



THE NEEDS OF RURAL LUNG CANCER PATIENTS:

RESEARCH STUDY INTO THE NEEDS (MET AND UNMET) OF PATIENTS DIAGNOSED WITH A PRIMARY LUNG CANCER WHO RESIDE WITHIN THE COFFS HARBOUR, BELLINGEN OR NAMBUCCA REGIONS OF THE NORTH COAST AREA HEALTH SERVICE



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Author: Christine Stanford
Clinical Nurse Consultant
Medical Oncology/Haematology
North Coast Cancer Institute
Coffs Harbour Health Campus

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AREA HEALTH SERVICE
NSW HEALTH

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Emma Webster

Rural Research and Executive Support Officer, NSW Institute of Rural Clinical Services and Teaching; Adjunct Lecturer Faculty of Medicine, University of Sydney

Caroline Heise

Nurse Manager, Bellingen District Hospital
Critical Research Friend

TABLE OF CONTENTS

Page Number

Abstract	3
Introduction	4
Background	4
Methods	8
Results	10
Discussion	22
Conclusion and Recommendations	25
References	25

APPENDICES

1. Demographic, Diagnosis and Staging Data Collection Form
2. Letter of Invitation
3. Patient Information Sheet
4. Participant Consent Form
5. Interview Schedule

ABSTRACT

Objective

The objective of this qualitative study is to explore the patient experience of lung cancer in the rural setting, and to determine the needs, both met and unmet, throughout the journey. Comparison of the findings with the evidence in the literature provides an evaluation of current service provision and identifies areas in which service provision could be improved.

Methods

A Health Information Exchange report using inpatient separation data under International Classification of Diseases (ICD-10) codes was cross referenced with local records to provide a saturated sample of patients diagnosed with a primary lung cancer within the Coffs Harbour, Bellingen, and Nambucca Regions of the North Coast Area Health Service during the period 01/07/06 to 30/06/07. Eligibility was confirmed from medical records, data collected using a semi-structured interview format, and interview transcripts coded and analysed using a method of thematic content analysis.

Results

Lung cancer patients and their carers face an uncertain future and experience a high level of need including a timely pathway to diagnosis; honest and sensitive communication of diagnosis, treatment options and prognosis; provision of co-ordinated family-oriented, multidisciplinary care; and provision of support, both practical and emotional. There is evidence of an attitude to support which prevents patients from accessing support services that are widely available.

Conclusion and Implications

There is overall satisfaction with services and teams providing care locally, and in the preferred metropolitan centres. There is a need to improve access to treatment in the local area. The diagnostic process needs to be refined and access to multidisciplinary team planning and care coordination could be improved to ensure access for all patients. Further research is required into the reason for reluctance to access support services; the challenge of providing individualised information; and the challenge of providing realistic, but reasonably hopeful communication of diagnosis, treatment options, and prognosis for this group of patients.

INTRODUCTION

This report is prepared for the NSW Institute of Rural Clinical Services and Teaching (IRCST) Rural Research Capacity Building Project as the culmination of a two year funded research study into the needs (met and unmet) of patients diagnosed with a primary lung cancer who reside within the Coffs Harbour, Bellingen or Nambucca Regions of the North Coast Area Health Service (NCAHS).

This study explores the experience of a group of lung cancer patients, searching to identify their needs, and evaluating if those needs were met or not.

The study concludes that the outlook for lung cancer patients remains grim, with these patients and carers having a high level of need in the areas of pathway to diagnosis, communication of diagnosis and prognosis, provision of coordinated care, and support. There is an overall satisfaction reported with service provision. There is a need to evaluate the diagnostic process, and improve access to multidisciplinary team planning and care coordination. There is evidence of an attitude to support that prevents patients from accessing support services that are widely available. Further research is required in this area.

BACKGROUND

Lung cancer is one of the leading causes of death globally. Despite advances in treatment, outlook for the majority of patients remains grim and most face a pessimistic outlook accompanied by sometimes devastating effects on emotional and psychological health. Since only those patients whose disease is operable at the time of presentation have a chance of cure, between 80% and 90% of patients are faced with an average survival from the time of diagnosis of about eight months.¹ This Cochrane review documented the need for qualitative research to further advance knowledge and understanding of the experience of lung cancer to gain insight to improve care of these patients.

There were 2,950 new cases of lung cancer in NSW in 2005 accounting for 9.2% of all cancers in males and 7.8% in females. Lung cancer ranked third in males and fourth in females for incidence. Mortality ranked first in males, and equal first with breast cancer in females. The five-year relative survival experienced in 1999 to 2003 in NSW for lung cancer was 13% for males and 15% for females. The Age Standardised Incidence Rate for lung cancer in NSW is 53.0 new cases per 100,000 in males and 29.8 in females.²

During 12 years experience as a cancer nurse, working with cancer patients across the spectrum of their illness, I have witnessed major improvements in service provision for these patients, including care coordination, access to multidisciplinary team care, strengthening of metropolitan / rural partnerships and access to physical and emotional support.

These changes in service provision are in accordance with state and local health services planning. By 2010 standard practice in NSW should include case coordination, treatment supported by known multidisciplinary teams, and comprehensive patient support (information, psychosocial, palliative care), with equity of access and expertise to the rural population through the development and strengthening of links between metropolitan and rural cancer centres.³ Strategic Directions for NSW Health focus on

creating better experiences for people using the health system and building regional partnerships for health.⁴

This study aims to provide a snapshot of service provision for the lung cancer population of a defined rural area by using personal experience to document the needs, both met and unmet, of a sample of patients diagnosed with a primary lung cancer. The anticipated overall outcome of this study is to determine the patient perspective of where gaps in service provision exist and what improvements in service provision would improve the experience for this patient population.

Lung cancer patients have been identified as a priority group because in addition to the documented needs of this patient population, the majority of these patients have the added burden of requiring multidisciplinary team care inclusive of metropolitan services for further investigation, surgical management and in some instances treatment with radiotherapy.

It is well documented in the literature that this group of patients have special needs to be considered. These needs are documented under themes of supportive care, practical issues, care-coordination, caregiver burden, and patterns of care.

The term “needs” has been defined as the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being.⁵ Needs assessment enables individuals and sub-groups of patients with higher levels of need to be identified and targeted with appropriate early interventions, and also makes it possible for aspects of health services that need improvement to be identified and prioritised.⁶ Results of an Australian study into supportive care needs concluded that subgroups of patients experience different types of needs, and that patients with advanced disease have significantly higher levels of need and unmet need.⁷

The supportive care needs of lung cancer patients has a significantly higher burden of unmet needs compared to other cancer patients, with more than 40% of the lung cancer patients reporting a high level of unmet psychological needs and half reporting a high level of unmet daily living needs, suggesting that priority action is required to ensure that these patients are offered the services and support required to assist them through their difficult cancer journey.⁸ This finding is collaborated in studies that document that out of 14 tumour types, lung cancer patients, as a group, experienced the highest levels of psychological distress⁹, and that 19% of advanced lung cancer patients experience clinical depression between the time of diagnosis and initial treatment, and recommended that psychological intervention for advanced Non Small Cell Lung Cancer (NSCLC) patients should be initiated soon after cancer diagnosis.¹⁰

The experience of cancer is full of fear, questions and a lot of stress, and an extra burden is felt when no concern for their feelings and opinions has been expressed. It has been shown that the period of waiting from the first suspicion of cancer until diagnosis confirmation of the disease was a period of great stress, and that the following period until the commencement of treatment was also a very difficult one. Receiving the diagnosis of cancer was remembered as being a very dramatic experience and the way in which diagnosis is communicated is important to lessen the patient’s fear, but also to lessen the stressful situation for the doctor when giving the patient bad news, and that in the diagnosis situation there was a need for some form of hope.¹¹

Despite the overwhelming evidence of the physical and emotional burden of lung cancer, few studies have explored patient's perceptions of the help or support they need to live with the disease. On this basis, a qualitative study identified four key domains of need: (1) the pathway to confirmation of diagnosis, (2) communication of diagnosis, treatment options and prognosis, (3) provision of co-ordinated family-oriented care and (4) support away from acute services. The findings indicate the need to evaluate the benefits to patients and carers of rapid access to diagnostic tests and results and support the establishment of effective and stream-lined supportive care pathways for patients with lung cancer.¹²

