RECOVERY FOLLOWING PNEUMONECTOMY: PATIENTS INITIAL 2 YEAR EXPERIENCE

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I discovered while conducting this research that research involves not only entering the lives of the people you are studying, but also entering your own life in terms of the discipline and focus that one needs in order to complete this type of work. I found this study to be an arduous yet inspiring task and it involved the lives of many people that I wish to recognise.

This study could not have been completed without the valuable assistance from my Supervisor, Dr. Jennifer Blundell. Jenni quietly guided me in the right direction when I needed it, and she provided me with timely encouragement and support.

I thank my dear children and very special friends for encouraging me throughout the study, and for patiently waiting for me to complete this study. My sincere thanks also go to my colleagues in the cardiothoracic department who provided me with endless encouragement and motivation. To Ruth, thank you for helping me with the editing of the final draft: you were a gift from God. To the surgeons with whom I work closely, I thank you for providing me with the opportunity to conduct the study, the incentive to go after my professional goal, and a professional environment that was conducive to me achieving my goal.

I dedicate this study to my late mum and dad who had the insight to send me nursing so that I could help other people, and to my late friends Chris and Judy who died of lung cancer while the study was being conducted.

While I was struggling with the study, I came across this quote in a research text. It gave me much solace: *Do not be afraid to seize whatever you have written and cut it to ribbons; it can always be restored to its original condition in the morning, if that...seems the best. Remember, it is no sign of weakness or defeat that your manuscript ends up in need of major surgery. This is a common occurrence in all writing, and among the best writers* (Strunk and White 1972, 72 cited in Dane, 1990, 211).
ABSTRACT

RECOVERY FOLLOWING PNEUMONECTOMY: PATIENTS INITIAL 2-YEAR EXPERIENCE.

Little is known about the recovery of patients after pneumonectomy and the impact of the surgery on the lifestyle of young, employed, ex-smokers and their families. This study was conducted to address this knowledge deficit, and gather information that would help health professionals to be able to assist people facing pneumonectomy. A qualitative study using van Manen's methodological approach to interpretive phenomenology was chosen, in order to capture a full and rich understanding and meaning of the phenomenon that patients live.

The names, age, operation, histological cell type, stage of disease, and disease free status of potential participants were obtained from a Lung Cancer Surgical Database after obtaining ethical approval for the study. Nine participants (three females and six males) met the inclusion criteria and gave informed consent for the study. Data collection comprised of open-ended interviews that were audiotaped, then transcribed verbatim into hard data. Data interpretation was based on the selective reading approach of van Manen from which six thematic statements arose. These are living the discomforts of treatment and recovery, discovering new limitations on myself; functional and emotional, my reliance on support, my financial security is threatened, my survival is at threat, and I wish I had known more.

The study found that each participant had a unique experience of recovery and consequently the degree of recovery attained varied between participants. They all had a very strong desire to survive lung cancer and considered the risks of major surgery and losing a lung to be insignificant compared to the certainty of losing their life if they did not undergo surgery. This study provided a glimpse of what it was like for a group of patients to live the experience of life after a pneumonectomy and it provides a basis from which nurses can explore further the experiences of patients who are subjected to lung cancer surgery.
KEY TO THE TEXT

An essential component of this study was the information contained in the transcripts of the interviews that participants gave. Sections of these transcripts have been quoted in this thesis to enrich the meaning of the themes.

Some editing of the spoken word has been necessary so that the written word would be more comprehensible. Some words have been left out, while others have been inserted, but the original meaning of the dialogue has been retained.

Alterations within the text have been symbolised as follows:

… An ellipse indicates that text has been deleted by the researcher to edit out irrelevant material.

[words within quotes] Square brackets around normal text indicate words that have been inserted to so that the reader can appreciate the body language/mood of the participant during that section of the interview.

[words within quotes] Square brackets around italicised text indicate words that the researcher inserted to assist the reader to comprehend the interview dialogue.

*Italics* Italicics indicate that a direct quote from the transcript has been used.

‘Single spaced normal text’ Singled spaced, normal text within single quotation marks indicate a direct quote from the literature.
1.1 Background to the study

The ability to breathe easily and without thought while carrying out all the activities inherent in daily living is taken for granted by most people. The surgical removal of one lung, called pneumonectomy, is a common operation performed as the treatment for lung cancer. From January 1984 to July 2001, cardiothoracic surgeons practising in a cardiothoracic service within one New South Wales Area Health Service performed surgical resections for primary lung cancer on 2,495 people of whom 557, or 23%, had a pneumonectomy (Data from the Lung Cancer Surgical Database, University of Sydney, NSW). Therefore, a significant number of people have the potential for their activities of daily living to be altered because of this operation.

My involvement with patients having a pneumonectomy began when I was appointed to the position of Case Manager for Thoracic Surgery. In this role, I guide and support patients and families through an entire continuum of care, and I have my first contact with them very soon after their first knowing that an operation is recommended. The patient, their family, and I usually meet face to face in the cardiothoracic surgeon’s consulting room (or over the telephone) and discuss together the expected course of their treatment, care, and recovery from the surgery. Verbal information is supported with written information in the form of a patient information booklet.

The patient is guided through the required pre-admission processing, then, once admitted to hospital my daily visits support them through their surgery and hospital stay. Prior to their discharge from hospital, the patient, their relatives, and I discuss their ongoing care and likely course of recovery. I review their progress after discharge from hospital and “trouble shoot” with them via a follow up telephone call. This contact provides important ongoing clinical and emotional support to the patient and family after their discharge from hospital. Referrals to local support networks and services are made where appropriate as a result of this communication.

Two-way communication between the case manager and patient begins at our first meeting and continues for as long as the patient feels the need for it. It was through these
communications that I began to hear from patients that the process of recovery after pneumonectomy was often quite difficult. Patients told me about the challenges they encountered during their recovery, and this led to my interest in this study. I found that while I was able to talk about the clinical issues that might impact on their physical activities of daily living, such as how the body coped with a reduced respiratory capacity during physical exercise, I did not have definitive answers to questions about personal and lifestyle issues. Patients wanted to know if they could live a “good” life with only one lung. They asked questions about how the surgery would affect their breathing. They asked, “Will I be able to play tennis again? When can I go back to work?”

While lung cancer is more frequently a disease of an older population, young people also experience it. I remember clearly a 35-year old mother being prepared for surgery. One of her concerns was about whether she would be able to return to work as she and her husband had recently taken out a mortgage to purchase a new home.

I realised that in order to begin to answer the many questions that patients had about living with one lung, I needed more information, but the information was not in textbooks, research articles, or professional journals. The answers therefore, could only come from those who had lived through the personal experience of pneumonectomy and were thereafter living life with their one remaining lung.

The impetus to explore this topic grew from several aspects of my clinical practice. There was a pragmatic professional need to learn more about the specific issues experienced by people living with one lung, and a wish to provide information that would improve patient outcomes. There was also a personal desire to be more helpful to the patients that I care for in my role of nurse case manager. It appeared to me also, that there must be ways in which nurses working in the acute care area could assist in reducing some of the fears and anxieties that patients have when faced with this operation and the prospect of living life with one lung.

Benner (1984), in writing about the helping role of nurses, pointed out that patients look to nurses for different kinds of help than they might ask of other professionals. This reminder, and the fact that patients do frequently ask for information and help at any time along their surgical care continuum, reinforced the need for the study. A search of all literature sources
at this stage revealed three publications related specifically to pneumonectomy. One was a personal report by a patient on the experience of losing a lung (Key, 1985). The other two were nursing articles addressing the immediate post-operative care of the patient following surgery (Burkhart, 1983; Brenner and Addona, 1995). Medical publications were plentiful but addressed issues specific to the procedure, morbidity and mortality, and quantitative measures of outcomes of the surgery. Patient concerns were not addressed in the medical literature.

Given the absence of published information on recovery after pneumonectomy, there was little doubt that the best way to gain that information was to go to the people who lived the recovery and talk with them about their experiences. To facilitate this process a qualitative research method with a phenomenological philosophical basis was chosen for this study.

Phenomenology would provide a ‘fuller understanding through description, reflection and direct awareness’ (Wilkes 1991, 232) of the meaning of the phenomenon that these patients were living. In particular, this study focused on the approach of Max van Manen (1990) who believes that ‘Phenomenology asks, “What is this or that kind of experience like?” ’ (9).

1.2 Purpose of the study

The purpose of the study was to explore the impact of pneumonectomy on the lives of patients and their families during their initial two years following surgery. To be more specific, the study would explore how the surgery affected the physical, social and lifestyle activities of previously healthy employed “normal” family people who underwent pneumonectomy, as opposed to older retired persons having this operation. It is expected that the analysis and interpretation of their experiences will provide valuable insight into the experience of recovery after pneumonectomy. Describing the phenomena will provide information for health professionals to use when they prepare patients for surgery and assist them in their recovery.

The study was seen as having importance for nursing knowledge and practice, patient knowledge and medical knowledge. Therefore, it was seen as having three major aims: to
improve patient care and potential outcomes following pneumonectomy, to contribute to the
body of nursing and medical knowledge, and to strengthen nursing practice.

This study will contribute to the current limited knowledge base of what it is like experience
and recover from pneumonectomy and live with one lung. It will help to close the gap
between what patients know and feel and experience on a daily basis and what professionals
have perceived they experience over a period of time called recovery. It is intended that the
information gained from this study will assist patients facing this major surgery to feel more
at ease, prepared and informed about the life they will have in front of them.

1.3 Organisation of the thesis

Chapter 1 introduces the background and rationale for the choice of the study topic and the
purpose and relevance of the study to nursing practice. A summary of the chapter content is
included along with a brief overview of the topics of lung cancer, smoking, and lung
surgery.

In Chapter 2, the literature is reviewed and the terms and concepts of treatment and
recovery are defined. Current management strategies and research findings from nursing
and healthcare literature are analysed. Literature and stories about personal experiences and
patient perspectives are also reviewed.

Chapter 3 describes the theoretical perspective that informs the study. Different
phenomenological approaches are examined and the rationale for the use of van Manen’s
approach in this study is discussed. The method used in this study is described, taking into
account the selection process and demographic details of participants. The display and
reduction of the interview data for analysis is described and the process of data analysis
presented. This is followed by a reflection on the research process, the interaction between
the investigator and participants, and the tension between the investigator and data.

Chapter 4 presents and discusses the themes arising from the transcripts of participant
stories. It is divided into six sections with each section describing and discussing how a
particular theme relates to the notion of living with one lung, or life after a pneumonectomy.
Relevant literature supports in-depth discussions. Section 1, *Living the discomforts of*
treatment and recovery addresses the physical and emotional discomforts experienced by participants as they recovered from their surgery. Section 2, Discovering new limitations on my self: functional and emotional identifies the physical and emotional symptoms that manifested into limitations, and discusses the negative impact of these limitations on the quality of life and lifestyle of participants. Section 3, My reliance on support discusses how participants acknowledged their need for support, and identifies the sources from which they gained support in order to sustain their recovery. Section 4, My financial security is threatened addresses return to work issues and the consequence of not returning to work on the quality of life and lifestyle of participants. Section 5, My survival is at threat, related the issues arising from a diagnosis of lung cancer, having treatment and then living life with one lung to an ever present fear of the cancer returning. Section 6, I wish I had known more is the final theme. It identified that nobody (patients or professionals) really understood what it is like to recover from pneumonectomy, and consequently, their not knowing contributed to some of the clinical and psychological problems that participants experienced.

The final chapter draws together the findings and discussions from the study and presents the conclusions. Limitations of this study and the implications of this study for patients and health professionals are identified. Recommendations for nursing research, practice, and education are identified and discussed.

To be compatible with the theoretical perspective of the interpretive paradigm a first person approach has been used rather than the third person, and the active voice rather than the passive has been used in writing where relevant beginning in this chapter and continuing through subsequent chapters (Webb, 1992). Pseudonyms are used to identify the voices and actions of the study participants as their voices are presented in print form.

1.4 Background information
Lung Cancer, Smoking, and Historical Background to Lung Surgery and Pneumonectomy

In preparing for this study my reading led to an abundance of historical information about lung cancer, lung surgery and tobacco use. There is unquestionable evidence that these three topics are inter-related and so for this reason an overview of each of these topics has been included in this introduction. The historical information provides evidence of the relevance
of this study to the 21st century because tobacco use is a voluntary behavioral activity and has been proven to cause lung cancer. Therefore, lung surgery to treat lung cancer is potentially a preventable operation. Prior to the 20th century, in the western world, lung cancer was rare, smoking rates were low, and lung surgery was an uncommon operation.

1.4.1 Lung Cancer

According to the notes of Brewer (1982), lung cancer was known as far back as the 16th century and the acquisition of information about lung cancer took place over two notable time periods. The first period was between the years 1521 and 1850, when lung cancer was describes as encephaloid and cerebriform because the tumours or masses resembled brain tissue. An autopsy report of 1805 used this terminology. ‘The root of the left lung was found to be occupied by a mass…which resembled brain…The liver contained numerous “cerebriform” masses…’ (Bayle cited in Brewer 1982, 650). The term cerebriform was changed to cancer du pomon around 1839, then in 1851 the first case of lung cancer in the USA was reported (Brewer, 1982).

The second notable period was between 1857 and the 1900s when cellular pathological studies by a number of scientists reported a variety of significant findings that contributed to information about how lung cancer behaved. Pulmonary veins (as opposed to the arteries) were found to contain tumour cell thrombi. The microscope identified cancer cells, tumour cell tissue was found in sputum, cancer cells were found in pleural fluid, and needle aspiration was found to be a positive diagnostic method (Brewer, 1982).

Brewer (1982) also highlighted a number of other important discoveries that are common to lung cancer behaviour and accordingly are part of the knowledge base that drives clinical practice today. In 1838, the now classical symptoms of a superior sulcus tumour were accurately reported. The ability of the disease to metastasize was reported in 1841, with cerebral metastases being reported as a common complication of lung cancer in 1843. The classical signs of an obstructed bronchus (pneumonia or pleurisy) were reported in 1842, while the effects of superior vena cava compression (facial swelling, distended superficial veins and dysphagia) was reported in 1844. Later came reports of epithelial proliferation within the lung tissue and the lymphatic system. Finally, the development of radiography based on the discovery of the roentgen ray in 1895, and the introduction of bronchoscopy in
1897 assisted the process of achieving a clinical diagnosis. All of these findings have become mainstay features of the clinical manifestation and diagnosis of lung cancer today.

Weller (1956, cited in Brewer, 1982) reported a number of irritant substances that contributed to lung cancer. Lung cancer was initially described as far back as 1898 as an endemic occupational disease. This was the case for miners of Saxony and Bohemia who inhaled dust from corrosive minerals. In 1921 exposure to radium along with other irritants such as cobalt, nickel, arsenic and exhaust hydrocarbons were reported as a cause of lung cancer. Some time later, lung cancer was known to develop in patients with asbestosis but an interest in cigarette smoking as a cause of lung cancer only began in the 1950s. This interest was aroused in 1952 with the landmark publication of Doll and Hill that showed ‘the strong statistical relation between cigarette smoking and lung cancer’ (Brewer 1982, 654-655). It is well recognized today, that cigarette smoking causes lung cancer and that lung cancer is a major cause of premature deaths. The real impact of the problem of lung cancer, however, is found in the lung cancer data recently published by Goumas, O’Connell, Smith and Armstrong (2001).

Goumas et al. (2001) reported that in NSW, Australia, in 1998, lung cancer was the third most common cancer and the leading cause of cancer deaths. In that same year there were 2,724 new cases of lung cancer diagnosed, of whom 1,870 were males and 854 were females. There were 2,236 deaths due to lung cancer, being made up of 1,540 males and 696 females. Incidence rates in 1998 suggested that 1 in 19 males and 1 in 45 females could expect to develop lung cancer by the age of 75 years. Their data also reported that between 1973 and 1998 the incidence of lung cancer decreased in males in all age groups below 75 years but increased in females in all age groups. Survival figures reported that for lung cancers diagnosed between 1980 and 1998 the chance of long term survival was abysmal. The relative survival rates of males and females reduced rapidly in the first year after diagnosis to a point where the five-year relative survival rate was 11% in males and 14% in females (Goumas et al., 2001).

Primary lung cancers have two major clinical classifications: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). SCLC is highly malignant, arises from neuroendocrine cells, and is not treated by surgery. Primary NSCLCs are grouped according to their cellular origin and are treated by surgical resection if a cure is intended. Squamous cell
carcinoma (SCC) arises from bronchial surface cells, adenocarcinoma arises from glandular cells and large cell carcinoma describes a tumour that has no specific cytological characteristics of either SCC or adenocarcinoma. Primary lung cancers are classified according to the American Joint Committee for Cancer Staging system using a TNM (Tumour, Node, and Metastasis) classification. A detailed description of this classification in relation to lung cancer appears in APPENDIX F.

According to this classification, Stage 1A and 1B, and Stage 2A and 2B NSCLCs are tumours confined to the lung or bronchial tree, with an absence of or limited lymph node involvement and no extra-thoracic disease. These tumours are ideally treated by surgical resection with the intent to cure the disease. Stage 3A NSCLCs are sometimes treated with surgery if the tumour has shown a good response to a course of pre-operative or induction chemotherapy. Stage 3B or stage 4 NSCLCs are not treated by surgery because the staging indicates advanced disease. Other palliative treatment methods (radiotherapy, with or without chemotherapy) are used to control tumour activity and relieve symptomatic discomforts. All participants in this study had either Stage 1 A, 1B, 2A or 2B non-small cell lung cancer.

Figures from the Lung Cancer Surgical Database, maintained at University of Sydney, demonstrate that people with Stage 1A, 1B or Stage 2A, 2B NSCLC, treated by a curative surgical resection have a favourable chance of being alive five years after their surgery. The survival figures are given in Table 1.

<table>
<thead>
<tr>
<th>Stage of NSCLC</th>
<th>5 year survival rate in %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1A</td>
<td>67</td>
</tr>
<tr>
<td>1B</td>
<td>50</td>
</tr>
<tr>
<td>2A</td>
<td>47</td>
</tr>
<tr>
<td>2B</td>
<td>34</td>
</tr>
<tr>
<td>3A</td>
<td>21</td>
</tr>
</tbody>
</table>

Table 1: Five-year survival figures for NSCLC treated by surgical resection. (Lung Cancer Surgical Database, University of Sydney, NSW, 2002)

1.4.2 Smoking

Goumas et al. (2001, 5) commented that, ‘Cigarette smoking is the primary risk factor for lung cancer’. They based this statement on their knowledge that epidemiological studies
published in the 1950s and 1960s had established the causal relationship between cigarette smoking and lung cancer. They also acknowledged that ongoing research identified that risks of developing lung cancer are affected by duration of tobacco smoking, tar content in cigarettes, cessation of smoking and passive smoking. Goumas et al. (2001, 3) published an interesting summary of smoking related data:

- ‘From the 1997 and 1998 NSW Health Surveys 27% of male adults were current smokers compared to 21% of female adults.’
- ‘In Australia smoking prevalence in males has been decreasing for the last 50 years, whereas the prevalence in females has only been decreasing for the last 20 years.’
- ‘Based on smoking trends, lung cancer incidence should continue to decrease in males and begin to decrease in females soon.’
- ‘The decline in mortality for females is thought to be attributed more to a reduction in the tar content of the tobacco than female cessation of smoking.’

There have been numerous national and international studies looking at the effects of tobacco use on cardiovascular health and lung cancer but a study by Taylor R. (1993) highlighted the potential problem of continued use of tobacco by young people. The study, a cross sectional actuarial analysis of 1990 mortality data produced information that estimated how many 15-year-old smokers who were in the 1990 population would have a premature death (from all causes) that could be directly attributed to tobacco use. A summary of the analysis produced the following absolute risk data:

- ‘From one year of 15-year-old male smokers (26,713), 3,916 premature deaths due to tobacco can be expected; this includes 1,106 lung cancer deaths, 991 ischaemic heart disease deaths…’
- ‘From one year of 15-year-old female smokers (32,355), 3,861 premature deaths due to tobacco can be expected; this includes 1,086 lung cancer deaths, 559 ischaemic heart disease deaths …’ (Taylor R. 1993, 358).

All of these figures highlight the fact that lung cancer, along with the other tobacco-related illnesses such as ischaemic heart disease, stroke and chronic bronchitis, ‘is one of the most avoidable forms of ill health in our community’ (CSAHS 1999, Foreword). There is an
increasing awareness that tobacco-related lung cancer treatment has a high-cost, low-cure rate.

The need to address the problem of tobacco-related illnesses through primary prevention strategies was embraced by Australia when a “Health for All Australians” report was released in 1988 (CSAHS Tobacco Control Plan 1995, 4). This report led to the first set of national goals and targets for Australia, from which the NSW Goals and Targets Priorities for 1995/96 (CSAHS Tobacco Control Plan, 1995) was formulated. From this point on, much work has been done both nationally and locally to implement strategies aimed at reducing tobacco-related illnesses, of which lung cancer is the major problem.

The health problem of lung cancer is gaining public attention with increasing efforts being made to warn smokers of the dangers of their habit. Programs and medications aimed at helping people to quit smoking are more readily available and accessible. There is also a drive within the medical profession to develop best practice guidelines for the management of lung cancer as a result of a Lung Cancer Workshop hosted by The Cancer Council, New South Wales, in December 2001. Thoracic surgeons and physicians have recognized the fact that smokers are more likely than other people to develop lung cancer. This is demonstrated in their practice today when they support the view of Brewer (1984, 655) ‘that the most important question that a clinician can ask a potential cancer patient is, “do you smoke and for how long?”’

1.4.3 Historical background to lung surgery and pneumonectomy

In their writings, Graham and Singer (1933), Nissen (1980), Brewer (1981 and 1984), Baue (1984), and Scannell (1986) provide a fascinating account of the difficulties and challenges that surgeons have encountered while trying to perfect pulmonary resections. There were a number of attempts at surgical resection of lung cancer reported: two were in Munich in 1920 and 1926, two were in England, one in Detroit, and there were several others. Consequently, there were a number of opinions about what technique constituted a pulmonary resection and how to perform the operation (Baue, 1984).

The process of developing successful lung surgery techniques took place over many years. Brewer (1984) identified that there were four distinct eras of development. The first was the
period of “fortuitous” pulmonary resection between 1496 and 1895 when the chest was safely opened without intra-tracheal anesthesia, and several other barbaric procedures were performed to remove necrotic lung tissue. The second period was one of animal experimentation between 1880 and 1900, which involved some successful experimental lung resections in Los Angeles and Chicago. The third period was the beginning of the modern period of 1890-1928, when intra-tracheal anaesthesia was introduced to counteract the forces of open pneumothorax while the chest was opened. The final period, being the present-day period, started from 1928 with a reporting of six pulmonary lobectomies being performed with only one death. Lobectomy became a successful operation. Pneumonectomy was yet to be mastered.

There were a number of surgeons striving to find the correct surgical technique to treat non-cancer conditions such as tuberculosis, bronchiectasis, and lung abscesses in the early present-day era. Richard Overholt, one of these notable surgeons, worked with a team of doctors developing a 2-stage technique to drain lung abscesses using an intercostal tube. By 1933 Overholt had performed three successful pulmonary lobectomies. He had performed a single stage complete lung resection (pneumonectomy) but the patient had died 29 days later. Overholt made the significant observation while performing lung surgery that smokers had darker, stiffer, and less easy to deflate lungs than non-smokers who had a smoother and quicker convalescence from the surgery. Despite scepticism and ridicule from medical colleagues he persisted with his comments on his findings and embarked on a plan to educate, warn, and convince people about the dangers of smoking (Berger, Dunton, Ashraf, Leonardi, Karlson and Neptune, 1992).

In Berlin in July 1931, Rudolf Nissen performed a two-stage pneumonectomy in a 12-year-old child with empyema after a crush injury to her chest. Prior to this, no surgeon had tackled the challenge of removing a complete lung, not because of problems related to technique but because they did not know what to do with the empty space once the lung was removed. Cameron Haight of Ann Arbor (USA) performed a similar two-stage procedure in 1932 on a 13-year-old girl with bronchiectasis. They both used a technique whereby the left chest was opened, and the upper and lower lobes were separately ligated then allowed to slough away (Nissen, 1980). There was much excitement about this feat but in 1933, Evarts A. Graham performed a successful one-stage pneumonectomy in a patient with lung cancer. This was the first one-stage pneumonectomy.
The operation took place in Barnes Hospital, USA on April 5th on a patient who was a 48-year-old physician (Graham and Singer, 1933). Graham and his team set out to perform an upper lobectomy but once the operation had commenced and the chest was opened the clinical situation led to a decision to remove the complete lung. The patient recovered and continued to practise medicine for 24 years, then died some 30 years after having his lung removed. Ironically, he showed no signs of cancer recurrence, while the great and talented Dr Graham died in 1955 from lung cancer, 22 years after performing the historic surgery (Brewer, 1984).

The following report by Graham, published in The Cancer Bulletin (1949, cited in Brewer 1984, 815-817), provides an eloquent description of events leading to the completion of the historic first pneumonectomy.

‘At the operation, however, it was possible to palpate the tumor; and I discovered that apparently it extended down into the bronchus of the lower lobe. It seemed certain, therefore, that the removal of only the upper lobe would not result in removal of all of the cancer. Moreover, a lobectomy presented some technical difficulties, because there was almost a complete absence of an interlobar fissure. It occurred to me at once, therefore, that the only kind of operation that might offer a chance of cure would be total removal of the left lung. The patient brought with him a physician friend who was in the operating room gallery during the operation. I told that it would be useless to perform a lobectomy and that I strongly advised removal of the lung. I asked for his opinion; it was not very helpful. He asked if such an operation had been done before. I replied, “No”. I pointed out that the operation had been performed successfully in animals, but that I knew of no case in the human being of a successful one-stage removal of the lung. After a little more discussion, and particularly because I was certain the patient would want me to take any changes that might effect a cure, I decided to go ahead with the total pneumonectomy. There was one aspect of the operation which worried me. It was whether or not a middle-aged patient could tolerate the sudden occlusion of the pulmonary artery to a lung. …The artery was ligated separately with heavy catgut. …I was horrified to see the enormous space left after the removal of the lung, and it seemed necessary for me to diminish the size of the space by the removal of ribs. Accordingly, I removed seven ribs, from the fourth to the tenth inclusive’.
Evarts Graham had a desire and even a passion for surgeons to help their fellow man. After his first one-stage pneumonectomy, the technique became accepted around the world as a correct procedure for bronchiogenic carcinoma where lobectomy would not provide complete clearance of the tumour. Graham proved that for early lung cancers there was a 30% chance of being alive and free of disease five years later (Brewer, 1984). For lung cancers with regional lymph gland involvement the chance was diminished to about 15%. He also reported a 7% mortality rate from his 101 cases. Graham (cited in Brewer 1984) commented that, ‘No other treatment up to the present time can offer a patient any hope at all’ (823). Survival figures have improved considerably since Graham’s time (refer to Table 1 for modern figures), thanks to early detection of lung cancer, more accessible diagnostic procedures, and improved surgical techniques and post-operative care. The mortality figures of Graham were favourable (7%) given that data from the Lung Cancer Surgical Database at then University of Sydney report an overall mortality rate for pneumonectomy as 3.59%.

In reading Graham’s account I was reminded that the intention of this operation has not changed. The intention has always been to cure the patient of lung cancer. Lobectomy is performed when the tumour is confined to the lobe of the lung and there is no evidence of disease in the lymph nodes or any structures outside of the chest. Pneumonectomy is performed when a tumour is located in the main bronchus, or when a tumour is bulky and situated near the hilum in the chest and it involves major mediastinal thoracic structures, and/or when mediastinal lymph nodes are involved or are contiguous with tumour or lung tissue. Pneumonectomy is always performed with the intention of removing all macroscopic and microscopic disease.

The operation in which Evarts A. Graham successfully removed an entire lung to treat carcinoma of the bronchus showcased the role of surgical pulmonary resection in treating lung cancer. Graham and Singer (1933) commented at that time ‘that the only method that at present can offer any hope is the wide surgical removal of the tumour and the surrounding tissue’ (257) and in some instances this meant the removal of an entire lung. In 2002, surgical resection remains the gold standard treatment option when a cure is the intention of treatment for lung cancer.

This background introduction helps to put into perspective some of the dilemmas that patients might face on hearing that they have lung cancer. On one hand they face imminent
death if their disease is incurable or their body will not tolerate an operation. On the other hand they face major surgery and a chance that they will lose a complete lung, but in the background there is the knowledge that smoking may have contributed to a diagnosis of lung cancer. The real issues that patients are confronted with when they face, experience, and recover from lung cancer surgery will be illuminated by this study.
CHAPTER 2    LITERATURE REVIEW

2.1 Introduction

This chapter introduces definitions of the terms and concepts of treatment and recovery as they appear in the title and body of this study. They have been included because an understanding of the context in which these words are used in this study is vital to the interpretation of the study’s findings and ongoing discussions. Following this is a description of the method used for the literature search and a review of the findings of the literature as they relate to recovery following pneumonectomy.

Healthy individuals take their bodies and minds for granted when they freely function without signs and symptoms of disease or illness in their “normal” world. They know, however, that when they feel unwell, and symptoms suggest that something is not right with the health of their body they should visit or consult their family doctor or general practitioner (GP). When this situation arises and they visit their GP, a course of action takes place. The action begins with the doctor making a clinical assessment of the state of health of the individual and performs and or orders diagnostic tests to assist making the diagnosis. Once a diagnosis is made, a treatment is recommended. The person undergoes the treatment until such time as the prescribed treatment is complete with an expectation that their symptom(s) will abate and they will make a compete recovery.

Unfortunately, not all people who become ill experience such a simple course of consultation, diagnosis, and treatment followed by recovery. When an individual receives a diagnosis of lung cancer, they realize that they have a critical life-threatening disease. They seek out a treatment for their disease, always hoping that the treatment will cure the disease. They expect and hope that the treatment will enable them to achieve a recovery that will return them to normal health.

2.2 Treatment

The Macquarie Essential Dictionary (1999, 861) says treat means ‘to deal with (a disease, patient, etc) in order to relieve or cure’ and treatment is ‘the act or manner of treating’. The Microsoft Word Thesaurus says treatment means ‘handling, processing and therapy’. The word therapy has a “health” connotation in that its synonyms are prescription, care,
mediation, regimen and doctoring. I could not find any definition of treatment in textbooks about health, illness and disease (Kleinman, 1988; Bergsma, 1997; Couser, 1997; and Salmon, 2000), but the word is in common use in health and everyday life, and its use encompasses all of the meanings mentioned above. These meanings imply that there is communication between a patient and health professional(s), whereby the health professional prescribes a therapy. If the patient accepts the offer of therapy, then someone delivers it and “takes care” of the patient. The therapy can be in the form of a single application, a specified course, or a set regimen of action.

In chronic illness, the use of the word treatment implies that a patient is or will be receiving a therapeutic action, and with it come numerous consequences, some of which are made obvious by the questions that patient’s ask themselves such as, ‘What treatment do I wish to receive? What do I expect from the treatment? What effects of the treatment do I fear?’ (Kleinman 1988, 44). Bergsma (1997), in a text exploring the problematic triangle between doctors, patients and illness, implied that a treatment is a physical therapy when he mentioned ‘…objective findings in diagnostic or treatment procedures’ (85).

Couser (1997, 10) on the other hand sees treatment as a complete package of therapy that involves interaction between the patient and doctor. He talked about ‘The treatment of illness…collaboration between doctor and patient…’ and says that ‘…Diagnosis leads in turn to prescription, treatment, and prognosis…’. He implies that treatment is the sum of a number of distinct processes.

Salmon (2000) reinforced the difficulty in defining treatment in his text. Six chapters were grouped under the heading of treatment but no definition for the term/word was given. The text did, however, discuss the many issues that fall under the umbrella of the word treatment and highlighted that treatment is a complex process. The author referred to treatment as a bringing together of an expert professional with the inexpert patient to diagnose and manage a health problem. The process is complex because it involves decision making by the clinician and the patient, empowerment, choice, control, information, communication, hospitalization and surgery, patient adherence, management of unexplained physical symptoms, recognizing and managing psychological conditions related to physical disease, and finally evaluating patient outcomes and care (Salmon, 2000). All of these issues are encompassed by the term treatment.
As can be seen, there is no simple meaning for the word *treatment*. In the clinical setting, treatment generally relates to either a single episode or a series of episodes of dealing with a person or thing. The dealings involve the delivery of a therapy, a prescription, and/or some form of care. It also involves mediation, a regimen or doctoring (Microsoft Word Thesaurus). Treatment is a dealing or communication that takes place between a health professional and a patient where some form of therapeutic advice or action takes place. In the case of lung cancer, the surgeon offers the best treatment, which is surgery providing the tumour can be safely removed. Patients can choose their treatment and do choose their treatment following discussion with the surgeon who usually says something such as, ‘The various medical and surgical treatments available for lung cancer are…’ (Pierce 1990, 22).

Clinical examples of supportive therapy that are labeled *treatment* are many and varied. Post-operative pain management is a treatment that nursing and medical staff deliver to patients while they recover from their surgery in hospital. The family doctor or GP takes over treating the pain once the patient is discharged from hospital. Nurses provide treatment and care when they help patients with personal hygiene and mobilization. They also provide “general” care when they perform activities that help patients achieve a level of comfort. Physiotherapists perform treatments such as teaching and assisting deep breathing and coughing exercises and carrying out chest percussion on patients aimed at preventing them from developing post-operative respiratory complications. Doctors prescribe medications that are called treatments, delivered to patients by nursing staff such as establishing and running a blood transfusion and administering intravenous antibiotics. Hospital medical teams perform doctoring when they assess the patient’s clinical progress at least daily and adjust prescribed treatments accordingly. Making appropriate adjustments to treatment is dependent on continuing communication or mediation between the patient, and nursing, allied and medical staff.

For the participants in this study, their treatment began at the time of their diagnosis, but more specifically the surgical aspect of their treatment began at the time of their consultation with the surgeon. It was at this visit that the surgeon made the clinical judgement that surgery was possible and offered the best chance of a cure. The offering of the surgery as a treatment option and the acceptance of the offer by the patient marked the real beginning of their surgical treatment. The treatment episode was expected to span a period of up to two months and culminate in recovery.
Treatment refers not just to the main event of having a pneumonectomy. It encompasses all of the professional, physical and emotional interactions (or dealings) that take place between a patient and their family, and health professionals during a period of time. It began with the diagnosis and was expected to end when they, the patient, felt they had recovered from the surgery.

2.3 Recovery

Arthur Frank (1991, 2) says, ‘Illness is something to recover from if you can…’ and ‘A problem with the view of recovery as the ideal ending of illness is that some people do not recover’. The Macquarie Essential Dictionary says to recover is ‘to regain health after sickness, etc.’… ‘to regain the strength, balance etc. of oneself’ (1999, 660). There are a number of unanswered questions about recovery — such as how do patients know when they have recovered? What is considered a normal recovery for patients who have had a lung removed to treat lung cancer? Is it realistic to expect patients to return to a normal state of health? These questions are raised in an environment where Frank (1991) believes that not all patients recover from illness.

Recovery can be viewed from two perspectives. One is an objective perspective where a physical recovery takes place and there is a definite end point of the illness event. The other is a psychological perspective from which recovery is viewed more as a process of being a survivor of a disease and there is no real endpoint. Frank (1991) highlights these two perspectives when he writes about his own experiences of a heart attack and cancer. He said, ‘Recovery has different meanings. After my heart attack it meant putting the whole experience behind me. I wanted to return to a place in the healthy mainstream as if nothing had happened. Cancer does not allow that version of recovery. I am reminded, every time I see a doctor or fill out an insurance form, that there is no “cure” for cancer, only remission’ (Frank 1991, 2). For Frank, an angiogram signified an end to an incident and it closed the book on his heart problem, whereas his cancer treatment left him with an ongoing experience. While both of these examples had a physical or objective component, the heart attack experience had a definite end but his cancer experience had no end. In the setting of surgery, there is an expectation that a patient will reach a point where they can say that they have recovered. For the patient who has had a complete lung removed, knowing what or how to feel when they have reached that point called recovery is yet to be documented.
Doctors, nurses, and allied health professionals use objective (or end point) data to measure recovery. They expect that when patients are discharged from hospital after pneumonectomy they will be able to perform activities of daily living independently. They will be able to shower, dress, mobilize, and feed themselves. They will be able to perform respiratory and mobility exercises on their own. Professionals expect that when patients have achieved full recovery they will have returned to, or near to, their pre surgery level of functioning. This means for example, that those who had been working prior to surgery would return to their work, those who enjoyed sport before surgery would return to sport.

