

# Pneumonectomy: what is it like to live with one lung?

Summary of Masters of Nursing Thesis titled:  
Recovery after pneumonectomy: patients' initial 2-year  
experience.

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## **INTRODUCTION**

Pneumonectomy is an operation where one lung is removed. In lung cancer, pneumonectomy is but one of a number of operations that provide the only chance of a cure. It is usually required when a patient has disease that is big and bulky or sits close to the centre of the chest. Living with one lung is relatively common in lung cancer patients.

The absence of literature made caring for pneumonectomy patients and answering their questions difficult. Only one article was found in the literature reporting a personal experience of losing a complete lung. Key (1985) experienced a complex and difficult recovery that involved hard work on her part. She acknowledged that 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.

The driving force behind this study was the absence of experiential information about the phenomenon of recovery after pneumonectomy and the need to be a more effective health professional. The goal of the study therefore, was to gain a fuller understanding of the effects of pneumonectomy on the physical, social and lifestyle activities of previously healthy, employed, family people and then to share this information with new patients and families preparing for a similar surgical journey.

## **METHODOLOGY**

Interpretive phenomenology according to van Manen (1990) was chosen for the study because this human science research method would enable the meaning of the human experience to be revealed. It combined descriptive and interpretive elements of phenomenology and also provided the foundation and structure for exploring the phenomenon of recovery after pneumonectomy. In this study, van Manen's approach helped make the differences between all participants' experiences stand out, have meaning, and be significantly important, instead of the experiences 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).

The individual experiences of nine patients who were free of disease 2 years after having a pneumonectomy for lung cancer were explored by open-ended interviews. Participants talked freely about their private and personal experiences — they were keen for their stories to be heard so that other patients and professionals might be better equipped to assist other patients in the future. The richness of the data became evident as the transcribed interview conversations were being interpreted.

The process of phenomenological reflection (van Manen, 1990), an essential step in interpreting the data, ensured a phenomenological understanding was gained from each participant's unique experience. Phenomenological reflection allowed the meaning of the experiences to emerge such that six thematic phrases were uncovered — six themes of phenomenological knowledge specific to patient experiences of recovery after

pneumonectomy for lung cancer. The six themes were:

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.

## **RESULTS**

### **1 LIVING THE DISCOMFORTS OF TREATMENT AND RECOVERY**

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; some were unpredicted and or unavoidable, while some might have been avoided had the professional care and attention been different. 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.

#### 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. The discomforts that participants in this study talked about were few considering the seriousness of the operation and they frequently arose from physical stimuli but were expressed in terms of physical and emotional discomfort. Post-operative pain was the most commonly identified discomfort but other discomforts were related to fluid space, epigastric symptoms, constipation, and hospital experiences.

#### Postoperative pain.

Pain has been a contention for surgical patients since operations have been performed and it remains a problem for patients following lung surgery. Effective management of pain is essential for optimal ventilation of the remaining lung — 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). Under-treatment of post-operative pain by nurses is also well documented (Carr 1990, 1997; Kroon, 1992). 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.

Pain management practice has been and remains based on the principal understanding of two pain experts. Mersky who 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) and Bonica (1983) cited by Kroon (1992) who 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).

A number of study participants’ experienced unrelieved pain early in their recovery period. A male participant said:

*I was given one morphine tablet twice a day [MS Contin] and quite frankly it just didn't control the pain... 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.*

One lady 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. She said:

*I was stressing wasn't I about coming home? .....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...*

Another male participant 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. ...*

Another lady said:

*I was really finished and I had to fight with every doctor at the cancer department at.... That man [the oncology specialist] said, "Every day you have some Panadeine Forte..." ..... But nobody wanted to give me 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.*

Hearing stories about patients struggling with pain relief leaves one with a feeling of emptiness because there is adequate evidence that it is more efficacious to prevent pain than to relieve pain (Eng and Sabanathan, 1993). Some participants endured avoidable unrelieved pain. Their expectation that professional care would relieve them of their suffering of pain was not fulfilled and they lost confidence and trust in their caregivers. The experiences as reported above were discordant with the knowledge and technology that was available to guide pain management practice. However, they did occur, perhaps because doctors and nurses failed to be attuned to the distress signals of patients and consequently failed to provide appropriate comfort measures to alleviate suffering (Morse, 2000).

#### 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 infrequently becomes a reality but very frequently hinders effective relief from pain for patients recovering from lung surgery. 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 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. One male had this experience:

*I stayed on Morphine from October to I think it was January and 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 ..... ..., yes it was a real change mentally.*

Partner: *He was so aggressive.*

Looking back at this dialogue 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.’

Ferrell (1991a) provides a succinct statement about the problem of postoperative 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, Colins and Willey 1995, 635). In practice, “using them,” means that professionals need to see and hear the pain discomfort signs of patients and then do something to relieve them. This is a basic function of human caring, not just part of the vital role of nursing.

#### 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 stabilize 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 postoperative care of patients after pneumonectomy is to minimize any risks of infection. A number of participants reported a sensation of fluid moving in their pneumonectomy space during the early days of their recovery. One fellow said:

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.

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 nowhere is there a patient’s account of an experience of space infection. This participant reported:

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.*

Participant *It was quite terrifying I can assure you. The smell was just appalling...*

Researcher *It was infected fluid in the space?*

Participant *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?*

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

Researcher: *So you actually felt the fluid inside moving?*

Participant *Yeah, it was really like a vault. In a bottle you know, that kind of feeling.*

This experience highlights the need for patients to have access to appropriate and timely supportive care once they are discharged from hospital.