There have been reports that in lung cancer, symptom distress is reported as being more severe than in any other type of cancer and extends throughout the illness continuum¹³. A retrospective US study concluded that symptom palliation and quality of life are closely related and that in patients with lung cancer it becomes of paramount importance to control their symptoms. In order to achieve this, this study recommends reassessment of patterns and timing of referrals to support care services.¹⁴

The symptoms of breathing, pain and fatigue are associated with the most distress in lung cancer patients, even when the study sample represents the 'healthiest' of this very ill patient group, providing a strong basis for preventive intervention and clinical education.¹⁵

The practical needs of patients and their families travelling from rural areas in New South Wales to cities for cancer treatment have been explored and documented. Information prior to travelling was a principal unmet need and few patients obtained benefits for travel and accommodation, adding to the economic impact of being unable to maintain an income and cover the unexpected expenses involved. The participants also indicated their anxiety and fear in coming to the city and the study highlights that the impact of coping with the diagnosis makes it difficult to manage the practical issues, and in turn the pressure of managing practical needs impacts on the ability of patients and families to cope with the diagnosis and treatment.¹⁶ This study was conducted on the basis of limited specialist cancer care in rural Australia with an example provided of only two regional towns in NSW having a resident medical oncologist, and even though multiple regional cancer centres have been established with medical oncology services on-site, it is still a requirement for many rural lung cancer patients to access multidisciplinary care in a metropolitan centre.

An evaluation of the literature relating to information needs of patients with cancer, accentuated that information is a much individualised aspect of care, and that a lack of information, explanation and support has been cited as the greatest cause of anxiety and stress in cancer patients. This study identified the following priority information needs: available treatment regimes; side-effects of treatment; extent of disease; likelihood of cure and prognosis; and self-care and return to normal life-style.¹⁷

The need for one individual to coordinate care across all parts of the health care system has been illustrated, and this provides potential to shift the emphasis from focusing solely on the physical aspects of disease management to include also the emotional and social needs.⁹ Care coordination is one of the six key areas for development in service provision for patients with lung cancer, along with encouraging patients to present earlier to their GP, rapid diagnostic clinics, nursing care in the community, equitable access to palliative care and social services, and supportive strategies targeted at carers.¹⁸

The top 20 list of problems reported by caregivers includes fears and emotional burdens, the need for support managing symptoms, and the need for professional coordination of services.¹⁹ Whilst the needs questionnaire used in this study had limited scaling in degree of severity, any discrepancy is likely to be in under reporting. The participants of this study were all caring for patients with a poor ultimate prognosis, and thus provide a relevant assessment of carer-specific needs.

In a study into the relationship between available support, unmet needs and caregiver burden, it was found that patients give lower estimates of available support and of unmet needs than caregivers, and across all domains of need, carers consistently reported that the patients had more unmet needs, than the patients themselves reported. Carers' reports of patient unmet needs are important to consider as they were associated with high levels of caregiver burden.²⁰

Significant differences have been identified in patterns of lung cancer care between area health services in NSW, indicating that there is inequity of care.²¹ One of the recommendations from this study was for data collection defining the process of lung cancer management.

This research project will contribute to defining that process of lung cancer management in this area, and provide an evaluation of current service provision from the perspective of the consumer, including the patient and the carer. This project will add qualitative data to gain insight into the experience of these patients, and compare the needs of this group to the needs that have been identified or explored in the literature, posing questions that are not yet answered.

The importance of this study is in the realisation that the only way to address unmet needs is to know about them and redesign the provision of services to cater for them. The benefits of evaluation and improvement of services belong to both the patient/carer population and the service provider.

Research question

What are the needs (met and unmet) of patients diagnosed with a primary lung cancer who reside within the Coffs Harbour, Bellingen or Nambucca regions of the North Coast Area Health Service?

Secondary questions

What are the referral patterns?

Is the diagnosis process adequate?

What is the impact of a diagnosis of lung cancer on the patient?

Are these patients receiving the care they need?

METHODS

This project is a qualitative study into the needs (met and unmet) of lung cancer patients who reside within the Coffs Harbour, Bellingen and Nambucca regions of the NCAHS and who were diagnosed with a primary lung cancer during the period 01/07/06 to 30/06/07.

Ethics approval was received from the Human Research Ethics Committee of the NCAHS on 17th August 2007, after a submission date of 12th July 2007.

Various literature searches were conducted in MEDLINE, CINAHL and PsychoINFO databases using keywords such as lung cancer, needs assessment, needs analysis, patient needs, psychological impact, psychological stress and rural health. These terms were broadened to include non-specific cancer types, and the reference lists in relevant studies were also searched to enhance the scope of the review.

SAMPLING METHODS

A list of patients diagnosed with a primary lung cancer was determined by a Health Information Exchange (HIE) report using inpatient separation data under ICD-10-AM (International Classification of Diseases) code C34 (C34.0 – C34.9) *Malignant neoplasm of bronchus and lung*. This list was cross referenced with local records of newly diagnosed patients treated at Coffs Harbour North Coast Cancer Institute (NCCI) with the following inclusion and exclusion criteria:

Inclusions: Patients diagnosed with primary lung cancer during the period 01/07/06 to 30/06/07 and who reside within the Coffs Harbour, Bellingen or Nambucca Local Government Areas of NCAHS
Diagnosis of Non small cell lung cancer (adenocarcinoma, squamous cell & large cell carcinoma)
Diagnosis of Small cell lung cancer

Exclusions: Diagnosis prior to 01/07/06 or after 30/06/07
Residence outside Coffs Harbour, Bellingen or Nambucca Local Government Areas of NCAHS
Deceased patients
Diagnosis of Mesothelioma
Personal friend or family member of the researcher

The population estimate in 2006 for the Coffs Harbour, Bellingen and Nambucca Local Government Areas combined was 101,140 (Bellingen 13,069 Coffs Harbour 69,399 Nambucca 18,672).²² The age-standardised incidence of lung cancer in NSW is 41.4 per 100,000 and the age-standardised incidence rates for lung cancer for North Coast Area Health Service residents are neither significantly higher nor lower when compared to NSW as a whole, reflected in the NSW Central Cancer Registry Statistics Module as 46.5 per 100,000 with a Lower 95% CI of 44.2 and an Upper 95% CI of 49.0.²³

Cross referencing of the HIE report and local records, yielded a saturated sample of 52 patients with a primary lung cancer diagnosis between 01/07/06 and 30/06/07, and resident within the defined regions of the NCAHS, after exclusion criteria were applied. Thirty one patients were immediately excluded on the basis that they were deceased.

Two further patients were excluded, one due to deteriorating condition, and the other excluded on the basis of being a personal friend or family member of the researcher.

Demographic, Diagnosis and Staging Data Collection Forms (Appendix 1) were completed from patient medical records for 23 patients. Data collected included name, date of birth, medical record number, age, gender, address, phone, next of kin and contact number. This form also included diagnostic data of type of lung cancer, date of diagnosis and staging according to International Cancer Tumour, Node, Metastasis (TNM) Classification System.²⁴ Each patient was assigned a participant identification number to enable de-identification of the data from this point onwards.

A further two patients were excluded at this time due to an unconfirmed tissue diagnosis, and recent death. Letters of Invitation, including the Patient Information Sheet and Participant Consent Form (Appendix 2 - 4) were posted to the remaining 21 eligible participants, with the opportunity to decline to be part of the study by phoning an independent contact. Given the high mortality rate associated with lung cancer and the debilitating nature of the illness, patients who had no documentation of being seen within the last four weeks, were not invited into the study until confirmation had been received from the appropriate General Practitioner (GP) that the patient was well enough to be contacted.

Follow-up phone calls were made approximately two weeks after the invitations were posted. Twelve patients accepted the invitation, six patients declined to participate, and three patients could not be contacted. One patient who agreed to participate was hospitalised and remained too unwell to interview, and one patient was subsequently excluded throughout the research process due to incorrect recording of diagnosis date.

METHOD OF DATA COLLECTION

A total of 11 interviews were conducted between the period 27/09/07 and 19/10/07 with an average interview time of 42 minutes. The interview schedules were very flexible and patients were offered the interviews in their own home if they preferred. The interviews were conducted by the researcher in a semi-structured format, allowing the patient to tell their story, with questions, prompts and probes included as required (Appendix 5). The interview focuses on personal experience from the time of diagnosis onwards, and looks at practical, physical and emotional needs. As consumers, the participants were offered the opportunity to evaluate and comment on the services they received, and make suggestions as to what services may have helped them manage their illness better.