Mathews and Ridgeway (1984, cited in Pitts and Phillips, 1991) identified seven ways in which objective data can be used to measure recovery. Clinical ratings such as vital signs measure outcomes, for example, a heart rate after a six-minute walk. Behavioural ratings measure specific behaviours relevant to a given operation, for example, the distance the patient can walk two weeks after surgery. Length of stay measures the time from surgery to discharge. Mood ratings measure levels of anxiety or depression. Pain ratings use visual analogue scales to measure pain levels. Lastly, physical indices assess rates of morbidity and mortality related to the surgery, and finally, amounts of medications taken, for example pain-killers, can be recorded. These measures are research-derived and while they do have a psychological basis, they do not take into account the patient’s own assessment of recovery. Typically, health professionals use a variety of this data to determine if a patient is ready to be discharged from hospital. This data measures patient outcomes that indirectly imply recovery.

The work of Morse and Johnson (1991) looked at recovery from a patient’s viewpoint. They supported the notion that patients take on an objective perspective to measure their recovery, for which returning to a pre-surgery state is an important measure. These authors reported on the experience of women recovering from hysterectomy to address four issues that contribute to recovery. The women recognised and adjusted to bodily changes by being aware of and adjusting to associated physical limitations. They associated anxiety and worry about how they might function sexually with their resumption of relational (sexual) activity. Attending follow-up with their doctor was found to be a very positive action because they were informed that there was no cancer present, and fourthly, this information enabled them to reflect on their experience and be satisfied that the decision to have the operation had been the right decision for them. For the women in this study, these four
issues were objective measures that were seen to be a signal that they had recovered from their surgery.

The subjective aspects of recovery are much less defined. It has only been in recent years that emotional and “feeling type” issues have been fully recognized as part of the overall surgical treatment, but they have been recognized in cancer work for many years. Subjective aspects of recovery see the patient as being a survivor of a disease process—a process that has no measurable endpoint. Frank (1991) talks about recovery in a chapter titled “Ceremonies of Recovery” and says that ‘recovery deserves a ceremony’ (129). His experience of cancer made him view recovery very differently in that he could never actually see recovery. He was only ever living in remission. This comment posed the question: do cancer patients ever experience recovery? Frank (1991) said, ‘I become less and less a person with cancer, but the continuing schedule of examinations, X-rays, and blood tests reminds me that I remain at greater risk than others. The risk diminishes over time but never disappears. Life remains a remission. But my sense of being a person with cancer is on the level of experience, not of medicine… As long as life remains a recovery, I try to seize the life I someday want to have lived’ (132).

Armstrong (2000) also recognized that reaching recovery involved a subjective perspective. Recovery was not just reaching a point of physical achievement, but was a physical and emotional event. He said, ‘I know now that surviving cancer involved more than just a convalescence of the body. My mind and soul had to convalesce, too’ (197). The subjective perspective of recovery from cancer is widely written about in the literature under the umbrella of surviving cancer, and many of these writings will be referred to later in the analysis of this study’s findings.

Recovery, like treatment, can be broken down into small parts of a big process. Nurses see patient recovery over a shorter time, the time in which they are directly involved with their care. Lawler (1991) looked at recovery through the eyes of nurses and identified that they have ‘a taken-for-granted trajectory toward recovery’ (14). As patients regain their independence and progress at a ‘normal’ rate towards recovery, nurses become less and less involved with patient body space and surveillance and inquire less about body functions. Lawler (1991) believed nurses used a compliance and control rule to determine recovery such that patients reached a point called recovery when able to comply with some basic
rules.

Nurses expect that physical recovery of a patient after pneumonectomy is achieved when a number of technical activities or rules have been met. The following are examples of typical activities used to measure recovery. The chest drain and intravenous lines have been removed. The patient is able to get into and out of bed without assistance. They do not need assistance from a nurse to shower (but they may have assistance from a relative). Their weight will have returned to at least their admission weight, and they will be voiding and opening their bowels regularly. The main activity of a nurse will be to administer medications, finalize discharge papers, and check that the wound and drain site are healed or healing. From a nursing perspective, the patient no longer needs a nurse to provide body care and so the nurse hands back to the patient their body and control of it (Lawler, 1991). To completely pass the “trajectory” requirements, the patient will have attained these achievements within a set time. Clinical pathways, the widely used clinical management tool that guides patients through an episode of care and a series of events leading to recovery, helps nurses to know when a patient has met trajectory requirements (Newman, 1995; Zevola, Raffa, Brown, Hourihan and Maier, 1997).

The meaning of recovery remains debatable but in general terms a patient is considered recovered from surgery when they are able to function independently in the world again. According to Benner (1994, 216) ‘functional independence is measured by physical, visible signs of self-care’. This means that the patient returns to their pre-illness level of health and activity. There was no specified time period in which recovery was expected for participants in this study.

2.4 Literature searches and review

Computerized searches of medical, nursing and allied health sources were conducted prior to and at regular intervals during the study using the following key words: pneumonectomy, lung neoplasm, lung cancer, thoracic surgery, thoracotomy, lived experience, survivor and phenomenology.

My search found one paper specifically addressing the experience of pneumonectomy (Key, 1985) and two studies addressing issues related to needs of patients who have lung cancer
surgery (Galloway, Bubela, McKinnon, McCay and Ross, 1993; Goodman, 2000). There is an abundance of literature related to surviving lung and other types of cancers, in which breast cancer features prominently (Carter, 1993; Ferrell, Dow, Leigh, Ly and Gulasekaram, 1995; Fredette, 1995; Held, 1995; Luker, Beaver, Leinster and David, 1996; Nelson, 1996; Breaden, 1997; Ott, 1997; Pelusi, 1997; Cooley, 1998, Shin, 1999; Flanagan and Holmes, 2000; Leydon, Boulton, Moynihan, Jones, Mossman, Boudioni and McPherson, 2000; Mills and Sullivan, 2000). Specific survival literature will be discussed in the findings of this study.

Pneumonectomy related nursing literature focused on the acute surgical nursing care of these patients immediately following surgery and in the early post-operative recovery period (Burkhart, 1983; Brenner and Addona, 1995).

Medical and allied health literature focused on clinical aspects of the operation and mortality and morbidity resulting from the surgery. This information was presented as empirical morbidity, mortality, survival and recurrence data. Medical literature did not address experiential issues related to pneumonectomy and recovery.

2.5 Personal experiences of surgery and recovery after pneumonectomy

Computerized searches found only one experiential article written by Marguerite Key (1985). It is a report of her personal experience of having a lung removed and the process of recovery titled ‘What it is like to lose a lung’. Although the article was written almost 20 years ago it contains the very basic questions that Key wanted answered while she was going through her experience of surgery and recovery. They were about what would happen to her, how would she feel after the surgery, and would she be able to function normally again. Interestingly, patients being prepared for pneumonectomy today ask similar questions.

Key used only two paragraph headings in her paper: Repository for old razor blades and Not a lot of advice and under these headings she highlighted many issues that concerned her. The headings provided a succinct summary of how Key endured a number of unpleasant experiences under a cloud of ignorance and unknowingness because nobody could tell her what to expect. Key talked about the scariness of the whole experience, which
arose partly because of the rapidity with which her diagnosis, surgery and after care happened, and partly because of not knowing what was to happen to her body. She commented on the busyness of people (doctors and nurses) and the pain and suffering she went through. She found her wound was painful and this made getting herself into a comfortable position difficult. She noted ‘the insane behaviour of that part of me that lay below the scar — that is, from midriff to feet’ (Key 1985, 143). The very slow pace that she was forced to take annoyed her and the heat of the hospital ward made her sweat. In particular she noted that there was little advice given about anything that she was to experience later during her recovery. She said that when she was discharged she was told “just keep warm and walk around a lot” (143). One of the moments she recalled that distressed her was her experience of a fellow patient being repeatedly resuscitated in the bed next to her in the intensive care unit while she was recovering.

Key recorded and published her account in a medical journal, presumably so that other health professionals might learn from her experience and so prevent other patients from enduring a similar suffering. She did not reveal in her story the underlying clinical reason for her pneumonectomy. Also, she did not state if she was telling her story as a patient with a health professional background or as a lay person, but she wrote her story in a tastefully humorous style that made it easy to read and gain meaning from. The real significance of her story, I believe, was her descriptive and passionate account of the events she experienced during her hospitalisation and recovery spanning a period in total of about three months. This personal paper was found quite some time after the study had commenced and it reinforced my belief that there was an urgent need for this current study to be completed and information disseminated to health professionals, patients and the wider community.

Later, as the study progressed, I found Lance Armstrong’s (2000) story about his battle with cancer. Armstrong, an elite cyclist at the time of diagnosis, had a primary carcinoma of a testes, with secondary deposits of this tumour in his brain and lung. His story is a personal account of the many issues that arose during the time of his illness, treatment, and recovery. However, it was the issues of recognizing that he had a health problem, accepting a diagnosis of cancer and being confronted with options and decisions about treatment that were his greatest challenges. His story addresses the many feelings he experienced during the process of obtaining a diagnosis. He talked about the anguish and pain and fears that arose when he was attending consultations and being assessed for treatment, and he talked
about the difficulties of deciding on what treatments he would undergo and who would provide them.

Armstrong (2000) searched for a meaning for his nightmare experience as he described living through the treatments and then living through the many obstacles that obstructed his recovery. He recounts the many demoralizing and painful decisions concerning his cancer journey until he eventually survived and returned to his elite sport. He faced and overcame numerous challenges. Many of them were not unlike those of Key (1985). Armstrong (2000) wrote ‘I left my house on October 2, 1996, as one person and came home another’ (4). He learned that life was not just a material thing that one has but that life was precious. This sentiment was reflected in his words, ‘When I was sick, I saw more beauty and triumph and truth in a single day than I ever did in a bike race — but they were human moments, not miraculous ones’ (5). His writing reflected the importance of the humanness of his experiences. Armstrong provided an easy-to-read descriptive account of his experience of cancer, its treatments, and his recovery. His work brought home the fact that cancer does not just affect the person with the disease but touches all those that that person interacts with — their partner, family, friends, colleagues, doctors, nurses, and the public. He wrote, ‘One thing you realize when you’re sick is that you aren’t the only person who needs support — sometimes you have to be the one that supports others’ (Armstrong 2000, 114).

Arthur Frank (1991) in his book titled ‘At the Will of the Body’ wrote about his two illness experiences, a heart attack and renal cancer. His work is well recognized for its contribution to knowledge about lived experiences and is referred to frequently in phenomenological and experiential studies. Larry Dossey summarized the account of Frank’s experiences in a review and commented that ‘Arthur Frank has written the best account of serious illness to appear in decades. Courage, fear, denial, anger, hope — nothing is left out as Frank takes us on a guided tour of his experience with close-to-the-bone honesty. He shows us the value of going through the experience of illness, not around it’ (Frank 1991, Back cover).

Breast and other cancer literature studies focused mainly on issues related to surviving the disease rather than the actual surgery and recovery process (Fredette, 1995; Breaden, 1997; Ott, 1997; Pelusi, 1997; Flanagan, 2000). These works will be referred to in the discussions about the findings of this study.
2.6 Nursing publications related to surgery and recovery after pneumonectomy

Early in the study, I found two nursing publications about pneumonectomy. The authors, Burkhart (1983) and Brenner and Addona (1995) focused on the technical and clinical aspects of caring for the patient after pneumonectomy in the acute/intensive care and early post-operative period and they addressed the anatomical and physiological changes that occur when a complete lung is surgically removed. They outlined the immediate and short-term post-operative care required for the patient and discussed the potential life-threatening complications that could present as a result of this surgery. Their focus was on preparing nurses to deliver crucial expert nursing care to patients undergoing this major surgery. These authors provided an overview of how to care for the object body that was experiencing pneumonectomy.

Burkhart (1983), published two years before Key wrote her personal paper, did not address any psychosocial aspects of caring for pneumonectomy patients. Brenner and Addona on the other hand published 12 years after Key, and under the heading ‘Ineffective coping’ talked about providing assistance for the patient and family ‘to cope with the diagnosis, operative procedure and postoperative course’ (1995, 70). Neither of these studies addresses the questions of what happens to “my body” and “my self” after the surgery has taken place and the patient leaves hospital.

Two nursing studies related to lung cancer surgery were located. The authors, Galloway, Bubela, McKinnon, McCay and Ross (1993) and Goodman (2000) did not specifically focus on pneumonectomy patients but they recognized through their studies that lung cancer surgery patients needed information about their disease, treatment, and recovery. The studies identified that professional carers had a responsibility to provide some of that information.

Galloway et al., (1993) explored the needs of patients after discharge from hospital using a convenience sample of forty patients who had had an open thoracotomy for primary lung cancer. The researchers wanted to determine ‘what information they (patients) perceived as being important and what effect selected symptoms had on usual activities prior to and after discharge’ (116). They measured discharge information needs using a patient learning need scale (PLNS) whereby patients rated their responses on a 0 (does not apply) to 5 (extremely
important) scale. A visual analogue scale was used to measure patient perceptions of the effect symptoms had on their ability to carry out activities. The authors acknowledged that there is little available empirical knowledge about discharge information needs of patients after surgery for lung cancer, but they believed that information might ‘enhance individuals’ understanding of illness-related events and management of treatment-induced symptoms’ (116).

Patients in the Galloway et al. (1993) study deemed information to be very important, especially information relating to treatment, possible complications, management of symptoms, and medications. They were also concerned about how lung cancer might impact on their present and future life. They wanted information on how to recognize and manage both complications and treatment-induced symptoms especially fatigue and pain as these were the symptoms that had the greatest impact on usual activities of daily living. This study confirmed that patients need access to essential information because information helps them to ‘objectively interpret an event when it occurs and institute effective coping behavior’ (Galloway et al. 1993, 118).

Goodman (2000) conducted a descriptive exploratory pilot study using patient diaries and unstructured interviews in order to explore the needs of patients after discharge following lung cancer surgery. The study was conducted at the Brompton Hospital in London and required patients to keep a diary recording any questions, thoughts, or feelings that they had during the first four weeks following surgery.

The diary contents were then categorized into two themes: psychological and physical. The study found that although many patients recover “quite well” patients themselves found there were many gaps in knowledge about psychological, physical and emotional issues that caused them distress. Such issues were alteration in mood, the potential for cancer recurrence, transition from the security of the hospital to home, physical needs about appetite, constipation, weight loss, sleep and exercise, expectations about pain and pain medication, and finally knowing where and how to get support or a listening ear.

The study concluded that patients who undergo lung cancer surgery have very individual needs and that social and psychological needs are often not thoroughly assessed. It confirmed that patients might experience psychological difficulties. The study suggested
that knowledge gaps could be lessened with the provision of appropriate verbal and written information along with psychological support.

2.7 Medical literature related to surgery and recovery after pneumonectomy

There were numerous medical publications about lung cancer surgery, but these focused on the surgical technique, complications, and morbidity and mortality issues. Survival and recurrence data for surgically treated non small cell lung cancer according to pathological staging were reported as quantitative statistical data. No medical publications addressed any part of living life with one lung.

2.8 Other literature related to lung cancer surgery and recovery

Other literature findings included information in the form of historic records, research articles, and books addressing the topics of illness, surviving, caring, and cancer. This information will be used in the body of the study as it relates to the specific themes that were uncovered.

2.9 Conclusion

There is little literature about recovery after pneumonectomy as a treatment for cancer. Personal experience literature about recovery from other cancer surgery is more readily available. This literature suggests that some people find the process of recovery after illness and surgery challenging, but they also find having access to information is a vital resource should they decide to meet their challenge head on.

Medical literature reports empirical data that says that lung cancer can be cured by surgery, and that the morbidity and mortality associated with lung surgery is low, but does not address lived experience issues related to surviving lung cancer.

As “nursing” has embraced a holistic approach to caring for patients, some thoracic surgical nurses have become interested in learning about the needs of patients facing lung surgery. They have become more sensitive to the physical and emotional experiences of patients and
they have been asking, “What is the experience of people having lung surgery?” “What information do they need to make their experience more comfortable?”

While studies have confirmed that patients need and want information when preparing for lung surgery, it is the intention of this study to contribute to a specific body of knowledge about the personal experience of people and their recovery following pneumonectomy to treat primary lung cancer.
CHAPTER 3 METHODOLOGY

3.1 Introduction

This chapter has two parts; an introduction to the philosophical underpinning of this study and a description of the research methodology as it was applied to the study. The first part identifies the need for this research, introduces the reader to the purpose of, and need for, human science research, and is followed by a presentation of reasons why phenomenology has become a popular human science research method. The philosophical methodology of phenomenology is explained along with the reasons why nurses have embraced phenomenology as an appropriate methodology for exploring patient experiences. The first part concludes with the reasons for choosing Max van Manen’s phenomenological methodology for this study.

The second part of the chapter discusses in detail the phenomenological methodology that was applied to this study in order to obtain information-rich data for analysis. The methodological issues that were encountered while conducting the research are identified and discussed, along with the ethical issues considered during planning and conducting the study. Lastly, there is a description of how the issues of reliability and validity were addressed.

3.2 Philosophical underpinnings

When “healthy” people undergo elective surgery, they expect to feel “recovered” within a reasonable period of time. Through their surgical experience they expect to feel some pain, but also expect that the pain will subside to a feeling of soreness. Preparations for a temporary curtailing of normal physical activities are made in advance, but they anticipate that they will return to work. These expectations of recovery from elective surgery are not unreasonable, given modern surgical techniques and technological support, and they are achievable, but they give the reader an impression that recovery is a relatively “smooth sailing” process. Pneumonectomy is an elective operation, but it is not known if participants recovering from pneumonectomy share these general expectations.
Two studies have explored how patients adjust to new situations that they encounter when they recover from lung surgery — situations that begin when they are discharged from hospital. Galloway, Bubela, McKibbon, McCay and Ross (1993) measured or quantified what it was that patients needed in order to make adjustments to situations and the transition from hospital to home more manageable. This study used visual analogue scales to measure patient needs, and it found that patients needed information in order to help them cope with new situations. This finding was similar to that of Lazarus and Folkman (1984). Goodman (2000) acknowledged the importance of information, but also recognised that talking with patients about their feelings, emotions and anxieties, would enable nurses and other health professionals to develop better discharge methods and follow-up procedures. Neither study questioned how patients perceive or interpret the feelings or emotions that they experience while recovering.

It is not possible to gain an understanding of the feelings and emotions associated with recovery from surgery using a natural science approach to inquiry, because natural science regards the mind as ‘subjective and not amenable to scientific study’ (Salmon 2000, 16). In the past, any notion that the mind and body were intimately related was dismissed because the practice of medicine, for which scientific inquiry played a major role, was based on Descartes ‘dualist’ theory: a theory that the mind and body were separate entities (Leder, 1984). Descartes believed the body was like a machine and could be ‘divided into organ systems and parts to be repaired, surgically removed or technologically supplemented in relative isolation. As subject to mathematical analysis, the body reveals its true condition through laboratory values adjustable by drugs and diet’ (Leder 1984, 30). In natural science inquiry, only ‘scientific methods to measure objective knowledge’ are used (Taylor B 1993, 171).

Feelings and emotions are normal bodily sensations that are noticed when attention is given to them (Salmon, 2000). Understanding the meaning and significance of them, especially in the context of surgery or illness, depends on ‘a process of interpreting, or “making sense” of, the sensation’ (Salmon 2000, 60). Human science enables us to make sense of, or understand the meaning of, bodily sensations as they are experienced, by questioning the way feelings and emotions are experienced in the world (van Manen, 1990). Phenomenology is one human science approach ‘whose purpose is to describe particular phenomena, or the appearance of things, as lived experience’ (Streubert and Carpenter
Based on Husserl’s rejection of natural science, phenomenology was to be a ‘descriptive psychology’ (Merleau-Ponty, 1962, ix) in which understanding comes from returning to the ‘things themselves’ (ix). Phenomenology, as a research approach, explores and describes the phenomena that people live and experience as they perceive and interpret the experience, not as the researcher perceives or interprets it.

Doctors, nurses, and physiotherapy staff are the main providers of care to patients after lung surgery, and the focus of their care has been primarily on performing physical or objective activities that assist the process of recovery. They perform objective activities like correcting cardiovascular and respiratory imbalances, helping patients to shower, mobilise, and achieve independence in daily living, and assisting patients to perform effective deep breathing and coughing exercises. These activities are all essential to the recovery of patients after lung surgery, but they do not tell us what the patient experiences while the activities are being performed. Much of the learning about thoracic surgery has stemmed from scientifically collected objective data about clinical problems that have manifest as morbidity and/or mortality, not from the patients themselves.

While nurses have traditionally provided essential physical body care and comfort to patients, they also fill an important role of helping patients to live through and with ‘what is happening to their bodies during illness, recovery or dying’ (Lawler 1991, 29). According to Lawler (1991) nurses are ‘concerned with the object body (an objective and material thing) and the lived body (the body as it is experienced by living people)’ (29) and they attempt to integrate ‘the object body with the lived body’ (29). Gaining insight into how the object body and lived body integrate has captured the minds of nurses, leading to a new area of information inquiry. Because nurses focused their inquiry on human science issues, phenomenology was seen to be an appropriate research method for their inquiry. Phenomenology enables nurses to become more informed about the phenomena that they are concerned about (Taylor B. 1993).

### 3.2.1 Phenomenology

Phenomenology is ‘the study of essences’ (Merleau-Ponty 1962, vii). It is a ‘systematic attempt to uncover and describe the structure, the internal meaning structures, of lived experience’ (van Manen 1990, 10). Van Manen says the meaning or essence can only be
understood or grasped by studying the ‘particulars or instances as they are encountered in lived experience’ (10). Phenomenology is not interested in how a person recovers physically from lung surgery, but inquires about the nature of the experience of recovery in order to have a better understanding of what the experience means to the person who lives it. From the literature, (Merleau-Ponty, 1962; Omery, 1983; van Manen, 1990; Gray and Pratt, 1991; Taylor, B. 1993; Beck, 1994; Koch, 1995; Rose, Beeby and Parker, 1995; Streubert and Carpenter, 1995, Draucker, 1999) the exact method for phenomenology is unclear. However, there seem to be two distinct approaches: Husserlian phenomenology and Heideggerian hermeneutic phenomenology (Koch, 1995).

Husserlian phenomenology was founded on the concept of ‘lived experience’ (van Manen 1990, 9). Husserl was concerned with knowing the meaning or reality of an experience within his world. This was based on his reasoning that ‘All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless’ (Merleau-Ponty 1962, viii). He envisaged phenomenology to be a descriptive psychology (Merleau-Ponty, 1962) in which the process of describing the lived experience took into account three specific domains of focus: intentionality, essences and bracketing (Koch, 1995).

Intentionality related to consciousness and how it cannot be separated from our being, ‘that consciousness is always consciousness of something’ (Streubert and Carpenter 1995, 32) therefore, our thinking, doing, and hearing is associated with something or an object. When patients remember, they remember about something specific. For example, they remember feeling the pain when they coughed, or feeling the fear that they might not wake up after an anaesthetic.

‘Essences are concepts that give common understanding to the phenomenon under investigation. Essences emerge in both isolation and in relationship to one other’ (Streubert and Carpenter 1995, 32).

Bracketing, the third domain of Husserlian phenomenology, requires the investigator, either as an ordinary interested person, a philosopher or a scientist, to suspend all preconceived ideas, knowledge, and beliefs, as an act of phenomenological reduction (Koch, 1995).
Bracketing enables the researcher to ‘go “back to the things themselves”’ (Streubert and Carpenter 1995, 33) in order to ensure that the original awareness of the phenomena under investigation was sustained.

Heideggerian hermeneutic phenomenology focuses on the experience of understanding, and is based on two notions: that ‘nothing can be encountered without reference to the person’s background understanding, and every encounter entails an interpretation based on the person’s background, in its “historicity”’, and secondly, that ‘the researcher brings her/his pre-understanding to the text’ (Koch 1995, 831-832). Hermeneutic phenomenology therefore aims to interpret the meaning of the phenomena being investigated.

Nursing embraces phenomenology as a research method because it provides a way for nursing, as a discipline, to continue to increase its knowledge base. According to Wilkes (1991) nursing is a practice and, ‘Practice is a lived experience and as such involves not only the nurse but other health professionals and at the centre the client (the nursed). It involves human beings experiencing and interacting’ (229). Collecting human science information through research adds to the present knowledge about people and how they interact in their world. Once it is collected, nurses can apply human science knowledge as ‘thoughtful reflective attentive practice by its revealing of the meaning of human experience’ (Van der Zalm and Bergum 2000, 211).

Phenomenological thinking makes it possible for nurses to ‘understand such experiences better, and therefore to act more effectively in our dealings with clients, even when we ourselves have not had that particular experience’ (Madjar and Walton 1999, xiii). The essential interest in phenomenology by nurses, therefore, has been that phenomenological research contributes to human science information, scientific knowledge, and clinical practice.

Preparing patients for pneumonectomy involves guiding them through the essential pre-operative clinical investigations that are required for all operations. It also involves talking to them about the physical things that will happen to their bodies as a result of having one lung removed, and discussing the effects of this surgery on their recovery in hospital and after discharge. Pre-operative preparation for pneumonectomy should involve preparing patients to live life with one lung and making them aware of the “normal” emotional
sensations, anxieties, and concerns and fears that they might encounter, but little is known about these aspects of post-operative recovery. Professionals do not know about the feelings and emotions that pneumonectomy patients experience and live through during recovery.

In order to fill this knowledge gap, individual experiences of recovery after pneumonectomy need to be explored. Patients need to tell their stories, have them reflected on, interpreted, and written about so that their experiences will inform professionals caring for other patients, and patients about to experience this phenomenon. This information would enable patients to formulate reasonable and achievable expectations about their recovery from surgery. Some patients no doubt find the phenomenon of recovery ‘uncommon, extraordinary and exceedingly remarkable, whilst for others it may be common, ordinary, and unremarkable’ (Taylor B. 1993, 174). A phenomenological approach to inquiry was seen as one that would shed a much needed and valuable light on this phenomenon.

For this study, the phenomenological approach of van Manen was chosen. Van Manen was introduced to human science, phenomenology and hermeneutics in the Netherlands in the 1960s and has since written on these topics (van Manen, 1990). He describes in his text an approach to human science research that combines descriptive phenomenological and interpretive hermeneutic methods. His combining of these methodologies helped me to comprehend the notion of “phenomenology”, and brought me to the realisation that in order to gain a full understanding of any phenomenon derived from an experience, the experience needs to be described as well as interpreted.

Van Manen says, ‘Phenomenological human science is the study of lived or existential meaning; it attempts to describe and interpret these meanings to a certain degree of depth and richness’ (van Manen 1990, 11). The acceptance of van Manen’s phenomenological methodological approach to human science research is demonstrated by the growing number of phenomenological research studies initiated by nurses, using his approach to underpin their methodology (Morse, Bottorf and Hutchinson, 1994; Lindsey, 1996; Nelson, 1996; Breaden, 1997; Robertson-Malt, 1999; Shin, 1999; Madjar, 1999a; Van der Zalm and Bergum, 2000). Lindsey (1996) explored and described the phenomenon of health within illness. Breaden (1997) used phenomenology to make sense of the process of surviving cancer as reflected in the experiences of cancer survivors.
Van Manen explains his viewpoint about what phenomenology is by making clear his beliefs about what phenomenology is not. He believes phenomenology does not produce empirical information that can be generalized because it goes beyond the interest of facts. It is a western human science that aims to gain understanding about a real situation through language, and it mediates in a personal way that which is unique and different, with being interested in the difference that makes the difference. His simple yet precise suggestion that phenomenology does not solve problems but seeks to find meaning and significance about a given situation (Van Manen, 1990), signals to me that phenomenology brings about an understanding of the everyday experiences of patients, irrespective of the illness or surgery they recover from.

The phenomenological methodology of van Manen (1990) is based on his belief that ‘the method of phenomenology and hermeneutics is that there is no method’ (30) and that it should be ‘pre-suppositionless’ (1990, 29). There should be no rules, procedures, or steps to govern the research project, but the researcher should exercise ‘scholarship!’ (29). He offers a research structure that involves ‘a dynamic interplay among six research activities’ (van Manen 1990, 30). These activities are:

1) turning to a phenomenon which seriously interests us and commits us to the world;
2) investigating experience as we live it rather than as we conceptualize it;
3) reflecting on essential themes which characterize the phenomenon;
4) describing the phenomenon through the art of writing and rewriting;
5) maintaining a strong and oriented pedagogical relation to the phenomenon;
6) balancing the research context by considering parts and whole (31).

The structure helped me to feel connected to, and focused on the task of my study. It made me feel stronger in my commitment to the study, and to helping patients live through their individual experiences of recovery after pneumonectomy. The structure also made me aware that I would be exploring the circumstances of “someone,” a private person, “not just a case,” and that their experiences would be “their” experiences, not to be compared to those of anyone else. As the study progressed I found reflecting on the themes helped me to become more in tune with the personal meaning of participant experiences and the special significance of these to each participant. Likewise, the process of writing and rewriting
enriched a similar understanding. The activity of considering parts and whole provided a situation in which, on reflection I could review where I was in the study, so that the parts fitted into the whole. To do this I looked at the symptom or situation that an individual experienced and related it to the complete or whole structure of the theme. Overall, van Manen’s (1990) phenomenological research structure provided a guiding foundation to my understanding of human science research, but more importantly, it made me acutely aware of how complex the phenomenon of recovery after pneumonectomy is.

3.2.2 Obtaining information-rich data

As my interest in exploring the phenomenon of recovery after pneumonectomy grew, I gave careful thought to how I could obtain ‘the richest and most descriptive data’ possible to study (Streubert and Carpenter 1995, 35). As my understanding of van Manen’s methodological approach to human science study grew, I realised that I could best achieve this by talking directly with the people who had lived the experience. Consequently, conducting an interview became an obvious and appropriate method of data collection for this study. My decision to use interviews was guided by van Manen’s (1990) statement that the purpose of interviews in hermeneutic phenomenology is twofold. …‘it may be used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of the human phenomenon, and (2) the interview may be used as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of the experience’ (66).

In preparing myself to conduct the interviews, I acknowledged that interviews ‘collect, identify and clarify facts, perceptions, feelings, experiences and attitudes’ (Schatzman and Strauss 1973, 71) that are relevant to a research question. I also acknowledged that participation in an interview exposes both the researcher and the participant to a shared intimacy, such that a respondent is more likely to disclose information that they might not disclose if any other data collection format is used (Sorrell and Redmond, 1995). I also embraced suggestions from the literature that the researcher (interviewee) becomes involved in the actual interview, not just the interview process; that the interviewer ‘provides for mutual sharing of information between interviewer and respondent, freely exchanging ideas, impressions and opinions’ (Sorrell and Redmond 1995, 1118). The statement that, ‘complete concentration and rigorous participation …improve the accuracy, trustworthiness,
and authenticity of the data’ (Streubert and Carpenter 1995, 44) helped me to focus on the task of interviewing. This was because I realised that at the end of the interview process, I wanted the participant to feel that their role in the research was important and valued, whilst I had vital information relevant to my research question.

3.3 How the study was conducted: the methodology

A purposive sample of nine people were chosen for the study who had all had their pneumonectomy performed by one of three cardiothoracic surgeons. These surgeons operate within one New South Wales Area Health Service—a service that performs more pneumonectomy operations than any other New South Wales Area Health Service. Six other potential participants were contacted and were willing to participate in the study but were not interviewed because of travel, time and eligibility issues. Five of the study participants had received professional care from myself as case manager. I believe my professional role did not influence the process or the outcomes of the study because my contact with these participants was brief and at least eighteen months prior to their participation in the study. The study population of nine was deemed sufficient in number to ensure the study would obtain rich data because, ‘The logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research,…’ (Patton 1990, 169, cited in Streubert and Carpenter 1995, 42).

In order to be able to describe and interpret the effects of pneumonectomy on the lifestyle and functioning of normal working active people, the following inclusion criteria was set. Participants could be male or female and needed to:

- be aged up to 60 years at the time of surgery. I expected that participants up to the age of 60 years would be still in the workforce and living a full and active life;
- be employed at the time of diagnosis and intending to return to work after surgery;
- have a diagnosis of non small cell lung cancer;
- have no recurrent or metastatic disease at the time of the interview;
- reside within a two-hour drive of the Sydney Metropolitan area.
In order to get my study population I first obtained names of patients from a comprehensive lung cancer surgical database along with demographic and clinical information. This information included their age, sex, date of operation, histopathological staging of the cancer, and their most recent disease status. I matched this information, along with additional clinical information held in their surgeon’s medical record such as their smoking history, with the study criteria. Ex-smokers and non-smokers were included in the study because the focus of the study was on the effects of surgery on younger people rather than on people who had smoked.

The crucial step in selecting the study population was my vigilant checking of the health status of patients to ensure that they were free of recurrent or metastatic disease. When my first check of their disease-free status in the records held by the surgeon did not reveal a current disease status, or a more recent status was required, I mailed a letter to the patient’s Local Medical Officer (LMO) requesting this information (Appendix D: Letter to Local Medical Officer). As a matter of courtesy, I included a copy of the letter headed “Information to Participant” (Appendix A: Information for Participants) so that they would be aware of the study. Once I received notice from the LMO confirming a current disease-free status, I contacted the patient by telephone.

The telephone call to each potential participant served four functions. It re-confirmed their health status, it enabled me to introduce and explain the function of the study to them, it enabled me to personally invite them to participate in the study, and it gave me an opportunity to begin building a rapport with them. Included in the invitation was the patient’s spouse, partner, or an alternative support person. I was very conscious, particularly at this point in the recruitment process, of the possibility that I could cause undue distress or anxiety to them, their spouse, and/or significant other. In particular, I was concerned about the effects of my contacting them if they in fact did have recurrent or metastatic disease or worse, had died since the surgery.

Each potential participant was mailed an information package containing the following documents:
Information for Participants. (Appendix A). This document outlined the purpose and methodology of the study.
Participant Interview Questions. (Appendix B). This document listed the study questions.
Participant Consent Form. (Appendix C). This document was a standard requirement of the Human Ethics Review Committee of Central Sydney Area Health Service, and The University of Sydney.

I awaited news of their willingness to proceed with the study. They did this by contacting me by telephone, at which time we arranged a mutual place and time for the interview to take place. Nine (9) patients gave verbal consent over the telephone and followed this up with voluntary, informed, written consent before they proceeded with their interview.

I discovered during the process of identifying people who were eligible to participate in the study that there were a number of self-regulating factors that made recruitment a prolonged exercise. Firstly, the natural course of lung cancer limits the number of people who are free of recurrent or metastatic disease in any designated time period and therefore limits the number of people eligible to study. The numbers of younger people who have this operation, and who are most likely in the workforce, are few. This further limits participant eligibility. The final self-regulating factor was my full-time case manager position. My professional commitment limited my opportunity to travel to conduct interviews. As a consequence of these three factors, the process of participant selection was staggered over a twelve-month period.

The nine study participants comprised three females and six males. Their ages ranged from 30 years to 59 years. Seven participants were either married or in a de-facto relationship, and of these, four had their partners present during the interview. One participant was single and one was divorced. All participants, except one male and one female, had a history of tobacco use, but had ceased smoking for a minimum of three weeks before the surgery. This three-week period was a mandatory requirement of the surgeon and anesthetist in order to lessen the risks of post anaesthetic recovery and respiratory problems.

