results of other studies done in similar health systems(38). Previous studies on lung cancer referral pathways have shown that lack of established trust between patients and GPs lead to delays in taking the patient’s concerns seriously and GP providing inadequate information provided to patients(30, 31, 39). These communication barriers were often exacerbated by a lack of GP continuity(31, 40). Rural areas can have problems with retaining GPs, which results in poor relationship with patients(41). Our study confirms these findings.

Another unique finding of this study is that many participants preferred face to face consultation or video-linked consultations over telephone consultations. Dissatisfaction with phone consults were due to lack of communication skills over phone, diagnosis and prognosis given by unfamiliar doctors and lack of adequate time to ask questions.

**Strengths and limitations of the study:**

This study highlights many significant issues for patients and their carers during lung cancer referral pathway. As far as we are aware, this is the only study done during the COVID-19 pandemic on patients’ and carers’ experiences of lung cancer referral pathway. But our region did not experience any outbreaks of COVID-19 during the study period. So, we expect most of the findings in this study are generalizable for non-pandemic situations as well.

Since the participants were purposively sampled, we reached thematic saturation (no new themes) after interviewing 19 participants. We were able to obtain data from a broad range of lung cancer presentations and stages. The study included seven participants who lived in regional and rural areas and some of the specific problems faced by this population were captured. Since seven carers participated in the interviews, valuable information on their’ experiences and perceptions could be analyzed. Given the diagnosis of lung cancer affects the patients as well as the carers and other next of kin, this data may help to improve their experience of lung cancer referral pathway.

This study has some limitations. This study was done during the COVID-19 pandemic and many restrictions were put on patients or family visiting the GP clinics or hospitals. There was increased adoption of tele-health services, including consultations by telephone(34). Increased use of telephone
and tele-health would have impacted on the quality of communication during the study period. It is notable that participants in this study preferred face-to-face conversation, with a clinician they are familiar with. During the COVID 19 pandemic, patients were discouraged from attending GP practices or emergency department, if they have respiratory symptoms(35, 36). These changes may have contributed to delays in diagnosis of lung cancer in many patients(37).

This study was done in a single referral hospital and therefore only the experiences of those patients attending this hospital were captured. Since THHS manages a large region with many geographically dispersed rural and remote populations, the findings of this study may be applicable only to similar health services. We may have missed patients with lung cancer who never attend the oncology clinics, such as early stage lung cancer patients who are cured after surgery, advanced lung cancer patients who are referred directly to palliative care or patients who refuse treatment. We did not include any lung cancer patients treated in the private sector as the ethics approval was limited to public patients. Almost all participants in this study were Caucasian and only one Indigenous patient was included in the study. It is possible that patients may not be able to recall all the details about their symptoms and investigations as described in other studies (23).

**Implications for future research and practice:**

This study highlights some of the difficulties faced by people being evaluated for suspected lung cancer, including like improper communication, delays, and anxiety. There is a need for health professionals to provide emotional support and respond to the psychosocial needs of patients by eliciting their concerns and attempting to address them in the early stages of the disease process(33) . Telephone consultations are not preferred by patients or carers, especially while discussing diagnosis or prognosis. If face to face consultations are not possible due to factors such as pandemic-related restrictions or geographic distance, video-linked consultations should be made available. The information from this study could be used to improve the referral pathway for people suspected with lung cancer in our region.

**Conclusion**

Lung cancer patients and their carers expressed various themes during the diagnostic and pretreatment interval. Significant improvements could be made to health systems to facilitate better patient and carer experiences of the lung cancer referral pathway. Methods to improve communication by clinicians and reduce delays in referral pathway of lung cancer patients need to be explored further.

**Declarations**

**Disclosure**

The author reports no conflicts of interest in this work.

**Ethics approval and consent to participate:**
Ethics approval was granted by the Townsville Hospital and Health Service HREC committee (HREC/2020/QTHS/58635). All participants provided written informed consent. The study was conducted according to Good Clinical Practice and the Australian Code for the Responsible Conduct of Research, and the Helsinki Declaration of 1975, as revised in 2008.

Consent for publication (Only for identifying information/images of patients or participants; otherwise NA):

NA

Availability of data and materials:

De-identified data can be provided upon reasonable request to the corresponding author.

Competing interests:

The authors declare no conflicts or competing interests in this work

Funding:

This work was funded by the Townsville Hospital and Health Service Study, Education and Research Trust and Administration (SERTA) grant (Reference: 14_2020)

Authors’ contributions:

ZO conceived the study. All authors contributed to the development of the study, including the interview guide. ZO and AB analysed the data, with interpretation discussions with RE, SL and SS. ZO drafted the manuscript. AB, RE, SL and SS revised the manuscript critically. All authors gave their final approval of the version to be published.

Acknowledgements:

Kareela Campbell assisted in conducting interviews.

Authors’ information (optional):

N/A

References


Figures
Figure 1

Example of referral pathway for people suspected with lung cancer.

Figure 2

inter-related themes.