It was made clear in the information sheet that carers were welcome to be present at interview but that they needed to complete a consent form if they wished to participate in the interview. Data from one interview was disregarded prior to analysis as inclusion had been based on an incorrect diagnosis date.

Analysis was performed using a method of thematic content analysis adapted from a grounded theory approach.²⁵ The approach taken was similar to that of a Norwegian study exploring what it is like living with a diagnosis of cancer, using the data collected to describe and explore the individual's own perspective.⁹ All patient transcripts were open coded into categories and sub-headings, with those categories and sub-headings surveyed and grouped together under higher-order headings. To add to the rigour of the study, sample transcripts were coded by a colleague against the categories and sub-

headings list, and the categories and sub-headings list adjusted accordingly. Interview transcripts were then coded according to this list. The list of categories and subheadings continued to evolve throughout the whole coding process and the write-up period.

RESULTS

The final study sample of ten patients included six males and four females with an age range of 58 to 81 years. Every patient had a spouse or carer listed as next of kin, five patients attended the interview alone and five had their carer participate. One of the patients suffered from significant Alzheimer’s disease and his wife was the major spokesperson for this interview. Of the ten patients, eight were required to travel to a metropolitan centre for investigation, opinion or treatment. Three patients underwent surgery and three were treated with radiotherapy in a metropolitan centre, with two of this three treated with concurrent chemotherapy/radiotherapy. One patient was due to commence radiotherapy locally. Nine patients in total were treated with chemotherapy, with eight of the nine receiving at least some of their treatment in the local centre. Three participants reported contact with a local cancer nurse coordinator and one with a case manager in the metropolitan centre. Only two patients were aware of their case being discussed by a multidisciplinary team.

Table 1. Participant details

Patient ID Number	Age	Gender	Next of Kin or Carer	SCLC or NSCLC	Stage	Date of Diagnosis	Treatment
1	72	M	Wife	NSCLC	IIB	10/07/07	S C
4	58	M	Wife	NSCLC	IIIA	30/05/07	C R
7	67	F	Husband	SCLC	Extensive	May 2007	RT C
9	57	F	Partner	NSCLC	IIIA	25/08/06	C/RT
10	66	M	Wife	NSCLC	IV	23/05/07	S C
11	72	M	Partner	NSCLC	IIIA	14/02/07	C S
14	72	F	Husband	NSCLC	IV	20/04/07	C
15	74	M	Wife	NSCLC	III	27/06/07	C/RT
16	69	F	Son	NSCLC	IV	29/11/06	C
19	81	M	Wife	NSCLC	IA	23/05/07	RT

Legend:

SCLC: Small Cell Lung Cancer

NSCLC: Non Small Cell Lung Cancer

S: Surgery

C: Chemotherapy

RT: Radiotherapy

C/RT: Concurrent Chemotherapy/Radiotherapy

The majority of patients reported investigation of a symptom leading to their diagnosis with only one patient diagnosed on an incidental finding. One patient was transferred to Royal North Shore Hospital (RNSH) with spinal cord compression prior to tissue diagnosis, and the remaining nine patients were investigated locally with CT (Computed Tomography) and biopsy. Seven of the ten patients were referred for PET (Positron Emission Tomography) scan.

Table 2. Symptom under investigation at diagnosis

Patient ID Number	Symptom
1	Incidental finding
4	Haemoptysis
7	Back pain, Spinal Cord Compression
9	Cough
10	Chest pain
11	Ataxia
14	Chest pain, SOB
15	Shingles, R) Shoulder pain, SOB
16	Dyspnoea
19	Cough

Referral patterns reflect a preference for Royal Prince Alfred Hospital (RPA) in Sydney for surgical opinion and management, with five of seven patients referred to a thoracic surgeon at RPA, and the remaining two patients choosing to be referred to a Brisbane hospital because of availability of support of family and friends in that metropolitan centre. Practice at the time of report was referral to RNSH for radiotherapy, reflective in the referral of one patient for palliative radiotherapy and one patient for combined chemotherapy/radiotherapy. The remaining two patients were not considered candidates for surgery and did not require referral to a metropolitan centre.

One female patient had a previous diagnosis of breast cancer and one male patient was receiving radiotherapy for prostate cancer at the time of his lung cancer diagnosis. One other patient reported a very strong family history of cancer including mother (bowel), three sisters (lung, bowel, ovarian) and one brother (lung). The younger sister of this patient had died recently from lung cancer. One further patient had lost his friend and neighbour to cancer recently.

The Bad News Journey

The transcript data reveals an overall acceptance of timing of investigations and delivery of results with timeframes ranging from a few days to four weeks. There were exceptions to this with one patient describing the impact of having to wait a number of months:

“I went to the doctor somewhere in mid January. Well, then it was after Easter before I actually knew what the ...score was. You wait .. you go for one and then you wait two weeks. And then you go for another one. And then you wait two weeks. And ... that waiting is the worst part, knowing is one thing but waiting .. wondering ...is worse. But that’s what we found to be the worst. Was wait, wait, wait. It was all very harrowing. And you know very well what the answer’s going to be. But you want to know.”

One other patient was dissatisfied with a six week waiting time and one carer considered five days unacceptable and thought that the doctor was responsible for notifying the patient as soon as he/she is aware of the result:

“When he should have had the decency to call us in the next day to notify us. He would have known at that time.”

Reflections on how the bad news was broken, are understandably diverse, as each patient has a very personal account of that experience. In this section of the data, there are instances of humour (reflective of attitude to be discussed elsewhere), contrast

between negative and positive sounding words, misunderstanding, dealing with an unfamiliar GP, the unexpected, and body language telling the story.

Participants were mostly able to report word for word how they had been told their diagnosis. There was a definite acceptability versus unacceptability in the telling process, focussed mostly on the wording used to break the news. The following were acceptable to the participant:

'Well, it appears we are looking at lung cancer.'

'I'm sorry to tell you, you've got cancer...it's inoperable. I'll have to... get some more information.'

"...and he didn't feel there was any doubt at all ... that it was. He said 'Oh, these things have a habit of hiding until they're ready to come out.' So that was all right."

'Its not good news.'

In contrast, there are many reports of wording that can only be described as negative, and which impacted on the participant:

'Well, I can't do anything here.'

'Well, you've wasted your time coming to see me. I can't do anything with you because it's on the move. So he said he wouldn't ever operate under those circumstances.'

'...do you want the good news or the bad news? Which do you want first? ..you've got cancer.'

'Well, it's cancer'. And with that I said "How long do I have?" He said 'About six months, so I won't need to see you again.'

Of interest is one example of the patient's perception of a good balance between negative and positive:

"... if I didn't have chemo I'd be ta-tas about Christmas. And if I did have it, she couldn't really say for sure, but there was a 50-50 chance it would work."

Other issues included misunderstanding of what was said by the doctor leading the carer to believe that the doctor had written the patient off, and having to see an unfamiliar doctor when the usual GP was away. Two participants reported that they had been unsuspecting of a problem until advised by phone that the doctor wanted to see them, and one patient described this as very traumatic.

Body language telling the story is best described in the following excerpt with one patient explaining how she became aware that there was a problem:

"... because where my bed was I was watching them all with the scans on the machine, and, all of a sudden ... there was one, there was two, and then ... ended up there were six people looking at them. And then at one stage they all turned around and looked at me, which I knew then that it was my scan."

Participants were asked to recall their biggest concern at the time of diagnosis. Practical issues were raised at this time, including getting travel and accommodation organised, timing of diagnosis notification, cost, and not being able to access treatment locally. Emotional concerns of fear of death, not pulling through the operation, getting over the shock and telling the kids were also reported here in addition to the carers' concern of losing a loved one.

Feelings and Attitude at Diagnosis

The emotional impact of a lung cancer diagnosis is evident in the words that most of the participants used to convey the way that they felt when they were first diagnosed. The remaining participant related that his scare of cancer came with his previous diagnosis of prostate cancer. Shock was described by a number of participants, apparent in words such as *dumbfounded, locked out, disbelief, and didn't know how to handle that*, in addition to the word *shocked* as a descriptor itself. *Complete and utter despair, devastated, heartbreaking, saddened, harrowing, angry, hurt and frightened*, are all explicit terms used by this group in describing the trauma of this time. *Like the bottom had dropped out of your world, just wiped everything from us, and did knock the wind out of us* were phrases used to convey the seriousness or enormity of the situation. For some there were visual associations with these feelings:

"I was picturing me in a casket"

"...going in the deep end – a dark hole to be in"

Interspersed within the conversation relating these negative feelings at diagnosis were examples of positive attitude from most of the participants:

"I don't want to even think that I'm not gonna get better."