Before any interview, each participant had received by mail an Interview Question Form, (Appendix B). The purpose of this form was to guide or prompt the thought process of participants prior to the interview – it was not designed to give structure to the interview. I decided to use an open-ended interview approach because I wanted to gain an understanding from participants, of their meaning (interpretation, understanding), of their experience by their drawing a vivid word picture of their lived experience (Sorrell and
Redmond, 1995). I knew that in order to obtain this understanding I did not need to measure physiological or biological parameters such as pain scores, or blood pressures, although I did expect participants to comment on physiological or biological processes that had an impact on their experiences. I also excluded the need for any observational process because the focus of the study was on interpretation of an experience, not human behaviour (LoBiondo-Wood and Haber, 1994). I began each interview by inviting the participant to, ‘Tell me about your recovery from lung surgery’.

During the interview, I did not ask questions except for the purpose of amplification or clarification of information that participants offered. However, there were occasions when it was necessary to use my clinical knowledge to clarify a participant’s understanding of their clinical situation during the interview. Sorrell and Redmond (1995) allude to this situation by suggesting that while the researcher maintains control of the interview they also have ‘sufficient flexibility to respond to important content responses and general non-verbal cues from the participant (1118).

Of the nine interviews, five were conducted in participants’ homes, three were conducted at a work place, and one took place in a professional consulting suite while the participant was visiting Sydney. I contacted all participants two or three days before the planned interview to confirm their willingness to participate.

Each participant had one interview, and the conversation was recorded by audiotape. The interview times ranged from forty-five minutes to two hours, with the average time being one and a half-hours. Prior to starting the interview and audio-taping process, I took time to talk with the participant (and partner) about general conversational topics because I wanted to build on my previously established trust and rapport with the participant. According to Smith (1992, 101) ‘A good interview necessitates that rapport has been established between the interviewer and interviewee’. I was mindful before and during each interview that some areas of discussion might evoke strong and sensitive feelings and emotions, for which participants might not be prepared (Sorrell and Redmond, 1995). This did occur during one interview, but in order that their trust in me was not violated I gave ample time for their emotions to subside and I invited them to terminate the interview if they wished to.
The interviews ended when participants felt they had no new information to offer, and I felt there were no further areas of clarification required. In qualitative research, this state is called data saturation. According to Morse (1994, cited in Streubert and Carpenter 1995, 24) data saturation ‘refers to the repetition of discovered information and confirmation of previously collected data’. Data saturation was not important to this study, but uncovering new information about the unique experience of recovery and life after pneumonectomy was.

3.4 Data Analysis

In phenomenological research, analyzing the data is called phenomenological reflection, and the purpose of reflection, according to van Manen (1990), is to ‘try to grasp the essential meaning of something’ (77). Phenomenological reflection is about trying to gain an understanding not of the actual experience, but the essence of each experience, and to comprehend the meaning of it as that person has lived it. Van Manen (1990) says this can best be done by ‘reflectively analyzing the structural or thematic aspects of that experience’ (78).

Before commencing the reflective analysis of the data obtained from the interviews, I assigned each interviewee a pseudonym. I entered this name into the auto-correct function of Microsoft Word to ensure that participant anonymity was automatically accounted for and adhered to in all written material. The reflective analysis process was ongoing, beginning with a detailed analysis of individual interview data. This was followed by an analysis of the interview data collectively. The process culminated in the development of six essential themes, but, to get to this point a number of activities were required.

My first activity was to transcribe each audio taped conversation, verbatim, into computerised text data. I did this as soon as possible after each interview so that I retained my feeling of being connected with the interviewee, and captured the “atmosphere” of the interview in the text. By capturing the atmosphere, I mean that I recorded in the text the events or behaviours that demonstrated a specific feeling of an interviewee during our conversation, for example, table tapping, sighing, crying, and laughing. The overall task of transcribing the interviews was arduous and very time consuming, but I discovered the value of personally performing this task when I found myself ‘immersed in the data’
(Streubert and Carpenter 1995, 24), trying to gain an understanding of each participant’s experience. At the completion of the transcribing process I felt I knew all the participants as persons, I was very familiar with their interview content, and I could perceive “their world.” This helped me move to the next step in the phenomenological reflection process: interpreting the data.

I used van Manen’s (1990) approach of selective reading to guide the process of interpreting the data. A process where the reader asks, ‘What statements(s) or phrases(s) seem particularly essential or revealing about the phenomenon or experience being described’ (93). To accomplish this I read and re-read many times a printed copy of the interview conversation, and I found and highlighted statements, key phrases, and words that were significant. I then returned to the highlighted script and wrote words in the margin that reflected my understanding of the participant’s interpretation of the phenomenon, topic, subject, or issue that they experienced. Looking for phrases or sentences that emphasised or made an issue stand out or appear thematic to the experience took many hours, and I was ever mindful of van Manen’s (1990) statement that ‘no conceptual formulation or single statement can possibly capture the full mystery of this experience’ (92). When I felt I had saturated my reading, highlighting, and notation of each transcript, I compiled an individual summary for each interview in a Microsoft Excel spreadsheet. The spreadsheet, headed with the interviewee’s pseudonym name, identified each key experience discussed, and the page number(s) that appeared on the transcribed text. This form of data recording enabled me to quickly return to participant text as the need arose.

After the nine interviews had been transcribed and individually analyzed, I drew from other relevant literature on lung cancer, lung surgery and then other cancer and/or other surgery to help broaden my thinking about the data I was working with. This aided my overall analysis of each individual interview.

The next major step in the reflection process was to carefully examine the individual summaries, see them as a collected group, and decide what information was incidental and what were essential to the meaning of the experiences of these participants (van Manen, 1990). Interpreting this data was a difficult task but van Manen’s (1990) statement guided me. He said, ‘In determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the
phenomenon could not be what it is’ (107). I had to ask myself, “Is the fundamental meaning of the phenomenon the same if I take away the theme?” That is, “Would the meaning of the phenomenon recovery after pneumonectomy be the same if I deleted the theme I wish I had known more?”

After many hours of data reviewing, reflection, and interpreting, six themes were uncovered.

(1) Living the discomforts of treatment and recovery,
(2) Discovering new limitations on my self: functional and emotional
(3) My reliance on supportive mechanisms
(4) My survival is at threat
(5) My financial security is threatened
(6) I wish I had known more.

3.5 Rigor or Validation

In quantitative or natural science research, testing for validity and reliability determines if the research instrument has provided accurate empirical data. Validity assesses whether a research instrument accurately measures what it is supposed to measure. Reliability assesses whether the research instrument comes up with the same result on repeated measures (LoBiondo-Wood and Haber, 1994). In human science or qualitative research, the validity and reliability of the research instrument has in the past been questioned and criticized because of its failing to demonstrate the same level of methodological rigor that is seen in scientific research (Sandelowski, 1986). Human science researchers have addressed this problem by using a format called academic rigor (Sandelowski, 1986; LoBiondo-Wood and Haber, 1994; Rose, Beeby, and Parker, 1995; Streubert and Carpenter, 1995) to ‘accurately represent what those who have been studied experience’ (Streubert and Carpenter 1995, 25). There has been a variety of terms used to describe the operational techniques that assess rigor. Sandelowski (1986) believes there needs to be evidence of credibility, auditability and confirmability while Streubert and Carpenter (1995) suggest credibility, dependability, confirmability, and transferability are the criteria required for judging the rigor of qualitative research.

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There is unfounded agreement that credibility of the study is important. A qualitative study is considered truthful and credible when participants who have lived the experience recognize the descriptions and interpretations of their experience as their own (Sandelowski, 1986), and when the findings represent a faithful description of the participants’ experiences (Guba and Lincoln, 1981). A threat to credibility lies in the closeness between the researcher and participants relationship, but the threat can be reduced by the researchers describing and reporting their own behaviour during the study, in relation to the behaviours and experiences of the participants (Sandelowski, 1986).

In this study, seven of the nine participants were able to receive and respond to a summary of the themes derived from the interviews. These participants were invited to confirm and/or comment on the theme headings and the theme contents. They agreed unanimously that the themes did reflect their experiences of recovery; in fact, many of their responses re-iterated what they had disclosed in their original interview. The reaction of the participants to being invited to make their judgement about the themes was overwhelmingly positive. I sensed that they felt that their role in this step of the research process confirmed that they trusted me as a researcher and the study as a whole, but more importantly, they viewed their role in the study with great importance.

Consistency and confirmability are similar operational techniques. Consistency measures the consistent use of an appropriate philosophical basis for a study (Rose, Beeby and Parker, 1995) as opposed to measuring objectivity, truths or falsehoods as is the case in objective sciences. In qualitative research, the researcher makes clear to others that the methodological process used for the study achieves consistency or confirmability when the methodology can ‘illustrate the evidence and thought processes which led to the conclusions’ (Streubert and Carpenter 1995, 26). Sandelowski (1986, 33) says ‘A study and its findings are auditable when another researcher can clearly follow the “decision trail” used by the investigator in the study’. I believe the reporting of the methodological processes used for this study, as reported in this chapter, demonstrate consistency and auditability.

Transferability relates to the findings of the study being meaningful to others facing a similar situation. In quantitative research, the sample size and make up of the study
population determine transferability. In qualitative research, a user is the only person who can judge if the results of a study can be transferred to their situation (Streubert and Carpenter, 1995). While the findings from this study have not yet been released through any formal publication process, some information gained from the study can be transferred to patients facing a similar situation through changes to my clinical practice. In fact, information that I as a nurse, case manager, researcher, and fellow human being gained from the stories and experiences of participants in this study, has already been shared with and transferred to people facing a similar dilemma of pneumonectomy and recovery.

Congruency takes into account the appropriateness of the research methodology (phenomenology) to the population and topic being studied. As the aim of this study was to gain a perceptive understanding and description of the phenomena of living a recovery after removal of one lung, phenomenology was an appropriate research inquiry method.

3.6 Ethical Consideration

Phenomenological research involves one person (the researcher) exploring very personal experiences of other people, and in so doing the researcher must ensure that the rights of their human participants are not violated. Participants are entitled to the protection of their right to self-determination, privacy and dignity, anonymity and confidentiality, fair treatment, and protection from discomfort and harm (LoBiondo-Wood and Haber, 1994). The proposal for this study was submitted to and approved by the Ethics Review Committee of the Area Health Service in which I conducted the study and The University of Sydney. I accepted that the committee’s approval for the study to proceed confirmed that I had taken into account and eliminated all possibilities of harm to any potential participants.

Participant privacy, confidentiality, and anonymity were addressed in this study by assigning pseudonyms to participants once the interview was completed. All written material then used the pseudonyms for identification, and any potential identifying interview content, such as places of work, were omitted. All audiotaped material was erased once the tapes were transcribed and the data analyzed, and the transcripts have been stored by the investigator in a locked cupboard. They will be held for five years, as recommended by the National Health and Medical Research Council Statement on Scientific Practice after which time they will be shredded.
In qualitative research, where there is researcher/participant interaction, there is a potential for a researcher to become consumed by a therapeutic role (LoBiondo-Wood and Haber, 1994). During my interviewing of participants, I was mindful that my primary role was as a researcher rather than a clinician, and that I needed to guide the interview rather than control it. However, there were occasions when I needed to temporarily put aside my research role and apply my clinical knowledge. I exercised this action in order to protect a participant from harm related to inaccurate clinical information.

3.7 Methodological Issues

Conducting the interviews was a challenging task but also a pleasure, because participants were very keen to meet and talk with a professional interested in them and their stories about their experiences. Conflict arose when the boundaries between my role as researcher and clinician became indistinct. It is suggested that a researcher should not have any clinical input when the researcher is the instrument of data collection, but should refer clinical issues to a clinician who is independent to the study (Rew, Bechel and Sapp, 1993). This was not possible in the reality of this study. It was essential on occasions for me to correct participant knowledge about specific clinical issues, for example, when participants had misinterpreted or misunderstood the concept of five-year survival and surveillance. It was not appropriate for me to refer this participant to an alternate clinician because clarification of this important information was essential to aspects of ongoing dialogue. I believe that clarifying information for participants did not hinder the study, in fact it assisted participants to have a fuller understanding of their situation. I believe that participants were grateful for any clinical information offered to them at the time of the interview, because this was the information they were missing and new information gave them a sense of renewed confidence to their life. It did not introduce bias, assumptions or alter my beliefs, but provided me with a deeper understanding of the importance of giving information to patients and checking that they have understood the information correctly.

Van Manen’s approach to bracketing in phenomenological research differs to that of Husserl who sees bracketing as an activity of reductive phenomenology (Omery, 1983; Bartjes, 1991; and Streubert and Carpenter, 1995). It requires the researcher to approach the phenomenon ‘with no preconceived expectations or categories’ (Omery 1983, 54). The
researcher must suspend their beliefs, assumptions and bias about the subject under study, and put them aside or separate them from consciousness. They must ‘take hold of the phenomenon and then place outside of it one’s knowledge about the phenomenon’ (van Manen 1990, 47). Van Manen (1990) argues that bracketing does not contribute to the research process or findings and thus suggests that the researcher should make known their bias, beliefs, understandings and presuppositions, and then put them aside to be used to expose how little they know about the meaning of the phenomenon.

An example of bracketing, relevant to this study is my knowledge or assumption that patients achieve recovery from pneumonectomy within two months of their surgery, and so I expected participants in this study to tell me that they had achieved recovery in that time. My previous knowledge led me to assume that all participants would have returned to their work after surgery, but in fact I had no concept of what their experience of returning to work would be. This example of returning to work is similar to van Manen’s (1990) example of parenting. He asked, ‘What does it mean, then, to have an understanding of the essence of parenting’? (50). I ask, “What does it mean to have an understanding of the essence of returning to work after pneumonectomy”? Van Manen (1990) says it is ‘not a problem in need of solution but a mystery in need of evocative comprehension’ (50). I have used van Manen’s approach to bracketing to expose how little I know about the phenomenon of patients returning to work after pneumonectomy.

3.8 Conclusion

Exploring the lived experience of recovery of patients after pneumonectomy for lung cancer will enable a fuller understanding of the phenomenon of recovery. Phenomenology provides a passage for investigation and description of patient lived experiences and so phenomenology was chosen for this study. I based the study methodology on van Manen’s methodological structure for human science research. I did this because it combined descriptive and interpretive elements of phenomenology, provided a structure, and enabled the true meaning and significance of the experience to be uncovered by ‘establishing a renewed contact with original experience (van Manen 1990, 31).
I have presented and described the methodology that was applied to this study in order to explore, interpret, and understand the essence and meaning of the experience of recovery after pneumonectomy as it was lived by the participants in this study.
CHAPTER 4, SECTION 1

LIVING THE DISCOMFORTS OF TREATMENT AND RECOVERY

4.1.1 Introduction

The theme of living the discomforts of treatment and recovery evolved because participants talked about the physical and emotional discomforts that they experienced during their recovery from pneumonectomy. The nature of discomforts experienced and the significance they had on the lives of participants varied, but they were commonly expressed as physical symptoms that had an impact on their personal, family, social, and business world. Sometimes participants found that a discomfort had its greatest impact early in their recovery, while others found the impact more noticeable later in their recovery. Some discomforts were expected, unpredicted, and/or unavoidable, and some might have been avoided had the care and attention provided by health professionals been different. It will become evident as discussions evolve that the discomforts that some participants experienced might appear to be extreme, but that is because they were extreme in the eyes of the participants. Readers need to be mindful that these experiences were from only a few people who had lived the first two years of recovery after pneumonectomy, and therefore it is unwise and inappropriate to make any generalized statements about these profound experiences. What was interesting about the discomforts reported, was that participants vividly described them as if they occurred yesterday, and they wanted very much to share their experiences with future patients in the hope that they would be spared a similar experience.

This section will begin with a discussion about the meaning of the word *discomfort*, with the purpose of making its use in the context of this study clear. The discussion will encompass the meaning as it is applied in everyday language, used by health care professionals, and in the language of nurses. The remainder of the section will reveal and discuss the discomforts that participants identified during their interviews. From these the real meaning and significance of these individual experiences will be developed. Nursing “comfort” literature and other health care literature will be used to advance and support discussion.
Post-operative pain was the discomfort that seemed to have the most impact on participants, both in the way it affected how they functioned in their world, and how the discomfort was recognized and managed by professionals. The discomforts of fluid space sensations, epigastric symptoms, constipation, and hospital experiences were all noted. The section will conclude with a drawing together of the essences of the discomforts experienced and a reflection of these essences in relation to embodiment literature.

4.1.2 Discomfort

All patients expect to feel some discomfort after surgery, but knowing what is “normal” discomfort is difficult for a patient to estimate or judge. In trying to determine what procedural events might contribute to feelings of discomfort after pneumonectomy, and in thinking about what might be considered “normal” or expected discomforts, it is appropriate to briefly describe the operation of pneumonectomy. This description will enable a beginning understanding of how the trauma to the anatomical structures associated with this surgery can result in patients feeling the discomforts that they can feel, and did feel, after thoracotomy and pneumonectomy.

Pneumonectomy (the surgical removal of an entire lung) is an operation performed under a general anesthetic, through an opening on the back and side of the chest called a thoracotomy. The incision is made in the space between the 5th and 6th ribs, and it passes through the skin and muscle and then through the chest pleura. To gain complete access to the lung, the ribs are stretched apart and held open with a retractor. The pulmonary arterial and venous blood vessels to the lung are located, ligated, and divided. The main bronchus is then exposed, dissected free from surrounding structures and then stapled and cut with a special gun. The lung is removed leaving behind an empty chest cavity. The bronchial stump is checked to ensure that it is airtight, and the chest cavity is checked to ensure that there are no bleeding sites. Lymph nodes in the areas around the lung are located and removed for examination. One temporary drainage tube is left in the chest space exiting the body at a site below the incision. The operation is complete when the ribs are realigned, the muscle layers are sutured and the skin is closed. The operation takes between 1½ and 2 hours to for a histopathological analysis. During the operation and in the period immediately after, the anesthetist administers intravenous narcotic (opioid) analgesic drugs to minimize or prevent pain.
There are two important priorities when caring for a patient after pneumonectomy. The first is to ensure that the patient’s cardiovascular and respiratory system adjusts to the changes associated with redirecting blood flow through the one remaining lung for oxygenation. The second priority is to ensure that the function of the remaining lung is not compromised by either retained respiratory secretions causing pneumonia, or fluid overload causing pulmonary oedema. Any deviation from the “norm” for either of these two priorities is likely to have a fatal outcome. However, astute doctor care and nursing care focused on careful assessment, monitoring, and adjustments to management results in a safe and rapid early post-operative recovery of patients from the trauma of pneumonectomy. Overall, modern anaesthetic, peri-operative, and post-operative management results in an acceptably low rate of operative mortality and morbidity (McCaughan, 1999).

Participants reported a variety of discomforts during their treatment and recovery after pneumonectomy, but before discussing them, the understanding of discomfort as it is used in this study will be explored. The Macquarie Essential Dictionary (1999) says comfort means ‘a state of ease, with freedom from pain and anxiety, and satisfaction of bodily wants’ (154) and discomfort means ‘absence of comfort or pleasure; uneasiness; disturbance of peace; pain’ (221).

The words comfort and comfortable as opposed to discomfort are used frequently by people in everyday life, such that a typical example of its use is the common greeting. “Come in and make yourself comfortable”. Health professionals also use the words frequently in their practice. They commonly ask patients; “Are you comfortable?” The word comfort is a part of the language and practice of health care professionals. More specifically, nurses have embraced the notion of comfort to be part of nursing, but defining what comfort is has been difficult. Comfort is a ‘complex and multidimensional concept’ (Bottorff 1995, 1077), but a brief review of relevant nursing “comfort” literature will help to unravel some of the complexity of the subject.

The topic of comfort has interested nursing over the last two decades because a significant part of the overall practice of a “good” nurse is assisting patients to achieve comfort (Benner, 1984; Morse, Bottorff and Hutchinson, 1994; Kolcaba, 1995; Bottorff, 1995; Jenny and Logan, 1996; Wurzbach, 1996; Morse, 2000). Some of the initial interest in
comfort came from Benner (1984), who while exploring the concept of nursing identified that comfort is something that nurses do in their helping role. Nurses provide comfort measures for patients and their families. Measures such as fixing pillows, helping patients to brush their hair or shave, relieving pain, changing a dressing, assisting with personal hygiene, and administering medications are just a few examples from an endless list of comfort measures that nurses do. For other patients, comfort comes from support in the form of talking and or touch. There are many avenues for nurses to provide comfort. One example of such comfort is when a patient learns that the surgeon was not able to remove the cancer because it would endanger their life. The nurse provides comfort by maintaining a presence with the patient and family as they take in the words of the surgeon and try to comprehend their meaning. According to Benner (1984), comfort that comes through doing, communication (which might be silence) and touch is an important and vital aspect of nursing.

Kolcaba (1995) conceptualized comfort within the context of nursing practice, theory and research with the notion of comfort care. She said ‘comfort care is a nursing art that entails the process of comforting actions performed by a nurse for a patient’ (Kolcaba 1995, 287). This model of nursing care supports the ideas of Benner (1984) as mentioned above. Wurzbach (1996) also added to the knowledge of comfort by describing it as ‘both something they [nurses] provide and something they feel when they believe they have met their practice ideal and the resident’s needs’ (263). She believes that nurses feel their own comfort only when they know that they have assisted their patients (residents) to feel comfort.

Comfort has been measured by an absence of pain in order to achieve a level of comfort. Morse, Bottorff and Hutchinson (1994) talk about ‘the maximum level [of discomfort] that a patient can bear or tolerate without becoming distressed. If this level is exceeded, the patient becomes distressed; the illness or the pain overwhelms the patient, produces discomfort, and occupies the mind. In this state of discomfort, the preoccupied mind has difficulty with the tasks of everyday living’ (194). Comfort is intangible and immeasurable and can only be attained when an individual believes they are free of the stimulus that presents as a discomfort, but what signals do nurses use to recognise comfort and discomfort?
Morse (2000) suggests that comfort comes from nurses ‘being attuned to patients’ cues of distress, and providing nursing measures to alleviate this suffering’ (34). Comfort is about nurses detecting cues through verbal, non-verbal and physiological changes, and it is about evaluating and interpreting physical signs and symptoms — nurses draw on intuition, insight and experience to do this. Comfort is also about implementing comforting strategies — strategies that can be varied according to the context in which the comfort is required (Morse, 2000). Examples of research-based strategies used by nurses to help cancer patients to achieve comfort include gentle humour, physical comfort measures, emotional supporting statements, and comforting and connecting touch. Inherent in these strategies were opportunities for patients to make choices, participate in social exchange, feel the closeness and trust of their nurse, and gather information (Bottorff, 1995).

Being attuned to cues of distress by patients who cannot verbalize their feelings of discomfort is an essential aspect of nursing care. Jenny and Logan (1996) reported language that patients used to describe the caring behaviours of nurses that are important to patients achieving of comfort (349). The language came from a study of patients’ perceptions of ventilator weaning in which four categories of expressions that reflected patients receiving of care and comfort in a critical care setting were identified. The expressions were physical discomfort, nurse caring, altered self and patient work.

Physical discomforts were commonly described as a sensation of pain and discomfort experienced as a result of procedural activities. Nurse caring identified positive nurse-patient interactions that conveyed the importance to patients of nursing behaviours like ‘advocacy, encouragement, support, positive regard and self closure’ (Jenny and Logan 1996, 350). Patients felt non-caring behaviors when nurses were impersonal and were oriented to their task rather than the patient. Altered self was a dominant feature in feelings of discomfort. Words used to express these feelings were ‘death, hell and nightmare’ (350) and they arose from feelings of ‘disorientation to time and space and person’ (350). Patient work portrayed just how hard patients had to work to get through their illness experience in order to live and recover.

The study highlighted how, after the event of ventilator weaning, patients found language to communicate with others about their inner world when every other medium was obstructed. Their expressions conveyed that it was “hard work” managing emotions, keeping positive,
and doing the physical work that was required (breathing), always knowing that death was a possible outcome. It also highlighted that they found comfort from what the nurses did, how the nurses did what they did, and from a feeling that the nurses were concerned about them even when barriers to physical communication were in place (Jenny and Logan, 1996).

The research by Morse, Bottorff, and Hutchinson (1994) brings to language how patients feel discomfort and attain comfort. The authors acknowledge that while nurses commonly ask patients the question, ‘Are you comfortable?’ (189), they know little about ‘the patient’s experience of comfort during illness or injury, or how it is best achieved’ (189). Using their earlier comfort work, these authors sought an understanding of ‘the essence of lived comfort’ (Morse, Bottorff and Hutchinson 1994, 190). They found that the ways that patients achieve comfort could be described using nine themes or states of discomfort that reflected a phenomenological concept of corporeality (Morse, Bottorff, and Hutchinson 1994, 190). To do this they used van Manen’s phenomenological methodology to reflect on and analyse data from patient narratives, phenomenological literature and biographical accounts, and previously identified themes.

The nine themes that Morse, Bottorff and Hutchinson (1994) unveiled are summarized as follows. The patient with a dis-eased body relies on knowing fully about the diagnosis, and allowing and trusting caregivers to provide appropriate and competent care in order to achieve comfort. They see that ‘interventions were being done for the patient and with the patient and not simply to the patient’ (191). A disobedient body achieves comfort by taking control of the situation and regaining independence despite the body pursuing its own course irrespective of the desires of the mind. The vulnerable body becomes evident when anticipation of dreaded or painful experiences become ‘all-consuming leaving the patients overwhelmed with feelings of powerlessness and vulnerability’ (Morse, Bottorff and Hutchinson 1994, 191) but comfort is attained when the patient feels safe, secure, and trusting of their caregivers.

A violated body becomes evident when strangers invade the body, for example, during a technical procedure but comfort might be achieved through the presence of a nurse, temporary detachment from the experience and or allowing humour to hide embarrassment. The enduring body just endures fatiguing and relentless discomfort when there is no alternative despite efforts from caregivers. Pain is a common presence in an enduring body
and comfort is sought from focusing on ways of gaining strength to endure and hope that the discomfort will end. The *resigned body* seeks comfort in accepting that the altered body will always be altered. For patients having a pneumonectomy, some shortness of breath is expected to be permanent and patients must learn to ‘live within new limits and to define life in ways that accommodate these changes’ (Morse, Bottorff and Hutchinson 1994, 192-3).

The *deceiving body* is one that allows a disease or problem to progress without the person knowing of its presence. Lung cancer often presents in this manner. Comfort comes initially from knowing that something can be done about the problem (an operation is possible) and then from knowing that the tumour has been successfully removed. The *betraying body* presents when failed attempts to cope with stresses, concerns and worries manifest as another illness or problem. Comfort is achieved when the patient recognizes their betrayed body, and seeks to find solutions through gaining knowledge, counselling, massage, relaxation, and other therapies. Finally, the *betraying mind* ‘runs amok, preventing one from relying on, from trusting one’s own memory’ (Morse, Bottorff and Hutchinson 1994, 193) and comfort is found in seeking support of others.

The discomforts that participants in this pneumonectomy study talked about were few considering the seriousness of the operation, and the discomforts related to sensations or things that made them feel uncomfortable. The sensations frequently arose from physical stimuli but were expressed in terms of physical and emotional discomfort. For some participants, the level of discomfort experienced was extreme. For others, a discomfort overwhelmed them to the point where it occupied their minds so much that they had difficulty with the tasks of everyday living (Morse, Bottorff and Hutchinson, 1994). In other situations, discomfort was mild and noted but caused no great distress. The discomforts were quite varied and not all participants experienced every discomfort, but the effect that a discomfort had on an individual participant was quite profound. The profoundness of their experience often became evident through their voices and body language.

Post-operative pain was the most commonly identified discomfort and so the effects of this discomfort will be addressed first, followed by discussion related to fluid space discomfort, epigastric symptoms, constipation, and hospital experiences.
4.1.3 Post-operative pain.

*We must all die. But that I can save him from days of torture, that is what I feel as my great and ever new privilege. Pain is more terrible lord of mankind than even death itself* (Albert Schweitzer 1931, 62 cited in Starck and McGoven 1992, 76).

Pain has been a contention for surgical patients since operations have been performed and it remains a problem for patients following lung surgery. Dajczman, Gordon, Kreisman and Wolkove (1991) suggested that long-term thoracotomy pain is common, and the experience of patients falls into three categories. The majority of patients are asymptomatic relatively soon after their surgery but report wound and chest numbness, or difficulty carrying heavy objects. Another large group of patients report mild but frequent chest discomfort that persists for months to years after their surgery, while a small group of patients experience severe disabling post thoracotomy pain that interferes with their daily life and requires medical treatment.

All patients expect and anticipate post-operative pain, but frequently they underestimate the severity of the pain they experience (Carr, 1997). In this study participants experienced varying levels of post-operative pain. Some participants found talking about their pain aroused very unpleasant memories and distress, while for others, the experience of pain was one of inconvenience. Still other participants had no significant memories of a pain experience.

Audrey described with much clarity and emotion her experience of pain after surgery. She talked about how her extreme feelings of discomfort aroused feelings of fear. In particular, she feared being discharged from hospital. She did not know how she would manage at home when she was feeling so much pain while in hospital. She said:

*Audrey:* I was stressing wasn’t I about coming home? [looking to her partner]
*Partner:* No. She was definitely not ready to go home.
*Audrey:* And I was really stressed right out about coming home because I was so sore.
*Partner:* I was stressed out, I didn’t know, I was panicking about it myself especially
when we just got a couple of mile up the road...

Audrey: They gave me a prescription to get some [painkillers] on the way home, didn’t they [turning to her partner]. That’s all they gave us.

Partner: Not only that, I think you had only just come off the morphine too. So it was off the morphine, into the car and onto the road.

Audrey: No I think I had been off it [the morphine] a few days,

Partner: Well you hadn’t been off it for too long.

The enormity of her pain experience was realized later in Audrey’s interview when I asked if she and her partner had felt prepared for their overall experience of surgery. Her mind immediately refocused on her pain experience.

Audrey: No, well it was very unknown. I just felt I didn’t know anything.

Partner: The pain was the biggest shock. The pain, especially when we left the hospital, like that was absolutely a nightmare in the car. We stopped over at the bridge at [L…]. Like we left [the hospital] with no painkillers or anything. Like we just left to go home and she really needed pain killers to get home. [She felt] every little bump on the road, she should have taken pain killers before we left.

Audrey: Um, that was a terrible thing, coming home, wasn’t it? [Looking at her partner] Shocking! And by the time I got home I think [my partner] was stressed out as much as what I was. He was nearly in tears.

Researcher: He probably wanted to take you back?

Audrey: Yeah, it was a terrible trip. I could not believe the pain. I could not believe I had it. No I just felt that I sort of …didn’t hold my hand up, I just thought I didn’t know anything about it did I?

Physiological pain after pneumonectomy is generated from ‘soft tissue injury and inflammation, bone and joint trauma, and visceral damage’ (Conacher 1990, 807). Skeletal and respiratory movement exacerbates pain. Audrey lived her experience despite current knowledge about what causes pain and that pain management is a major priority of care for patients after pneumonectomy. Effective management of pain is essential if optimal ventilation of their remaining lung to be achieved. Without good pain management, patients die of pneumonia. Evidence supports the fact that following thoracotomy (the incision for
pneumonectomy) severe pain is the most significant factor to contribute to ineffective coughing and sputum clearance, inability to deep breathe and sigh, and ineffective ventilation (Conacher, 1990; Sabanathan, Richardson and Mears, 1993; Kavanagh, Katz and Sandler, 1994). Pneumonectomy patients have only one chance at recovery.

4.1.3.1 Pain management and patient experiences of pain

Pain management practice has been and remains based on the principal understanding of two pain experts, Mersky and Bonica. Mersky believes that ‘pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage’ (cited in Melzack and Wall 1982, 45). Bonica (1983) cited by Kroon (1992) believes that ‘severe acute pain in the post operative period has no useful function, and if not adequately relieved, produces abnormal physiologic and psychologic reactions, which often cause complications’. Modern pain-relieving practice takes into account the understanding of Bonica and Mersky with the added understanding that pain is a subjective phenomenon and perceptions of pain will be different for individual patients. McCaffery (1972) adds to the understanding of pain with a definition that ‘pain is whatever the experiencing person says it is and exists whenever he says it does’ (cited in Thomas 1997, 21).

Unrelieved pain in hospital while recovering from pneumonectomy was also the experience of Nathan. He recalled the experience of his pain being neither managed nor prevented while he lived the most miserable three days of his life. He said:

*Nathan: I went in for the operation on the Wednesday, and I got off the morphine [PC infusion] on the Friday. No it wasn’t morphine it was the other one.*

*Researcher: Pethidine.*

*Nathan: Pethidine and um I was given one morphine tablet twice a day [MS Contin] and quite frankly it just didn’t control the pain for the weekend and the Monday. They were the three most miserable days of my life I think. Dr L... told them straight to put me on the Endone as well [for breakthrough pain] and that didn’t happen. Um It wasn’t until the Tuesday or Wednesday the following week that I started to feel even half human again.*

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He confirmed this pain experience when he reviewed the content of the themes. He reiterated that the problem of pain was that nobody treated the pain that he had. He said:

...in hospital, pain was an issue. I was prescribed drugs, Endone, however, the nursing staff were not forthcoming even after repeated requests, including requests to the doctor.

Despite evidence that it is more efficacious to prevent pain than to relieve pain (Eng and Sabanathan, 1993) Audrey and Nathan endured avoidable unrelieved pain. They both experienced the severe discomfort of a dis-eased body. Their expectation that professional care would relieve them of their suffering of pain was not fulfilled. Their care was not ‘for the patient and with the patient’ (Morse, Bottorff and Johnson 1994, 191) and they lost confidence and trust in their caregivers. Their vulnerable bodies dreaded the thought or anticipation of ongoing pain both in hospital and when discharged, because they were denied the comfort that they expected to come from safe, secure and trusted caregivers. Their enduring bodies suffered the avoidable fatiguing and relentless discomfort of unrelieved pains (Morse, Bottorff and Johnson, 1994), and for Nathan this was despite repeated requests to nurses and doctors to have his pain relieved.

These experiences are incompatible with the knowledge and technology that is available and guide modern pain management practice, but they did occur. In trying to find an explanation for this finding, I drew on the recent work of Morse (2000) who suggested that nurses fail to be attuned to the distress signals of patients and consequently fail to provide appropriate comfort measures to alleviate suffering. It is hard to believe that professionals (doctors and nurses) would not interpret a verbal request from a patient to be relieved of their pain as a verbal indication of their suffering, but according to Morse (2000) verbal, non-verbal and physiological cues can be undetected or ignored. Another answer may come from the work of authors Kleinman and van Manen (not nurses) who have examined methods of caring for the sick.

Kleinman (1988), whose work focuses on chronic illness, identified that in caring for these people the skill of a clinician is to treat the illness, not just the disease. By this he meant that you treat the whole person and the effect the illness has on that person in their usual sociological setting, not just the physical symptoms that the problem presents. He suggests that this can best be achieved by using a method of care that encompasses the words
‘empathic listening, translation, and interpretation’ (228). He bases this statement on his recognition that the standard biomedical model of care is important because it provides technical control of physiological processes that cause an illness, but also believes that there is a need for a model of care that is neither ‘reductionist nor mechanistic’ (228). A model where management of the ‘uniqueness of the illness as a human experience, in all its many social and personal manifestations, becomes the center of the healer’s gaze’ (228). These principles could very easily be applied to the acute care setting but Kleinman (1988) points out that the constraint of time often prevents this from happening. The biomedical model has contributed greatly to the professional understanding of the mechanisms that cause pain, and the action of drugs that relieve pain, but for Audrey and Nathan this understanding seemed to stand in isolation. The effect that unrelieved pain had on their social, personal and life worlds was not addressed.

