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Delays in lung cancer referral pathways between Rural and Urban patients in North Queensland: A Mixed Methods Study

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List of Abbreviations:

ASGC: Australian Standard Geographical Classification

CBH: Cairns Base Hospital

GP: General Practitioner

Indigenous patients: Patients of Aboriginal and Torres Strait Islander Origin.

MBH: Mackay Base Hospital

RA: Remoteness Areas

TAFE: Technical and further education

TCC: Townsville Cancer Centre

Abstract

Introduction: Aims of this study were to examine time delays in lung cancer referral pathways in North Queensland (NQ), Australia, and explore patients' perspective of factors causing these delays.

Methods: Prospective study of patients attending three cancer centres in Townsville, Cairns and Mackay in NQ from 2009 to 2012. Times along referral pathway were divided as follows: Onset of symptoms to treatment (T1), symptoms to general practitioner (GP) (T2), GP to specialist (T3), and Specialist to treatment (T4). Quantitative and qualitative methods were used for analysis.

Results: 252 patients participated. T1 was influenced by remoteness (125 days in Townsville vs. 170 days for Remote, $p=0.01$), T2 by level of education (91 days for Primary education vs. 61 days for Secondary vs. 23 days for Tertiary/TAFE, $p=0.006$), and age group (14 days for 31-50 years, 61 days for 51-70 years, 45 days for >71 years, $p=0.026$), T3 by remoteness (15 days for Townville and 29.5 days for remote, $p=0.02$) and T4 by stage of disease (21 days for stage I, 11 days for Stage II, 34 days for Stage III 18 days for Stage IV, $p=0.041$). Competing priorities of family and work and cost & inconvenience of travel were perceived as rural barriers.

Conclusion: Remoteness, age and level of education were related to delays in various time lines in lung cancer referral pathways in NQ. Provision of specialist services closer to home may decrease delays by alleviating burden of cost and inconvenience of travel.

Introduction

Lung cancer has been the leading cause of death due to cancer in Australia. Disparity in lung cancer survival rates between rural and urban areas has been well documented worldwide. In Australia, the 5-year survival for lung cancer in urban areas was 15% compared to 13% in inner regional and 11% in outer regional and remote Australia.¹ In addition, Indigenous communities were reported to have a higher incidence of lung cancer than their non-Indigenous counterparts.²

Lower survival among rural patients could be due to many factors including delays in diagnosis, advanced disease at presentation, delays in initiation of treatment, higher proportion of indigenous populations in rural areas and lower uptake of medical therapies. A study from Western Australia reported that rural patients reported more symptoms and took longer to consult their general practitioners (GPs) compared with their metropolitan counterparts. This often led to later diagnosis. They also experienced longer waits for specialist consultations and underwent less diagnostic testings, raising concerns regarding equity and quality of lung cancer care for rural patients.³ In a Scottish study, lung cancer

patients living more than 58kms from a cancer centre were more likely to present with later stage disease than patients living closer to cities.⁴

In the Australian state of Victoria, it was found that radiotherapy and chemotherapy were under-utilized by patients, and 26% of patients did not receive any treatment for their Lung Cancer. Patients whose cases were discussed at a multidisciplinary meeting (MDM) were significantly more likely to receive anticancer treatment and had longer survival.⁵ In another recent Victorian study, it was found that there were significant delays at various stages of patients' journey from the first presentation to treatment commencement, and patients treated at public hospitals experienced longer delays than those attending private hospitals.⁶ A Queensland study comparing the survival of indigenous and non-indigenous patients receiving treatment for lung cancer found that indigenous patients had a lower survival rate even after adjusting for histological subtype, stage at diagnosis and co-morbidities.⁷

Although these studies have established the presence of survival disparity between rural and urban populations and the impact of delays in medical consultations or treatment on survival, most of them were retrospective in nature and studies examining possible reasons for such delays were limited. Therefore, prospective studies examining referral patterns are required for understanding these delays.

In North Queensland, where this study was conducted, patients from rural areas may travel distances up to 1000km to access specialist care and may be referred to one of the three centres, namely Townsville, Cairns and Mackay for diagnostic work-up and further management. Townsville provided comprehensive cancer services including cardiothoracic surgery in private and public sectors. Cairns offered radiotherapy services and Mackay had recently begun radiotherapy services in 2017.

The objectives of this study were to identify any differences in time delays in lung cancer referral pathways between rural and urban patients and explore patients' perceived barriers to timely lung cancer diagnosis and management.