"I don't think anyone can fix that because you're not the only pebble on the beach, you know."

Surprisingly, amidst the strong feelings, there was a sprinkling of humour evident in the data concerned with feelings at the time of diagnosis:

"I'm dead". (laugh) And I had my funeral arranged. And then I thought well I'm not dead... I'm still alive. But I'm not boxed up yet (laugh)."

"Ultimately it's a pretty serious operation apparently (laugh). And I wasn't really worried about it at all."

"I just thought 'Bugger', you know (laugh)."

The impact of previous experience with cancer was evident in response to major concerns at diagnosis, even when participants had not disclosed any such experience:

"I was already worried about chemotherapy, even before the operation."

"Wondering how I'd die really...whether I'd be in terrible distress when it gets to the end. I sort of .. you feel yourself not being able to breathe, I suppose. I've been around cancer a fair bit myself."

"We just wanted to get treatment. After seeing his sister, I just had to get the treatment, I thought. Cause that was a dreadful thing, to see her die like that. It was dreadful. As much as you try to put it out of your mind, you can't. It all sort of comes back."

Information: Attitude, Adequacy and Understanding

Information needs and attitude to seeking and receiving information varied greatly within this group of patients. For some patients the information seemed almost threatening:

"But I didn't want all that information. Because even I knew that ... lung cancer statistics are horrific. But I wanted only positives. I didn't want anything that was going to affect me."

"I think the booklets are going too far. I reckon they, sort of ... frighten the hell out of people."

"...well it goes in here and...I don't really care what you say."

For other patients the information wasn't needed because they felt that was the responsibility of the doctor:

"I didn't really want to know much about anything. I just wanted to get fixed up."

"He is the expert. I put myself over into his hands. I say 'Well, here I am. You tell me what'."

For some it was evident that they made a choice about what and how much they read, and others spoke of actively seeking information on the internet or from their doctors. One participant was grateful that the doctor had guided her in which internet sites to access, in contrast to one other report of self-learning on the internet:

"Because there's too much information, that you can't possibly emotionally cope with."

"Any wording that I didn't understand I got off my computer. So I bombarded myself with education about it all."

The majority of this group of patients reported the medical practitioner as the major source of information, supplemented by the treating nurses. Interestingly, one patient who reported a reluctance for information, then reported getting most of his information from a fellow cancer sufferer:

"I had a neighbour of mine that died not long ago. And he was going through it, so he used to come down and we used to talk and he informed me a lot. I think he had the cancer in the stomach and I was in the lung, but I thought I was ... sapping information off him more than anything else,.. ... because I could talk to him and he was ... in a position the same as mine."

For those seeking information, there was an overall satisfaction with the amount of information received, both verbal and written with only one report of the timing of information being too late. There was evidence of poor understanding of some information leading to alarm and anxiety:

“That probably wasn’t explained to me why. I was alarmed. But of course I didn’t know it was normal.”

“... they try their best to put it in the letter what you’ve got wrong. But there are words that the lay person doesn’t understand.”

Support at time of consultation by family members or a health professional added to recall and understanding of information received:

“He would tell you things and you sort of understood what he was saying. He said ‘Two minds are better than one, I know you’re taking it in, but you’re not really, whereas your daughter will take it in.’”

“And she even asked if she could come in with that first appointment which was lovely, as well. She came in. She wrote everything down, gave me a copy of it.”

There were reports of conflicting information, mostly around treatment options based on incomplete staging and there was one example of a carer and patient having a different interpretation of the information provided.

Making Decisions

There were no reports of difficulty with making a decision regarding surgery. This is not surprising given the curative intent when surgery is offered as a treatment choice in lung cancer. There were two patients who struggled with making a decision regarding the treatment option of chemotherapy. The first of these raises the issue of influence by family, and the issue of quality of life post treatment:

“My daughter said she would, so it looks like I’m saying “yes” and we haven’t got a hell of a choice (laugh). But I put it on my wife. I said, well...what do I do? And she said what would you do if I had the cancer? You’ve gotta know that he would make me go and do it. So ... She won me over.”

The second patient described the thought of chemo as “trauma”, and recounted his struggle with the decision:

“Oh, no ... I’m not gonna do this and .. naaah ... no. Then after that I talked to my GP. And I was totally unconvinced. I asked him his opinion about chemotherapy. He said ‘You might get some thing out of it, but you might not get something out of it.’ But the other thing is that what I said. “What I think you should take the chemotherapy is because you’ve had the operation. You’ve solved the problem for 90%. Drive that nail down all the way. And take the 10% also and get it over and done with. And I said okay. Well I have decided that I will do it.”

It is worth noting that this same patient’s attitude to information was - “Well here I am. You tell me what” - and understandably he was perfectly comfortable with the surgeon’s approach described here:

“And I said to him “What are you doing?” ‘Oh, I’m admitting you to Royal Prince Alfred Hospital.’ I said “why” and he said ‘Because you’re going to have an operation.’ I said “What are you going to do?”. He said ‘I’m going to take your lung out. That’s the only thing I can offer you and it has to be done as fast as possible.’”

Financial Implications

The majority of patients who were required to travel to a metropolitan centre were aware of the NSW Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS), and were satisfied with reimbursements and medicare coverage of expenses. There was only one report of dissatisfaction with reimbursement:

"...we went by train, and we had pensioner discounts so we used those and we got a taxi to the station and a taxi back. And I claimed the train ... like it cost us \$75 at the rail, over and above your voucher, and \$20 each way taxi. They said you couldn't claim the \$75 that we'd paid because it was termed a booking fee. And you could only claim one taxi fare because you have to be down there and back in the same day to get two taxi fares. And because it all ended up to be that they gave you \$20 out of that, \$20 was too low to claim."

There were other issues identified regarding financial costs associated with travel including using funds that had been saved for a holiday, inability to afford travel without the assistance of a Cancer Council voucher, financial embarrassment when not advised of up-front costs when there was no access to credit, and having to pay for air travel when a patient was discharged prior to travel date already booked. There was one report of financial impact of driving to and from the local centre every day for radiotherapy.

Treatment Tolerance

Of the nine patients treated with chemotherapy, four reported that they tolerated chemotherapy well. Side-effects reported included nausea, temperature, fatigue, swelling, loss of taste, blood noses, sore scalp, diarrhoea, constipation, "zapped on steroids", and blood clots. Four patients reported a total of five admissions to hospital because of elevated temperature, diarrhoea and blood clots, or for blood transfusion. One patient was hospitalised with reduced mobility at the commencement of treatment and remained hospitalised for the duration of her illness.

There was an overall sense of treatment with radiotherapy being well tolerated with one report each of pneumonitis, rash, cancer burns and fatigue post radiotherapy. One participant describes a serious side effect of radiotherapy as a trade off:

'Oh, it's a pity that the lung's so damaged.' I said "Well, there's not much alternative" He said 'Actually, without the treatment you would be dead.'

There were two important issues around treatment that were mentioned at this time. These include the sense of security around starting treatment, mentioned by only one patient, and the difficulty understanding the concept of preventive treatment:

"... we are doing something which we can't see. So if they can't see what they're treating, then it's going to be very hard to say if the treatment is successful, yes or no."

Support: Attitude and Source

The provision of support was dependent on the attitude of the patient, evident in the findings that seven patients reported having rejected the offer of support or stated that support was not needed at that particular time. However, there is evidence that nine of

the patients did in fact accept some form of support from the health team. It is relevant to distinguish between physical and emotional support as eight instances of that support were in the provision of practical support with travel and accommodation, and of medical and nursing support throughout treatment. There is just one positive report of emotional support by a social worker and it is worth noting that this same patient reported support from a local priest as well. One participant reported two encounters with a social worker as less than helpful:

“And I just kept thinking – please go away.”

Overall, there is a strong sense of reluctance to access support, despite recognition by this group of the psychological trauma associated with this illness:

“I wasn’t ready to talk. I just wanted to ...handle it myself and when I come to the bloody bridge, I’ll cross it.”