Van Manen followed a similar vein of care methodology when he wrote about a concept he called “the pathic nature of inquiry within nursing” in which pathic means ‘suffering’ or ‘a quality that arouses pity or sorrow’ (van Manen 1999, 30). He talked about how things (and people) are named in this world and how language, names or labels that are attached to things restrict a true and deep understanding of the thing that is named. In relation to naming an illness, he says that in order to better understand an illness or symptom, for example pain, we have to know it not from its diagnostic label, but from how it impacts on the complexity, subjectivity and variability of different people’s lives (van Manen 1999, 19). Van Manen says that to ‘understand people’s experiences we would need to get really close to them so that their hopes become our hopes, their pain becomes our pain…’ (van Manen 1999, 19). The pain that Audrey and Nathan felt after their surgery and their hope that the pain would be relieved was not ‘felt’ by the nurses or doctors. Nurses and doctors failed to provide pathic support, in an era when research-based knowledge about cause, effect, management, and prevention of pain is plentiful. They failed to provide comfort to fellow human beings that were dependent on them. The doctors practised what van Manen (1999) called the (dia)gnostic healing attitude where they analyzed, anatomized, dissected, made a diagnosis and prognosis but this only separated the patient from their body. Nurses on the other hand failed to practise their expected pathic healing attitude of consoling and comforting, being aware of times of suffering, being present in moments of need, and supporting and assisting the process of convalescence.
Kleinman (1988) and van Manen (1999) seemed to advocate similar concepts of care delivery that I believe complement the notion of comfort care and comforting measures that I discussed earlier in this chapter. They each presented a case for an approach to care that would maximize healing through a pathic approach, an approach that requires health professionals, not just nurses, to be consoling and comforting, attuned to patients’ suffering, being present and supportive, and assisting the process of convalescence (van Manen, 1999).

The pain experiences of Audrey and Nathan are examples of the absence of pathic care in practice. Audrey and Nathan did achieve the expected clinical goals of recovery. The doctors used their gnostic healing approach of locating the problem (the cancer), they removed the problem by pneumonectomy, and then they supported the patient through a period in hospital. At the end of the “normal” time of six days, the patient was discharged from hospital. From a medical perspective, these patients had achieved the expected milestones and had therefore achieved a positive outcome, but the participants Audrey and Nathan had a different view. They witnessed mechanistic gnostic care overshadowing any pathic healing approach, such that caring touch, encouragement and listening that helps put a patient back in touch with their body, ‘thus making life livable again in whatever way this has to be learned by the patient’ (van Manen 1999, 31) was absent.

Pathic healing is important according to van Manen (1999) because even brief encounters between patients and carers that are specific and unique might have a desirable healing effect. It is clear from the description of Audrey’s pain experience that she did not feel integrated with her body or with the world that she was going back to. Her experience of extreme pain and fear might have been avoided had health professionals recognized, verbalized, interpreted or translated her feelings into appropriate and timely actions.

While this analysis of the pain experiences of based primarily on the experiences of two participants for which just a small part of their recovery is captured, their feelings of unrelieved pain were profound experiences. Audrey felt that the staff focused on her becoming independent. Nurses viewed the fact that she was able to shower herself and get herself into and out of bed as total independence, but her confidence in performing these activities was not questioned. She and her partner felt that her discharge day (Sunday) was set in concrete, that they were committed to a time schedule of:
Audrey recalled a conversation that took place one morning while she was recovering in hospital, that left her feeling frightened and upset. She told me:

There was a nurse in there and actually she said to me, “Now you’ll never be able to sleep on your left side. All you can do is sleep on your back.” She sort of upset me a little bit. And she said, “When you go home, have two weeks and then you’ll be able to get out there and do everything for yourself. Your own shopping and everything…”

I suspect the nurse was trying to use a pathic attitude to entice Audrey in her process of convalescence by encouraging her to become independent, but this was not how the participant interpreted the interaction. Audrey viewed the nurse as displaying a non-caring impersonal behaviour that lacked ‘advocacy, encouragement, support, positive regard and self closure’ (Jenny and Logan 1996, 350). The comment that the nurse made about Audrey not lying on her side was an important clinical fact that she needed to be aware of while she was recovering, but the method by which the nurse chose to give that information aroused discomfort in the form of fear.

Problems of pain management that patients encounter probably stem from a universal dichotomy between what is known about pain mechanisms and pain preventing technologies and how this knowledge is applied in clinical practice. Pain specialist doctors on the one hand are reporting major advances in pain management with comments such as this. ‘There have been remarkable advances in our understanding of pain mechanisms in the last 20 years which have had a profound impact on the management of pain in the clinical setting’ (Siddall and Cousins 1995, 74). Nurses on the other hand are reporting that post-operative pain management has been and remains a problem, with statements like, ‘The under treatment of pain by health professionals has been reported for the past 20 years’ (Brunier, Carson and Harrison 1995, 436). Carr (1990) confirmed the problem of undertreatment of post-operative pain by nurses. Her study found that post-operative pain is poorly managed in hospitals because patients underestimate the pain they are likely to experience, and they expect that nurses will give to them the pain medication when they (the nurse) think it is appropriate. Kroon (1992) also found problems when she surveyed a
group of nurses in a Tertiary Referral Hospital in New South Wales about their knowledge of post-operative pain in the elderly. Her study confirmed that pain is not well managed because nurses often have misconceptions about pain and insufficient knowledge about the pharmacological aspects of analgesia, and these two factors contribute to their administering of insufficient amounts of pain medication. Patients look to nurses to obtain relief from pain, but in the real world they do not always find the help they need. Carr (1997) found that patients believed that nurses played a big role in helping to relieve their pain by giving them painkillers but were often too busy to perform this role. Patients also perceived that nurses provided emotional support by their presence, and willingness to help, often by providing comfort strategies. Touch was a powerful intervention.

The issue of poor pain management is not new to nurses or doctors despite numerous research studies and published statements like those reported above. Wakefield (1995) acknowledged that a 1990 report by the Royal College of Surgeons and the College of Anaesthetists Working Party (London) suggested that health professionals are ineffectual in relieving distressing pain symptoms. She also suggested that nurses categorize patients according to the overt behaviour they display rather than by the symptoms that signal pain is becoming distressing. Her conclusion identified that there was a need to change the attitudes of practitioners from implementing an almost exclusively scientific based practice to one that ‘encompasses the notion of humanistic, eclectic [drawing one’s philosophy from a number of schools] principles’ (Wakefield 1995, 910). Modern pain-relieving drugs, technology, and practices are available for patients but sadly, sometimes access to them is denied by health professionals.

Nathan tried to rationalize his suffering by comparing his experience to that of the man in the bed next to him who had also had a pneumonectomy. Nathan wondered if his experience was “normal” or was it because each one’s perception of pain might be different. He said:

...but perhaps everyone goes through that although talking to Bill [the man in the next bed], he was on Pethidine for three days and he went straight onto Panadeine Forte and never had a moments problem with pain as such, but I suppose you have different people...

He was correct. Individual perceptions of pain do vary greatly especially after thoracotomy/pneumonectomy but pain can be and should always be relieved.
Pain was not always a negative experience for study participants. Victor had difficulty recalling any significant pain experience. He said:

*No, I don’t think so. There was the PCA in ICU….Just discomfort more than anything else. I’m probably looking back with rose tinted glasses now but it doesn’t stand out.*

*After he reviewed the themes he added:*  

*I do not recall any major problems although I recall a fear of not having the painkillers available if needed.*

Michael had little to recall about his pain.

*No, not all that painful. Actually after the operation I thought to myself, beaut. It turned out quite good.*

David recalled that while he did have problems with pain in his early recovery it was mainly because of difficulties in obtaining a supply of pain-relieving tablets. He did not have an adequate supply of painkillers when he was discharged from hospital. He said:

*When I was discharged from hospital, six Digesic tablets were supplied. This small quantity of medication necessitated my wife making a hasty visit to our local GP for a prescription. This added stress was not needed after the trip from [the city] to [the country].*

Audrey too had a similar experience of being discharged without medications. She was discharged from a city hospital on a Sunday to the care of her partner. They had a two-hour car drive to their home in a small outer-metropolitan town. She left the hospital with uncontrolled pain and no medications in her hands. She said:

*I had a prescription and they [the hospital staff] said, have this filled.*

Problems related to the management of early post thoracotomy pain have been addressed, but patients also face difficulties and obstacles related to obtaining adequate relief from
pain, after they have been discharged from hospital to the care of their local community health care services. It is not uncommon for patients to have their need for opioid pain relieving medications challenged by pharmacy staff, relatives, and their local doctor with end result being that their effective pain management therapy is terminated. Doctors, pharmacy staff, and patients and family members fear drug addiction and this fear often dominates any understanding of the physiology of pain after thoracotomy and pneumonectomy. It seems that this issue is not unique to Australia. A Finnish study by Donner, Raber, Zenz, Strumpf and Dertwinkel (1998) demonstrated that patients are frequently questioned and challenged about their need for pain-relieving medication.

The following account of Louise demonstrates the difficulty she had in having her need for pain relief recognized. While her language is a little difficult to understand, her message about how she endured and struggled to get analgesics so that she could achieve comfort is quite clear.

I was really finished and I had to fight with every doctor at the cancer department at [... hospital]. That man [the oncology specialist] said, “Every day you have some Panadeine Forte...”

But nobody wanted to give it. I went to my local doctor. That is the one other reason I wanted to change [my local doctor]. He gave me only one prescription [and] he said that it was not necessary. Oh, but when I was on them every 4 hours [I was OK]. Say I was planning to go from here to the street [if] ...I did not have them I [could not] did not go half way, and nobody believes it.

Her struggle to obtain the medications left me feeling empty. She had difficulty enough with getting to appointments because of physical limitations, problems of driving, poor respiratory reserve, and the distance between appointments, without having to fight for medication to relieve her pain.

Louise: This [is what] I think I [am] supposed to do. I go all the way to [...hospital] to the cancer dept again and ask the doctor [for tablets] because [the doctor at the cancer center] called straight on the telephone to Dr Z [to give me the tablets]. Really, everybody was feeling so upset and angry with me ...but
nobody wanted to listen [to me] in the first place. Eh! Now every time I have to see Dr Z I only get 5 repeats on it. Still, I cut it out [I am reducing them] when I’m not doing anything I don’t use them. I don’t eat them but when I have to go out somewhere before like going to the shops or so I really make sure I have them every 4 hours.

Researcher: So when you go out, you take 2 Panadeine Forte every 4 hours and it helps your breathing?

Louise: Yeah, it really works. I don’t know why. A lot of doctors say that’s no good but that is what [the oncology specialist] he said in […]hospital and it really works. Yeah!

4.1.3.2 Acute pericarditis

Acute pericarditis was the cause of another pain experience for Nathan that may have contributed to an ongoing problem related to long term use of opioid therapy. However, his story was that about one week after Nathan had been discharged from hospital he felt severe stabbing pain deep inside his chest. He was admitted to his local hospital where the diagnosis of pericarditis was made. Pericarditis is a recognised problem following an intra-pericardial pneumonectomy. [Intra-pericardial pneumonectomy: when a bulky tumor presents in the hilar region of the lung, it may be necessary to peel the outer membrane of the pericardium off during pneumonectomy to ensure complete macroscopic clearance of the tumour]. His pericarditis, once diagnosed, was treated with antibiotics, narcotic analgesia, and anti-inflammatory pain-relieving medications. A repeat episode of pericarditis resulted in another admission to hospital. During his recovery from the surgery and the episodes of pericarditis his body became less tolerant to the narcotic drug, he became less confident about his progress, and he became dependent on medication for relief from the pain.

4.1.3.3 Fear of drug addiction, physical dependence, and tolerance

Fear of addiction to pain-killing medication is a fear encountered by patients, doctors, and nurses. It is a fear that very infrequently becomes a reality but very frequently hinders effective relief from pain for patients recovering from lung surgery.
The common fear amongst health professionals is the fear of causing a patient to become addicted or physically dependent on narcotic (opioid) analgesics. The fear generally arises out of a lack of understanding of pain mechanisms, and results in under-prescribing and under-use of opioid analgesics. This fear is unsupported according to published data (Twycross 1999, 52). Drug reduction (or withdrawal) usually coincides with the normal tissue healing process, therefore side effects of drug withdrawal are uncommon. Drug tolerance, where a patient’s ‘requirement for a higher dose of the drug in order to achieve original analgesic effect’ (Thomas 1997, 163) is also uncommon for the same reason. Nurses can be fearful of patients becoming addicted to narcotic drugs and consequently dispense lesser doses of prescribed medication (Kroon, 1992). They also often underestimate the amount of pain a patient has despite the availability of a variety of pain assessment methods.

Patients generally fear taking drugs and frequently have to be encouraged to take appropriate pain-relieving drugs. Overall, the understanding about how much pain to expect and what causes pain after thoracotomy has been poorly understood, and this has been reflected in less than ideal pain management practices. These facts frequently contribute to confusion about managing unrelieved pain after lung surgery as can be seen in the following words of Audrey.

[to her partner]...because I’m not one to take anything am I? I sort of, I wait until I’m really bad before I take anything, but I certainly needed something then …and I think it was only Digesic, because when I went to my own GP he said, “Oh no, you’ve got to have Panadeine Forte” and he ended up prescribing Panadeine Forte.

When practice is based on the definitions of pain that have been cited earlier in this chapter, then prescribing or administering medication to relieve pain in order that a patient achieves comfort should not be problematic. In the acute care setting, using an opioid or narcotic drug to gain relief from pain is not usually problematic because levels of pain naturally decrease as healing takes place and so the need to take the opioid / narcotic medication also decreases. There is ample literature, some of which has been cited earlier, that discusses the various methods of drug delivery available in order that pain prevention or minimization can be achieved.
Some patients experience severe, persistent and prolonged pain after thoracotomy for which the cause is not well known. Research literature addresses post-operative and thoracotomy pain in general and makes mention of what is called post-thoracotomy syndrome but little is known about how to effectively treat the main symptom of neuralgia. The neuralgia presents as pain that either recurs or persists along the scar. It changes in nature from the usual ‘ache’ feeling to a ‘burning dysesthetic component’ (Cousins and Power 1999, 483). The skin sometimes shows hyperesthesia. It is thought that the problem may be caused by neuroma formation within the scar or from stretching or scarring of intercostal nerves when the chest is opened at the time of the operation. Ways of treating the problem of post-thoracotomy neuralgia are being investigated, but so far treatments are often ineffective according to patients.

Nathan had a problem related to prolonged use of a narcotic analgesic. He made it clear that his feeling of persistent and prolonged pain for which he took opioid drugs (in combination with non-opioids) over a prolonged period of time caused discomfort. Discomfort that overwhelmed him, occupied his mind and made managing everyday living tasks difficult (Morse, Bottorff and Hutchinson, 1994). He developed side effects from the treatment and he tells here what the experience was like for him.

Nathan: ... I stayed on Morphine from October to I think it was January and
Partner: [I] blame the doctor.
Nathan: That was far too long. I mean it was all too easy to blame the doctors who were prescribing it, but the other point is that I was asking for it and I don’t think I really needed it. So I think I was on Morphine too long for one reason or another, um, far too long in fact. I was having some rather weird sensations, some mental sensations and I actually ended up seeing a psychiatrist [psychologist] here. At that stage I was determined to get off them and we agreed after talking that I would only come back to her if I failed or if I didn’t get any better but after I did get off them, yes it was a real change mentally.
Partner: He was so aggressive.

Looking back at the above experience lived by Nathan, it would seem that he suffered undiagnosed post-thoracotomy neuralgia, and consequently his pain treatment was not
tailored for that problem. His altered mental state may have stemmed from his unrelieved pain because according to Cousins and Power (1999, 448) ‘there is now convincing evidence that unrelieved acute pain may result in harmful physiological and psychological effects.’

4.1.3.4 Other pain experiences

Non-specific pain or discomforts seemed to be reported by most participants. Some just recalled that they felt pain or discomfort or unusual sensations that they expected during recovery after an operation as big as a pneumonectomy. Karen reported:

> When I got home I moderated the pain-killers so that I had one Panadeine Forte and one Panadol and that killed the pain quite well... I was told I had to sleep sitting up and I slept like that for six weeks so half way through the night I would wake up with my back really sore and aching... To begin with I was frightened because I didn’t want to have pain. Things like the bra, if I tightened it to the first notch I couldn’t stand it....I probably didn’t wear a bra till I came back to work because I couldn’t stand the tightness.

She commented that she does not feel any pain now, but she does feel some sensations.

> There is the sensation that the diaphragm is higher there [pointing], but not all the time.

Audrey reported how pain was a frequent discomfort later in her recovery. In fact, she noticed the pain at varying times as her account here tells.

> Another thing I find too, it’s funny how all these things they sort of start coming back, is that if I sit too long in one position. I am a bit of a fidget. I have to move around a bit, because I do get a bit sore.

Steven also reported uncomfortable sensations.

> Well I have always had [pain]. It’s funny, it’s not sore to touch but when you [are] walking around... Well ...I found if I am backing [the car] back and I have to twist around that way, it’s not painful, but it is noticeable. Or putting a seatbelt on, if the seatbelt goes across
there it just irritates.

Chris was a previously very fit male despite having two previous episodes of surgery for coronary artery bypass grafting (CABGs). The pain and discomfort he felt after pneumonectomy was much more severe, traumatic and debilitating than after CABGs and the following conversation conveys his feelings.

Chris: ...most of the time I don’t feel good, I mean most of the time I’m in some kind of discomfort. [Long pause] We don’t talk about it.

Researcher: Some sort of discomfort!, what do you mean?

Chris: Oh, at the moment my back’s killing me. It is just hard to get comfortable. I can only sleep in certain positions, and most of the time I have some discomfort somewhere. But what I mean I guess [is that] there must be lots of people with the same sorts of problem, incapacity of one sort or another and they cope with it.

The pain experiences of some of the participants discussed in this theme unfortunately typify the experience of Key (1985). Key, without prior information about the surgery had a notion ‘that the wound would hurt’ (142) and she ‘expected the actual site of the operation to cause grief’ (143). This was in fact her finding, ‘despite all that the hospital staff said about how improved techniques had lessened the pain’. She described the situation like this, [I] ‘began to feel as if the surgical team had used me as a repository for their old razor blades’ (142). Key confirmed that improved techniques of managing pain have been around since the mid-1980’s but it seems there is still a problem with applying these techniques to practice.

Ferrell (1991a) provides a succinct statement about the problem of post-operative pain management that helps to draw the pain experiences of participants and the discussion about them into some sort of context. She said, ‘the relief of pain is awaiting no scientific breakthroughs. We have the innovations and tools to manage pain effectively, the problem is one of using them’ (cited in Dufault, Bielecki, Coils and Willey 1995, 635). In practice, “using them” means that professionals see and hear the pain discomfort signs that patients experience and then do something to assist them to attain comfort. This is a basic function of human caring, not just part of the vital role of nursing.
4.1.4 Fluid in the pneumonectomy space

When a complete lung is removed, the vacant chest cavity slowly fills with haemo-serous fluid — fluid that seeps from the mediastinal structures and the moist membranes that line the chest cavity. It accumulates over several weeks and remains in a “sealed sterile container” that becomes known as the pneumonectomy space. As time passes, the fluid congeals and forms a fibrin mesh making up a fluid-gelatinous matrix. The matrix helps to stabilise the mediastinal structures in the initial few weeks after surgery. In any space, like the pneumonectomy space, there is always a potential for the fluid to become infected. Part of the post operative care of patients after pneumonectomy is to minimise any risks of infection, like removing intravenous lines and indwelling catheters early, and monitoring the patient for early signs of infection.

Some participants reported feeling a sensation of fluid moving in their pneumonectomy space during the early days of their recovery. While the sensation was not a distressing discomfort it was a real sensation that they identified as being unusual and sought explanation for. I was unaware of any previous description of this sensation as it is not described in textbooks or in other literature, but given the physiological processes of fluid accumulation in the chest space after pneumonectomy it seemed an explainable and appropriate sensation. Steven reported his sensation like this.

No you feel [the fluid] inside the chest.

And I was telling my doctor, my local doctor, because he’s never had any one who’s had it done [had a pneumonectomy] and he said to me, “What’s it like?” I said it’s a funny feeling because, ah, there’s bubbles going up and you can feel them. You know they are bubbles... but now its [the space is] filled up, I don’t get any [bubbles] now.

Louise had a similar experience and provided this descriptive account.

Louise: [When my daughter was driving the car] ... I was going blurb, blurb.
Researcher: So you actually felt the fluid inside moving?
Louise: Yeah. It was really I think like a vault. In a bottle like you know, that kind of feeling.

Researcher: What about now?

Louise: Not any more. I think it was for lets say about a month and an half or something, and then it was over just like that.

Researcher: What did it feel like, did it feel warm?

Louise: No, but it was a terribly scary feeling you know... But you could not tell my daughter. She was 19 years old. They don’t believe these things because you look all right. They take all things for granted.

Early recognition and treatment of a pneumonectomy space infection is paramount if major life threatening complications are to be avoided. While space infections are more likely to occur earlier rather than later in a patient’s course of recovery, good management is dependent on early detection of the problem. The incidence of pneumonectomy space infection is very low and the literature addresses the medical management of the emergency but no where is there a patient’s account of this phenomenon. Michael and his wife told about their experience that seemed daunting and very frightening.

Wife: ... you were having a shower before you went [to the doctor] and sneezed and all of a sudden it [the drain site] just popped a little fluid. Oh the smell was shocking. I put a dressing over it. I don’t drive so [my husband] had to drive. We were half way around ...Road and it [the fluid] just came pouring out so we got to the hospital. [My husband] parked the car and I raced up ahead. He was standing in the gutter with this stuff just pouring out.

Michael: It was quite terrifying I can assure you. The smell was just appalling. I suppose it was gangrenous was it?

Researcher: It was infected fluid in the space.

Michael: Well it was rather rotten and it didn’t do the car much good either...

Researcher: So what happened to you then. Were you admitted to hospital?

Michael: Oh yes! Dr Z got in touch with [the surgeon] and they shot me straight back to [...hospital]. I was in another 8 days.

For this participant, the infected fluid was projected out of the pneumonectomy space through the healed chest drain track. The experience was distressing and terrifying for
Michael and his wife, so much so that they lost confidence in the treating local doctor (a locum) who was slow to recognize the signs of the infection and initiate appropriate action to treat it.

**Wife:** I would never go to Dr X again. I rang him on Thursday night and said I was really worried [about my husband] and he said it was nothing to worry about. Then on Friday after he [the doctor] had obviously spoken to [the surgeon] he rang and said how bad it was and I said, “But I rang you” and he said, “No, No, I had a patient with me and I didn’t want to discuss it in front of them.” Guess he just didn’t realize what it was.

**Michael:** …[Dr X] was not my normal doctor. My normal doctor is [Dr Z] but I couldn’t get to see him so I saw this other doctor I didn’t have any confidence in him at all. …Let’s face it, I had an infection and he did not spot it. I was saying it was internal. Oh I would walk out and get the paper and I would feel it bubbling away inside. Oh, when it [the fluid] came away it came away!

A pneumonectomy space infection can manifest as one or both of the following two clinical situations. The first situation is where the fluid alone is infected. The patient presents with overwhelming localised infection in the pneumonectomy space causing them to be very unwell, and with or without septicaemia. The primary treatment in this situation is to kill the infective organisms with systemic antibiotic therapy. Draining of the space, and re-sterilization of the cavity is sometimes required. If local sepsis is not identified and managed early, the infective organisms can break down the tissues of the healed bronchial stump leading to the second clinical situation of a broncho-pleural fistula.

It is difficult to comprehend how the sensation of a “volcano” about to erupt inside your body could feel like a “normal” sensation. Clearly, Michael had a serious problem that fortunately responded well to the treatment of systemic antibiotic therapy which allowed the bronchial stump to remain intact throughout this episode of sepsis.

Michael’s experience highlights the need for patients who receive highly specialised care in major teaching hospitals and to have access to appropriate and timely supportive care once they are discharged from hospital. As a result of this study, prior to any pneumonectomy
patient leaving hospital, I [case manager] provide one-to-one patient education and written information, addressing amongst other things the problem of possible space infection. I include in this information lines of communication that are available to patients should they suspect that they are becoming unwell.

4.1.5 Epigastric symptoms

Quite some time prior to this study, I had a brief conversation with a gastro-intestinal surgeon who commented that he often sees patients with gut disturbances who have also had a pneumonectomy. I could not find any enlightening literature about this phenomenon and I had not heard from patients in follow-up phone calls that they had this problem, and so I wondered what truth there was in his comment. Two female participants described their experiences of epigastric discomfort. One had had a right pneumonectomy, and the other a left pneumonectomy. Karen’s epigastric discomfort was burping for which she considered was more an inconvenience and embarrassment than anything else. She said:

Another thing that I live with is that I burp a lot. I feel the wind getting caught and I find if I move to the side, my digestive system is on an angle now. I know that if I move to the left the wind will come up and I feel comfortable. I have to sit in a lot of team executive meetings and it’s embarrassing. I burp like a brickie…..and I hate that too but it is settling down.

Louise talked about her epigastric discomfort as a symptom that caused her great concern. While her English is poorly constructed, I think her message can be very adequately understood.

Louise: …since the operation that’s right, I have something wrong with my stomach or it is my bowels or something [because] cause my stomach. I had [symptoms] for a year. I had a real burning coming up that I had to do something [about] and they gave me some new tablets and it [got worse] get worser and at the moment I don’t use any tablets and it is all gone. But, for a year … I had to fight with all that heartburn. [It was] very very bad. [I] even had to take some x-rays of my stomach after something was wrong with it. I still have the noises in my stomach they go rurr rurr. I never had that in my
life before [but] since the operation. [I wonder] if it had anything to with it [the operation] I don’t know…

Researcher: Some people have told me that they had some unusual sort of epigastric symptoms.

Louise: Yeah, very badly. Let’s say I was lying in bed after brussel sprouts, it was almost all out of my mouth it was so bad… [she was able to laugh about it] Really bad, really bad, that bad. Really, that hard solid burning and then you have all them tablets and one makes it worse than the other. And I don’t use them anymore and it’s much better.

The physiological reason for this symptom is again not documented in the text but is probably related to the displacement of the gastro-intestinal tract by a raised diaphragm caused by the severing of the phrenic nerve during the operation. The symptoms seem to occur later in the recovery of patients, hence, I have not heard about the discomfort in early post-operative follow up communications.

4.1.6 Constipation

A patient satisfaction survey (McLean, 1995) found that constipation was the second most problematic symptom patients experienced after thoracic surgery, while they were in hospital and at six weeks after their surgery. There is ample literature warning of the problem of narcotic induced constipation (McMillan and Williams, 1989; Cameron, 1992; Canty, 1994; Wright and Thomas, 1995) and there are strategies available that will prevent opioid induced constipation, but the problem still occurs and it is distressing to patients. Constipation was not a major concern for participants in this study, but Karen verified that it was a problem.

Constipation, yeah I got that from the Panadeine Forte, and I think because there is only one diaphragm then when you bear down…that was difficult for a short period of time in the immediate post-operative period, but when I stopped the Panadeine Forte it was all OK..

4.1.7 Hospital experience
The stay in hospital was brief for all participants and the impact of that stay on their overall hospital experience and levels of comfort varied considerably between participants. Victor had what would be described as an uneventful stay.

Researcher: Ok, so it sounded like you just breezed through it! [the operation and recovery in hospital]
Victor: Yes. I felt a bit like a fraud, so sometimes I would think that maybe [the tumour] was not cancer.

How was Victor meant to feel? What does a cancer patient feel like? The opportunity to explore these questions was missed but perhaps one of the reasons he felt like a fraud might have been because he was not dependent on nurses to assist him with the physical activities of ordinary daily living. Audrey found her overall experience quite the contrary and was shattered by it. She described her first shower like this:

Oh, the first shower in hospital, I didn’t even think I would survive it. My first day out of bed I didn’t think I would survive, and then I saw that physio lady coming. I wanted to dive under the bed. I wanted to hide from her, even though I knew that what they were going to do was going to be good for me. “Oh no. Please don’t touch me…” They were very good those physios.

The chances of having a lung operation postponed in a specialized center are small, but for Steven, the small chance became reality. The feeling of let down could be heard in the words that he used to describe this incident:

Steven: They had me all ready. They had the hat and everything on and they took me up to theatre and, you know where the operating room is, they had me sitting there. Something went wrong with one of the other patients and I stopped there for about half an hour and the [surgeon] come round the corner and said to me [told me I was being put off]. [He] got up the nurses a bit and said take me out of there [the recovery area]. So they done me the next day. They had to take me down to the ward.
Researcher: So you were postponed?
Steven: Yeah, and then they didn’t do me until about 2 o’clock the next day, but ...that was a bit of a drama you know.

Researcher: It was a let-down was it?

4.1.8 Concluding comment

During the time I was grappling with understanding the experiences of discomfort participants identified, I listened to a Christian sermon titled Suffering and Comfort. The sermon, taken from 2 Corinthians Chapter 2 (New Testament, Bible) focused on the notion that comfort is attained when a Christian knows of and feels the presence of God. The words comfort, trouble(s), suffering(s), trust, endurance, struggles and hope were all key words used in the sermon. Immediately, my attention was drawn to this sermon because these words were similar to those I had found in the dictionary definitions of (dis) comfort, and in the nursing comfort literature. I realized that the notion of comfort was not new, and that the meaning of having comfort (or being comfortable) had not really changed over time. Comfort has been part of human nature and suffering for a long long time, and while it is still a vague and intangible thing, it nearly always comes from “something”. The something can be a physical act of doing, an emotional act that involves listening, touch, and voice, or from a spiritual feeling of having the presence of a spirit or God. In the reading that the sermon expounded, Paul was writing to the people of Corinth, and he was talking about comfort that came from knowing that there was a spiritual God, God that the people could trust and rely on. He said, V 4 ‘He (God) comforts us every time we have troubles, so when others have troubles we can comfort them with the same comfort’ … V 7 ‘Our hope for you is strong, knowing that you share in our sufferings and also in the comfort we receive’. The speaker said that, comfort came to Christians from the spiritual feeling of knowing that a God was caring for them, and that they could place their trust in that God. This is not dissimilar to the comfort and relief from suffering that patients attain when someone (a nurse or a doctor or a relative rather than God) does something physical, emotional or spiritual for and with them (Morse, Bottorff and Hutchinson, 1994).

Reflecting back to the notion of embodiment, with the physical body and the mind working in the one body, helped me develop an understanding of why participants might have suffered some of the discomforts that they did. Arthur Frank (1991) reminds us that doctors still practise treating the object body despite acknowledging the lived body paradigm which
constitutes ‘our being-in-the world’ (Merleau-Ponty 1962, 79). He also draws attention to the fact that while doctors fulfil their vital role of diagnosing and treating the disease that causes a patient to be ill, they become detached from the person they are caring for. Doctors place more priority on the importance of physiological processes that take place in the patient’s body rather than on the impact of the experience and the consequence of it on how the patient functions within their world. Frank (1991) demonstrates this detachment using pain as an example to make his case in the following statement.

‘The ill person actively tries to make sense of what is happening in her body. She tries to maintain a relationship between what is happening to her body and what is going on in the rest of her life. When a person becomes a patient, physicians take over her body, and their understanding of the body separates it from the rest of her life. Medicine’s understanding of pain, for instance, has little to do with the ill person’s experience…For the person, pain is about incoherence and the disruption of relations with other people and things; it is about losing one sense of place and finding another. Medicine has no interest in what pain means in a life; it can see pain only as a symptom of a possible disease. Medicine cannot enter into the experience; it seeks only cure or management. It does offer relief to a body that is suffering, but in doing so it colonizes the body. This is the trade–off we make in seeking medical help’ (Frank 1991, 52).

While Frank’s work identified the issue of detachment of doctors, nurses too have similar behaviours despite an abundance of phenomenologically based nursing research. Lawler (1991) described a somological approach to nursing practice, in which nurses are concerned with ‘integrating the object body with the lived-body’ (29). This usually requires the nurse to share the experience of the patient, thus enabling the patient to gain trust and confidence from the nurse. Clearly, the participant Nathan who experienced preventable pain was not able to share his experience or gain trust and confidence in either the nursing or medical staff, as he experienced the worst three days of his life in pain in an acute care institution.

I feel it is fitting to close this theme with this comment, ‘There is no profit in curing the body if in the process we destroy the soul’ (Sam Golter, cited in Ferrell 1995, 610).
CHAPTER 4, SECTION 2

DISCOVERING NEW LIMITATIONS ON MY SELF: FUNCTIONAL AND EMOTIONAL

4.2.1 Introduction

Prior to surgery, participants in this study were unaware of how new functional and emotional limitations might impact on their lifestyle and quality of life. This was despite being very aware that they were having a major operation, that it would take them six to eight weeks to recover from the surgery, and without this surgery they would probably die from lung cancer. Written information specifically about recovery after pneumonectomy was not available but they did have access to limited information about lung surgery in general and lung cancer.

This section identifies the physical and emotional things or symptoms that manifest as limitations, and it discusses the impact of limitations on the quality of life and lifestyles of participants. The information is presented mostly as direct dialogue from participants because this provides the most accurate and richest description of the limitations and impacts. Dialogue is the vital voice to participant stories about the body’s experience of the illness (Frank, 1995) and this was certainly the case for participants recalling their experiences of lung cancer, surgery and recovery. Frank (1995) says ill people need to tell their stories ‘in order to construct new maps and new perceptions of their relationships to the world’ (3). They need to tell not only of what has happened to them, but about how the experience was ‘through a wounded body’ (2) and they do this by socialising their story; by telling it ‘to someone’ (3). I believe the power of socialising one’s story was confirmed by one participant from this study. Some months after his prolonged interview with me, he reviewed the study findings and themes and made the following comment: ‘I am pleased and surprised to state that I now accept my limitations’. His accepting of his limitations is a complete turnaround to his feelings at the time of the interview, and I suspect this is because the interview enabled him to socialise his story to someone who was interested in his well being.
4.2.2 Limitations

‘What is it like to be ill? Our ability to imagine the illness experience and to empathize with those who are ill is severely limited. Until one is actually in the patient role, it is difficult to place oneself in the position of a patient’ (Morse and Johnson 1991, 1).

A limitation is something, usually a physical or emotional symptom that restricts how a person does something that they could do before their illness or surgery. Limitations can be short term or long-term concerns and they can have a physical and/or emotional origin. A person recovering from major surgery expects to find short-term limitations to their daily activity just as they expected to experience physical and emotional discomforts after their surgery.

In exploring and researching the topic of illness experience, Morse and Johnson (1991) reported that limitations are part of an adjustment process that patients go through when recovering from an illness. The authors described a four-stage process that begins with a patient distancing themselves from the reality of their diagnosis. The second stage involves the patient coming to terms with the illness or understanding the events that unfold related to the illness and diagnosis. The third stage, which is particularly relevant to this discussion, is about the patient taking control of the situation and learning to live within the constraints that result from illness and treatment. It involves learning about and understanding the limitations that affect ones life. Morse and Johnson (1991) suggest that patients develop self-confidence and then they test their limitations — testing enables them to become more in tune with their bodies. The final stage, living again, is about the patient accepting that there are limitations, refocusing their attention on other aspects of life, and finally mastering the ability to carry out tasks of everyday life without conscious effort (Morse and Johnson, 1991).

Illness victims and pneumonectomy patients are alike in that they experience many and varied limitations, but before they can take control of their situation they need to face the limitations. This is an essential part of coming to terms with an illness (Morse and Johnson, 1991). Surgical patients expect to face limitations directly related to the surgery such as restricted mobility and the need for assistance with hygiene until they can do for themselves. They ponder over how limitations might affect their future and they fear that
temporary limitations might become permanent limitations. Moreover, they are challenged by the knowledge that they cannot survive the life-threatening disease without a major operation. They realise that any limitations they face as a result of surgery need to be faced with a goal of learning to live again.

Facing limitations enables the ill person to move forward to the point where they become aware of their limitations, monitor their abilities, and then make adjustments and modifications to their lifestyle (Morse and Johnson, 1991). These adjustments result in them feeling that they are living again as opposed to feeling they want to abandon the struggle to live. Modifications often reflect the ways an individual has made sense of their illness. Most of the participants in this study behaved as Morse and Johnson (1991) suggested, in that they made appropriate adjustments to their lifestyle that resulted in them feeling that they were living again. Several participants found the process of making adjustments difficult and distressing, while some participants felt that their life was an endless struggle.

The limitations that most influenced the participants in this study had a physical origin or had a strong physical component. While participants were recuperating in hospital and at home, they expected they would experience discomforts such as pain, breathlessness, and tiredness that would limit their mobility for a short period of time. They found they became short of breath very easily when exercising, showering etc, because of their reduced respiratory reserve. However, it was when they began to increase their levels of activity and their presence in the world again, that the real impact of the physical limitations became evident to them, their partner, family and friends.