Methods

Setting and participants

Lung cancer patients presenting to Townsville Cancer Centre (TCC), Cairns Base Hospital (CBH) and Mackay Base Hospital (MBH) in North Queensland, Australia from 2009 to 2012 were approached for participation in this prospective study. Patients from Mt. Isa who required treatment via teleoncology at the TCC were also included in the study. The study was limited to patients from the state of Queensland. The Inclusion criteria specified patients diagnosed with lung cancer, age >18years, and a residential address in the study catchment area at the time of diagnosis. Patients electing not to sign consent were excluded from the study. Patients were divided into outer regional (urban) and rural or remote (rural) based on their residential postcodes and Australian Standard Geographical Classification system (ASGC); summarised in Table 1.

Referral times along lung cancer pathway

The study examined various time frames from estimated date of onset of symptoms to commencement of treatment. The time periods of referral pathways were described as follows:

- T1: Time from first symptoms to commencement of treatment.
- T2: Time between first symptoms to first GP consultation
- T3: Time between GP and specialist consultation
- T4: Time between specialist consultation and commencement of treatment

Clinical data collection

Data pertaining to treatment and consultation times at TCC, CBH and MBH were extracted from their oncology information system MOSAIQ[®]. Outside of cancer centres, data were collected from hospital medical records and phone calls to general practitioners and private specialists.

Data analysis

Fisher's test was used to compare the correlation between ASGC classifications and the various time periods. Besides remoteness, influence of other clinical, social and demographic factors such as gender, ethnic status (Indigenous or non- Indigenous), education level (primary, secondary or tertiary/TAFE), income (<\$20,000 or >\$20,000), and stage of disease on these times were analysed using Kruskal-Wallis and Mann-Whitney tests for statistical significance.

Qualitative data collection and analysis

Semi-structured, open-ended interviews lasting 5-10 minutes were conducted on all consenting patients. An interview guide was used in exploring the factors leading to late presentations, and poorer outcomes of rural oncology patients in comparison to those living in regional or urban areas. A single researcher, who had no clinical involvement and no prior relationship with any study participant, conducted interviews. Interviews were undertaken with all participants, either face-to-face, over the telephone or via videoconference. Each Interview was transcribed, coded, and summarised using thematic analysis.

Ethics approval:

This study was approved by ethics committees of the Townsville, Mackay and Cairns Health services.

Results

Demographics

Our study identified 132 patients from Townsville, 60 from Cairns, 41 from Mackay, 16 from Mt Isa and 3 patients referred from private practice. Out of all patients identified, 88% of patients were diagnosed with Non-Small Cell Lung Cancer. Further data on demographics and diagnoses is presented in Table 2.

Of the 252 lung cancer patients who participated in the study, 182 (72%) were classified as urban and rest as rural/remote. Only two patients declined to participate in this prospective study. In rural compared to urban patients there were more males (73.6% vs. 60%, $p=0.046$) and more Caucasians (96.2% vs. 90%, $p=0.068$). Also, the level of secondary or higher education was significantly higher in urban compared to rural cohort (88.5% vs. 62.7%). Tumour demographics like histology and stage were balanced between the two cohorts.

Time delays

Factors associated with time delays at various point in referral pathways were summarised in Table 3. Location was associated with delays in T1 and T3. Age and level of educations were associated with delays in T2 and stage of the disease was related to T4. Although numerical difference seemed large between Indigenous and Non-Indigenous patients in T2, this result was not statistically significant.

Patient perspectives of factors contributing to delays

112 patients agreed to take part in short interviews following completion of questionnaires. Common themes arising from analyses of transcripts were summarized below:

Misinterpretation of symptoms by GPs

Misinterpretation of symptoms was considered as a factor in first presentation to the GP among rural and urban participants [rural 42% vs. urban 40%]. In addition, it was common among participants to delay presentation until their symptoms were severe enough that they could not be tolerated or impeded on their day to day activities.

Some quotes from participants were as follows:

"I went to the GP for other reasons. When he observed me coughing up some blood he did an X-ray. Thanks to him the cancer problem was discovered [L010]."

"I didn't feel good. I kept coughing and I couldn't ride my bike anymore. I even went off the beer. Probably about 4 months I was like that [L074]."

"I noticed the shortness of breath for more than 9 months. It was getting worse with time. I couldn't sleep, but it did not interfere with my golf. I thought it would get better [L026]."