“I’ve virtually told most of them at the moment I’m fine on my own. I’ll carry on as long as I can. When I need help, I’ll ask for it.”

“I just don’t know that at the present time that that would help. It’s not going to fix anything.”

Concepts of support are found in the attitude of some:

“There is a lady in this group who belongs to about seven different support groups. And ... their whole life revolves around cancer. See, our life hasn’t. To me that’s not very healthy.”

“But I don’t want to hang around. The cancer bit is too much. I just want to get on with it.”

“I’m fine. I can cope on my own. I have my family. You know, if I need you I’ll call you.”

There is a very strong sense of family and friends being the major provider of support, both emotional and physical, and it appears that for many, support is sourced from other patients in the treatment setting, in structured support groups, or in support programs such as Look Good Feel Better, with references to the perceived benefits:

“... talking to them down there....hearing what their problems are and it made a difference for every one of us when we go through it. Whether we are a carer or a patient. And I think word of mouth is ... tremendous.”

The findings also indicate that for some, support services were not offered. There were a few references to lack of physical and emotional support:

“But nobody come to say, well, come in here and we’ll have a yarn, and you do feel like you want somebody there to help you, talk to you .. explain things.”

“And I was quite surprised that we were not contacted by any social or support group here in this area.”

Current Physical Status

The majority of patients had a good physical status at the time of interview and remained reasonably independent with daily activities. Symptoms reported by a number of patients included pain, breathlessness and fatigue, with sweating, weight loss, headaches and alteration in food tolerance each reported by a single participant.

Two of the three reports of pain were post-operative and the remaining patient described his pain as well managed with medication, supported by the GP and Medical Oncologist. Breathlessness was mentioned by most patients with varying degrees of severity. Of note was the implication of fear and panic associated with acute shortness of breath, and the physical support and security of home oxygen which two patients had accessed. Fatigue was a common complaint and often described as:

“very, very tired” or “I never felt like ... like this.”

There were reports of co-morbidities of aneurysm, sciatica, emphysema and diverticulitis experienced by some patients. Positive lifestyle factors were identified by other patients as contributing to their successful treatment and/or recovery, including being a woodwind player for most of a lifetime, fitness prior to treatment, and active participation in the sport of lawn bowls contributing to repair of muscle and recovery post surgery.

Current Emotional Status

There was an open and ample response to this question. There was only one patient that chose not to talk about this subject. Some themes emerged from this data, including remaining positive and hopeful, feeling lucky to have services and treatment available, and acceptance/resignation, but for the most part the reality of living with this illness with all its implications was described uniquely on an individual basis:

“It really scares me. A week? A month? Or whatever, but it’s going to come back. It’s going to kill me.”

“... feeling that it was really important that I help people that have got it.... very commendable... but sometimes it can be .. and I was overwhelmed that night. I just ... it’s too much.”

“I don’t plan it. I’m living day by day”.

“Realistically I’m human, so there have been times when I cried all day.”

“Well, it’s there. I can’t do anything about it, but .. follow the medical ... possibilities. If that doesn’t work well, and I have to pass away, well, so be it. So be it. I’ll pass away. That’s the end of it. That’s how I feel about it”.

“She virtually said there’s nothing more that can be done. Cheated. The hardest part is realising that you’re not going to see your kids grow up. It’s hard. I’ve basically arranged my funeral. It’s paid for. It’s all done. The kids have been told what I want. They all know that. I’ve sort of got everything in order.”

“And I mean, the questions you want to know, you know nobody knows the answer and so there’s no point asking it.”

Some patients exhibited a very positive attitude to their illness:

“Okay, I’ve got cancer. But I don’t want it to rule my life.”

“And I’d been on the prayer list since I was diagnosed. And I went to them yesterday and saidTake me off the prayer list”.

“...and even if they say 80% of people with lung cancer will be dead in five years. But 20% won’t. So I can be in that 20% can’t I?”

“So I can only trust in the people. And that’s basically what I do.”

Smoking and Blame

The issue of smoking was purposefully omitted from the interview questions because it does not have a direct bearing on service provision, although arguably it is a very real part of personal experience. It was obviously an issue for a number of participants as they chose to report it as part of their story. The issues identified include blame or reason for the illness, feelings of guilt and shame and a source of conflict within families:

“I have only smoked for ... five months of my life. And I could well have had the cancer before that anyway. I never ever said ‘Why me?’ And I never thought it was unfair because ... these things happen.”

“I have a feeling and I might be wrong. But lung cancer is a self-inflicted illness. That’s how it is treated and that’s how the medicos think. I am convinced this is totally wrong. Yes, we do wrong things with eating too much fat or too much this, too much this ... and smoking. All things are wrong, eventually. But in the medical world, when you have a cancer which is mouth cancer, throat cancer, lung cancer. That’s all from smoking. You’re ... almost a second hand citizen. And I have that feeling very much. I am a dedicated smoker.” (Carer)

“She’s had a lung removed too. Smoked like a chimney. Her cancer was not caused by smoking. According to the doctors. I’m very surprised that I’ve got lung cancer. And I’m not going to say my cancer is caused by smoking. I would almost be inclined to say my smoking is probably caused by the principal of the school where I worked for five years in dusty conditions and all that sort of stuff. Particularly after I found out that they also took some scrapings, which were silica scrapings and she has said - building dust.”

“You sort of half expect it if you know you’ve smoked all these years. You just say you’re lucky if you escaped, really.”

“I stood outside smoking ... outside with the patient’s there and I absolutely was ashamed to belong to the human race when and I used to be very proud.”

“They can’t prove that smoking really did it. And this is what those doctors told me up there, so there you are. Wife: At the same time as they told you that, I was taken to one side and told that yours was through smoke. And that a patient will very rarely accept the fact that it is cancer via smoke. They would rather block off ... and men are the worst. Would rather block off and pretend it was anything else in the world but that which is so important to them.”

Life Altering Implications

For those patients with a love for, or plans for travelling, the loss of this lifestyle had a major impact. Even short term travel was an issue for one patient who was reluctant to be away for very long or very far from a hospital:

“Oh.... we’ve been travellers for ... most of our lives together. We just can’t do it.”

Physical condition (lack of strength, low energy level, inability to climb stairs, recovering from treatment) prevented many patients from completing tasks they normally would enjoy such as work and gardening, or maintaining hobbies or sporting interests:

“I used to play golf twice a week. I can’t play golf any more. Because I just can’t walk. I used to love going for a walk around the lake, taking the dog for a walk and a swim in the lake. I can’t even walk down to the lake, without even walking around the lake. I can’t mow my lawns any more. I can’t garden any more. And that hurts because I love my garden. I used to be a florist, so I love flowers.”

During discussion around lifestyle changes, there were reports of change in outlook on life, a sense of urgency to do things now including travel, and contact with friends, and a loss of ability to make plans into the future:

“If I want to go around Australia I better go next year because I might not be here any more”.

“I felt ... not able to plan your life. You’ll do this and you’ll do that. And you think ohh, well maybe I won’t. And you felt as though you were on ... borrowed time”

Spirituality

Not all patients reported their experience with religious beliefs or the spiritual impact of this illness journey. Some reported a definitive support from the church, some were immediately dismissive of any sense of spirituality, and some provided an incongruent report around this topic:

“But religion....Not a thing in my life. Oh, the closest I got to spiritual was when I had the aneurysm. I thought I left my body. So I’ve been there. I did. I talked about it. People thought I was a nut. But I honestly thought I left my body and come back again.”

“I’m not religious really. I don’t practice it but I do believe it.”

Carer Specific issues

The spouse/carers of the patient was present in 50% of the interviews performed. This enabled an opportunity to identify issues or gaps in service provision that may not have been identified by the patient alone. There are reports of the patient being unable to support the carer because they themselves are lost, and recognition of the value of the carer, especially for those people who do not have a spouse or carer. Providing information for children and helping them understand, sometimes getting annoyed with the patient and feeling that they are catered to, and fear of losing a loved one were the other issues highlighted in the data.

Overview of Best Managed Aspects of Care

Participants were asked what part of their journey with lung cancer was best managed. Overall the data suggests that the participants were pleased with the level of service received on a local and metropolitan level, and that the treating teams provided a competent and caring service. All of the participants reported a positive experience with either local or metropolitan hospitals or facilities, and in some cases both. Access to local services was a very positive factor for those patients who received treatment locally.