4.2.3 Participants’ experiences

4.2.3.1 Shortness of breath

One participant, a young mother, found she was quite short of breath early in her recovery. Karen made this comment:

_What made me feel worse was the breathlessness I had. I had good days and I had bad days. I would go in the garden and dig a few weeds and could hardly breathe. My husband_
would say, “Go inside, look at you, you can hardly breathe.” A few weeks later I could hardly breathe. Comments like that I wouldn’t really take to heart but I would feel a little bit annoyed.

But she faced and overcame her breathlessness through increasing her exercise.

...but I am doing netball now, sometimes it really kills me ...[she made a huffing and puffing noise]. I am involved with the team players....but, I really only joined to play half a game just so I could make myself feel good and say, “Yeah, this was my goal”. ...but everyone said come back so I said, “OK!” so this has given me the motivation to exercise so that I am OK on the court.

Another participant, Chris, was also troubled by shortness of breath but adamantly declined the thought of attending physiotherapy rehabilitation to improve his respiratory function, with this response.

They would depress the shit out of me.

His approach to facing the problem of shortness of breath may have been because ‘the way in which an individual makes sense of the heart attack’ [or in this case the illness] ‘appears to have a significant impact on his or her attitude’ (Morse and Johnson 1991, 37).

4.3.3.2 Lifting

Lifting was a limitation that a number of participants made comment about. It had its greatest impact on participants whose work required lifting, but lifting limitations also affected the personal and family lives of some participants.

For Audrey, the result of not being able to lift was that she needed to make adaptations and compromises to activities.

My partner’s son came around here one day and he had to push my car out by himself because I just couldn’t sort of [manage it]. One thing I do is that I push a lot with my legs.
If I have to push something I just shove it with my legs and my backside, as long as it is not too heavy.

At times this meant that she was not able to enjoy fully the pleasures of her grandchildren because she did not have the capacity, strength, or confidence to lift them.

**Audrey:** My grand daughter, as she was getting older and heavier I couldn’t lift her. My daughter-in-law now has had another baby, so it’s all right [now because I can lift the new baby], but as he gets older they will have to lift him for me.

**Researcher:** So it takes the spontaneity out of things, you have to think about it first?

**Audrey:** Yes, sometimes it’s a little bit frustrating because I think I wish I could do it. I don’t want someone to do it, like I used to love changing the furniture around and I can’t really do that now [Laughing].

The problem of lifting had a different impact for Steven. He reluctantly had to admit that he was not able to partake in “boy” things with the same enthusiasm that he had enjoyed in the past. This left him with a feeling of uselessness, as his dialogue suggests. His dull toned voice reinforced how he felt about this limitation.

**Yeah,** ... and you try to tell people you know, look we have had to lift some heavy things and I just [can’t] and you feel like you are a bit of a sook but I just tell them now. It is no good me even trying, I just can’t do it...anything heavy or any bending down I just can’t do it.

4.2.3.3 Social, leisure, and pleasure activities

Some participants needed to modify their social, leisure and pleasure activities. Audrey had previously found dancing and water aerobics a challenge. Facing her limitation resulted in her adapting her dancing activities but ceasing the water aerobics. About dancing she said:

**Audrey:** Yeah, you can dance for a certain amount of time then you are puff, puffing and panting...but you sort of get out of breath really quickly. Well that’s what I’m like.
Researcher: You must get frustrated with that! [Pause] Yes, sometimes, but I seem to cope with it well. I learn to live with it anyway.

About water aerobics she said:

I used to do water aerobics, and I gave that up.... I couldn’t do a lot [of the activities] that the rest of the class did, but oh, the teacher, she was fabulous... and she would show me what to do and that was very good, because I couldn’t walk across the pool front ways. I’ve got to go back ways. I can’t stand the water on my front.

Michael reflected on how holidays and family life underwent major modifications.

Wife: We used to go on a few driving holidays but they are out now. Actually we haven’t been on a holiday for years.

Researcher: Does that bother you?

Wife: It bothers me rather than him.

Researcher: And the reason you don’t go is because?

Michael: No, It isn’t easy. I don’t like to be dependent on people, um, we’ve got the oxygen concentrator. Um, I can go for days without using it, other days I need it quite a bit. We have friends who come around and we play cards and I’ll sit at the table with the oxygen going. They are quite happy with it. But as far as holidays are concerned I don’t think I’d travel too well.

Others managed travel without too many problems.

Researcher: What about travelling, do you travel for your holidays?

David: Oh yes.

Wife: We’ve been to WA, we’ve been to Melbourne, and we’ve been to Queensland.

David: Yes... the year I had the operation we went to WA...my mother passed away...We went down to Bendigo at the beginning of this year by car.

4.2.3.4 Activities of daily living
Attending to personal hygiene is a basic activity of daily living that well people take for granted, but for Louise, she discovered a new limitation that she struggled with tirelessly. Her body and mind struggled because of a reduced respiratory reserve and function of her remaining lung. She found the activity of showering and in particular washing her hair to be a problem.

And then you find out just how quickly your energy goes, like under the shower. I had no idea. Yes, yes, I’m still sitting [sit in the shower] not when I have my shower but when I wash my hair or do something above me, you know. I really feel like tingling goes to my arms.

Louise accepted that her mobility was severely limited by her reduced respiratory reserve, but found that other people (the public) did not realise the significance of her limitation because outwardly she had no visible signs of it.

Well, the worst part is that I look all right, eh. Everybody thinks she’s going about [life as normal]. There’s not anything wrong when I sit, but that’s not the same when I’m [not sitting].

She faced her limitation in a way that most humans would not voluntarily do. She made adjustments to daily living schedules and activities to accommodate her desire to be living in the world. She said:

Already I’ve been up since around six o'clock to make myself ready for now [the interview at 10 am] because I cannot rush, rush, rush, anymore. I take it easy. I can do a lot. A lot of things [that] my daughter could do in an hour, I take a whole day [to do]. But now I find the way I walk, when I take [the dog] to the park, I can just sit in a lot of places when I need too.... Other people have been ten times around the block and I do [it] once.

I sometimes go in the morning twice [around the block] and then I’m really finished. That’s that. I really have to sit down and get my air back and then I’m all right again. But [when] I think about [it], I never would have expected that I couldn’t work any more.

She told me about a situation where her reduced respiratory reserve, reduced physical
fitness and desire to look after her dog resulted in a terrible and frightening experience.

For 1 week [after discharge from hospital] it was really good because my daughter was still in school [and she helped me]. After that I never saw her, then the dog had to go so badly out [to the toilet] so I had to take him out. It was really cold and I was a little bit down....and I was standing there and something cracked. That was something I didn’t know, just three days out of the hospital and I could not move any more. I was standing [outside] for over one hour against a pole. It was 11 o’clock at night [laughing]. Nobody was around there because there was nothing there, then slowly I had to crawl up [to my place].

People who are well might never imagine how the limiting and disabling effects of surgery on daily living and pleasure activities might affect their ability to be fully living in the world (Breaden, 1997).

4.2.3.5 Sport and fitness

Sport is an activity that most young people enjoy and sport was an area where new physical limitations resulting from the surgery prompted modifications and adaptations to physical activities like sport.

Victor was a healthy and fit man before his surgery, playing competition squash regularly. After his surgery he tested his ability to play the game and found he needed to alter his “game.”

...I had a couple of games of squash with my colleagues ... but my game, I became quite slow, I had to change my total game.

After the surgery he found that he never regained the little bit of water confidence that he had before the surgery.

I’m not confident in the water but I was less confident due to buoyancy and breathlessness and panic attack if you like. My wife complained that I had let myself slip. I lost muscle tone, I lost seven kilograms after the operation, and it stayed off.
The impact of losing a lung for Victor was most notable when his overall fitness and stamina was put to the test. He said:

I think the area that I think I felt it most was in the Army reserve. [I would] walk instead of run. [It was] impossible to run. You really have to walk flat out. [It's] not an easy task. It used to be eight kilometers in sixty minutes, [but] now walking it is five kilometers in forty-five minutes. It's a little bit better but I have to work at it. Then once a year we do a combat exercise, which is a run, dodge, and jump course. I tried it once. I went over the circuit but decided I wouldn't go back the same circuit. The walk is fifty kilometers in two-and-a-half hours. Some would do it in an hour or less. It took me the full two and a half hours walking flat out...I found in both cases I could handle it but it needed a steady effort all of the time, that was probably the biggest impact.

Victor also enjoyed sailing but found that the pneumonectomy had left him with a reduced stamina and this posed problems such that he was unable to sail at his usual competitive level.

Victor: A friend of mine cruises on [... Harbour. It was a bit of a problem. If things got a bit hectic then I needed thirty seconds to recover. There was no point in just deep breathing again...If there were four of us on the boat it would be OK but when there were only three [I could not keep up the pace].

Researcher: Is that disappointing for you?
Victor: A bit. Yes, but again I think I try to put it in perspective, I am 54 [years old] now.

Sport played a big role in her family life of Karen, and participating in sport brought reality to her presence in the world. She viewed sport with importance because it both returned her to her usual role and function in the family, and it involved her in the social world again despite the physical limitation of reduced respiratory capacity and stamina. The following dialogue brings to words her thoughts.

Researcher: What about sport and leisure activities? Are you back to where you were before the operation?
Karen: I think so. I like bushwalking and I am doing that again although I am slow...I wasn’t doing netball before but [I am] playing netball now. Sometimes it nearly kills me ...[demonstrating huffing and puffing noises] ... so this has given me the motivation to exercise so that I am OK on the court.

Making lifestyle adjustments to accommodate physical limitations was something that affected not only a participant but it also involved the family and friends as Karen’s experience highlights.

It is awful, like we went ...on a 4-wheel drive expedition with [...friends] and we went on a bush walk. They were saying, “Oh that’s the one with only one lung, hope she’s all right. What if something happens to her if we are out here”. And that was awful because I really feel I am all right.... And I kept up with everybody and I could do the same things as they did but always felt they were looking behind at me to see if I was there.

4.2.4 The emotional impact of physical limitations

Not only did the functional status of participants lead to lifestyle adaptations, but the emotional impact of these limitations resulted in some profound experiences.

Victor found during his recovery time his focus of life moved from a need for physical survival to one of emotional somberness. He was not bothered by the fact that his physical energy became overtaken by mental stimulation. This fact was most noticeable when he talked about the effects that his wife’s trauma on his response to his own trauma and recovery. He said:

Well we had a double whammy, because 12 months before [my surgery], my wife had been diagnosed with breast cancer. ...I think she was a little bit annoyed that I had lost my muscle tone. I found that mental stimulation seemed to take over from physical [activity]. I used to sit on the back verandah reading. I was amazed at how quickly time went. Time flies when you...

4.2.5 Disability
Unresolved physical limitations due to illness or surgery are called physical disabilities. Patients living with the chronic disability of shortness of breath or respiratory disease can be granted a status of being “medically disabled” and are consequently entitled to apply for community disability privileges, such as a disability parking sticker for their car. One participant, Karen, was adamant that the words disabled and disability played no part in the language or process of her recovery.

*People would say to me, “Why don’t you get a disabled drivers permit because you really should park in the disabled spot because you are disabled”. But I didn’t feel disabled. Sometimes I felt Yeah! I deserve to have a disabled parking spot because this has happened to me, then I would think, No! I’m not disabled. I’m OK, so I never did, but I guess I could have.*

I asked Karen why she felt embarrassed by the number of cards and letters of support that she received from colleagues and she replied:

*Because I don’t want to appear disabled. I do not want to appear less than what I am. I don’t want people to see me less than I am.*

The issue of disability for Karen, was perhaps really an issue of gaining control of the course of her recovery, and regaining control of her life (Salmon, 2000). Her life had already been disempowered by the limiting impact of her shortness of breath early in her recovery, but she worked hard and made the necessary adjustments required for her to regain control. In her eyes, applying for a disability parking notice would have been a sign of failure and could have had an unquestionable emotional consequence.

The experience of illness and treatment presents patients with many psychological challenges (Salmon, 2000). Challenges such as ‘irrational fears’, uncertainties about the illness and their life, ‘exposure to unfamiliar people, procedures and environments’, and challenges from ‘disclosing suffering, weakness or anxiety to others’ (97).

Salmon (2000) points out that emotional reactions to the challenges of illness, like limitations, can be positive, but it is the negative reactions like anxiety, depression, and
anger that are most damaging to patients. A number of participants reported incidents supporting these reactions.

Nathan had a profound experience of his physical limitations manifesting as an emotional limitation. His profound lack of motivation had a major impact on his level of function in his working world, on his general health and fitness and in particular on his relationship with his wife. He was very open about his lack of motivation. His story is this.

Nathan:  
I noted it in the questions about motivation, I’ve got none. The only thing that I am motivated in is work, computers, and family. Nothing else. I don’t want to exercise as you can see, um, I just don’t feel like doing anything you know. Having to go and wash the car or mow the lawn it’s a real effort.

Wife:  
And it is a real effort too.

Nathan:  
But it’s a mental effort.

The problem of lack of motivation was so profound that he required prescription medication.

Nathan:  
... I mean I suppose [the local doctor] ordered it for all the anxiety I was going through and subsequently put me on a medication called Zoloft.

Wife:  
They called it post traumatic

Nathan:  
Which I’ve been on ever since.

Wife:  
[Even to] get out of bed too. He just takes so long. Before the operation he was up and out, he was go go go, and now...

During the course of his recovery, Nathan was separated from his wife while he had radiotherapy in Sydney. He told me that the treatment did not bother him but the driving to and from the treatment did.

Nathan:  
Oh I didn’t have any problems with it [DXRT] but um, I was away from [my wife] for a number of weeks, and I guess that didn’t help. But just coming here every day didn’t worry me too much, I wouldn’t say it was something I’d like to do again but um, yeah no it wasn’t a worry, although I did find I was becoming very aggressive for one reason or another like on the roads.
Wife: Road rage oh, oh, oh, he was terrible, I’ve never seen him like that before. I don’t know if it was a combination.

Nathan: I am a totally different driver now [he says chuckling].

Wife: But that was not long after the operation when he started to have the radiotherapy

Researcher: So the road rage, the anger — do you still have that when you drive down here?

Nathan: Oh, no that’s passed off now,

Wife: Oh no, no, that only happened after the operation and the ray treatment, ...

yeah, but I have never seen that aggressiveness in him before, ever.

Nathan: I wasn’t aggressive anywhere else, only driving, I wasn’t aggressive at home or at work.

Wife: Well it’s not your nature.

Nathan: No, but once I got behind the wheel it was like Jekyll and Hyde.

Steven, another participant found that his physical limitations and the consequence of leaving his job contributed to his feelings of temporary loss of control of character. This made life very difficult for his partner. He said:

Well, I have changed in myself a fair bit, like I get very short fused. It’s been bitter hell for [his partner] here you know. Not now, but say for the first six months... I’ve given up work, I had too. Like I had no other job. And that probably made things worse. That’s what it was, but I am fine now.

When physical limitations are enmeshed with emotional feelings, making modifications to one’s behaviour and lifestyle can be difficult. Chris found his physical limitation of physical fitness created an emotional barrier to making appropriate and timely lifestyle adjustments. This was despite his view that retaining his physical fitness was a higher priority than being fearful of cancer recurrence. He found his emotional self being taken over by the disabled physical self. He said:

Chris: I don’t think about it [cancer] often. I don’t think about it often because, you see with the heart veins clogging up, what I think about is the current level of
physical fitness that I have, and energy that I have and it’s not good enough for, it is not good enough for me to do the things that I am really good at.

Researcher: You seem to be well equipped here, “Do you have some exercise equipment?”

Chris: I already have it.

Researcher: You have a gym?

Chris: Oh yes, it’s here in the building and it usually just sits. I haven’t used it [the gym equipment] since, but maybe I could do. You see part of the other problem is the terrible assault on the body, [referring to his previous cardiac surgery] mind you [I] have had it [surgery] twice from the front and now from the back.

4.2.6 Sexuality

The impact of surgery and recovery on patient sexuality after pneumonectomy has never been explored, and the topic of resuming sexual activity after lung surgery is rarely raised by patients either before or after surgery. In the hope that I might gain some information from young family people I included the word “relationships” on the prompt list of issues they may consider discussing in the interview. Three participants commented on their sexuality and/or relationship and their willingness to comment suggested that part of their adjustment to living with one lung included making physical and emotional adjustments to accommodate their sexual needs. Each of the participants’ experiences was quite different as is revealed in the following dialogue.

One participant reported that the adjustments she and her partner made to accommodate their sexual needs were necessary and well accepted.

Participant: Yes, yes, yeah, we had no worries with that. Well, after the surgery for a long while there was nil but then gradually we got back to it again.

Researcher: So there are no barriers?

Participant: He knows he [is] just to cuddle. [He] knows he can’t sort of cuddle me tightly. Sometimes he can’t touch me but otherwise we manage OK.

Another participant made the comment that he had no interest in sex.
... I mean I am really not interested in sex. I've lost all interest.

However, he acknowledged that this might be a symptom of his problem of lack of motivation.

As an interviewer, I was hesitant and a little embarrassed to introduce the topic of relationships despite it being listed on the interview question sheet and participants who raised the topic were a little reserved about discussing it. I introduced the topic by asking participants if the surgery had had any impact or had changed any aspect of the relationship between them and their partner. The wife of one participant gave me a very quick response:

Wife: Yes, [pause] I assume you mean the sexual relationship. Yes, it has [surgery has changed it]. [Laughing] It is not existent now.

Researcher: Does that worry you?

Wife: No, I don’t think so. I think I was terrified at first. At first he got me to go on top of him [said with an embarrassed giggle].

Participant: Actually, the stoppage has only been really the last couple of years.

Wife: Yeah.

Participant: Yeah, so there is no urge there whatsoever, before that, um,

Researcher: Do think fear has blocked the urge?

Wife: Oh I don’t know. Maybe.

Participant: Oh, we’ve had a pretty good relationship, sex life, whatever you like to call it, all the way through, haven’t we?

Wife: Yeah.

Participant: As I said, we’ve been married for 39 yeas. We’ve had no problems. I’d say it’s been the last two years.

Wife: Its sort of... Perhaps it has been fear that has blocked out any urges but you know I am quite....I’m not sort of. [Finding it difficult to find words]

Participant: No. We still have our cuddles and that sort of thing, um. [Pause] Almost say we are down to the stage where we don’t need it [sex]. [Pause] No it’s gone.

The importance of a sexual relationship is usually related to pleasure and gratification, but it can also be a sign of masculinity. One participant in this study found the physical limitation
of reduced fitness and respiratory reserve, along with the emotional fear that stemmed from his previous cardiac surgery, severely altered his ability to perform sexually. He was not able to attain the same level of sexual gratification that he had enjoyed before his lung surgery. In his eyes, his level of sexual performance was a measure of his self-worth and masculinity and his inability to perform at his expected level after the surgery amounted to being a failure. His choice of words tell his story and sum up how strongly he felt about his sexuality.

Participant: …but no, as matter of fact it is simple. This operation has affected my sex life the same as it has affected everything else in as much as... I mean I can still walk to the mailbox, I can still walk around the block just as I can still perform sex but I can’t perform it with the energy and zest. I mean that is the best way to put it.

Researcher:  What limits you?

Participant: … Oh I still enjoy sex but I don’t enjoy it psychologically because [tapping the table and taking a long pause] well the best way to explain it is just to say this. Just to be very blunt, just being very blunt, what I am saying is not for impact but for explanation. ...I made love to her, but I can’t fuck her, and there is a difference. I would have thought that if I had still wanted to at 60 years, if I hadn’t had this surgery I could fuck her, but there is a difference, and it is a psychological difference for me. And I don’t mean it in a sense that it represents a man’s ability to [perform] in a power game. I don’t mean that at all. I just mean it represents physical prowess.

A limiting respiratory reserve has the potential to devastate a relationship if physical and emotional fears overpower desires. Kleinman (1988) alludes to the potential devastation of a relationship (which could be assimilated to the devastation of one’s self) in his story about an asthma sufferer who said, ‘It’s been disastrous for our marriage. We don’t go out. All we talk about is his illness and medicine. He's afraid even to have sex with me because of how it may further hurt his health….’ (125).

The need to inquire about sexual activity was important to this study for two reasons. Firstly, there is no literature about how limitations resulting from pneumonectomy might impact on sexual activity and relationships. Secondly, preparing a patient for this operation
should include all aspects of the whole person, and so the topic of sexuality should be addressed. In reality, however, most patients are just pleased to have an operation that will offer a chance of cure from lung cancer, so issues other than the immediate concerns are often not raised.

4.2.7 Quality of Life

One of the first questions that patients ask after being told of a diagnosis of cancer is how long will I live? Their need to know how long they will live is also entwined in their interest in what the quality of their life will be. Quality of life was not formally measured in this study, and so I do not intend to address the issue of quality of life in detail, but it is essential that I report how one participant viewed his physical limitations as a severe impact on his quality of life. This participant conveyed that he had no quality of life at the time of his interview, and that his life was hardly worth fighting for. He felt like abandoning his struggle to live again.

He was a self-employed very successful businessman who had experienced a number of episodes of life-threatening events (this included two episodes of cardiac bypass surgery) prior to learning about his lung cancer. At the time of the pre-interview telephone discussion he sounded as if he had returned to a “good” quality of life, but at interview, while he appeared “well” his feelings about his quality of life were quite the opposite. What quality of life really meant to this man will become evident as his story unfolds.

His words are not necessarily in order of his thoughts because throughout the interview his thoughts often came randomly. He began his interview recounting his follow-up experience at the surgeon’s rooms. This meeting seemed to be the beginning of a downhill slide in his accepting of his quality of life. N.B. he did not see the surgeon who had performed the surgery; he saw one of the surgeons colleagues.

... I was extremely depressed because my recovery was very long. I could hardly walk from the elevator to your office [the surgeon’s rooms] without being extremely out of breath. I felt totally incapacitated. I didn’t know what to expect and I was most apprehensive and concerned to learn what I could anticipate in terms of my recovery..., and when I asked this man [the surgeon’s colleague], he didn’t seem to have any answer and what he said
to me was I might not get any better. I said to him, I was quite frustrated, and I said to him, “Surely you people [the surgeons] must follow up [your patients]. You must have some sort of evidence of what to expect from a man of my age with my condition [and] so forth”? No, he just said to me “look, you may have to accept the way you are and you may not get better”. …and of course I didn’t feel any better, in fact I felt worse after that. But since that time my recovery has probably been a little slow, I wouldn’t know that. I am concerned that I could see myself to be incapacitated. I am certainly not the person [I used to be]..., I used to keep myself fit, swim three times a week and walk and do weights. I never saw myself as a person who was aging at 57 years....um, now it is just the opposite. There is no drive, you can see I am still working, the brain is still functioning but it is the faculties and the concentration, the levels of concentration and length of time. I used to be able to focus, I used to concentrate.

In trying to find out the key issue for this participant, the following dialogue took place.

**Researcher:** Does the fact that you are here today telling me about your experience, but are not able to do the things you used to do, balance out the fact that you may not have been alive today if you hadn’t had the operation?

**His reply was:**

**Chris:** ...The way I look at my life is that I’m borderline. If I become more physically incapacitated than I am now, I wouldn’t be happy. I guess it is because there have been too many additional things in [my] life that have been important to me. I mean I am an earthy type and to have to give up...

**Researcher:** So it is full on or nothing?

**Chris:** Well I can’t have full on, and I don’t feel I can live the way I am, and I am just really searching for some value.

The dilemma of this participant prompted me to reflect on the work of Arthur Frank (1991). Frank talks about illness as being an opportunity to make a choice about how you might lead your life, rather than just reverting to the life you are used to and the expectations you have gathered during your life. At the time of the interview, this participant had been unable
to revert to the life he was used too, but questioned his decision to have the lung removed in an attempt to rationalise why he was like he was.

... But my point is that if I had had four or five years of good quality of life and that was it, [if he had declined surgery] I’d rather have that than 10-12 years puffing around where you have to get everyone to do things for you.

He continued:

Chris:  ... so the effect of this operation in my summing up [is that it] has dramatically altered the quality of life and the values that I had in life, and for that reason I guess I am a different person now. I know everyone else says to me hey, you are lucky you are 60 years old, had all this done to you and you are still out here working and...I mean the fact that I am out here working on a $ Million project, and I am here working for myself, well a lot of people feel and say, that’s a great achievement.

Researcher: And it is.

Chris: Hopefully that may be, and that may be part of me and certain parts of my persona and my character. I mean my character hasn’t changed. My persona has changed. I guess because when I said, your persona is probably the sum total of who your are and what is your every standard, it is part of that business of knowing. [Pause] Just a self-assured attitude.

Some eighteen months after the interview this participant conveyed to me these feelings.

Due to complications, infections..., nearly one year [had] elapsed before any state of psychological health that promised encouragement in the sense that my life might attain some value, due to my age, 63, and previous medical history. I am pleased and surprised to state that I now accept my limitations graciously.

No doubt the participants who struggled desperately to recover were living the reality of what Morse and Johnson (1991) describe as ‘a sense that an irrevocable change had occurred prompted many of them to grieve the loss of a previously enjoyed life-style’ (35). Arthur Frank (1991) confirms that patients need to grieve their lifestyle losses in his
comment, ‘The losses of future and past, of place and innocence, together or alone must be mourned’ (39).

4.2.8 The overall impact of physical and emotional limitations on recovery

This theme has reported an array of personal physical and emotional limitations that had an impact on the recovery of participants in this study. Recovery was measured by how quickly or otherwise they attained independent functioning in the world. The findings were very enlightening as ‘completeness of recovery’ ranged from complete to very incomplete.

Three participants seemed to achieve a complete recovery in that they did return to independent functioning even though this took some months to achieve and the “family” needed to accept some permanent lifestyle modifications.

Four participants made a prolonged but significant recovery by facing their limitations, and accepting that they were not going away. They accepted the need to modify their lifestyle in order to get on with the life that they had.

The remaining two participants, one might say, never recovered. They both struggled to attain an acceptable level of independent functioning. One participant accepted that her lifestyle was not going to improve much and struggled on, while the other felt so strongly that his self had changed that he regretted having the surgery. These two participants struggled to reach the final stage of adjustment to their limitations. They had difficulty accepting that their limitations were not going to disappear, found refocusing their attention on other aspects of life a challenge, and were unable to master carrying out tasks of everyday life without conscious effort (Morse and Johnson, 1991).

Perhaps the two participants who experienced such enduring limitations experienced continuing illness rather than recovery. Their recovery path seemed to fit with the definition of illness that Kleinman (1988) uses which is that ‘illness refers to how the sick person and the members of the family and wider social network perceive, live with, and respond to symptoms and disability’ (3).
4.2.9 Conclusion

This study demonstrated that the limitations and their impact on the lives of participants and families were varied. Some participants found they needed to make minor lifestyle modifications to enable them to live a nearly “normal” life with minimal limitations. Some found they needed to make significant lifestyle adaptations because of the constraints of the limitations, and a few participants found the limitations extremely disabling. One participant was so disturbed by the impact of the limitations on his lifestyle that he believed he was a changed person.

I close this section with a quotation from a wise practitioner, Husserl (cited in Toombs 1992, 7) who said ‘…the contents of another’s world are, therefore, only available to me in an “appresent” manner. I cannot experience them directly.’
CHAPTER 4, SECTION 3  MY RELIANCE ON SUPPORT

4.3.1  Introduction

Support is a word commonly used in nursing and healthcare practice and literature but it is difficult to define. Support is a valuable resource for the sick and recovering — a resource (material, emotional or social) that helps protect them from the challenges of their environment (Salmon, 2000). Participants in this study identified that partners, family members, friends, and health professionals played a vital role in supporting them through their surgical experience. They also identified situations where access to “better” support might have resulted in a different experience of recovery.

This section begins with an introduction to the concept of “coping,” because how people cope with illness and recovery is closely aligned with how they mobilise the support that they do. Discussions about the supportive mechanisms identified by participants will be presented, along with participant dialogue that reinforces the mechanisms that influenced individual experiences.

4.3.2  Coping, suffering, and enduring

How patients respond to a critical health event has been explored in nursing and health literature (Fredette, 1995; Morse and Johnson, 1991; Pitts and Phillip 1991; Dewar and Morse, 1995; Salmon, 2000). Clearly, patient responses are subjective and are dependent on how patients judge the event. It is judged to be either a challenge or not a challenge. According to their judgement, the challenge may or may not lead to stress, but it does provoke an attempt by that patient to “cope” with the challenge (Salmon, 2000).

According to Pitts and Phillip (1991) coping is a common phenomenon that is related to stress, where stress is ‘seen as a transaction between the environment and the person’ (50) and coping is the business of how a person perceives the challenge of that transaction. For example, a person who loses a lung to cure lung cancer might perceive living with the loss of their lung differently to a person who loses a lung because of an infective process or through trauma. Therefore, their differing perceptions might manifest as differences in how they view a challenge and the way they cope with it.
The view of Lazarus and Folkman (1984), that coping stems from either a ‘problem-focus or an emotion-focus’ has been the foundation of coping research. ‘Problem-focused coping addresses the problem itself’ (Salmon 2000, 34). A problem is identified, a solution is sought, necessary changes to stressors and their expectations are made, and new skills and behaviours are learnt. ‘Emotion-focused coping deals with the emotional feelings caused by the challenge’ (Salmon 2000, 34). In some instances individuals find this useful. It gives them breathing space by letting them take their focus from the immediate problem. It sometimes involves the person distorting the facts of a stressful situation in order to change the meaning, and this enables them to retain some hope. Emotion-focused coping is a potentially destructive psychological defense mechanism and can present as an outburst of anger and frustration, or even denial that there is actually a problem (Salmon, 2000).

Activation of either of the above coping mechanisms requires resources, and these are said to be the factors that ‘precede and influence coping, such as health and energy, positive beliefs, problem-solving skills, social skills, social support, and material resources’ (Fredette 1995, 37). In other words, how a person copes, using either a problem-focus or emotion-focus approach or both, depends on how they might draw from past experiences of mobilising resources and support. However, not all individuals have a past experience to draw on.

Support can be mobilised from a number of sources but primarily it comes from family and friends, and professional clinicians. It can take the form of physical, material, or emotional assistance, and all of these are equally valuable.

4.3.3 Family and friend supports

According to Kleinman (1988) ‘illness is not simply a personal experience; it is transactional, communicative and profoundly social’ (186) and frequently the family plays a major role in the ‘illness drama’ (182). Consequently, understanding the meaning of illness is shared and negotiated, and becomes an issue of not just understanding the illness, but understanding the family itself (Kleinman, 1988). All participants in this study had support from at least one family member, but the quality and duration of that support varied among participants because individual domestic circumstances varied.
Karen told how her husband and family activated their support by taking over the household and daily living chores until she felt ready to take them on again. Material support of this kind may appear obvious but it is a vital form of support that not all sick individuals have access to.

*He [my husband]lavished all the attention on me. He waited on me hand and foot. He took 3 weeks off work. My husband is ...he just snapped out of it and rallied round. He thought, “Wow! This is something I can do”. He was very positive, he was very supportive, he waited on me hand and foot and he looked after the kids...*

She chose to suspend her dependence on her family early in her recovery. She initiated changes that helped her expedite her rehabilitation by taking back some control over her recovery. She said:

...*in fact after 3 weeks I had to say to him, “You’re not to bring the cup of coffee to me from the bench any more, because if you keep doing it for me I will just sit there and never do it”, and there I would sit for the rest of my life, so I had to make him stop doing that and I had to do it for myself.*

On occasions Karen was forced to relinquish her control and accept a dependent role. This required tolerance, negotiation, and patience for all concerned. Simple tasks like the family shopping became a major event.

*We tried to walk a lot too, but I couldn’t really walk a lot although he [my husband] would take me out to a place and I’d probably walk the length of the street. I certainly couldn’t walk around the block because I’d be too breathless. I wanted to do the things like the weekly grocery shopping which I couldn’t do, but I’d go with my husband and I’d do one or two isles then I’d have to sit at the front of the shop where there were seats. That was OK.*

Support sometimes brought out feelings of ambivalence. The warm fuzzy feelings of care and concern were contrasted with stern communication that signalled control as well as care and concern.
What made me feel better was my husband’s support. What made me feel worse was the breathlessness I had. I had good days and I had bad days. I would go in the garden and dig a few weeds and could hardly breathe. My husband would say ‘go inside, look at you, you can hardly breathe’. A few weeds later I could hardly breathe. Comments like that I wouldn’t really take to heart but I would feel a little bit annoyed.

On occasions Karen’s husband felt insecure about his role and was fearful about how he would manage if something went wrong while he was caring for the person he loved. Juggling attention between the “sick one” and the rest of the family also posed challenges that required careful consideration and negotiation.

I wanted to be well enough to go to my daughter’s netball tournament but I was only allowed to go one day in case something happened to me. He [my husband] was frightened. My husband said, “If anything should happen to you, I don’t know what I’d do because I would be all of the way out at the netball field”. Plus he said, “I’ve got to give the attention to my daughter so you’d better stay at home”. That was really hard to stay at home.

Support from family members and friends needed to be carefully and delicately managed, and sometimes declined, because the support offered was sometimes inappropriate.

On no, I certainly wouldn’t tell [so-and-so] because she would have told everybody. It was a sensational piece of news for her. I can’t hold it against her, she lives by herself and has nothing better to do than to pass on other people’s news. The more sensational the better...

When a person is well, activities of daily living are taken for granted. When a person is unwell, basic tasks become a major challenge. Audrey needed her daughter to provide her with physical and intimate support so that basic activities of daily living (like dressing herself) could be met. She found her family became very much involved with her ‘illness drama’ (Kleinman 1988, 182) as she relied on the help and support of her daughter to get her through her struggles. She told me:

Well, my daughter came home from England and she stayed with me for about five and a half months because [my partner] was back at work, and I couldn’t even bend down and dress myself. She had to put my knickers and all on for me. And that went on for quite a
while. And to dry the lower part of my body [was difficult]. I sort of couldn’t bend over to dry the lower part of my body.

The experience of pneumonectomy was very much a shared experience for Nathan and his partner. The need for careful negotiation was something they both were very conscious of. Nathan’s recovery path was not smooth, and his partner took on and lived the challenges of his recovery almost as much as he did. He identified in the interview that he had a real problem with self-motivation. His symptoms were having no desire to be active in the world, tiredness, weight gain, inactivity and unfitness, and shortness of breath. They had become more predominant after his first twelve months of recovery. He recognised that these symptoms were having a negative effect on his body and life in general, and a similar effect on his partner. However, he was not able to initiate any action to change this predicament. His partner recognised the problem and challenge also, but was not able to effect any change in his behaviour. He seemed to be a living example of rationalisation, a situation of poor coping, in which he provided logical explanations for why he was feeling the way he was but avoided confronting the real problem. The following dialogue demonstrates the difficulties they both lived.

Nathan: Well I used to absolutely love going [doing an outdoor recreational activity]. I used to love it. I’d go away to a place called [...] once or twice every year. Sometimes with [my partner], sometimes with friends of mine. I’ve just lost all interest and it’s nothing to do with physical fitness because at that time I was fit and twelve months ago I was also coming on quite well.

Partner: Actually he was a lot fitter 12 months ago than he is now.

Nathan: But even then I had no inclination to go into a [...] again. I just lost all interest. ...just going out to mow the lawn and wash the car is a mental effort [Laughs]. ...But when I was having the Ray [Radiotherapy] treatment down here [in the city]... the place I was staying at, they [the owners] were out at work all day. I had the day to myself so I used to go and walk all around Sydney. Everyday I would walk, but now, I just walk to the coffee machine and back. I know I have to get into it [the walking] somehow. I know I have to get stimulated and do some walking. Get stimulated or force myself back into it. Yes!
It seemed to me that Nathan and his partner had lived some pretty challenging moments so I asked his partner the following question:

*Researcher:* How do you feel about the whole journey that you have been on?

The following dialogue tells that she coped with the challenges.