"I couldn't lift the drum and the pain my side got really bad [L092]."

Many participants described their doctors attributing symptoms to benign causes such as infection [rural 26% vs. urban 28%], or exacerbations of co-morbidities [rural 5% vs. urban 1%]. For example:

"My referral to the specialist was delayed because of my asthma. My doctor thought the cough was due to the asthma and treated me with 2-3 courses of antibiotics. When the cough did not get better a chest X-ray was done and the lung cancer diagnosis came up [L021]."

Not being doctors' person

Patients in the rural cohort were more likely to cite the reason of "not being a doctor person" for the increased delay in presenting to a GP [rural = 4% vs. urban = 0%].

A number of patients refused investigations such as bronchoscopies. This resulted in further delays in diagnosis and management [rural 4% vs. urban 0%]. The reasons for this included fear of the investigations, as demonstrated in the quote below from a patient stating "he did not want to die from bleeding [L014]."

Competing commitment to family and work

Participants often perceived other priorities as more important than their health, such as family commitments and work, leading to delay in presentation [rural 4% vs. urban 0%]. This was displayed in this participants' account:

"I am working hard looking after my handicapped son, that I did not pay attention to my cough, and that it had been worsening [L003]."

Long distance travel and financial difficulties

Participants residing in rural communities frequently described travelling as a significant barrier to receiving their chemotherapy and follow up in tertiary centres [rural 15% vs. urban 0%]. One participant described how she "drove from Mt Isa [L002]", a distance of 1000km from the Townsville Cancer Centre.

Financial difficulty was a central theme reported by rural patients as a key barrier to their management [rural 12% vs. urban 5%].

“Now there is a problem with me getting to Townsville. My friend drove me last time and I still have not got any petrol money or accommodation money. So I don’t know what to do about my next trip on the 25th of November. If it all gets too hard I might let nature take its course but if its fixable I would like to be treated [L076].”

“I had to give me work up and need a carer now. My wife had to give up her job as well [L154].”

Discussion

Our prospective study identified several factors associated with referral delays among lung cancer patients while adding their perspectives to such delays.

We found that remoteness was associated with delays in onset of symptoms to commencement of treatment and GP referral to specialist review. This could be explained by poor health seeking behaviour, competing demand on caring for family and work, and cost and inconvenience of long distance travel to major centres for appointments and treatment. Contrary to the expectation, there was no difference between rural and urban patients in onset of symptoms to first GP consultation. Our study did not examine system factors such as timely processing of referrals and coordination of multiple appointments within major centres that may have contributed to these delays.

The number of indigenous patients was very small in this study (13 indigenous vs. 232 non-indigenous). Though Indigenous status had no impact on any of the timelines, meaningful comparisons were difficult because of smaller number of indigenous patients.

Among lung cancer patients, the literature had described lack of awareness and lack of symptom perception as the biggest factors that delay first presentation to GPs. In a study conducted by Koyi et al.⁸ in Sweden, it was found that patients did not present early because of lack of awareness and difficulty in accessing primary care. Another study conducted in England by Bowen et al.⁹ identified non-recognition of symptoms as the major cause for delayed presentations. Our study identified that at least half of the patients attributed their symptoms to benign causes and/or did not recognise their symptoms. In our study, 61.2% of patients presented with stage IV disease and there was no difference between rural and regional areas (60.8% in regional vs. 62.1% in rural areas). This was in contrast to a study conducted in Scotland, where only 28-33% of patients presented with stage IV disease⁴ and patients in rural areas were more likely to present later in the disease process than urban areas. Regardless of conflicting results reported by studies, it would be important to improve symptom recognition among patients, regardless of the location of residence to reduce these delays.

Older age and level of education had an impact on time between first symptoms to first GP consultation (T2). Older patients tended to present earlier. This could be explained by the presence of multiple co-morbidities in elderly patients and the need to visit GPs regularly and thus were better educated in their symptom recognition. Though the level of secondary or high school education was lower among rural patients in our study, location of residence was not related to delays in T2 in contrast to the Western Australian study.³ It was possible that there might be differences between patients from capital cities such as Perth and regional cities in symptom recognition and health seeking behaviours which was beyond the scope of our study.