Confidence and trust in the medical team is evident in the favourable responses regarding medical staff, from the local GP through to local and metropolitan specialists, with reports of expertise, concern, confidence, trust, direct approach, comfort and care. Patients who received chemotherapy at NCCI described a competent and caring nursing team using terms including beautiful, wonderful, friendly, absolutely marvellous, really good, and know what they are supposed to do. Clerical staff, the palliative care team and pathology staff were described as helpful and caring.

“they have all just got this special thing that that’s where they are supposed to be working”.

“... look, it’s not a matter of feeling confident to me. It’s a matter of me trusting”.

Physical support with travel and accommodation arrangements and actual transportation within the city with volunteer transport services were cited by a number of patients as a positive experience. Participants related support groups, positive responses from their doctors, and support gained from other patients in environments providing accommodation for rural patients, as sources of emotional support.

Overview of Worst Managed Aspects of Care

There was concern for patients not having access to services locally, especially where those services were physically available, and the understanding was that these services were available to everyone now.

Reports of worst managed aspects of care also elicited responses related to a disregard for what the patient was saying:

“And I was brought here to the Emergency Department by ambulance. And the doctor said there was nothing the matter with me, and I could walk. So I was sent home. And three days later it got a lot worse. I couldn’t walk at all. Couldn’t move. And I was in agony.”

“I think the thing that I was more cross with was trying to get someone to listen to the fact that I had pain. I was a bit angry about that. “

“And I said I don’t know if you read this card or not but it says that I am at risk of infections. And that’s the only thing that I’ve got a complaint about. They put me at risk.”

Further to this a third patient reported a lack of follow-up post discharge from ICU and inconsistent medication times at a metropolitan hospital.

Negative experiences with team members included difficulties with venous access, lack of information, and the way in which bad news about prognosis was delivered.

Issues with communication and medical information exchange were reported as failure to provide important information regarding treatment and follow-up, the inadequate dissemination of information between hospitals, and shortfall in coordination of care with the system failing to ensure follow-on appointments were made on behalf of the patient.

Difficulties related to travel included the distance for patients to walk to gates at Sydney Airport, handling luggage and changing platforms at Central Railway Station, financial costs, lack of community transport in rural towns, distance of travel required, restrictions in flying post thoracic surgery, and issues with coverage for interstate services such as ambulance.

Making the Journey Easier

The question of what would improve services for people with lung cancer in this area health service was met with a varied response. Some participants remarked on the shortage of staff they had personally noted, especially in the chemotherapy administration setting, and suggested that lack of funding and staff was the reason that services like radiotherapy were not available to everyone on a local basis. On this issue it was also suggested that accurate advice to the public regarding limited access to local services was important. It was suggested that clarity around entitlements would assist in resolving some of the issues around travel and accommodation expenses. According to the participants, there was a need for better communication, especially between medical services, improvements in streamlining diagnostic tests, and provision of support for carers. There was one suggestion that respect and understanding for the patient needed to be improved.

DISCUSSION

Planning of services is paramount in the provision of equitable and optimal health care. Evaluation of service provision provides the opportunity to identify and prioritise aspects of health services that need to be improved. It is recognized that the data provided at interview is the patient or carers perspective of their journey which may be influenced by any number of factors such as current physical and emotional status, socioeconomic status, level of education, and previous experience with illness and health services. Considering that the important reality is what people perceive⁹, it can be argued that all these factors contribute to the reality of the experience and make this study a feasible evaluation of the experience of this group of rural lung cancer patients.

As a snapshot evaluation of service provision for lung cancer patients, this study offers some insight into how service provision is perceived by the consumer, and indicates what areas of care are well managed, and those that could be improved. There is overall satisfaction with services and teams providing care locally, and in the preferred metropolitan centres. There is a need to improve access to local services for those patients who could receive the treatment they require in the local area.

The findings of this study confirm the four key domains of need identified in the literature: (1) the pathway to confirmation of diagnosis, (2) communication of diagnosis, treatment

options and prognosis, (3) provision of co-ordinated family-oriented care and (4) support away from acute services.¹²

Pathway to Confirmation of Diagnosis

There was an overall satisfaction with the timing of investigations and diagnosis where the time frame ranged from a few days to four weeks. There were instances of diagnosis taking longer than this which was viewed as unacceptable. The literature reports that this is one of the most stressful times for patients^{9,10} which was confirmed in this study. As recommended in previous studies, it is important to evaluate this process within service provision. The literature reports that the time from diagnosis to treatment is also a stressful time for the patient. This was reflected by some of the participants in the current study, certainly not the majority, and possibly influenced by the nature of treatment, i.e., curative versus palliative intent.

Communication of Diagnosis, Treatment Options and Prognosis

This study confirms the view that patients diagnosed with lung cancer need honest, sensitive and timely communication of diagnosis and prognosis,¹⁰ and that the way in which a diagnosis is communicated will have an impact on the patient's fear. It is evident from the study that the patients who were not satisfied with the way they were told their diagnosis, suffered as a result, and lost confidence in the health professional concerned. It was also indicated that in the diagnosis situation there was a need for hope. Other than those with early stage disease who are eligible for surgery, these patients are going to suffer deterioration in health and die. It is therefore important to offer programmes which engender a positive approach to their illness without raising unreasonable hopes of treatment and cure.¹ Tempering reality with hope is an extremely difficult task to achieve when dealing with the grim outlook faced by the majority of these patients, and an area that requires further research.

The diversity of needs identified, for the amount and content of information provided to the participants in this study, confirms the findings of an extensive literature review concluding that information is a much individualised aspect of care.¹⁵ Who needs to know what, how much do they need to know, and when do they need to know it? The answer to this question would differ, in some form, for every patient, and every carer or family member. The concept of providing individualised information remains a challenge for the information giver, is beyond the scope of this study and requires further research.

Provision of Coordinated Family-Oriented Care

Inconsistencies of care, including seeing different health care personnel and hearing conflicting information from different people, often left patients and carers feeling they were not seen as important and that the disease was not being monitored as closely as they would like.¹⁰ This was reflected by participants who reported differing opinions regarding stage of disease and treatment options. These issues could be minimised by access to multidisciplinary team planning. For the participants of this study, access to multidisciplinary team planning and case coordination via a designated care coordinator was limited. However, it is important to note that in accordance with services planning, the enhancement of rural and metropolitan partnerships has seen the establishment of fortnightly multidisciplinary team meetings with RPA Hospital since the commencement of this project. This provides access to multidisciplinary team planning for a limited

number of patients, and the role of the cancer nurse coordinator within this team, ensures that the care of these patients is well coordinated. It is acknowledged that in current practice, care coordination is not limited to patients presented at multidisciplinary team meetings. Practical issues raised in this study such as poor communication and information exchange between medical facilities, and ensuring follow-on appointments are confirmed, are within the realm of care coordination and addressed within that service provision. It is recognised that this remains an aspect of service provision that can be improved with the expectation that by 2010, multidisciplinary team planning and care coordination will be standard practice in NSW.

Support Away from Acute Services

The emotional impact of a lung cancer diagnosis as reported in the literature is confirmed in this study. There is a very strong sense of family, friends, and informal patient contact being the major source of emotional support for this group of patients. The issues for carers in this study all revolved around the need for emotional support. It is acknowledged that support services and programmes are widely available to address the needs that arise as a result of a lung cancer diagnosis. This study introduces evidence of attitude to support which acts as a barrier to the access of emotional support. Despite acknowledging the trauma of a diagnosis of lung cancer, and identifying emotional and physical needs, the majority of patients reported that they did not need support and often declined support services when they were offered. It appears that patients are much more likely to access physical than emotional support. This is evident also in the majority of participants' failure to access known support services on offer. Possible reasons for reluctance to access emotional support are: a limited or misunderstanding of the concept of support; the timing of the offer of support; or the view that admitting a need for support outside of the family, is a sign of weakness or not coping. Further study needs to be completed in this area to guide interventions to encourage patients to access support services.

The benefits of support provided by a third person, independent or otherwise, being in attendance at initial consultations to help understand and clarify information, have been realised in this patient group and reaffirmed as a supportive measure.

Practical issues regarding travel and accommodation such as distance and unfamiliar surroundings are unavoidable whilst ever patients are required to access care in a metropolitan centre. Clarification of costs and reimbursement entitlements, and assistance with travel and accommodation arrangements has been confirmed by this study as a major source of support.