*Partner:* Well, I was the one that worried about the cancer and I used to get angry with him because he would never sort of discuss it, and because he was not that way inclined. He wouldn’t sort of worry about it. I am the worrier but, um, well, I *coped*, you know.

The comment “Well, I *coped*, you know” is one that many individuals make when they find themselves facing critical life events. I believe this statement in this context had two messages. The first message was obvious in that they were both alive but had endured many physical and emotional discomforts since the surgery. The second message was not so obvious, but importantly, Nathan and his partner were saying that while they were suffering and enduring a number of discomforts there were times when they felt the experience was almost unbearable (Dewar and Morse, 1995).

‘What do you do when you can’t bear it? There is only one thing to do: Bear it…You bear it because what else are you going to do?’ says Rollin (1976, cited in Dewar and Morse 1995, 957). Dewar and Morse (1995) asked, ‘How do individuals respond when situations become unbearable?’ (957). What do individuals do when they reach a point where they can hardly “bear” any more physical or emotional discomfort? These authors found that individuals begin to endure a situation by first holding themselves together so that they appear and act normally, often to the detriment of themselves and their support person. ‘The desire to protect their loved one from further pain leads to internalization of feelings, increases concealing behaviours, and distances individuals emotionally from their support system’ (Dewar and Morse 1995, 959).

Nathan and his partner seemed to manage to hold themselves together by supporting each other even though some of their behaviours may have seemed obscure.
Nathan: I became very dependent on [my partner]. Extremely dependent on her. Even if she went away for just a few hours, you know, I found it really difficult to cope. It’s different now though, that’s it. It’s different now.

Partner: You see when he got home, he couldn’t lie down in bed. He had to sit up in the lounge chair so I had to bring a bloody fold up bed out in the lounge and lay down on the fold-up bed just because he wanted me there with him. I suppose I was there with him 24 hours a day.

Nathan: [My partner] has been a tremendous support. Absolutely tremendous support. Yeah absolutely. Yeah it’s funny even now, suppose [my partner] is at her job now where she has to work weekends. Um and during the day I don’t have any problems but it’s really nice to have her, see her come in the evenings.

Partner: But that’s normal isn’t it? [laughing]

Nathan: Yes, but it’s more so now...

When critical events amass, managing them is difficult for some individuals. They might at some point find that an event takes them by surprise, pushing them to the point where they “lose it”. Losing it usually presents as an emotional or physical outburst. Nathan’s partner, in telling her story about their shared illness experience “lost it” briefly during the interview when I asked Nathan a question relating to the outdoor activities mentioned earlier.

Researcher: How does your breathing affect you doing those physical things?

Partner: He’s no good. I’ll tell you that now.

Nathan: I have to stop every now and then and have a break.

Partner: Like he was puffing and panting just to walk to here [to the interview].

Nathan: No I wasn’t!

Partner: Yes, you were. See! [to the researcher] he won’t admit it.

And

Partner: [crying] You upset me.

Researcher: I guess it’s frustrating when you see this person ... [interrupted by partner]

Partner: You have to admit it to yourself. [Can I have some tissues]. I keep
telling him he’s out of breath all the time and he’s got to do something about it, but he won’t.

Nathan: I mean, I know. I want too, but getting motivated to do it is a different story.

The feelings that Nathan’s partner had in her supportive role are akin to feelings that some women experience after mastectomy. They have difficulty sharing their experiences with others and are left feeling quite alone (Shin 1999, 93). Nathan’s partner probably felt alone, isolated, and fearful for her partner as he became very dependent on her and she felt powerless to induce him to change his behaviour.

According to Dewar and Morse (1995) ‘Such unending assaults to the physical self and frequent threats to psychological integrity bring the individual to the limits of endurance’ (962) and sometimes they exhibit behaviour that does not conform to the norms and expectations of their carers. So how does one overcome the challenges of their illness experiences? Most individuals silently accept the reality of their situation and learn to manage the physical and emotional limitations of their illness and treatment. Others display inappropriate behaviours such as denial, projection, repression, reaction formation, rationalization and displacement (Salmon, 2000). Perhaps the preceding dialogue is an example of denial or non-acceptance of the reality of losing a lung and its impact on ones physical ability to interact in their “normal” world.

For some individuals, the ultimate limit to endurance is suicide (Dewar and Morse 1995). One participant in this study raised the issue of suicide but made it clear that suicide was not an option for him. He said:

I have always said suicide is so selfish... I mean I know that I've been in pain at times and I feel to myself, what the hell, but I wouldn't put [my wife] and I wouldn't put it on my kids.

The support that participants received from family and friends helped to minimize their suffering by ‘reducing the physical and psychological discomfort of illness, the social distress extending from changed roles and responsibilities, and the uncertainty of the unknown future’ (Morse and Johnson 1991, 337-8). The supportive role may at times have been reversed. Although this experience was not brought out by the study participants it was made obvious by Armstrong (2000) who said, ‘One thing you realize when you’re sick is
that you aren’t the only person who needs support — sometimes you have to be the one that supports others’ (114). He found that sometimes he had to be the one telling the support team that he would be OK, and so sometimes he was the one saying, ‘I’m going to make it. Don’t worry’ (114).

4.3.4 Professional support

Professional support comes from clinicians such as doctors, nurses, and allied staff. Patients measure the effectiveness or appropriateness of that support by the amount of stress they are subjected to while under the care of professionals. We know that patients are naturally anxious when they enter hospital, and they accept that it is not possible to have all tensions related to their hospital admission removed. According to Bergsma (1997), tension or stress is ‘a result of the inability to solve or avoid a problem’ (101) and as mentioned earlier, it is directly related to how an individual perceives a problem (Bergsma, 1997).

In this study, professional or clinician support came primarily from local medical officers, respiratory physicians, surgeons, and nursing staff. Each had a potential to play a vital role in providing patients with material and emotional support. One participant felt the professional support he received was impeccable and so voiced his confidence about the overall professional care that he received.

Michael: I had a lot of confidence in him [the local doctor] um. He was a nice chap to talk to..., but I also had a lot of confidence in him. It makes a big difference. Oh yes, Fred is um, like sitting down and talking to a friend but I also have confidence in his ability. Dr ZZ is my respiratory doctor and I have a lot of confidence in him too.

Wife: Well thanks to him...

Doctors commonly offer support in an objective form by offering clinically based information. Patients expect this support because to them it has an underlying meaning. It tells them [the patient] that somebody [the specialist] is genuinely concerned about their health and wellbeing. Karen voiced this sentiment.

Dr ZZ was quite good. I think he was sensitive to the fact that he didn’t want to scare me to
begin with or alarm me. There were things he didn’t tell me straight away. He waited. He kept calling me back. When I had finished when I had the operation I felt quite well. I recovered quite well I think. I didn’t feel I needed any doctor’s assistance but Dr ZZ kept saying come back. I’ll see you in four weeks. I’ll see you in six weeks.

I certainly had a lot of wonderful support. I had a medical team of course. I think [the surgeon] came every day or sometimes he came twice a day.

Clinicians can and should play an active role in promoting open doctor/patient or clinician/patient communication so that all interactions are meaningful and free of unproductive stress (Bergsma, 1997). Communication that is supportive and encouraging, however, needs to be realistic and achievable as Karen discovered. She was offered support and encouragement by way of a passing comment and she used the content of that comment to set an objective goal. The set goal turned out to be unachievable by her. The following dialogue tells what happened.

I was told, I think for encouragement, [the surgeon] said to me, “Oh you’ll be right. I do these things for farmers and they have to get back on the land and they’re right in three weeks and they’re out chasing the cows’. So I set myself a goal of three weeks. I’ll be right running around the back yard with the kids. So on the third weekend I was feeling well and I went for an afternoon ride ...but by one o’clock I was very tired and sat in the car...

Karen heard the surgeon’s encouragement, (an objective timeframe of three weeks), and set herself a goal to be fit and active within three weeks of discharge from hospital. This proved to be an unrealistic goal and it left Karen feeling shattered. She endured unproductive and unnecessary stress and the following dialogue describes how she felt.

That was unrealistic and then after that I really hit a low point where I thought I’m not going to make it. This is as good as I’ll be because three weeks had gone and I was still really quite difficult I suppose, so I did a lot of crying. My husband did a lot of supporting.

Fortunately, good family support and care enabled her to make the necessary positive adjustments to her disappointment and failing. On reflecting on the support she received from professionals, and her hearing the surgeons message but failing to achieve her goal,
she made the following statement:

*I don’t think there was anything that the medical team could have done differently because I feel I was supported really well. There were things that I didn’t know and it was because I didn’t ask so I guess that’s my own fault. I suppose the three-week bit, but that’s my own silly thought. If the farmer went back on the land in two or three weeks…*

Karen acknowledges that she set an unrealistic and unachievable goal but her unpleasant experience highlights the need for clinicians to use simple and clear communication with their patients. This is so because patients interpret any clinical input as support. Karen’s story reminded me that patients do cling to every word of encouragement they receive from their surgeon, especially when time frames are involved, and so when offering support they need to be mindful that their words should be encouraging but also appropriate, timely and realistic.

Frequently in clinical practice patients are heard saying, “I didn’t want to ring the doctor because he’s a busy man”. One of the study participants voiced these very words. She was hesitant to seek supportive information from clinicians via the telephone:

Karen: *It would have been good for me personally if there had been someone I could have rung. I didn’t want to ring the medical team because they’re so busy.*
Researcher: *Yes, but that is what they are there for.*
Karen: *Yes I know, and I was invited to ring but I thought that’s a silly question and there are silly questions that come up now and then.*

This comment by Karen says a lot about how patients feel once discharged from hospital, because the transition of leaving hospital and getting into a routine at home can be a very unsettling experience. David reported feeling alone, uncertain, and insecure on returning home after his surgery because the security of being able to get professional help quickly by pushing a call button had ended. He said:

*Well, I guess we never got time to sit down and worry too much about it [what might go wrong] but I suppose if I felt that if anything hadn’t been right I certainly would have been on the phone. It is a bit daunting when you come home and you haven’t got backup. Like in*
the hospital, like the trained staff and all the rest of it, and you come home and you are
totally alone and quite a distance from where you had the surgery, and the person who
performed the surgery, so you did feel alone.

Not all participants felt they were well supported by their clinicians. Some struggled to find
the support they needed. The following dialogue illustrates why Chris felt very strongly that
professionals failed to provide the support that he needed and expected. He expected to
receive answers, information, encouragement, and some positive vibes from his surgeon at
his six-week post-operative visit but they were not forthcoming. It should be noted that all
patients attend a post-operative review and consultation with their surgeon six weeks after
surgery, but this participant, due to communication problems, had his post-operative review
conducted by the surgeon’s colleague. This participant left his appointment feeling shattered
and angry and he verbalised his feelings as follows.

I can’t really think [of anything] you can do differently other than I really was
disappointed, very annoyed with the lack of professionalism I thought with the doctor I saw.
When I went in to see him [it was a post-operative visit]. I said, “Look, will I get any
better”? And he didn’t seem to know anything. Now to me, maybe your report [this study]
will address that, if you take the time to read it and you talk to people. But to me, I felt
worse coming out of there. And I said to him, I said, “Is this the best that I am ever going to
get”? and he said he didn’t know. So I said, “Well what do you know”? He just couldn’t
proffer any [advise]. He said, “Look, the best way to look at it is that you have a healthy
lung, and some people get better [and] some people don’t”. So I said, “I might as well go
and jump out the window now because I am not worth the crap... I am no good to myself. I
am no good to anybody else, and honestly I want to know [if I am ever going to be any
better]”.

The only thing I think maybe that you could do better is, maybe, if you do enough of your
study and you get enough evidence together about the recovery of people and what they do
with their lives, then maybe the next time somebody walks in with an expectation... I mean
what I wanted to hear was something positive. I wanted the man to say look you are out of
breath walking from the elevator to here, and I was. I was really out of breath just walking
from the elevator, [it was a] level walk [describes with a huff puff sound]. When I got out of
Chris found he was in a state of crisis. His spirit was broken because he had not achieved his expected level of physical fitness and recovery in his given time frame. This amounted to uncertainty about his future and quality of life. When he compared the power displayed by the surgeon at the post-operative consultation to his own situation he felt vulnerable and powerless (Bergsma, 1997).

Usherwood (1999, 27) said, ‘We all know doctors who, while knowledgeable and technically competent, succeed in alienating their patients’. Chris’s words might be an example of that situation. Clearly, there was an absence of emotional rapport, sensitivity, and empathy by the surgeon conducting the post-operative review. The surgeon failed to hear, comprehend, or understand Chris’s plight when he asked, “Is this the best that I am ever going to get”? He expected to receive an answer based on knowledge and truth about his current health state. He also expected to secure some empathic advice on how he might change his situation. There was no offer of material or emotional support to help him cope with the critical events hindering his recovery. He probably felt alienated because the surgeon did not appear interested in his problem as his words would suggest:

*Look my point is this. That’s how bad I was when I saw the man [the surgeon]. Now if he were to have spent five or ten minutes saying, “We think you should get a lot better by doing this, this and this, and this is the level of expectation”, instead he said I’m fucked and...*

The interaction between Chris and the surgeon is an example of what Toombs (1992) describes as the separate worlds of doctors and patients. Time is viewed from differing perspectives. Doctors use objective or clock time to measure progress and assess experience, while patients experience their illness and symptoms in terms of “lived” or subjective time (Toombs, 1992; Breaden, 1997).

Chris assessed his symptoms of breathlessness, weakness, and fatigue and viewed them as a continuum of discomfort. They were experienced as sustained discomfort, they amassed to the point where he found no relief, and as a result he questioned the quality of his life.
Toombs (1992, 15) said, ‘Illness as it is “lived through” is experienced as an ever-present, enduring consciousness of disorder which resists measurement in terms of objective time’. Chris was not interested in clock time, he was experiencing and assessing his recovery by its impact on his “being” in the world, or “lived time.” The surgeon on the other hand, using objective or clock time assessed Chris’s clinical and physical progress to be appropriate for the type of surgery that he had had, his past medical history, and the given period of time after his surgery.

The temporality of the illness and disease state was viewed ‘according to two different and incommensurable time dimensions’ (Toombs 1992, 15). Chris, using lived time to assess his progress, was actually saying that his life was in ruins and he was not happy about this, while the surgeon, using objective time and the biomedical mind of doctoring was saying that his progress was satisfactory given the time frame since his surgery.

Living a life-threatening experience is traumatic, especially when family support is limited. Louise found her referral to a professional cancer counsellor to be quite beneficial.

Louise: Yeah, I didn’t want to go but the social worker at the hospital’s Cancer Care Center said [I should see a counsellor]. I was really getting upset every day. Coming here [for radiotherapy] from the car park to the department. I could just make it [she was short of breath] and that was really the end. I’d start crying... for three months and I saw the lady [counsellor] and she was writing and writing. In a way I was glad I had done that because afterwards I feel [felt] better. Why I don’t know, but oh just to get it out [talk] with somebody.

Researcher: Just to be able to share it with somebody was helpful?

Louise: Yeah. And now I start getting in a way, enjoying a bit of life because...

As stated earlier, physical professional support needs to be timely. Louise had a real need for support when she was discharged from hospital but it did not arrive when she needed it. Her story tells how inadequate one aspect of her professional support was.

I was operated on in the last days of September, then I got a call half way through December. I had a telephone call from [...] Hospital to see if I needed a nurse. It was half
way through December! I thought that’s strange, why should I need a nurse now? ... They said they had completed the papers from when I came out of hospital and that someone should come over.

4.3.5 Nursing support

According to Lawler (1991) nurses are very aware of ‘how the relationship between the nurse and patient is crucial in illness experience’ (155). They know that the patient is more than just a body — they have a personality, they come from differing contextual backgrounds, and they are vulnerable. After lung surgery, opportunities for surgical nurses to establish deep relationships with patients are limited, because the time that patients spend in hospital is brief, however, it is possible for nurses to make even brief relationships meaningful and supporting. Caring activities such as providing body care, sharing information, negotiating, being an advocate, and teaching and learning sessions provide opportunities for nurses to develop good relationships with lung surgery patients.

Nursing practice is a complex activity founded on experiences of day-by-day work with patients, but nurses learn from this work and ‘become experienced’ (MacLeod 1994, 362). In a study about nursing practice, MacLeod (1994) concluded that experienced nurses make the “little things” count — “little things” like offering the patient a drink, helping them into and out of bed, arranging their belongings in the bathroom to minimize exertion. Little things are so often taken for granted but when attended to, they support and help patients recover by helping them “over the hump” (363). Experienced nurses make ‘a difference to patients because they are imbued with nursing knowledge and skill’ (MacLeod 1994, 365).

In a recent study, nurses recognised that caring was an intersubjective phenomenon. ‘They understood that “being cared for,” meant more than just receiving attention to obvious needs’ (Euswas and Chick 1999, 175). The study recognised that patients felt cared for when they sensed a nurse being there. It was not just a physical presence of the nurse saying and doing and being there, but a feeling of the nurse being in touch with the person— there was a feeling of relationship between the patient and nurse.

In this study two participants commented on how nurses cared for them, but their comments suggest there might be a dichotomy between the nursing literatures view on nursing and the
participants experience of being nursed. Karen, a health professional herself, had this experience:

*Um the nurses pretty well stayed away except for the four hourly obs [observations] but that was OK.*

Karen’s comment suggested that she expected to receive more “care” from the nurses, and that no meaningful relationship developed between her and any nurse.

Audrey’s dialogue also suggested that there was no meaningful relationship between her and the nurse. The notion of any “little thing” counting was also absent in the nurses comment:

*...when you go home, have 2 weeks and then you’ll be able to get out there and do everything for yourself. Your own shopping and everything....*

The overall absence of participant comments about nursing support might indicate that participants were happy with the support and care that the nurses provided or perhaps it suggests that participants were afraid to comment because the researcher was a nurse.

### 4.3.6 Support groups

A number of participants made it very clear during their interview that support from another person who had experienced the illness drama of treatment and recovery after pneumonectomy would have been very beneficial. Audrey’s comment expresses how she would have gladly accepted an offer to talk to another patient.

*Audrey: Yes, I would have. Yes definitely, because I know with [Jo Bloggs] in the shop ... he used to come in and talk to me all the time. I felt good because I felt I was helping him. Even after he died his daughter used to come in and she said, ‘oh dad used to love coming to talk to you because you understood. You’d been there and had it done’. ... yeah, I think it would have, because they have all this support for breast cancer and everything else, but for this [lung cancer] I don’t hear about it.*
Partner: The thing is too with talking about it and speaking with someone who has had it … If someone had said, “Yes, you will get that pain” or “Yes, that will happen to you, that is all part of the operation” then that would have helped her a lot.

Another participant said:

Participant: …I tried to ring a few people, like be in touch with a few people but I couldn’t. But I just wanted to know how they felt and if it was like what I was going [through] or how I was going myself.

David used his wife’s illness experience and her desire and need for support from other patients, to uphold his overwhelming desire to meet another pneumonectomy patient.

David: [To his wife] Yeah! You would have noticed it when you had the leg off.
Wife: Yeah but,
David: There was nobody there to tell you anything.
Wife: No, there was no support groups or anything then David.
David: That’s what I mean.
Wife: I would have given them quids [$$$] if someone had just walked in and said, “Hey, I’m a [so-and-so]” and I would have thought, “Yes, I will walk again.”
Researcher: Would you have liked to have spoken to somebody who had had the operation, either before your surgery or after your surgery?
David: I would have liked to have met somebody who had this operation. Yes! So I was just going to ask you, “Does that happen now at all”?

Karen was interested in the idea of a support group and responded to my question:

Researcher: If there had been a support group available to you, would have used them? Would you have participated?

She replied:
Karen:    I would have led the group [laughing]. Yes! I would have contacted someone.

She made a positive comment about the value of support groups that was based on her experience of her child and major surgery.

I had a daughter who was quite sick and she had [an organ] removed....and I remember going up to a couple who had a 3 month old baby about to have the same operation, and I was able to sit down and talk to them about the operation and help them through it. I felt good because we had been through that experience. There must be a lot of other young people who have this operation...

As the interviews progressed, I heard from participants that knowing what other patients had experienced and how they had managed after their pneumonectomy would have been helpful to them. Unlike patients recovering from mastectomy or living with emphysema, there is no formal support group for pneumonectomy patients. They are not able to talk with other patients, share experiences, and discuss limitations unless they know through friends and family people who have lived this experience. A number of participants offered to talk with new patients facing this surgical journey.

There is no support group for pneumonectomy patients because the needs of these patients have not previously been identified. Added to this, is an understanding (true or otherwise) that pneumonectomy patients' are cured of their problem [cancer], make a full recovery, and therefore do not need support, or they develop recurrent or metastatic disease and obtain support from an established cancer care center and or a palliative care service.

4.3.7 Conclusion

Support is a subjective item that helps patients to cope with the challenges of critical health events, and patients feel supported when they sense ‘that someone is available who understands, and respects his / her concerns’ (Salmon 2000, 40). Having support is having available a person such as a spouse, family member, friend, and or clinician to do physical things for the person like monitoring their progress after the surgery, helping with showering, the cooking, cleaning etc. Support is also having access to other items like
information, a listening ear, a shoulder to cry on, someone to share experiences with, and someone who will instill confidence in them.

Participants in this study acknowledged freely that they needed and relied on support to help them through their experience of pneumonectomy and recovery. Their dialogue implied that support came from human interactions that made a positive difference to their feeling of wellbeing. For most of the participants, support was a plentiful resource and it had a positive influence on them. However, a few participants struggled to find good support especially when they needed it most.

This section concludes with words from a patient who battled lung cancer against all odds. He reinforces how support is vital to recovery. He said, ‘What are the major lessons learned that might be of use to other patients? In my case family support was vital. You need comfort and somebody to talk to and share feelings with. Don’t forget that the family is just as, if not more, upset than you’ (Montague and Burley 1997, 9).
CHAPTER 4, SECTION 4  MY FINANCIAL SECURITY IS THREATENED

4.4.1  Introduction

Most people take for granted good health and a comfortable lifestyle. However, when they are confronted with a health crisis like lung cancer their comforts are challenged. In the twenty-first century, lifestyle comforts are dependent on one’s ability to earn sufficient money to meet their needs. When illness threatens their ability to work, their financial security is also threatened.

Prior to this study, some patients were reporting during post-operative telephone follow-up conversations that returning to work after pneumonectomy was difficult. Indeed, some found returning to work was not the automatic step in their recovery that they had expected. When patients were preparing for pneumonectomy, they were very keen to know if they would be able to return to their work, and how soon after their surgery they would be able to do that. There is no evidence on which to formulate answers to these questions because the impact of pneumonectomy on one’s ability to return to remunerated work has never been explored.

4.4.2  Experiences in returning to work

Initially, two issues appeared to be the main threat to the financial security of participants in this study. These were the age of the participant, and their need to return to work. There seemed to be two categories: the younger ones who were dependent on a set income to meet financial obligations such as a mortgage(s) and rent, for whom work was a necessity, and the older people who were nearing retirement age and who were working to organise their retirement arrangements.

Later, it became apparent that the type of work that a participant performed was the major determiner of the likelihood of their returning to their pre-surgery occupation and earning capacity. A study by Watson (1990, cited in Berry, 1993), had a similar finding: blue-collar workers took a significantly greater time off work compared to white-collar workers or management-level workers. In this study, the likelihood of a return to work was determined
by the type of work performed – the lighter the work the greater the chance of a return to pre-surgery work.

Participants fell into two occupational categories: workers who performed light and not physically demanding activities, and workers who performed heavy and physically demanding activities. The impact of their work on their earning capacity fell into three distinct categories. People in the first category were those who performed light or office-type work to which they were able to return. Then there were those who performed heavy or demanding work, who could not return to that work but were able to change to lighter work. The final category was those who performed heavy and physically demanding work, who could neither, return to that work nor change to lighter work.

There is no literature reporting the experience of patients returning to work after having a lung removed, but Berry (1993) provides some insight into this topic in a study reporting the experience of patients after treatment for genitourinary cancer. The core process required for their return to work was one of ‘mobilizing social support in the work environment’ (Berry 1993, 905). The importance of professional and personal support to the person recovering from pneumonectomy has been discussed in a previous theme, so it comes as no surprise that gaining support from an employer would assist the process of recovery and return to work for any person after illness or surgery.

Berry (1993) reported that the time people were absent from their work was important and this varied according to ‘the nature of the treatments that each received and by the tasks that each was expected to perform while at work’ (909). The nature of the treatment was critical to patients in the Berry (1993) study because they required a variety of treatments including both stand-alone, and combined, oncology and surgical treatments, whereas all participants in this study had the same treatment. They all required radical surgery (pneumonectomy) for early lung cancer, with the exception of two participants who required additional mediastinal irradiation to surgical margins six weeks after their surgery. What was significant in both studies, however, was that the work that participants were expected to perform determined their ability to return to work.
Category 1: Light work

Participants in this category had been employed in office based positions. They performed professional or administrative functions that were not physically heavy or demanding. They did not require excessive and/or continuous levels of physical and respiratory energy. These participants returned to their pre-surgery employment and resumed their usual earning capacity with minimal disruptions to their financial commitments and lifestyle activities.

Karen was the youngest participant. Aged 36 years, she was a wife, a mother, a non-smoker, and a health professional. She was physically very fit and active prior to her surgery, and highly motivated towards a return to a full and active personal and professional life after her surgery. She made a complete recovery from her surgery and achieved her goal of returning to work.

I was going to get back to work, there were no two ways about that, [she said laughing], because I had just started this new job. It was a job I liked in a very pro-active community. Um, I had no pressure in my mind that I wouldn’t come back, so I suppose I was motivated. There were two things I wanted. One was my Masters degree and the other was to go back to work, and I achieved both.

Victor was 50 years old, married, a non-smoker and he too was fit and enjoyed a very active lifestyle prior to his surgery. He held a senior position in the Public Service and he returned to it. Although he was content to be back at work with a secure income, he found after his surgery, that his applications for promotion to more senior positions were unsuccessful. He attributed this to his age and his diagnosis of lung cancer, and believed he was a victim of workplace discrimination. The issue of employability is not new to cancer survivors as one participant in a study by Pelusi (1997, 1348) voiced ‘…And besides who would employ me once they find out I had cancer’. Victor chose not to confront the issue of discrimination but accepted that his current position enabled him to meet his financial commitments. He said:

I joined the public service in 1991 ... and in 1995 ... the Carr government decided to cut Senior executive [staff] by 30% and 27 positions were identified [to go] here and I was one of them, so at the end of my 5-year contract ... I was offered another job with the public
same job at 75% remuneration. Whether it was because my colleagues knew I needed the operation or whether advancing years but I tried [applied for] half a dozen jobs and couldn’t get an interview so I decided to accept this as it paid the mortgage.

Category 2: Heavy, physically demanding work with an option to alter work practices.

The second category was those participants whose work prior to surgery was heavy and physically demanding but who were able to change or modify their work practices. This meant that some participants were able to change the work they performed within the company they worked for, and retain most or all of their pre-surgery earning capacity.

In the Berry (1993) study, gaining support from employers (supervisors) assisted the return-to-work process, but in this study the support that participants gained varied considerably, and accordingly the opportunity for participants to return to their pre-surgery employment also varied.

Nathan, aged 50, was married, and held a senior position in tourism. Prior to his surgery he found the business a stressful place to work because its isolated geographical location contributed to an insulated occupational environment. After his surgery, his work was relocated to another department in the same company whose headquarters was in a nearby small city. He and his partner moved residence so that his employment would be continued and his capacity to earn would remain secure. Nathan was retrained for another senior position. He initially doubted the company’s motives behind the changes and move. He said:

Well, I used to be a senior (person) down there. They kicked me out of there because they thought I wasn’t fit enough. Before the operation I used to enjoy all the hassles and stresses and things but after the operation I didn’t like it.

In trying to clarify the reason for the move to another place in the organisation, and perhaps the organisation’s support for him I asked this question.

Did they [the employer] ask you to do that [move to the other department] because they saw it as a light duty?
He replied:

*I think they may have, behind the scenes.... I think they saw me opposing the regime and I didn't like the regime very much down there. I think they needed to get me out of it.*

When asked if having one lung might have had any bearing on the decisions of the organisation he said:

*Yes... But I am just wondering if they, in some respects, especially one of them anyway, if maybe they had my best interests at heart anyway because of the pressure.*

Audrey was 48 years old and worked with her partner. She worked as a shop assistant in a food store. She was well supported by her employer and other staff, such that she was able to modify her work practice. She found that when she could not perform the physically demanding heavy work required, other workers chipped in and helped her out. The owner of the shop held her position open while she was recovering from the surgery until she felt she was ready to return to work. Her employers supported her by allowing her to be flexible with her hours of work as her dialogue tells.

Yes, well you see this is where I have been so lucky with my job. The boss up there, he kept my job for me and had someone in casual, and then he just sort of kept it on until I was ready to come back, so I was lucky.

Chris ran a very successful manufacturing business for which family members provided much of the clerical and business support. He was 58 years old when he had the surgery. He returned to running the business after the pneumonectomy because he felt he had to. He felt compelled to maintain the business despite his difficult course of recovery because he believed that “he was his business”, and that other people depended on him for their financial security, as his dialogue tells.

*I mean there are some things I get a buzz out of doing but honestly, but if I was financially secure and every one else wasn’t dependent on me for financial security I probably*
wouldn’t be working. Oh I’d still be giving them a hand but I wouldn’t be working and I’ve been working seven days a week the last few weeks.

Category 3: Heavy demanding work with no option to return to the same work.

The third category was those participants who were not able to return to their pre-surgery employment where their was heavy and physically demanding. They did not return to work because (1) they were not able to perform the work they were expected to do, (2) they were not offered retraining or lighter work, or (3) they were just too sick to return to any work. They had to leave their usual work and consequently lost their capacity to earn a reasonable living. These participants found their lifestyles severely altered. Some of them found their lives shattered by unplanned long-term hardship.

Lifting was the main physical activity that challenged the ability of participants to perform heavy work. Interestingly, one of the participants in the Berry (1993) study reported the same problem. He said, ‘I’d go back [to work] tomorrow if I didn’t have to do all that lifting…’(909).

David was approaching retirement age and had been working with a government authority for many years before his surgery. He performed outdoor and heavy work. He chose to retire early after his surgery. He said:

"I [He] could have gone back to work but I [he] couldn’t have gone back to the work I [he] was doing. And ...at that time I wouldn’t have been able to do the work. The alternative was to travel to ...but I would have had to walk down the road and get the train to work and get a bus back."

When asked how he and his wife managed financially, they agreed that they had been affected by the early retirement.

"David: But we’re managing all right."

And they were managing because of their attitude to life. His wife commented:
Wife: I think you very soon get your priorities sorted out. Material things really don’t mean an awful lot.

Michael was a younger male who had retired from his private and very successful small business some years before his diagnosis of lung cancer and surgery. He loved golf and played it regularly and he and his wife enjoyed an active social life. He had been a very heavy smoker until just before his surgery and was very quick to volunteer this comment:

[My life] changed a lot as far as lifestyle concerns and capacity to earn. I wouldn’t have been able to work after I had that [the lung removed] even if it had been clerical work; I wouldn’t have been able to do it.

The next two participant stories demonstrate how not being able to return to their usual heavy work severely impeded their capacity to earn, and consequently resulted in financial insecurity, an altered lifestyle and unplanned experience of extreme hardship.

Steven, aged 52, was an underground coal-miner and had worked for the same company for more than 25 years. His income had been in excess of $50,000 per annum. Following his surgery he returned to the mine for a short period but found the dust affected his breathing. He tried to get work above the ground but was unsuccessful, so reluctantly accepted an early retirement / retrenchment package. During the interview he displayed signs of his continuing anger over the lack of support he got from his employers. They told him:

“If you can’t work underground then they [we] are not going to create a job for me [you] on top”, which they could have [done] if they’d wanted too, [but] because there are blokes there who could have gone underground and I could have taken their jobs so I just said, “Well I’ll try it”, which I did. I tried it for about two months underground again, and I just couldn’t breathe and I said to them could they put me on pit top and they said no. If you can’t do what you are doing now you’re finished, so just at that time they [the company] brought out voluntary redundancies ... and so I took it and that was it.

When I asked Steven about finding alternative employment he brought to my notice that it was very difficult for an unskilled male in a small country town to find light work that paid well. The range of work that he could perform was limited by the respiratory capacity of his
remaining lung. He could no longer perform heavy physical work or work that involved lifting. He said:

... like lifting anything heavy. If I lift anything heavy I’ve got to spell, I’ve got to stop and get my breath... if I have to lift something heavy or do something physical, but as I said squatting down on your haunches is alright but as soon as you bend...

When trying to find out what mechanical action causes the problem with lifting I asked:

So is it anything [that causes constriction] that compromises your lung expansion?

He replied:

Yeah, that’s exactly what I’m trying to say. And you try to tell people, you know, look we’ve had to lift some heavy things and I just [can’t do it], and you feel like you are a bit of a sook but I just tell them now. It is no good me even trying, I just can’t do it. But other than that, as I said lawn mowing ...I used to clean windows at the hotel when I lost my job. That was all right. You know, cleaning windows or washing cars, but anything heavy or any bending down. I just can’t do it. It must just box up my air or something, I don’t know.

For this participant, the implication of losing a lung, a job and the capacity to be financially independent resulted in a change of temperament, personality, lifestyle, and attitude to life.

Well, I have changed in myself a fair bit, like I get very short fused. It’s been bitter hell for [my partner] here you know. Not now, but say for the first six months. …I’ve given up work. I had to. I had no other job. And that probably made things worse than what it was, but I am fine now. I’m still fine but you just can’t do things that you used to be able to do and that’s all there is to it.

Louise also provided an example of a life shattered by her illness experience and inability to return to work. She immigrated to Australia in 1981 as a sole parent with her baby daughter and lived initially in a refuge for women. Living through tough times was not a new experience for her. Her command of English was poor which did not help her situation but importantly, at the age of 49, she regained control of her personal life. She broke free
from a relationship where physical and verbal abuse were common, so that she and her
daughter, now 19, enjoyed a newfound freedom and independence. Louise settled into full-
time employment as a kitchen-hand in a retirement home and for the first time in her life
began to save money. She saved a rental bond and settled into a rental property, purchased
a car, and gained satisfaction from being able to purchase items for her flat. Louise had
been a very heavy smoker right up to her preparation for surgery. Her words tell her story
best.

Yeah and the worst part of everything was that I lived in circumstances with a drunk where
I was used and abused for ten years long and just…

Before my surgery ... just as my daughter got out of the whole situation and was living in
that place[with me]. [We were] there ten months. We were lucky together and ten months
this came up. Only ten months we lived together. To be honest I could buy a new fridge
and I got the car because I got a good job....

The diagnosis and surgery dealt her a devastating blow. Although she had a good initial
recovery from the surgery, her life has been a constant struggle because of health and
wealth concerns. She reflected on the hardness of the times she had lived through in the
previous two years.

Yeah, not much then for that year. We done really bad because we had not much to live on.
Sometimes in the evening we just had sandwiches or sometimes we were just sitting there
with a bowl of rice with nothing. No veggies, no meat or nothing. No, for a year we done
really bad but still we survived, isn’t it. We came on top of it.

Following the surgery Louise required radiotherapy to the central area of her chest. To have
this treatment she needed to travel daily to a cancer care centre. The cumulative affects of
the radiotherapy delayed her already slow progress of recovery. She found she did not have
the energy, respiratory reserve, or physical stamina to be able to return to her heavy kitchen
work. Her capacity to earn enough money to sustain her independence was suddenly
eliminated. She was unable to feed herself and pay the rent and bills associated with
flatting, so on the advice of a social worker she sought assistance with financial and housing
matters through Centre-Link. Arranging her pension and finding accommodation caused her
much anger, frustration and demoralization. She found the process of completing the forms and the interrogation that went with that task formidable, as she tells her story:

...really they did not believe me but you had to fill the forms. It was ridiculous the forms. Can you sit on a train? Yes of course I can sit on a train.