One of the issues expressed by rural patients in our study was the limited access to care closer to home and resulting inconvenience and cost of long distance travel to attend appointments and treatment. This issue was compounded by the fact that some patients had to simultaneously manage their family and work commitments while undergoing medical

therapies. Hopefully, adoption of various teleoncology and telehealth models of care by health systems to improve rural access to all aspects of patient journey may alleviate some of the burden and enable rural patients attend appointments and treatment in a timely manner.¹⁰

Though our study was a prospective study, date of onset of symptom was based on patients' recollection. However, patients' recollection in our study would be more accurate at the time of presentation than that of retrospective studies where patients were expected to remember events after multiple encounters with multiple specialists and treatment providers. Our study also failed to investigate system deficiencies within larger centres that may have contributed to delays. Some of these deficiencies could include chaotic referral processes and lack of coordination of multiple appointments. Consistent use of cancer care coordinators and adherence to lung cancer optimal care pathways could minimise system deficiencies.

In conclusion, our study, while confirming remoteness, age and level of education as factors associated with delays in lung cancer referral pathways, highlighted issues faced by patients that may contribute to these delays. Educational campaigns aimed at improving symptom recognition among all populations (both rural and regional) and creation of systems to provide specialist services closer to home for rural patients may decrease some of the delays.

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Table 1: Separation of patients based on postcodes.

<i>Cohort as per ASGC classification</i>	<i>Urban/Outer regional (RA 3)</i>	<i>Rural/Remote (RA 4 and 5)</i>
<i>City (Postcodes)</i>	Townsville (4810-4817) Cairns (4868-4871) Mackay (4739-4741)	All other areas were under this classification

Table 2: Demographic details of participants

Characteristics	Total N=252(%)	Outer regional N=182(%)	Remote or very remote N=70(%)	p-value**
Demographic				
<i>Male</i>	176 (69.8%)	134 (73.6%)	42 (60.0%)	P=0.046
<i>Mean age (SD); range [years]</i>	65.2 (10.0); 37 to 91	65.5 (10.5); 37 to 91	64.5 (8.7); 38 to 81	p=0.482
<i>Indigenous patients</i>	14 (5.6%)	7 (3.8%)	7 (10.0%)	P=0.068
<i>Born in Australia</i>	205 (81.3%)	148 (81.3%)	57 (81.4%)	P=1.0
<i>Secondary or higher school education</i>	109 (79.0%)	77 (88.5%)	32 (62.7%)	P=0.003
<i>Private health insurance</i>	81 (32.1%)	61 (33.5%)	20 (28.6%)	P=0.018
<i>Income less than \$20,000</i>	70 (54.7%)	48 (60.0%)	22 (45.8%)	P=0.144
Diagnosis				
<i>Incidental finding</i>	51 (20.2%)	44 (24.2%)	7 (10.0%)	P=0.014
<i>Small cell lung cancer</i>	29 (11.5%)	20 (11%)	9 (12.9%)	P=0.664
<i>Non-Small cell lung cancer</i>	223(88.5%)	162(89%)	61(87.1%)	P=0.676
<i>% Treatment palliative</i>	190 (75.4%)	138 (75.8%)	52 (74.3%)	P=0.870

Table 3: Factors contributing to delays at various time points in referral pathways.

T1 – Time between first symptoms to treatment					
Location	Townsville (n=81)	Cairns and Mackay (n=60)	Remote (n=111)	p-value	
<i>Median delay; (days);</i>	125; (21-465)	148; (21-689)	170; (32-938)	0.040	
T2 – Time between first symptoms to first GP consultation					
Indigenous status	Indigenous	Non- Indigenous			p-value
<i>Mean delay; range (days);</i>	92; (14-242)	57; (0-905)			0.055
Age group	31 to 50	51 - 70	>71	p-value	
<i>Median delay; range (days);</i>	14; (0-150)	61; (0-881)	45; (0-905)	0.026	
Level of education	Maximal primary	Secondary	Tertiary or TAFE	p-value	
<i>Median delay; range (days);</i>	91; (0-905)	61; (0-881)	23; (0-367)	0.023	
T3 – Time delay between first GP consultation and first specialist consultation					
Location	Townsville	Cairns or Mackay	Remote	p-value	
<i>Median delay; range (days);</i>	15; (0-401)	14; (0-364)	29.5; (0-389)	0.041	
T4 – Time between first specialist consultation and treatment commencement					
Stage of disease	Stage I	Stage II	Stage III	Stage IV	p-value
<i>Median delay; range (days);</i>	21;(0-105)	11; (0-364)	34; (0-643)	18; (0-257)	0.031