Strengths and Limitations

The strength of this study lies in the richness of the data, evident in the open disclosure of feelings, attitude and experience. Some of the participants were known to the researcher, raising concern that responses may have been influenced by this. The data provided did not indicate any such influence, in that there was a willingness to speak openly of their experience, detailing both the positive and negative aspects of their experience.

The presence at interview of 50% of carers may have had an impact on the responses of the patient. This is countered by the reports in the literature that patients under-report

needs and symptoms, and added an opportunity to include needs of the carer in the study.

This study is limited in that it provides a snapshot – a single measurement – of the experiences of this group. Problems and needs of both patients and carers are likely to evolve over time, and thus this study cannot be viewed as a comprehensive review of all needs, both met and unmet. In addition, the potential scope of the study is so large that some areas of experience have only been touched on or not explored at all.

The semi-structured format of the interview process adds to the richness of the data, but it is evident in the analysis that certain areas of experience could have been explored in more depth.

CONCLUSION AND RECOMMENDATIONS

The outlook for lung cancer patients remains grim, with these patients and carers having a high level of need. These needs include a timely pathway to diagnosis; honest and sensitive communication of diagnosis, treatment options and prognosis; provision of co-ordinated family-oriented, multidisciplinary care; and provision of support, both practical and emotional. There is overall satisfaction with services and teams providing care locally, and in the preferred metropolitan centres. There is a need to improve access to local services for those patients who could receive the treatment they require in the local area. There are indications that the diagnostic process needs to be refined to ensure timely access to diagnostic investigations and results, and that access to multidisciplinary team planning and care coordination could be improved to ensure access for all patients. There is evidence of an attitude to support which prevents patients from accessing support services that are widely available.

Recommendations from this study include strategies to improve access to treatment in the local area, evaluation of the diagnostic process within service provision, and strategies to improve access to multidisciplinary team planning and designated care coordination, to ensure that this becomes standard practice for all patients. This study indicates a need for further research into the reason for reluctance to access support services; the challenge of providing individualised information; and the challenge of providing realistic, but reasonably hopeful communication of diagnosis, treatment options, and prognosis for this group of patients.

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Appendix 1

**NORTH COAST CANCER INSTITUTE COFFS HARBOUR
NEEDS OF RURAL LUNG CANCER PATIENTS RESEARCH PROJECT**

DEMOGRAPHIC, DIAGNOSIS AND STAGING DATA TO BE RETRIEVED FROM MEDICAL RECORD

PATIENT IDENTIFICATION NUMBER _____

SURNAME	FIRST NAME	MEDICAL RECORD NUMBER	DATE OF BIRTH	AGE	MALE / FEMALE

ADDRESS	PHONE

NEXT OF KIN / RELATIONSHIP	PHONE: HOME / MOBILE

DIAGNOSIS	
Small Cell Lung Cancer	
Non Small Cell Lung Cancer	
No Pathological Diagnosis	

DATE OF DIAGNOSIS

STAGING SYSTEM FOR LUNG CANCER (Cameron & Schwartz 2005)		
Non-small cell lung cancer		Please tick
Stage	TNM	
0	Carcinoma insitu	
IA	T1 N0 M0	
IB	T2 N0 M0	
IIA	T1 N1 M0	
IIB	T2 N1 M0	
IIIA	T3 N1 M0 T1-T3 N2 M0	
IIIB	T4 N0-3 M0 T1-4 N3 M0	
IV	T1-4 N0-3 M1	
Small cell lung cancer		Please tick
Limited stage disease	Tumour confined to one side of the chest, supraclavicular lymph nodes, or both	
Extensive stage disease	Defined as anything beyond limited stage	

INTERNATIONAL TUMOUR, NODE, METASTASIS (TNM) CLASSIFICATION SYSTEM

PRIMARY TUMOUR (T)	
TX	Positive malignant cell; no visible lesion by imaging or bronchoscopy
T0	No evidence of primary tumour
T1	Tumour ≤ 3 cm in diameter, surrounded by lung or visceral pleura, and not involving the main bronchus
T2	Tumour > 3 cm diameter, or involving the main bronchus ≥ 2 cm from carina, or invading the visceral pleura, or associated with atelectasis or obstructive pneumonitis, not involving the entire lung
T3	Tumour extension to the parietal pleura, chest wall diaphragm, or pericardium, or < 2 cm from carina, or associated with total atelectasis of an entire lung
T4	Tumour invasion of major mediastinal organs, or malignant pleural or pericardial effusion, or tumour with satellite tumour nodule(s) within the ipsilateral primary tumour lobe of the lung
REGIONAL LYMPH NODES (N)	
N0	No nodal involvement
N1	Ipsilateral bronchopulmonary or hilar nodes
N2	Ipsilateral or subcarinal mediastinal nodes
N3	Contralateral mediastinal hilar or supraclavicular nodes
METASTATIC INVOLVEMENT (M)	
M0	No metastases
M1	Metastases present



Appendix 2

NORTH COAST CANCER INSTITUTE
Coffs Harbour Health Campus
Locked Bag 812
Coffs Harbour 2450
Phone: Reception 66565737

Date

Name

Address

Research Study into the Needs of Rural Lung Cancer Patients

Dear Mr/Mrs,

As part of the North Coast Cancer Institute team at Coffs Harbour Health Campus, I am conducting a research study into the needs (both met and unmet) of people from the Coffs Harbour, Bellingen or Nambucca regions of the North Coast Area Health Service, who have been diagnosed with lung cancer within the last twelve months.

This project is funded by the NSW Institute of Rural Clinical Services and Teaching with the aim of using the personal experience of lung cancer patients to gather information about the impact of a lung cancer diagnosis, the needs arising from this illness, and whether the services that are currently provided by this health service could be improved to enable those with lung cancer to manage their illness better.

I realise that participating in this study may not benefit you personally, but am confident that your contribution may lead to improved services for future patients diagnosed with lung cancer.

Please find attached a detailed information sheet describing what the study involves, and a consent form for completion if you choose to participate. Participation in this study is completely voluntary and you may withdraw your participation at any time without penalty or prejudice. All information provided will be treated confidentially and the results of this study will only be presented in a group format without any identification of participants.

If for any reason you do not wish to be a part of this study please contact Lisa Hardcastle on 66565728 and advise that you do not wish to be contacted further.

If you have not declined to be part of the study, I will telephone you in 10 – 14 days to set up a time to conduct an interview to hear your personal experience. This interview should take about one hour of your time, and can be completed in your home or at the North Coast Cancer Institute.

*Thank you for your time and help.
Yours truly,*

Chris Stanford
Clinical Nurse Consultant / Research Project Coordinator
NORTH COAST CANCER INSTITUTE

RESEARCH STUDY INTO THE NEEDS OF RURAL LUNG CANCER PATIENTS
PATIENT INFORMATION SHEET

What is the purpose of the study?

The aim of this study is to use the personal experience of lung cancer patients to gather information about the impact of a lung cancer diagnosis, the needs arising from this illness, and whether the services that are currently provided by this rural health service could be improved to enable those with lung cancer to manage their illness better.

Who will be invited to enter this study?

All men and women who have been diagnosed with a primary lung cancer during the period 01/07/06 to 30/06/07, and who reside in the Coffs Harbour, Bellingen or Nambucca regions of the North Coast Area Health Service (NCAHS) will be invited to participate.

Participation in this study is entirely voluntary. You are in no way obliged to participate and, if you do decide to participate, you can withdraw from the study at any time. If you withdraw, this decision will not effect in any way your future treatment or relationship with your doctors and other members of the health care team.

What does the study involve for the participant?

The study involves an interview that I will conduct either in your home or at the North Coast Cancer Institute (NCCI), which ever is preferable for you. During the interview I will be asking you a number of questions relating to your personal experience of lung cancer. The interview will take approximately one hour of your time. Interview days and times will be very flexible to ensure that you are feeling well enough to participate, and there will be the option of rescheduling at short notice if required.

If you decide to participate in this study, you will be asked to complete the attached consent form and the interview will be tape recorded to ensure that all of the information you are providing is captured and to enable that information to be compiled.

The information from all interviews conducted will be grouped and analysed to determine the current needs of rural lung cancer patients. The findings of the study will be presented to the North Coast Area Cancer and Palliative Care Clinical Services and Workforce Advisory Committee and submitted for journal publication.