While she was telling me about her circumstances, I began to feel for her and inadvertently read into her next comment with my query:

**But can you walk up the steps to get to the train?**

Louise responded:

*Yes but that question was not there. There was a really nasty young girl on the telephone. She said, “You said on your form you could sit on the train.” [Louise replied] “Yes I can sit”, I can’t lie about [that] but to get [to the station] there is a different story...I could get the bus at the other place but there was a hill. I was already beggared before I got to the bus stop. But no, she said I could sit, so that was the end and it has messed up the whole process and that has taken a year. A whole year and then I had for half year to pay it back... and if I apply again I can [have to] start all over…*

In the two years following surgery and radiotherapy Louise persevered doing voluntary work despite being very weak and breathless because of the reduced respiratory capacity of her remaining left lung. She often started getting herself ready for the voluntary work at six am to be ready by ten am, as the tasks of showering, grooming, dressing and eating demanded so much of her energy. Louise later gave up voluntary work because it was just too hard for her, and took on what she called “undercover” work to supplement her pension. This extra money helped her to pay the insurance and registration of her car. Her car was a vital resource because it enabled her to be active in the world and not confined to her little unit.

*Yeah, ... it has to do with the money. For a year I tried to find a little job. You know, to do something [so I could save] for the insurance for the car otherwise if I don’t have the car. [If I don’t have the car ] I cannot [get about] . [I cannot] walk up all the stairs, up and
down all the time at the trains [station] and the bus stop is too far away. But insurance is quite expensive and now I find a little job baby sitting for $5 an hour... I just do it once in the week just so I can get the insurance for the car going...it took me [a] year to find that one.

By “undercover” I mean that Louise had to be secretive about earning extra cash for fear that she would lose her pension. This was her biggest fear other than cancer recurrence. She was afraid that if the authorities knew about her ‘little job’ she would lose her pension. The reality of her fears is evident in the following dialogue:

I asked Louise: *I suppose it is a bit difficult financially to plan any trips or anything?*

She replied:

*...That is what my daughter said. Now that I have my little job...maybe we [I] will have an extra shift because when somebody [the authorities] knows that, then you have to pay more rent here and I get that money in my hand and that is why all the old people [ask] where are you going? What are you doing?*

So that is another stress again. They [the authorities] are not allowed to know that I have the little job because they will dump me in. There we go again, it does not stop. [Laughing] But that is what I am planning to do...if I can get one shift extra in the week I will put a bit away and I want to go to the Barrier Reef [to see] all that nice fish. That is what...I want to do. I have never had a holiday so I can save some [money] up.

4.4.3 Return to work and power

Returning to work is said to represent positive change because it provides patients with an opportunity to gain control over their cancer experience and regain control over their lives (Berry, 1993; Little, Jordens, Paul and Sayers, 2001). None of the participants in this pneumonectomy study reported returning to work as a control factor in their recovery but there is evidence in their stories that control, or lack of control over returning to work did play a part in their recovery process.
For Victor and Karen return to work not only represented control over their lives but also control over their financial obligations. A change of position in the same company produced a very positive outcome for Nathan:

*Well they asked me to [take on the new job] for a period of six months to look into their computer system, which I did and I have saved them a lot [of dollars], since. It’s a role I far far more enjoy than when I was down there [at the other location] far more, I enjoy it far more.*

David, Steven, and Louise found accepting the lifestyle changes they faced difficult. For them, regaining control of their lives involved accepting retirement or retrenchment and a reduced income. However, regaining control also signaled their regaining of power over their illness and domestic situation. A recent Australian publication by Little et al. (2001), using narratives from people recovering from colon cancer surgery, commented that for one participant, returning to work was an indicator of his ‘social power’ because work provided a ‘sense of identity and social power’ (60). These authors described power as it is commonly used in medical relationships as *power-to*, *power-over*, and *power-with*. *Power-to* means to control a resource that is sought by another. *Power-over* is the power of dominance. *Power-with* is the most useful form of power as it fosters communication, prevents conflict, and gives a person control over their situation.

Participants in this study were unknowingly exposed to “power” issues. They did not verbalise power as being an issue because they did not recognise it as an issue, but their stories reveal how their financial security was undermined and their lifestyles permanently altered. For some, the control and power that their employers had over them completely obscured any opportunity of “power-with” and they were left feeling disempowered. Disempowerment leaves people with feelings of anger, uselessness, worthlessness, and degradation. They ‘lose “face,” and our face is an important part of our social interactivity’ (Little et al. 2001, 67). Being a strong, useful, and worthy person in a social context breeds a feeling of honour and dignity, but a number of participants in this study suffered loss of face, honour, and dignity as the dialogue suggests.

*Yeah, It’s a bit depressing. Personally I was a bit depressed and went really quiet…and as I said the least little thing, before it wouldn’t worry me, it would go over my head but [now] I*
get very uptight about things sometimes and I suppose it is caused from this. I know I wasn’t like it before but I have changed a bit. But it’s better than dying.

Well, I have changed in myself a fair bit, like I get very short fused. It’s been bitter hell for [my partner] here you know. Not now, but say for the first six months…

Stevens employers activated their power-to control him by not offering him an opportunity to perform lighter work and forcing his acceptance of a redundancy package.

In the case of Louise, one bureaucrat had the power-to control her access to the vital resource of money and accommodation by holding up her application because of her answer to the question: Can you sit on a train?. They had no understanding of the significance of the outcome from her surgery and therefore could not comprehend that she could not get to the station or onto the platform to catch the train. They did not ask the question that to Louise was essential: But can you walk up the steps to get to the train?

Victor too had a similar experience of power-over in that he was not able to secure a more senior position after employers knew of his lung cancer surgery.

The importance of power-with is made obvious by the experience of Karen. She was able to maintain her identity as a successful nurse with an important job to do, by collaborating with her family and employers in order to achieve her goals: One was my Masters Degree and the other was to go back to work and I achieved both.

4.4.4 Conclusion

The presence of this theme in this study demonstrates that the issue of returning to work after major surgery was significant for a number of participants. As a consequence, all participants in the study had their financial security threatened. For some, the threat was only temporary. For others, the threat became a real financial concern and had a significant impact on their ability to cope with the resulting lifestyle changes.

Returning to work and retaining financial security is a normal expectation of patients having elective curative surgery. It is also part of the process of recovery and of surviving lung
cancer, however, according to Dr Anna Meadows ‘the burden of a cancer diagnosis does not end when treatment is complete’ (cited in Ott 1997, 24).
4.5.1 Introduction

‘My highest priority was survival. “Just let me live”’
(Lance Armstrong 2000, 98).

Participants in this study found surviving lung cancer involved a number of struggles. They struggled through their process of recovery, coping with the physical discomforts that were a consequence of their surgery. They were prompted to make adjustments to their priorities of life. They discovered that they needed and relied on friends, professionals and others for support, and they were challenged by unplanned threats to their financial security. The struggles took place when they had little knowledge of the physical and emotional consequences of the surgery and how they might impact on their return to their normal world.

A major struggle for a number of participants was a daily fear that the cancer would return. This fear was a constant reminder of the uncertainty of their continuing presence in this world, and the reality that they could lose their life. They hoped that the struggles had not been in vain when they hoped that the surgery would be a cure for the lung cancer.

4.5.2 Surviving cancer: surviving lung cancer

Stephen Leeder made an opening statement in the foreword of the text Surviving Survival that said, ‘Cancer is a chronic disease’ (Little, Jordens, Paul and Sayers 2001, v). It seemed to me at first a little unusual to link cancer to chronic disease, especially in a surgical setting, because surgery actually takes disease away. However, this statement was made in the context of people with chronic illness and who lose trust in their body. They lose trust when their genetic makeup fails them and allows cancer cells to behave as they do, and they find the relationship they have with their body becomes damaged and needs to be rebuilt. The rebuilding process, says Leeder (2001), can be long and arduous, and might never render the body and the person to be in absolute harmony again, even when the cancer sufferer feels they are one with their body. There would always be some element of doubt and mistrust, and uncertainty.
Nelson (1996) also identified the chronic nature of cancer when referring to the uncertainty that comes from a diagnosis of breast cancer. She said, ‘Whatever the disease outcome, a common thread foundational to the breast cancer trajectory is facing an unknown future and uncertainty’ (59). Likewise, Pelusi (1997) found that uncertainty was a real issue for women when they realized their control over their lives was threatened and their mortality could become real. These concepts tied in well with the thoughts and feelings that were voiced by the participants in this study.

Surviving lung cancer is a milestone achieved by only a small number of people after lung cancer is diagnosed. The fortunate few are those patients found to have early disease, and who are fit enough to withstand a surgical resection of the cancer. The surgery often necessitates the removal of a complete lung, as was the case for the participants in this study. Achieving this milestone has taken the participants in this study along a tortuous journey, the journey beginning with physical symptoms of an illness and proceeding through a series of unpleasant, poorly understood (by the patient) and sometimes painful tests, culminating in the terrifying discovery of a diagnosis of lung cancer. They then journeyed through the processes of agreeing to, preparing for, having, and then recovering from a treatment called pneumonectomy. They accepted a second chance at life, and a chance to survive lung cancer despite there being no guarantee of a cure, long-term survival, or quality of life after having the surgery.

‘Survival is the phase that each cancer patient enters when disease, diagnosis and treatment are over’ say Little et al. (2001, 9). For the participants in this study, the treatment was pneumonectomy, and their survival journey began the day they were discharged from hospital. They began their journey with the knowledge that they had attained two very positive predictors of survival. The first predictor was that the operation, pneumonectomy, had removed all of the cancer (tumour) from their body. The surgeon had reported that all visible or \textit{macroscopic} disease had been removed. The second predictor was that the histopathological testing of the resected lymph nodes and tumour specimen(s) found no \textit{microscopic} evidence of spread to the lymph nodes for any participants and complete tumour removal for all but two participants. To ensure optimal results, these two
participants were recommended and underwent adjuvant radiotherapy to “mop up” any residual tumour cells at the resection margins. The only way the study participants would know if these two predictors were accurate, was to be alive and free of disease five years after the date of their surgery.

Free of disease in this study means disease is absent at the primary site (where the lung was removed), and secondary or metastatic disease is absent at all other sites in their body. Patients are considered cured of lung cancer when they have been free of disease for five years after the surgery. Disease-free survival is the ultimate outcome measure of the success of surgery as a treatment for lung cancer, but achieving this goal brings with it constant feelings of uncertainty about life and living, and cancer recurrence. These feelings are also said to be a “normal” part of the cancer experience. Armstrong (2000, 177) verified this notion when he said, ‘While I was being treated I was actively killing the cancer, but when the treatment stopped I felt powerless, like I wasn’t doing anything but waiting for the other shoe to fall off’. For the participants in this study, discharge from hospital signalled the start of their waiting for the other shoe to fall off. Their destiny was unknown and only time would tell them what the destiny would be.

4.5.3 Participants’ experiences

There is no literature about what it is like to be a survivor of surgically treated lung cancer. Discussion about threats to survival and fears of dying came not only from knowing that the cancer was the problem, but also from symptoms that lead to a diagnosis and the knowing that a major operation was required. Karen was fearful about dying before her lung cancer was diagnosed.

*Before I was diagnosed I said to my husband, “I think I am going to die.” And he said, “Don’t be stupid,” and that was before the doctor picked up that anything was wrong, but I said then, “I think I am going to die.” Before I went in for the operation my husband asked me where the will was. I was a bit scared about that.... Since I came home I haven’t thought I was going to die.*
The reason she thought she was going to die was not explored, but I am certain that fear played a part in her thought processes. Fear is a recognized prominent feeling in illness and disease, and the greatest fear is a diagnosis of cancer because this represents uncertainty of prognosis and a real potential for premature death (Morris, Kearsley and Williams, 1998; Pitts and Phillips, 1998). People are fearful about the diagnosis. They are fearful about what, if any, treatment can be offered, and they are fearful about what they will experience while having treatment. If surgery is offered, then the prospect of surgery unleashes a new set of fears. Fears about the anaesthetic, fears of not waking up, fears of not being able to communicate, and fears about pain. Interestingly, the patients in this study had very mixed reactions to needing major surgery, and in general they were not fearful about losing a lung and what this might mean to their way of life. They just wanted the cancer removed as this dialogue states:

That [removing a lung] did not make for me any difference. The only thing I thought was, if they take the whole lung out, that was [would be] the end of that [the cancer].

Karen fainted when she heard that the complete lung would be removed. She told me:

When I was told I was going to lose a lung I fainted. Dr ZZ was quite shocked that I would have such a reaction but I had no idea that that was going to happen to me….I fainted. I felt OH! This is just bizarre.

Nathan was not fearful of the operation or of dying. He said:

I didn’t worry about the operation until I was actually in the bed. But um, I never gave it [dying] a thought really. I just knew it was going to be done and that was all there was to it.

A real concern for some people facing this potentially curative surgery is that the surgeon might not be able to remove the cancer because of its close proximity to and/or involvement with vital mediastinal organs and structures. For Audrey and her partner, this issue posed a major fear. They knew that all of the preoperative assessments suggested that her body
would tolerate this operation, but there was doubt about whether the surgeon, for technical reasons, would be able to remove the cancer. They voiced their concern like this:

**Audrey:** The thing I think what worried us, what really worried us more than anything was when we went to see Dr ZZ. He did say to me, he said, “Look we don’t know whether we can take the lung, um, and it is up to you if you want to have the operation. We don’t know if he [the surgeon] can save you or open you up, and if not, do a CT scan and tell you how fast it’s growing, and how long you’ve got [to live].” Well, I think that was the worst part, wasn’t it, when that was said to us?

**Partner:** And [the surgeon] said the same, virtually, didn’t he. He wouldn’t be sure if he could operate and he wouldn’t know until he got in to see what was going

**Audrey:** They had to open me up to check first...because they said it was pretty bad and was pretty serious, so when you sort of hear that, you think....!

The uncertainty about whether Audrey was going to die from her cancer or live through an operation and hope that the surgery had cured the cancer posed a significant amount of emotional outpouring. They said:

**Audrey:** I know the day after we were told we both sat down and cried together.

**Partner:** We cried together.

**Audrey:** We cried for I don’t know how long. It didn’t matter about going out the back [of the yard] we just cried together, didn’t we darl? [now laughing about it].

While the fears of dying from cancer were present, there was also an urgency to get the problem treated. The time between diagnosis and treatment was often very short.

*It was all [happening] quickly. It was not something that takes long or over months. It was all [happening] quite quickly. I see [saw] Dr ZZ ...he say, “Sit down”, and then [the] first thing I say while standing [was], “Is it cancer?” ... I was not scared. I think I am more scared now than then.*
The choice between the surgery or no surgery brought varied responses from participants but overall the sentiment was that surgery was the preferred or only option as this comment suggests.

*Well, it was have surgery or that was it. That was the way I looked at it. The only thing that worried me was having an anaesthetic, not the actual surgery.*

Not all participants reflected on surgery as being the only option. Chris was quite categorical at the time of the interview that his quality of life was so poor that he wished that he had looked at other options of treatment. He said:

...*But I am not convinced that there was not an alternative treatment to having my lung out.*
...*But in the back of my mind I feel that perhaps I should have explored the possibility of ...before having my lung out, taking my chances.*

We know from stories from victims of cancer that they desperately want their bodies fixed. David voiced his feeling as follows.

*I was glad he [the surgeon] took the whole lung.*

He viewed removing the complete lung as removing all possible traces of the disease, just as some women view total mastectomy as a way of ensuring no cancer is left behind. We also know that victims of cancer are very grateful to the medical people who can assist the “fix my body process” and are willing to accept that ‘even when medicine can fix the body, that doesn’t always put the life back together again’ (Frank 1991, 8).

The expression *being stuck between a rock and a hard place* is often used to describe the predicament that patients find themselves in, especially when they are signing the consent form for their surgery. I have noticed in my practice that they often sit, pen poised with a dazed look on their face, and comment “I have no choice”. Rarely do they decline surgery, because they see that a chance for a cure and living far outweighs the risks of death and complications from the surgery. They take the one chance they have of being cured of lung cancer, which is major surgery.
Fear and hope are two emotions commonly encountered by individuals whose lives are threatened by cancer (Fredette, 1995; Nelson, 1996; Breaden, 1997; Shin, 1999). While participants did not directly use the word hope in their stories, their acceptance of the risks of surgery and the consequences of losing a lung was a sign of their desire and hope to live. The following comment demonstrates the presence of a fear of dying early and a hope to continue to live and enjoy life.

*The alternative was shocking. I’ve got no fear of dying. I just don’t want to die. Um, how can I put it? Um, I have two grand kids that I didn’t have before the operation* [tears in his eyes and looking at his wife].

*Audrey voiced a similar feeling of hope for survival by her desire to see her grandchildren grow up. She said:*

Yes, because when I was having my surgery and when I first found out about the cancer… my grand daughter was only 6 months and I used to look at her and say No! I’ve got to live through it. I’ve got this far. I want to see her grow up...

*Armstrong (2000), when faced with the challenge of living through the diagnosis and treatment of testicular cancer identified how hope played an important role in his life and recovery. He said, ‘What is stronger, fear or hope? ... I was fearful without much hope but as I sat there and absorbed fully the extent of my illness, I refused to let the fear completely blot out my optimism. Something told me that fear should never fully rule the heart, and I decided not to be afraid’ (98).*

The biggest threat to survival after any cancer treatment is recurrence of the disease in either the primary site or a secondary site. The fear of discovering recurrent or metastatic disease was always present in the minds of participants in this study. As mentioned earlier, the absence of macroscopic and microscopic disease was a good prognostic indicator of survival, but this did not stop participants from being fearful of cancer recurrence. The fear was real, and it was frequent, and it was often shared with a partner as was the case for Nathan.
Partner: You see I always worry too about if it is going to come back again.
Nathan: What? The cancer?
Partner: Yes! [I worry], whereas [he] doesn’t.
Nathan: It’s because I have no control over it [the lung cancer] whatsoever, so I just don’t worry about it.

Survival is monitored by regular surveillance and this involves a physical and radiological examination at regular intervals over five years following the surgery. Some participants told me that the days leading up to their examinations were quite stressful. One delightful gentleman told me how anxious he became and he remained this way until the doctor viewed the chest x-ray film, read and confirmed the report and gave him the good news that there was no clinical or radiological evidence of recurrent or metastatic disease. He said:

... I suppose [I am] frightened about what Dr ZZ might see in that x-ray. That there might be something wrong, but I feel all right [well in myself]. One thing I do, [I] make a point of is [to] have the x-ray the same day as I see her [the Physician].

Another participant verified this feeling of anxiety after I commented that people commonly feel anxious around the anniversary of their surgery. She then told me how she was becoming less anxious as time passed.

This year I didn’t find I was as bad around the anniversary. I seemed to have better vibes this year. I don’t know, maybe I am just better adjusted this year.

Louise found the fear of cancer recurrence overwhelming. She worried about it daily and could not understand why the medical professionals failed to endorse the reality of her fears. She said:

... and that [recurrence of cancer] is the worry I have many time[s]. So [I ask the] doctor how can you see that there is nothing wrong and he looked at me again ...and I really think he got annoyed that [I] you worry about it. I get it from my local doctor too, “Oh, here she comes again, em, worried again.”
Her continuing dialogue told me how she became consumed by her fears to the point where she would tell strangers about her cancer.

*Yes! Do you know something what [was] very bad and I notice it myself. I walk in the park [and] oh meet [people], and the first thing I say [to them] is, “Yes, I had cancer”, and then I think to myself, why am I saying that. [My] mind is so full of it ...*

It is common for aches and pains to persist for an indefinite period after pneumonectomy because of the damage to nerves during the operation. Some participants found that trying to distinguish this “normal” surgical pain from cancer pain was a challenge. Pain regularly provoked a fear of recurrence.

*If I have an ache or a pain, it’s not so bad now, but you always think it is cancer again.*

When I asked Louise if there was ever a day that she did not think about cancer she replied:

*Oh yeah, now there is, but probably for the first couple of years I would just keep thinking about it and stress out, ...*

To clarify how frequent these feelings were I commented:

*So every day, every day you think about your cancer?*

She again replied:

*Yes*

Her worry and uncertainty were further reinforced by her knowing that she had to live through a five year surveillance period to know if she had been cured. She continued:

*I feel really alright and keep feeling all right, but as soon as something goes wrong that is really the first thing [cancer thoughts]. It is the first thing that you think about and it should not be there. That five years is a long time and it should be that when it is gone [the cancer*
has been removed] it is gone, eh, that would be better [said with a chuckle as she finds some relief from her worry].

I found that some participants in this study did not have a good understanding about how cancer behaves and some were not aware of the significance of the five-year surveillance period. Chris asked:

*What is the critical period for the cancer to come back? You see, I don’t even think about that. You asked me if I think about it. I don’t even think about it…. What are the symptoms of the cancer coming back? What is the first symptom anyway?*

The wife of one participant, while telephoning for her husband to accept the offer to participate in the study, asked me to explain what “the five years” meant. Her request arose because Dr ZZ had made reference to this time frame at a recent surveillance review and they were too afraid to ask what it meant. Michael had interpreted the five years of surveillance to mean the maximum time he had to live, and was counting how much time he had left to live. His following words verified his thoughts:

*When I saw him [Dr ZZ] last for my annual [checkup] and my records were out and he looked at them and said, “Two years, you’ve done well.” I thought, what the hell, is there a time limit on this.*

Our prior telephone discussion about the meaning of being under surveillance for five years, resulted in his wife making this comment:

*...you have been calmer than you have been for a long time. Um, and that was mainly because of the conversation I had with you [looking at the researcher] asking about the five years...*

The interpretation of information about chances of surviving plays an important function in how one responds to the information. Karen was very confident about her prognosis and survival chances because she was given a copy of the histopathological report, and her
professional knowledge helped her to interpret the report. Her understanding led to this response:

*I do worry every now and then. Dr ZZ gave me the pathology and I was able to read that, and it [the cancer] was cut clear so if anything starts it must be something new or different.*

4.5.4 Literature about surviving lung cancer

There is no literature addressing the issues of survival after lung cancer surgery, so to interpret the meaning of the experiences of this study group I drew from the experiences of women with breast cancer and other cancers. In doing this, I needed to keep in mind that the natural behaviours of lung and breast cancer are different, and consequently, so are the chances of long-term survival. The five-year actuarial survival rate for women with breast cancer treated with surgery is 74% (Loveridge, Kennedy, Janu, Carmalt and Gillett, 1998), compared to around 50% for lung cancer patients (APPENDIX H: Lung Cancer Surgical Database, University of Sydney). What is common to both groups, however, is that survivors have similar feelings of uncertainty about the course of their disease and how it might threaten their survival.

Breaden (1997) used Van Manen’s methodology to explore the experience and meaning of survival for Australian women with cancer, in an attempt to answer two questions. ‘Do people pass over an invisible line that demarcates surviving from not surviving?’ ‘Could the many years of hoped-for-survival be wiped out in an instant, because of returned malignancy?’ (978). She invited women who had completed active treatment to tell about their experience of surviving cancer, and found that the recurring themes of ‘living in a body’ and ‘living in time’, best described their experiences. The body provided the physical means of living and being in the world. The women moved from feeling that their bodies were separated from their minds, so they felt disembodied, to a feeling of being whole or embodied again.

Disembodiment is a common feeling in illness experience (Benner, 1984; Kleinman, 1988; Frank, 1991; Lawler, 1991; Madjar and Walton, 1999). Frank (1991) says, ‘My body is the means and medium of my life; I live not only in my body but also through it’ (10). Nurses
can play a vital role in helping to prevent patients from becoming disembodied. Audrey told me about her experience with a nurse that resulted in her feeling that her mind and body were not co-ordinated. She said:

_They had one nurse in there, actually she said to me, she said, “Now you’ll never be able to sleep on your right side. All you can do is sleep on your back”… and she said, When you go home, have two weeks and then you’ll be able to get out there and do everything for yourself, your own shopping and everything.”_ She was an older lady, a nice nurse.

Audrey wanted in her mind to care for herself, and it appeared from the nurse that she was expected to care for herself but her body was not willing. Knowledge that was ‘interpretive, contextual and integrative of objective and subject’ (Lawler 1991, 5) was absent from the nurse providing care. Perhaps the nurse was offering positive encouragement as she prepared Audrey for discharge but there seemed to be no acknowledgment that the task of connecting body to mind during recovery from this surgery is difficult. The nurse may have been inadvertently redefining the level of dependence the patient had on carers (Lawler, 1991) or she may have been busy and thought the patient could do things for herself. It was obvious from Audrey’s description that the interactive and intimate component of nursing that becomes knowledge was absent (Lawler, 1991) and the emotional/mind part of the patient that is so vital to recovery and healing was obscured.

Victor talked about his experience of mind/body separation during his recovery at home. He was talking about how his wife (who was a survivor of breast cancer) was coping with his illness, and then he told me that she was concerned about his lack of interest in resuming his physical activities. Victor found his physical and body interests were overtaken by a desire to sit and read books for hours, whereas before his surgery he was very fit and involved with outdoor activities. He made this comment:

_I think she [my wife] was a little bit annoyed that I had lost my muscle tone. I found that mental stimulation seemed to take over from physical… I would sit on the verandah reading. I was amazed at how quickly time went._
I believe she was witnessing his ‘disembodiment’ in which his mind blocked his view of himself in a different body. He objectified his body to be “purposeless” by allowing his mind to be totally occupied.

‘Living in a body’ also found ‘the body as the house of suspicion’ according to Breaden (1997, 980). When I read this I felt strongly that these words aptly described the fears of recurrence that participants in this study felt. The suspicious feeling that was common to participants in this study group was verbalised like this:

*And when something goes wrong you think, “Oh it’s there again, eh.”*

Shin (1999) tells us that Korean women after mastectomy also become suspicious and lose confidence in their bodies. She says, ‘Even minor symptoms appeared as omens of recurrence of cancer and death’ (94).

“Living in time” in the study by Breaden (1997) was not just the linear or clock time that tells of the present moment. Living in time was experienced ‘as something to be questioned, a concept in which change and chance take place and as part of a shared journey’ (980). Four chapter headings captured this notion; “the future in question”, “changes in time”, “lucky to be alive”, and “sharing the journey”. These headings related well to the participants in this pneumonectomy study. The future of these participants was uncertain. Would they live to see their children and or grandchildren grow up? Would they be able to go back to work? Would their disease recur? Living with this uncertainty was difficult and the difficulty was inadvertently reinforced by the guardedness of doctors to talk optimistically about long-term outcomes of lung cancer. This dialogue took place at Audrey’s annual check-up.

*Audrey:*  *Oh yes, he was just so pleased, Dr ZZ. It was the first time he has actually turned around and said, “I can’t see any cancer,” whereas before he would just say, what did he say’?* [turning toward her partner].

*Partner:*  *He [Dr ZZ] would never say the word cancer.*
Audrey: I think he even mentioned the word cure and he has never done that before and he said [to her partner], I bet you never thought she would be cured.

How might this experience change or affect a patient’s lifestyle? What effect would it have on them as a person? Would it make them view life differently? One gentleman found the whole experience quite devastating.

*It has changed my whole life, it has changed my values, it changed everything in life, for my personal life....*

No participant journeyed through survival alone, it was a shared journey, but some had more support than others. One couple commented:

*So we’ve been married ... and I reckon from then on we gradually got closer and closer, then when this happened to me we got even close[r] still. No I reckon it brought us together, much closer.*

For Karen, who had a young family, her children (pre-teenagers) participated in the journey with her. She said:

*The kids... they didn’t worry too much. They knew I was sick when I came home because I was still vomiting when I came home. They’d stand around and they would yell, “Oh she’s doing it again, dad. There she goes again!” but they were OK.*

Finally, participants saw that they were lucky to be alive on a number of fronts. Davids wife voiced how lucky she felt that she and her husband were with this comment:

*I think he has been extremely lucky and I hope he continues to be lucky. I think we were very lucky that it [the cancer] was caught in time. We were very lucky going to Dr ZZ. We were extremely lucky to get Dr YY [the surgeon] who I think really knows what he is doing and is an extremely nice man into the bargain. Um so yeah, I think we were extremely lucky and David has come along really well.*
4.5.5 Conclusion

The uncovering of this theme, “my survival is at threat” is not an unexpected finding. The stories and comments that participants shared have exposed the fears and uncertainties that threaten the survival of patients recovering from lung cancer surgery. Like women with breast cancer, the many challenges arising from the fears and threats to their survival were faced by the participant who had the disease and others who were caring for them (Nelson, 1996).

Patients are constantly reminded of the threats to their survival by the physical things that they feel like aches, pains and unusual sensations, but they are also inevitably reminded of them by medical visits, tests and discussions that take place (Little et.al, 2000). By facing the fears of cancer recurrence or spread that threatened their survival, participants were facing death.

I again draw on the work of Armstrong (2000) in order to conclude this theme on a positive note. During his cancer experience he came to know why people feared cancer: ‘because it is a slow and inevitable death’ (118) but he attempted to overcome this fact through believing. He believed in his doctors, believed in the treatment, and he believed in whatever he chose to believe in because believing was most important to him. He said that without belief, ‘we would be left with nothing but an overwhelming doom, every single day…. I didn’t fully see, until the cancer, how we fight everyday against the creeping negatives of the world….So I believed’ (117-118).
4.6.1 Introduction

“I wish I had known more.” These few, powerful words simply state the feelings of participants in this study. Before I discuss the meaning of these words in relation to this theme, I want to consider an incident that occurred early in my practice as case manager for thoracic surgical patients. I do this because it provides clear anecdotal evidence that knowledge about a proposed surgical experience could be useful to patients provided they have access to information.

The incident took place at a period when health care providers and patients were feeling the effects of patients being fast-tracked through the hospital system in response to a reduced health care budget. One answer to this dilemma was for the cardiothoracic surgeons to appoint a nurse case manager to support thoracic surgical patients through their surgical experience. The following incident occurred on my second morning as case manager, when I was observing a consultation between a surgeon and a patient.

The patient, aged in his 60s, had a biopsy proven primary non small cell lung cancer. He had driven 100 kilometres to the meeting, alone, because his wife was at home babysitting a grandchild. The surgeon explained to the patient all available treatment options and related risks, and then gave him time to consider the options, from which he gladly accepted the option of surgery. The surgeon arranged for the surgery to take place in a tertiary hospital within Sydney, ten days after the consultation. The patient left the surgeon’s office with his admission dates and times on a piece of paper, commenting that somehow he would find his way to the hospital. The next contact either surgeon or I had with this gentleman was during his admission to hospital for the surgery.

At the completion of the consultation, the surgeon and I both agreed that we could “do better than this for our patients”. We arranged for a one-on-one consultation between patient and case manager, and the provision of an information booklet to be part of the routine preparation of all lung surgery patients. The ongoing function of the case manager was to provide verbal information and support to patients, partners, and families as they journeyed through their surgical experience. The case manager’s close liaison with patients ensured
that patient safety was not compromised by the shortened period of recuperation in hospital, because timely access to information and professional guidance from the case manager was available when needed. The case manager became the linchpin between the patient and their vital resource; information. A review of the case manager’s role (McLean, 1999) confirmed that patients needed and wanted access to information.

Having considered the above incident, it is important that readers be aware that this research study was conducted early in my practice as case manager. At that time, I knew little about what happened to pneumonectomy patients after they were discharged from hospital, but I was hearing in the post-operative follow-up contact telephone calls that managing at home was not easy. The only information available was scientifically based objective surgical data. There was nothing about a patient’s experiences of life after pneumonectomy that I could use to help other patients with.

4.6.2 Information

Textbooks tell us that that information and communication are important for people coping with disease and illness (Lazarus and Folkman 1984; Kleinman, 1988; Morse and Johnson 1991; Bergsma, 1999; and Salmon, 2000), because information helps to reduce stress and anxiety. Not knowing creates stress. Patients need information so that they can understand what is happening to them and be informed when making decisions. Information helps them to make sense of any symptoms they feel. Furthermore, information is especially important when an illness is related to cancer (Key, 1985; Galloway, Bubela, McKibbon, McCay and Ross, 1993; Fredette, 1995; Luker, Beaver, Leinster and Glynn Owens, 1996; Sanson-Fisher, 1999; Goodman, 2000; Mills and Sullivan, 2000; Leydon, Boulton, Moynihan, Jones, Mossman, Boudioni and McPherson, 2000; Rees and Bath, 2000).

There is only basic information about the needs of patients after lung cancer surgery, (Galloway et al., 1993) and this information does not relate specifically to the needs of patients after pneumonectomy. Galloway et al. (1993) explored the perceived information needs of patients following thoracotomy for primary lung cancer. Six of the forty patients had had a pneumonectomy. Their study confirmed that information was most important to them, and it helped them to manage at home once they were discharged from hospital. The information was most valuable when it related to preventing, recognising and making
judgments about complications, resuming physical activities, and understanding the impact of lung cancer on their present and future life.

A comprehensive literature review of the information needs of women with breast cancer supports these findings. Rees and Bath (2000) concluded that the needs of women changed as time passed after diagnosis, and with treatment-related events. Their review reported that family members had a great need for information and that verbal information around the time of diagnosis was most helpful. Within the review, individual studies found that information was essential for decision-making, helping women cope with their illness and treatments, and reducing anxiety and distress.

The need for participants in this study to know more about their illness and recovery became apparent very early during the interview process. Participants asked questions about clinical aspects of the disease and treatment, and the long-term effects of both, which I felt professionally and morally bound to answer, especially when there were glaring gaps in participant knowledge. Participants gladly accepted information and seized an opportunity to learn more about what they had been experiencing and living through. There was a variation in the need for knowledge amongst participants’. This reflected some of the factors that were reported by Bergsma (1997, 21) such as ‘their upbringing, life experiences, education, occupation, attitude, one’s temporary mood or actual situation and the presence or absence of a deliberate decision’. Some of these factors are evidenced in participant dialogue presented in the body of this theme.

Not all participants in this study felt they were left wanting for information. One participant had very positive feelings about the information he had received, as demonstrated by his response to the following question.

Researcher: Were there times when you wanted to know things but you couldn’t get Information or get questions answered?

Participant: Apart from finding out the cause [of the cancer], that was the only question I didn’t have answers for. I didn’t have any real long conversations with [the surgeon] but I did with Dr XX. She was the main one.
Researcher: So she was very supportive?

Participant: Oh yes, she was well qualified and all questions were answered.

4.6.3 Information and decision making

Information assists patients to make decisions, and for the participants in this study one of the big decisions they had to contemplate was whether to have their lung removed or not. They needed to be informed about the risks related to the surgery and the anaesthetic before they could give consent for the surgery. Information provided by the surgeon enabled them to understand their dilemma. While patients rarely decline the offer of surgery when faced with the alternative — losing their life, they still seek information and are happy to leave the final decision about their treatment to the surgeon. The following statement from a participant makes this point obvious.

As far as I was concerned I had to have the operation, that was it. That’s how I looked at it. [pause] No matter how hard it was going to be.

There were no medico-legal issues raised by any participants in this study, but, one participant made it clear that he felt very disappointed and angry about his physical recovery from the surgery. He questioned the decision to have his lung removed. He recalled that his concern was discussed with him prior to the surgery, but he took the opportunity to raise his concerns again during the interview because his quality of life since the surgery had been so poor. He said:

It was explained to me by the specialist that it [the lung] would be just taken out. He just said, “That’s the treatment”, because .....I asked him that question before we went [to surgery] and I said to him, “Look, I think I will get a second opinion. I want you to know this now, that if there is a better treatment in America or something, or there’s something that you don’t do here [but they do there] I want to know about it. I don’t want to lose my lung if I can avoid it, and if I can live four or five years and have quality of life that’s fine. I’ll take that rather than...” I’m an invalid, I remember that, and look now what I am.

Sometimes patients preparing for lung cancer surgery give consent for the operation even
when they do not know what the final outcome of the surgery will be. This was the case for Audrey. She and her partner were given all available information, but she went into the surgery not knowing if the surgeon would be able to perform a curative operation. Audrey was very much aware that if the surgery were to be successful a complete lung would be removed, but she had to wait until she had woken from the anaesthetic to know if this had been possible. This is a common situation for patients facing life-saving lung cancer surgery despite the availability and utilisation of modern diagnostic equipment. Audrey and her partner explain their feeling of not knowing.