Confidentiality

All aspects of this study will be strictly confidential and only the researchers will have access to your personal information. The results of this study will only be presented in a group format without any identification of participants. All personal information and audio tapes will be kept in a locked filing cabinet at NCCI for 5 years then securely disposed of.

The NCAHS Human Research Ethics Committee has approved this research project. Any complaint or concerns can be made to the committee through:

Research Ethics Officer

NCAHS Human Research Ethics Committee,

PO Box 126 Port Macquarie NSW 2446

Phone: 65882941 Fax: 65882942 Email: EthicsNCAHS@ncahs.health.nsw.gov.au

Thank you for considering this invitation. This research project is funded by the NSW Institute of Rural Clinical Services and Teaching. If you would like any further information about this study, please contact Chris Stanford, Research Project Coordinator on 66565748.



Appendix 4



NORTH COAST CANCER INSTITUTE
Coffs Harbour Health Campus
Locked Bag 812
Coffs Harbour 2450

RESEARCH STUDY INTO THE NEEDS OF RURAL LUNG CANCER PATIENTS
PARTICIPANT CONSENT FORM

I,(name) of
.....(address)

have been invited to participate in the above named research study and have discussed the study with the Research Project Study Coordinator Chris Stanford.

- I acknowledge that I have received and read the Patient Information Sheet and that the purpose and nature of this research has been explained to me.
I agree to take part in this study by doing an interview to talk about my personal experience with lung cancer, and understand that the interview will be tape recorded.
I understand that my participation in this study is entirely voluntary and that I may withdraw at any stage. If I withdraw, this decision will not effect in any way my future treatment or my relationship with my doctors and other members of my health care team.
I understand that the information from all interviews will be grouped and analysed to determine the current needs of rural lung cancer patients, and that the findings of this study will be presented to the North Coast Area Cancer and Palliative Care Clinical Services and Workforce Advisory Committee, and submitted for journal publication.
I understand that all aspects of this study will remain strictly confidential and any report will be presented in a group format without any identification of participants.
I understand that this study has been approved by the North Coast Area Health Service Ethics Committee and that I can contact the Research Ethics Officer on 02 65882942 if I have any complaint or concern.
I understand that if I have any questions or concerns relating to this study I can contact Chris Stanford on 66565748.

I hereby consent to participate in this research study.

Name(Print): Name of Witness (Print)

Signature: Signature:.....

Date: Date:

Research study funded by NSW Institute of Rural Clinical Services and Teaching.
Research Project Coordinator: Chris Stanford
Telephone:6656574

Appendix 5

RESEARCH STUDY INTO THE NEEDS OF RURAL LUNG CANCER PATIENTS

INTERVIEW SCHEDULE

INTRODUCTION

Thank you for agreeing to share your experience with me.

The aim of this study is to use the personal experience of lung cancer patients to gather information about the impact of a lung cancer diagnosis, the needs arising from this illness, and whether the services that are currently provided by this rural health service could be improved to enable those with lung cancer to manage their illness better.

I will ask you a number of questions, giving you the opportunity to tell me your story on lung cancer, from the time of diagnosis until the present time.

Can you tell me about when you were first diagnosed with lung cancer?

Probes:

How was your lung cancer diagnosed?

Prompt: Because of a symptom? What symptom?
Found by accident? How did that happen?

Can you describe the process that led to your diagnosis and how long that took?

Prompt: What investigations did you have and where were they performed?
(chest xray, CT scan, PET scan, bronchoscopy, other?)
How long did you have to wait for the tests and the results?

How did you find out that you had lung cancer?

Prompt: GP or Specialist? Local or metropolitan? Medical Oncologist? Radiation Oncologist? Surgeon? Respiratory Physician?

Who was with you when you were first told that you have lung cancer?

Prompt: Was anyone else there – family member, social worker/counselor/other?

What do you recall about that first consultation?

Prompt: Did you remember what you were told?
Did you understand the information you were given?
Was it verbal information only, or written information?
Did you look for more information? Where from?
(Cancer Council, Social Worker, Nurse Coordinator, Internet?)

Did you have to travel away from home for further investigations?

Prompt: Where to? How soon? Did you know about IPTAAS?

What support did you receive?

Prompt: Emotional, practical or financial? Who from? Family? Friends? Social worker?
Nurse coordinator?

What was the biggest concern for you at this time and why?

Prompt: Emotional, practical such as travel away and accommodation, financial, work concerns, family concerns, other?

Describe how this concern was dealt with and what would have helped you to manage this aspect better.

Can you tell me what happened after your diagnosis?

Probes:

Were you invited to have your case discussed at a multidisciplinary team meeting? Where was this meeting held?

What treatment options were you offered?

Who explained these options to you?

Did you have any surgery? Where and how long after your diagnosis?
Did you have any radiotherapy? Where and how long after diagnosis?
Did you have any chemotherapy? Where and how long after diagnosis?
If you did not receive any of these treatments who provided care for you and what did that care involve?

Prompt: GP, local cancer services, palliative care, other?

When did you get linked in with local cancer services?

Prompt: Immediately after diagnosis, on return from metropolitan centre, sometime later, not at all?

When would have been the best time to be linked in with local services?

What did local cancer services provide for you?

Can you describe your relationship with the cancer services team?

Prompt: Do you feel comfortable with your doctors and nurses?

Do you feel comfortable about contacting the team for advice?

Do you feel confident in the ability of the team?

Any frustrations? Problems?

What was treatment like for you?

Prompt: Were you frightened? Do you think you were well informed? Were you well prepared for treatment?

What side-effects did you experience?

How did they affect your life?

Did you know how to manage these?

Did you receive any help managing these side-effects? Who from?

Did you feel supported through your treatment? Who provided that support?

Can you describe any after hours services that you have accessed during your illness?

Can you tell me about any physical problems you experience because of your lung cancer?

Probes:

Do you have any symptoms caused by your lung cancer?

Prompt: Breathlessness, fatigue, cough, pain, loss of appetite?

What problems do these symptoms cause you?

Prompt: Prevent you from caring for yourself (bathing, dressing, getting around) stop you from going out, interfere with work, hobbies, sporting activities?

Who helps you manage these symptoms and what sort of help is provided?

Prompt: GP, Specialist, Nurse – cancer nurse/nurse coordinator/palliative care nurse

Regular assessment and monitoring of condition

Medications – access/availability to scripts/advice

Complimentary therapies (massage, aromatherapy, relaxation, meditation)

Are your symptoms managed well enough?

If not, what service could be offered to enable you to manage your symptoms better?

Can you tell me what your life was like before lung cancer, compared to now?

Probes:

What sort of things did you enjoy doing?

What can you no longer do?

What do you miss the most?

What things have you been able to continue doing?

What do you think would help you to be able to do more of the things you enjoy?

Can you tell me about your home life before cancer?

Prompt: What would a normal day entail? Maintaining the home, caring for family/other?

What does your day entail now?

What effect does your illness have on your family or relationships?

Prompt: Change in role, stress for others, financial hardship?

Tell me about any support you are aware of to help you with any of these issues?

Prompt: Social Work, Cancer Council Helpline, Living with Cancer Education Program, Support Group, Information Packages?

Have you accessed support from any of these options?

Describe how it helped or not.

What has been the financial implication of having lung cancer?

Probes:

Can you describe the costs to you and your family?

Prompt: What sort of expenses have you incurred because of your illness?

Were there costs involved in travel and accommodation?

Did you have to give up work or cut back on your working hours?

Does the family rely on your income?

Who has provided any help with your financial situation?

Prompt: Any advice from a social worker? Have you applied for financial assistance from Centrelink or any other organisation?

How much worry does your financial situation cause you?

Can you tell me how having lung cancer has made you feel?

Probes:

What are your feelings about the future?

What sort of feelings have you experienced throughout your illness?

Prompt: Disbelief, anger, anxiety, fear, roller-coaster ride, other?

Who have you talked to about these feelings?

Prompt: No-one, family, professional (social worker, doctor, nurse, psychologist) other people with cancer?

Who do you think would be able to understand these feelings best and help you to work through them?

What do you think talking to other people with lung cancer would add?

Can you describe any changes in the way you feel or think because of your illness?

What spiritual effect does having this illness cause for you?

Can you tell me anything else about your experience with lung cancer?

Overall, what aspect of having lung cancer was best managed and how?

Overall, what aspect of having lung cancer has not been managed well?

What do you think would improve the experience for a person diagnosed with lung cancer?