**Audrey:** *The thing I think, what worried us, what really worried us more than anything, was when we went to see Dr Z. He did say to me, he said, “Look, we don’t know whether we can take the lung, um, and it is up to you, if you want to have the operation. We don’t know if he can save you... and tell you how fast it’s growing and how long you have got.”*

**Partner:** *And [the surgeon] said the same virtually didn’t he. He couldn’t be sure if he could operate, and he wouldn’t know until he got into the chest to see what was going on in there.*

Keys (1985) vividly recalled her experience of not having information and not knowing what to expect after her pneumonectomy. She said, ‘There could have been many reasons why I had to go into the operation without really knowing what to expect and one of them could have been that all the staff were so very busy... Another reason could have been that all the people I was asking had two good lungs and were obviously hoping to keep it that way. Their theoretical knowledge may have been exhaustive but their actual experience of what it felt like was zilch. Whatever the reasons, none of us patients was told much and the whole ward leaned heavily on astrological predictions and clutching at straws’ (142). Her comment suggested that care centered on the technical and theoretical aspects of the surgery and her recovery in intensive care in order to get her safely through the operation and out of hospital. She said, ‘Two and a half weeks after the operation I was discharged. There was not a lot of advice, just “keep warm and walk about a lot”’ (Key 1985, 143). There were no information sharing activities that might have enabled her to know what to expect when she was discharged. Her comments are not dissimilar to some of the comments made by participants in this study. Quite simply, Keys, and the participants in this study, wanted to
know more about what to expect of their recovery. We hope that patients having this surgery in the 21st century will not suffer the same experience of not knowing.

4.6.4 Information making sense

Patients need information to help them understand what is happening to them, and to make sense of any symptoms or feeling they have, because knowing reduces anxiety (Salmon, 2000, 174-5).

Karen knew that she would need a lung operation before she visited the surgeon but had no idea that the surgery would involve removing a complete lung. This was her reaction to the information.

_When I was told I was going to lose a lung I fainted. [The surgeon] was quite shocked that I would have such a reaction, but I had no idea that that was going to happen to me until [the surgeon] said, “Oh, I am just going to take out the left lung”, as if to say, “I'll just remove that mole,” you know. I fainted. I felt oh, this is just bizarre._

Karen talked about how information was important to her after the surgery. She made particular reference to the information that her medical respiratory specialist provided progressively over a number of visits as if he was sheltering or protecting her. His progressive sharing of information helped her make sense of the sensations she had been feeling and she was most grateful for that.

_Dr Z was quite good. I think he was very sensitive to the fact that he didn’t want to scare me to begin with or alarm me. There were things he didn’t tell me straight away. He waited. He kept calling me back. When I had finished, when I had the operation I felt quite well.... Dr Z kept saying, “Come back.” ....I only went to see him because I thought he was probably doing some history case. But one time I went back and he said, “You know your diaphragm is going to shrink right up there”. I said, “What! I won’t be able to sing any more.” He said, “You’ll be right, you’ll adapt.” The next time I went back he said, “Your rib cage is going to start sticking out a little bit, it’ll stick out a little at the back.” I said, “Oh! I didn’t know that, I don’t want to look deformed.” Actually it is protruding a little ...so little things like that he told me bit by bit...it didn’t upset me._

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She also commented about her limited access to people who could relate to or understand her experience, and how this made her feel isolated.

*I felt quite alone, because there weren’t any [doctors]. There were no doctors in the area that had handled a pneumonectomy case. I had a few questions which I felt were quite stupid questions so I didn’t ring [the surgeon], I thought he’s a busy man so I won’t ring him.*

Not knowing what to expect in the course of recovery, especially after being discharged from hospital, challenged some of the participants in this study group. Some participants were unable to distinguish if what they were feeling was normal or abnormal. If they had had access to information to answer their concerns they might have been relieved of an enormous amount of stress and worry. The following statements confirm how access to information might have made a difference to the stress levels of some participants.

*Partner …like with all her stressing. She does stress a lot and if [she] gets a little pain here [or if] something is happening here she’d be thinking, “Oh, I’ve got it back,” and “Oh, is this supposed to happen? They never told me about this.” and really her stress level was very high a lot of the time, because she didn’t know what was happening. If someone had said, “Yes, you will get that pain” or “Yes, that will happen to you, that’s all part of the operation,” then that would have helped her a lot.*

Another participant commented:

*And that’s another thing, I reckon everyone when they have [this operation], there is not enough information. When you come out of the surgery they all ask, “Are you OK.” There is just not enough information, like that bubble thing [bubbling in his chest]. That worried me because I thought every ache and pain was a problem.*

Nathan took the opportunity to ask a question about lung transplantation. This helped him to assess his health situation from another perspective.
Nathan: If the other lung, if I were to get it [cancer] in the other lung, why couldn’t they do a lung replacement?

Researcher: Because you have had cancer and the cancer has already spread from that lung to the remaining lung ...

Nathan: Well!! [silence]

Researcher: If you have a history of cancer you are excluded [from transplant chances] because of the risk of the cancer recurring.

Nathan: ... Yeah, OK, so I really have to look after this one, my remaining lung.

Louise had little knowledge about how and why she should use the puffers that were prescribed for her some months following her surgery. Her language difficulties, the absence of family, social and professional support, and financial status may have contributed to her situation. She said:

Louise: ...and when my good lung [was] only working for one third. [Lung function tests showed her remaining lung to be functioning at one third of its capacity].

Researcher: Did Dr Z do your breathing test?

Louise: Yeah, and let’s say it was on the paperwork, and then every three months when I came [to see him] it was little bit more [worse]. The last time it was not even one half of what it was after that thing [testing], and then he [the doctor] said, “That’s impossible”, then he started talking about [a] spray. The nose spray I stopped using. The inhaler I did not keep using, but nobody told me that I should do that for the rest of my life.

Louise: You know ...in the beginning there were four things I needed from the chemist. I had no money for [them] ...I only had one lung left and I did not connect the things together. [The need for sprays to help improve the remaining lung function.] I did not use them anymore and I was really going downhill. I could not even walk from here [her home] to the car park.
Nathan wanted to know if he was managing or progressing in recovery at the same rate as other pneumonectomy patients. Being able to compare his progress with another patient was important to him. He asked:

*How much different am I to others?*

Understanding the information was vital as Michael and his wife realised.

**Michael:** *When I saw him [Dr ZZ] last for my annual checkup, my records were out and he looked at them and said, “Three years, you’ve done well”. I thought, “What the hell, is there a time limit on this?”*

**Wife:** “You should have asked him [what he meant]?”

**Michael:** *I should have but he stunned me a bit. In the meantime I saw a doctor at the hospital when I had my arm…. and something came up and he said how long is it since you had the operation and I told him. He said, “Oh, you’ve done well”. I started to think to myself, you know, I’m not supposed to be here, so I asked my doctor, I can talk to him, and I asked him.*

**Wife** *You didn’t ask him! You mentioned how a couple of people had said how well you had done and he said, “Well it’s five years”, so we assumed the worst.*

**Michael:** *I just closed up actually.*

**Researcher:** *So you thought come five years, now I’m gone!*

**Michael:** *That’s right, so what I have now is bonus time.*

Michael and his wife did not understand the meaning of the “five year” surveillance period and he was afraid to ask the doctor what the jargon meant. I corrected this knowledge gap at the time of the interview.

The importance of knowing more has already been raised in a previous theme related to support. Participants felt strongly that they would have benefited from having contact with another person who had lived the experience of losing a lung.

I want to conclude this theme by using participants’ comments that came from their review of the study findings for this theme. While their reflections on their knowing, or not
knowing, took place some years after their interview, they commented on how valuable the
information that they had received at the time of the surgery was to them. They also
commented on how often they lacked information. They saw information as a key to a
better recovery and they expressed their need for information in these statements:

*Personally, I would have liked more information. Nursing staff were not able to answer my
questions to my satisfaction, and yes, I felt isolated.*

*I tended to latch on to statements made by medical staff, for example, “A New Zealand
Davis Cup player only had one lung,” and “You won’t be entering the City-to-Surf again.”*

This participant translated this statement into a meaningful understanding of his future lifestyle.

*Although I was told about the post–operative phase I could have done with more
information about the recovery stage. I remember being told about a man who was playing
tennis... It inspired me to dream of playing netball when I recovered. I achieved this, one
year post-op.*

4.6.5 Conclusion

The study participants wished that they had known more about the operation, what their
hospital stay would be like, and what they would feel and experience during their
hospitalisation and recovery. Furthermore, they wished they had known more about what to
expect of their future in terms of returning to “normal” living and family life. They were
very interested in what other patients had experienced and how they had managed their
recovery. Their desires and wishes echoed those of participants in the studies conducted by

The study highlighted that patients who have lung cancer surgery have very individual
needs, but a common need of these patients is a need to know more about the physical and
emotional aspects of their surgery. This need can be met when appropriate and timely
information is made available to them. The experience of Armstrong (2000) bears this out
in his words, ‘But knowledge was more reassuring than ignorance: at least I knew what I
was dealing with, or thought I did anyway’ (92).
CHAPTER 5 SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Summary of the study

The purpose of this research was to study the phenomenon of recovery after pneumonectomy. The study did this by exploring the individual experiences of recovery of nine patients spanning a two-year period that began at the time of their surgery. I wanted to gain a fuller understanding of the effects of pneumonectomy for lung cancer on the physical, social and lifestyle activities of previously healthy, employed family people. My intention was to share the new knowledge gained with those for whom this knowledge could make a difference to what they do — professionals who prepare and care for patients having this surgery, and new patients and families preparing to embark on a similar surgical journey.

I realized there was a need for this study when I struggled as a case manager to find appropriate answers to the questions that patients asked in relation to the health and lifestyle issues that they might encounter as a result of their surgical experience. I drew from the knowledge that I had gained during my past surgical nursing experiences, and I searched numerous literature sources but I was unable to find relevant information on which to formulate responses to the specific questions patients asked. During this study, I searched the literature regularly but only found one article reporting a personal experience of losing a complete lung (Key, 1985). Key made it clear that her experience of recovering from pneumonectomy was complex, difficult, and involved hard work on her part. She identified how her ignorance of what to expect, and the absence of information provided by professionals about what she should expect, contributed to her overall challenging experience of recovery.

The absence of experiential information about the phenomenon of recovery from pneumonectomy, and my passion to be more effective in my role as case manager became the driving force of this study. I wanted the study to stimulate health professionals into thinking about their clinical practice so that their practice would reflect a deeper understanding of human experience and its meaning.

I chose interpretive phenomenology according to van Manen (1990), a human science research methodology to guide my study because I was interested in human experiences,
and a human science research method would enable the meaning of the human experience and expression to be revealed.

I had the privilege of gaining rich data for this study through the use of open ended interviews as the method of data collection. This enabled me to enter the private and personal world of each participant. Participants openly talked about their experience of recovery. They were keen for their stories to be brought out in the open through language so that other patients and professionals might be better equipped in the future, to assist people with their experiences. I realized the value of my data as I was interpreting each transcribed interview conversation - participants disclosed very personal information to me.

The use of van Manen’s approach helped make the differences between all participants’ experiences stand out, have meaning, and be significantly important, instead of the experience being recorded solely as empirical information (van Manen 1990, 23). Furthermore, it enabled a phenomenological description of patient experiences to be heard so that readers might “see” something to enrich their understanding of everyday life (Van der Zalm, 2000). It also provided a foundation and structure from which to explore the phenomenon of interest.

The process of phenomenological reflection (van Manen, 1990) was an essential step in interpreting the data in order for me to gain a phenomenological understanding of each participant’s unique experience. Phenomenological reflection allowed meaning of the experiences to emerge, such that I uncovered six thematic phrases. Six themes of phenomenological knowledge specific to patient experiences of recovery after pneumonectomy for lung cancer.

5.2 Summary of the findings

Participants in this study talked freely about living the discomforts of treatment and recovery. Discomforts such as pain, space sensations, space infection, fear of drug addiction that were often an individual participant’s experience rather than a common experience of the collected study group. Such discomforts were few given the magnitude of the surgical procedure. One important message to arise from this is that clinicians need to listen to patients and obtain a good description of their discomforts in order to plan how they, as
practitioners, can turn discomfort into comfort.

*Discovering new functional and emotional limitations* that restricted the things (usually physical activities) that participants used to do and/or enjoy before their surgery impacted on their physical, social, and lifestyle activities, but limitations were mostly accommodated by participants making lifestyle adjustments. Some participants accepted their limitations with difficulty, but most participants “got on” with living their lives within the bounds of their physical and emotional limitations. Three participants found their limitations disabling and problematic. The overall impact of functional and emotional limitations on recovery after pneumonectomy resulted in “completeness of recovery” ranging from complete to incomplete.

The return to work experience of participants revealed that all felt that “*my financial security is threatened*” because returning to work amounted to financial security, social freedom, and maintaining a lifestyle that preceded surgery. The financial security of all participants in this study came under threat. For some the threat was just a threat, but for other participants the threat became reality when they were unable to return to their pre-surgical work or to any work at all. In this study, the likelihood of participants returning to their pre-surgical work was determined by the nature and the type of work that they were expected to perform. Participants whose work involved heavy, physically demanding, manual labour had difficulty performing this work. Their inability to return to this work had a substantial impact on their emotional “being” and financial status. Uncovering this theme has influenced my clinical practice in preparing patients for this surgery. For patients who are employed, returning to work and retaining financial security is part of surviving lung cancer but ‘the burden of a cancer diagnosis does not end when treatment is complete (Meadows, cited in Ott 1997, 24).

The theme *My reliance on support* identified how important professional, family, and social support was to participants in the study and it reinforced the fact that support helps patients and protects them from the challenges of their environment (Salmon, 2000). Participants relied heavily on support from health professionals, and in particular doctors despite their focus of attention being primarily on objective clinically based information, aimed at helping them make a physical recovery. They voiced strong feelings about how support from partners and family helped them through their recovery, and they were very interested
to know about the experiences of past patients. Participants believed knowing how other patients had managed after pneumonectomy would be beneficial to their recovery.

Participants voiced through the study a feeling of *my survival is at threat*. Their fear of cancer recurrence was commonly reported, but the level of their fearfulness diminished as their recovery progressed. The fear experiences expressed by this study are similar to the experiences of other cancer patients reported in the literature. Slowly, participant fear was overtaken by hope—hope to live and survive and see their families grow. Participants reported a reluctance by doctors to use the word “cure” during follow-up consultations and this contributed to their feelings of uncertainty about their future. This theme reinforces the fact that recovery after pneumonectomy is a slow and progressive process, for which facing and dealing with the fears and uncertainties about one’s life plays a prominent role. If nurses and other professionals can realise and understand this phenomenon, then their experiential learning and clinical expertise will be enhanced.

Underpinning all of the above themes was an overall participant feeling of *I wish I had known more*. While participants were not adversely critical about their not knowing more about the operation, their hospital stay and recovery, they were keenly interested to hear what other patients had experienced, and how they had managed during their recovery period. Information was what they needed but unfortunately, information other than scientific clinical information was not available. This study highlighted the value of access to specific information, emphasised the crucial role of information in informed decision making, and reinforced that information helps patients make sense of the things they experience.

5.3 Limitations of the study

The study, like that conducted by Lindsey (1996), explored the experiences of only a small group of people therefore the findings are not representative of all people experiencing the operation pneumonectomy, and should be interpreted with caution. Readers should be mindful that many patients live the experience of pneumonectomy and recover to live full and active lives. While some of the reported experiences of participants might seem exaggerated, I remind readers of McCaffreys (1972) definition of pain, (cited in Thomas 1997, 21), ‘Pain is what the experiencing person says it is and it exists whenever he says it
does’. Recovery, like pain, is what the experiencing person says it is. How people perceive their recovery depends on physical, psychological and social factors. Not all patients have a positive attitude to life and a high level of fitness to return to, but they are grateful for any opportunity to regain their lives by surviving lung cancer. This study highlighted how very different patient experiences can be, consequently, the study has a number of implications for patient care, clinical practice, education, and research.

5.4 Implications for patient care

There has been a growing interest in the needs of patients following thoracic surgery (Galloway et al., 1993; Goodman, 2000) and this study adds to this knowledge base. Gaining knowledge from this study have wide-ranging implications, not only for nurses and other professionals working in hospitals but also for community nurses, local doctors, respiratory physicians, surgeons, physiotherapists, and patients themselves. It illuminates the fact that recovery after pneumonectomy is not just a simple process of getting over an operation, getting back to work and, and getting back to a “normal” lifestyle.

Recovery is a complex process of overcoming challenges, obstacles and hurdles related to living with the discomforts of treatment and recovery, making lifestyle adjustments to accommodate newly discovered physical and emotional limitations, and accepting support from various sources. It involves facing threats to one’s financial security and dealing with momentous uncertainties about survival. Furthermore, these challenges have taken place in the past with little understanding of how and why the physical and emotional body has behaved as it has. Once a phenomenological perspective of the information gained from this study is understood, the meaning of the experience of recovery, as it is lived as the everyday existence in the participant’s ‘lifeworld’ (van Manen 1990, 11) will become obvious to professionals and carers. Patient care and in particular nursing practice can then reflect a sensitive awareness and understanding of the phenomena that patients experience—phenomena that indicate that recovering from pneumonectomy is hard work.

5.5 Implications for clinical practice: in nursing and other fields

Opportunities to change or improve clinical practice in the acute setting arise mostly from preventing, controlling, and managing symptoms such as pain, nausea and vomiting, and
constipation. The findings from this study imply that there is an additional need, a need for practitioners to take advantage of opportunities for sharing information with patients: information about the sequence of events that patients will experience during hospitalisation and recovery, sensations they will experience and feel, and the physical and physiological changes that will take place in their body. Patients want information about how pneumonectomy might affect their life and living as they recover.

Opportunities to implement change to clinical practice in the non-acute setting also focus on access to specialised information. At present, access to specialised information is limited. In my practice, it is mainly available through the case manager via a written information sheet and the telephone, but other avenues of access, such as via computer technology, are being explored.

5.6 Implications for patient and nursing education

This study explored the experiences of only a few people recovering from pneumonectomy but it identified very clearly that there were major gaps in the knowledge of patients and also of professional carers. In order to fill these gaps the valuable information uncovered by the study needs to be disseminated to the appropriate people in a format that is easily read and understood. An initial method of information dissemination has been through a patient information leaflet titled “Life after Pneumonectomy.” This leaflet was produced from information gained from participants in this study and from my ongoing clinical practice and. It is provided to patients and discussed with them prior to their discharge from hospital. Additional copies are available for interested family members and local medical officers.

The need for information and education to assist recovery was voiced by a number of participants in this study by their strong desire to meet with a person who had been through a similar experience. After much careful consideration, study participants were invited to an informal luncheon to meet each other. Five participants attended, three with their partners and they chattered furiously for around two hours about their experiences. This meeting prompted me to explore further the logistics of forming a support network for people recovering from pneumonectomy and living with one lung. The participants in the study believed that they had HAD lung cancer, but did not have lung cancer, and so wanted reinforcement of that fact through education and information.
5.7 Implications for research: in nursing and other fields

The implications of the findings of this study on nursing and other research is endless because the beginning information presented in each theme raises new questions such as why do patients still experience unrelieved post-operative pain despite complex scientific pain management information being available?

The impact of a reduced respiratory reserve on opportunities to return to work, and on the lifestyles of patients after pneumonectomy, deserves and requires further inquiry because shortness of breath impinges on people’s everyday life activities, mobility, motivation, sexual function and their enjoyment of social and leisure activities. A project investigating the role of pulmonary rehabilitation as a means to maximizing respiratory function of the remaining lung is currently being conducted.

The issue of “Quality of life” after pneumonectomy has only briefly been touched on in this study and in other studies, so there remains a domain of inquiry begging exploration.

5.8 Conclusion

This study has enabled the voices of the bodies who have lived through, and are still living through the experience of illness, surgery, and recovery from pneumonectomy to be heard. Therefore, the aims of this study — to improve patient care, improve patient outcomes following pneumonectomy, to contribute to the body of nursing knowledge, and to strengthen nursing practice, will have been met once the information gained from this study has been appropriately disseminated. It is hoped that health professionals will hear what has been said, and use the information to better prepare other patients for their surgical and life experience.

Jenny and Logan (1996) used the words patient work to convey how a group of patients found it was “hard work” managing emotions, keeping positive, and doing the physical work that was required (breathing) for recovery, always knowing that death was a possible outcome. Patients in the study also found recovery after pneumonectomy to be a slow and gradual process, a process involving feelings such as relief, happiness, fear, horror, anger,
frustration, impatience, sadness, uncertainty. The words *hard work* describe this process. They also describe the phenomena uncovered by this study.
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APPENDIX A: Information for Participants

RESEARCH STUDY INTO RECOVERY FOLLOWING PNEUMONECTOMY: PATIENTS’ INITIAL 2 YEAR EXPERIENCE

INFORMATION FOR PARTICIPANTS

You are invited to take part in a research study into recovery following pneumonectomy. The objective is to investigate your experience so that other patients can be better prepared for their experience. The study is being conducted by Jocelyn McLean, Case Manager for Thoracic Surgery, for a Masters Degree in Nursing by Research under the supervision of Jennifer Blundell and Professor Jocalyn Lawler, Senior Lecturers from the University of Sydney.

If you agree to participate in this study, an interview will be arranged at a location suitable to you. The interview will be informal in that you will be able to talk about any topic that affected your recovery. Clarification of your comments may be necessary and questions about topics you did not discuss may be asked. The interview should take between 1 and 2 hours. It will be audio-taped. At the completion of the taping the conversation will be typed and then the tape destroyed. The interview can be with you alone or if you wish another family member can be present. The interview is not expected to cause harm but we appreciate some sensitive issues may be discussed. The interview will be suspended or stopped if you find the issues you talk about distressing.

All aspects of the study, including results will be strictly confidential and only the investigators named above will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Participation in the study is entirely voluntary; you are in no way obliged to participate and if you do participate you can withdraw at any time. Whatever your decision, please be assured that it will not affect your medical treatment or relationship with medical staff.

When you have read this information, Jocelyn McLean will discuss it with you further and answer any questions you have. If you would like to know more at any stage, please feel free to contact either Jocelyn McLean, Case Manager on (02) 9515 6111 pager 30356 or Jenny Blundell on (02) 9351 0525 or Professor Jocalyn Lawler on (02) 9351 0599. At the completion of discussions you will be invited to participate in the study. You must confirm your acceptance by reading and then signing the consent form.

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Central Sydney Area Health Service. Any person with concerns or complaints about the conduct of a research study can contact the Secretary of the Ethics Review Committee (RPAH Zone) on (012) 9515 6766.

This information is for you to keep.
APPENDIX B: Interview questions

RESEARCH STUDY INTO RECOVERY FOLLOWING PNEUMONECTOMY: PATIENTS’ INITIAL 2 YEAR EXPERIENCE

INTERVIEW QUESTIONS

Background Information

What does the loss of a lung (pneumonectomy) as a cure for lung cancer mean to the person experiencing recovery from this surgery? In particular, how does it affect the life and family of the young, employed ex-smoker?

1 Tell me about your recovery from your lung cancer.

   It is expected that the following issues may be discussed:

   - Breathlessness,
   - Appetite,
   - Lack of motivation, pain,
   - Constipation,
   - Fears related to cancer recurrence and not being cured,
   - Fear of death,
   - Returning to work,
   - Sport and leisure,
   - Relationships.

2 How has your life been affected by this experience / what does this mean to you?

3 What is important to you now that was not important to you before the Surgery?

4 What would you like to have known that we did not tell you?
APPENDIX C: Participant Consent Form.

RESEARCH STUDY INTO RECOVERY FOLLOWING PNEUMONECTOMY: PATIENTS’ INITIAL 2 YEAR EXPERIENCE

PARTICIPANT CONSENT FORM

I, ______________________________________________________ of

(address) ___________________________________________ have read
and understood the Information for Participants on the above named
research study and have discussed the study with _________________

I am aware of the procedures involved in the study, including any
inconvenience, risk, discomfort or side effects and their implications.
I freely choose to participate in this research study and understand that I can
withdraw at any time.

I also understand that the research study is strictly confidential.
I hereby agree to participate in this research study.

NAME         _______________________________

SIGNATURE   ________ _______________________

DATE    ________ _______________________

NAME OF WITNESS  ____ ___________________________

SIGNATURE OF WITNESS ____ ___________________________
APPENDIX D: Letter to Local Medical Officer

CENTRAL SYDNEY AREA HEALTH SERVICE
CARDIOTHORACIC UNIT, ROYAL PRINCE ALFRED HOSPITAL

RESEARCH STUDY INTO RECOVERY FOLLOWING PNEUMONECTOMY:
PATIENTS’ INITIAL 2 YEAR EXPERIENCE

<Patients name>, who had a pneumonectomy at <hospital> on <date> was according to
our data-base free of disease as at <date>.
I.e. there were no clinical or radiological signs of recurrent or metastatic disease.

Please would you confirm this information by completing the following information and
then return it to me in the enclosed envelope or fax to the number below.

Last seen: ……/……/……

Last date with no recurrent or metastatic disease ……/……/……

If recurrent or metastatic disease is present, then please indicate the

(1) Site ………………………….

(2) Date it was diagnosed…../…../…

If the patient is no longer alive, please indicate the cause of and date of death

(a) Cancer related death Y / N

(b) Cause other than cancer Y / N

(c) Date of death if known ……/……/……

Signed : DOCTOR <name>

…………………………….               DATE ……./……/…..

RETURN MAILING ADDRESS

FAX     (02) 9550 6669
PHONE   (02) 9550 1933

Jocelyn McLean
C/- Specialist Surgeon Rooms
304 / 100 Carillon Ave., Newtown, NSW 2042
APPENDIX E: Letter of Introduction to Potential Participants

CENTRAL SYDNEY AREA HEALTH SERVICE
CARDIOTHORACIC UNIT, ROYAL PRINCE ALFRED HOSPITAL

Contact person: Professor BC McCaughan, Director of Thoracic Services, phone (02) 9550 1933

<Patients name> <Date>
<Address>
<Town>
<State> <Post code>

Dear <Mr / Mrs> <Name>

My name is Jocelyn McLean. I am a nurse who works with patients who have lung surgery within the Central Sydney Area Health Service. I am also a student at the University of Sydney working towards a Masters Degree in Nursing by Research. My research project is to explore the experience of people who have recovered from lung surgery and specifically to explore the experience of people who had a pneumonectomy (a complete lung removed) hence this communication. I would like to invite you to participate in the study.

Enclosed for you is an information sheet. This sheet provides details about the purpose of the study, how you would be involved, names and telephone numbers of people you may wish to contact for more information and a statement indicating the study has been approved by the University of Sydney and Central Sydney Area Health Service Ethics Committee. Also enclosed is a consent form for you to sign if you wish to participate and the interview questions. The interview questions will be very open. You will be able to say what you like about any topic that influenced your recovery.

Please read the enclosed information, and if you wish to participate please contact me on (02) 9515 6111 and ask the switch people to page Jocelyn McLean. Alternately, you can call (02) 9550 1933, <surgeons name> rooms and ask the staff to contact me or you may wish to complete the consent form and mail it to me at which time I will then contact you. Thank you for taking the time to read this letter.

Yours sincerely,
Jocelyn McLean.
APPENDIX F: The Revised American Joint Committee for Cancer Staging System

T = TUMOUR STAGES

T1  Tumour <  (3cm) 30mm diameter in lung tissue only
T1  Tumour in subsegmental or segmental bronchus or lobar bronchus
T2  Tumour > (3 cm) 30 mm diameter in lung tissue only
T2  Tumour any size invading visceral pleura
T2  Tumour in main bronchus at least (2cm) 20mm from carina
T3  Tumour any size that has direct extension into Chest wall
T3  Superior sulcus tumour having direct extra-pulmonary extension
T3  Tumour involving diaphragm, mediastinal pleura, pericardium without
   Involvement of the heart, great vessels, trachea, oesophagus or
   vertebral bodies.
T3  Tumour in main bronchus < 20 mm (2 cm) from carina
T4  Tumour involving mediastinal structures.
T4  Presence of malignant pleural structures (blood stained or exudate or
    cytology positive).

N = LYMPH NODE STAGE

N0  No demonstrable metastasis to regional lymph node
N1  Interlobar and peribronchial lymph nodes
N1  Ipselateral hilar lymph nodes (including direct extension)
N2  Ipselateral mediastinal lymph nodes,
N2  Sub carinal lymph nodes
N3  Contra lateral mediastinal supraclavicular scalene nodes

M = METASTASES

M0  No distant metastatsis
M1  Distant metastasis

6  OVERALL TNM STAGE

| Stage 1 | A  | T1 | N0 | M0 |
|         | B  | T2 | N0 | M0 |
| Stage 2 | A  | T1 | N1 | M0 |
|         | B  | T2 | N1 | M0 |
|         |    | T3 | N0 | M0 |
| Stage 3 | A  | T3 | N1 | M0 |
|         | B  | T1-2| N2 | M0 |
|         |    | T4 and/or N3 | M0 |
| Stage 4 | anyT | anyN | M1 |
APPENDIX G: Letter to participants re themes and content

CENTRAL SYDNEY AREA HEALTH SERVICE
CARDIOTHORACIC UNIT, ROYAL PRINCE ALFRED HOSPITAL

RESEARCH STUDY INTO RECOVERY FOLLOWING PNEUMONECTOMY:
PATIENTS’ INITIAL 2 YEAR EXPERIENCE

Dear

This letter is to provide you with an update of the above study and to invite you to assist me with verifying the findings of the study. I am now at the difficult stage of having to interpret and discuss the results of the thousands of words you good people gave me, and then put these results on paper in a meaningful and skillful manner to produce a thesis. My problem is that writing is not my forte, talking is! The thesis will be completed and submitted for marking by the University of Sydney by the end of June 2002.

The information I gained from the interviews you gave me has been most valuable. Despite there being a time lag from the interview to this stage of the study, the overall information I collected has been regularly shared with other patients facing or going through the same experience of recovery after removal of a complete lung. This study made me very aware of how difficult the journey was for most of the participants and I now try to make this awareness visible in my day to day nursing practice. The interviews revealed that the operation had a major impact on the lives of all of the study participants. Some of the participants got their lives back to ‘normal’ within a reasonable period of time but others found their lives very disrupted. Some participants might say they never recovered. Thank you for your openness and honesty when I interviewed you.

At the completion of the interviews I transcribed the tapes, word for word, (an arduous task to the untrained typist) into a computer file. I then highlighted key words and phrases that pointed to an overall feeling about an issue from the many statements of each interview. I then thought about the true meaning of these words and phrases and grouped them into six common themes related to recovery after pneumonectomy. The six themes are: living the discomforts of treatment and recovery, living with a different body and altered priorities, my survival is at threat, my financial security is threatened, reliance on supportive mechanisms, and I wish I had known more.

I am inviting you to read and comment if you wish on these themes, as this will assist me to verify my findings. The themes are summarised on the following page(s). They also contain a brief description of issues raised under each theme title. Please keep in mind when reading and commenting on these themes and descriptions that you may not have experienced every topic raised.

Thank you in anticipation of your ongoing help. Please call me if you need clarification of any of the enclosed papers. I can be contacted on (02) 9550 1933 daytime or in the evenings on (02) 9799 9337.

Kind regards
Jocelyn McLean
APPENDIX G ctd.

RECOVERY FOLLOWING PNEUMONECTOMY: PATIENTS’ INITIAL 2 YEAR EXPERIENCE

Following are the six themes that were common to the participants in this study. Each theme is named and then a summary of issues raised under that theme is presented. Do keep in mind that some participants did not talk about issues that others raised and some focussed on one issue more than another, therefore not every participant had an experience related to every issue mentioned in the summary.

Please read each theme and description. After reading, please ask yourself the following question: does this theme reflect my experience of recovery after pneumonectomy? Make any comments you wish in the space provided and send it to me in the enclosed return addressed envelope. If you agree with the overall theme and do not wish to comment then please just say so in the comments section and return the sheets in the enclosed envelope.

1. Living the discomforts of treatment and recovery

This theme addresses the physical symptoms or discomforts that patients felt during their recovery. Some symptoms were experienced in hospital and others were felt after discharge. They commonly related to the actual procedure and associated tissue and nerve damage related to the operation.

Pain was the most common symptom reported. The nature, intensity, and duration of pain and how it was managed (or mismanaged) affected the comfort of participants. Some people had difficulty having their need for painkillers recognised and some had difficulty getting supplies of tablets. Epigastric discomfort and burping was noted, and nausea, vomiting and constipation induced by painkiller medications was a problem for some participants. Sensations of fluid in the vacant lung space and spontaneous drainage of the fluid from the space was a noted terrifying experience for some participants.

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2. **Living with a different body and altered priorities.**

This theme suggests that participants became aware that their body was different after the surgery and during their recovery. They had a reduced respiratory capacity and had to learn to live life around that reduced capacity. For some participants, this amounted to discovering new limitations to their physical function for which some were short term and others were permanent limitations. Participants did not only feel limitations but they had them imposed on them by family and others caring for them. Physical limitations transposed into emotional concerns and these had an impact on participants as a whole. For some, the result was a “changed person” setting new priorities.

Issues contributing to the above statements related often to physical fitness. Both lack of fitness and the presence of fitness had a major impact on leisure activities, sporting activities, social activities, and holidays and family life. It also had an emotional impact that affected sexual activity, levels of motivation, emotional highs and lows and a desire to appear, behave and be treated as a “normal” person. These issues provoked a need to look at life differently.

Comments: _________________________________________________________  
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________________________________________________________________________  
________________________________________________________________________

3. **My survival is at threat**

This theme recurred frequently throughout the interviews. People who undergo this surgical treatment for lung cancer are like all other cancer sufferers, in that they are constantly reminded their life is at threat. Cancer literature documents fully, the concerns of patients. There was an overwhelming fear that the cancer would return but there was also an overwhelming desire to survive the cancer. The chance to survive the cancer outweighed the risks of a major operation. Partners played an integral part in discussions, as they were fearful that their partner might die.

Comments: __________________________________________________________  
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4. **My financial security is threatened.**

The reality of losing a lung because of cancer materialised into concerns about being able to earn money and maintain a “comfortable” lifestyle. The significance of the concerns varied greatly amongst participants. Decisions about work issues that ultimately affected people’s financial security were suddenly confronting. Some participants were in a position that they could make decisions based on choices, while others had no “good” choices available. Options that participants took are tabled as follows. Early retirement with a retirement plan in place, a temporary change in pace until usual workplace activities could be resumed, a change in the type of work performed within an organisation, struggle on to maintain a highly successful business, redundancy and retirement with reliance on social security support. The need to have money and problems related to arranging ongoing financial assistance had a major impact on the emotions of a number of participants.

Comments: ______________________________________________________
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5. **Reliance on supportive mechanisms**

The need for support featured in all of the interviews and support was present in many forms. There was a partner/spouse or family person(s) constantly present to assist participants through their surgical experience and recovery. They provided steadfast support in the form of physical and verbal care and encouragement. Most participants viewed their medical teams as a vital support mechanism. They acknowledged the skills of the surgeon in particular but they also recognised the skills and knowledge of the other medical practitioners who provided care and support in the weeks or months leading up to the surgery and the many months after surgery. These qualities enabled participants to feel confident about the treatment they were receiving. There was an overwhelming feeling from interviewees that they would have gained support from a person(s) who had lived the experience of recovery following pneumonectomy. Unfortunately, this form of support was not present.

Comments: ______________________________________________________
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__________________________________________________________________
6.  I wish I had known more.

This theme arose because there seemed to be pockets of information and knowledge missing for most participants. More information about what to expect during recovery would have very beneficial to participants. There were occasions when medical staff lacked knowledge and were not able to answer questions, which left the patient feeling alone. The concept of measuring “cure” of lung cancer by the absence or presence of disease over a 5-year period caused some angst to a number of participants until it was explained to them.

Comments:__________________________________________________________________
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Thank you again for your assistance with this study.

Jocelyn McLean

The following space is provided for additional comments if needed.

Comments:__________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
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Five year survival data for surgically treated breast cancer and lung cancer.

The graph was kindly provided by the Lung Cancer Surgical Database, University of Sydney, NSW, 2002.