### Epigastric symptoms

Two female participants described epigastric discomfort. Symptoms seem to occur later in the recovery of patients.

*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...but it is settling down.*

The second lady talked about her epigastric discomfort as a symptom that caused her great concern. While her English is poorly constructed, her message can be understood.

*...since the operation ... 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...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.*

## Constipation

A patient satisfaction survey found that constipation was the second most problematic symptom experienced by patients after thoracic surgery, while they were in hospital and at six weeks after surgery (McLean, 1995). 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 one lady verified that had been a problem.

*Constipation, yeah I got that from the Panadeine Forte, and I think because...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..*

## Hospital experience

Participants reported a variety of hospital experiences. One participant felt like a fraud:

*Yes. I felt a bit like a fraud, so sometimes I would think that maybe it [the tumour] was not cancer.*

Another said:

*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.*

One male experienced the consequence of a busy unit:

*They had me all ready. They had the hat and everything on and they took me up to theatre and.... Something went wrong ...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] .... So they done me the next day.*

## ***Summary of the study findings:***

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

## 2 DISCOVERING NEW LIMITATIONS ON MY SELF: FUNCTIONAL AND EMOTIONAL

A limitation is something, (usually a physical or emotional symptom) which restricts how a person does an activity that they could do before their illness or surgery. They can be short term or long-term symptoms and they can have a physical and or emotional origin. 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). Appropriate adjustments result in feelings of “living again” as opposed to feelings of “I want to abandon the struggle to live”. The limitations that most influenced the participants in this study had a physical origin or had a strong physical component and 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.

### Shortness of breath

It is expected that after a pneumonectomy all patient will experience shortness of breath especially on exertion because his or her oxygenating capacity has been reduced by at least a half. All patients’ will experience shortness of breath and most will experience a panic attack but all can live well by adapting their lifestyle. One young lady said:

*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.” ... Comments like that I wouldn’t really take to heart but I would feel a little bit annoyed.*

Increasing exercise and learning to modify the rate at which an activity is performed as this lady discovered could overcome breathlessness.

*...but I am doing netball now, sometimes it really kills me ... [she made a huffing and puffing noise] .... ...so this has given me the motivation to exercise so that I am OK on the court.*

Another participant adamantly rebuked the thought of attending a physiotherapy rehabilitation programme to help improve his respiratory function with this response:

*They would depress the shit out of me.*

### 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 it also affected the personal and family lives of some participants.

*My grand daughter, as she was getting older and heavier I couldn’t lift her.  
...Sometimes it’s a little bit frustrating because 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 on one participant who reluctantly admitted 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:

*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.*

### Social, leisure, and pleasure activities

Some participants needed to modify their social, leisure and pleasure activities:

*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.*

Holidays and family life underwent major modifications for some participants:

*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..... But as far as holidays are concerned I don't think I'd travel too well.*

Others managed travel without too many problems:

*We've been to WA, we've been to Melbourne, and we've been to Queensland.... Yes, the year I had the operation we went to WA..*

### Activities of daily living

Attending to personal hygiene is a basic activity of daily living that well people take for granted, but for some it is a new limitation that they struggle with tirelessly. The activity of showering and in particular washing hair can be a problem. One lady said:

*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.*

Patients begin to accept limitations to their mobility because of their reduced respiratory reserve, but find other people (the public) do not realize the significance of their limitation because outwardly there are 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].

### Sport and fitness

New physical limitations resulting from pneumonectomy prompted modifications and adaptations to physical activities like sport. One fellow 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.*

The impact of losing a lung was most notable when his overall fitness and stamina was put to the test. He said:

*A friend of mine cruises on.... 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?

*A bit. Yes, but again I think I try to put it in perspective, I am 54 [years old] now.*

Making lifestyle adjustments to accommodate physical limitations affected not only the participant but it also involved the family and friends as this 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.*

### The emotional impact of physical limitations

During the recovery time one male found his focus of life moved from a need for physical survival to one of emotional somberness. 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...*

## 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 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.*

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.

One male found his physical limitations manifest 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:

*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. ...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. ...But it’s a mental effort. ....*

*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...*

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...*

When physical limitations are enmeshed with emotional feelings, making modifications to one’s behaviour and lifestyle can be difficult. One male found the limitation of his 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:

*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 have a gym?

*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.*

### 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.

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

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 giggle of embarrassment].*

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.*

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 him being a failure. He told me:

*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 mail box, I can still walk around the block just as I can still perform sex but I can't perform I t[sex] with the energy and zest....*

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). 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.

### Quality of Life

The need to know how long one might live after having one lung removed is entwined in the issue of quality of life. Most participants were just happy to be alive and with their partner, spouse or family. One 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.

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 rationalize why he was like he was.

*... 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. ....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.*

Some eighteen months after the interview this participant conveyed these feelings:

*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).

#### The overall impact of physical and emotional limitations on recovery.

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.

#### ***Summary of the study findings:***

*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 were accommodated by participants making lifestyle adjustments. Some participants had difficulty accepting their limitations 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 ranged from complete recovery to incomplete recovery.

### 3 MY RELIANCE ON SUPPORT

Support is a valuable resource for the sick and recovering – it is a resource (material, emotional or social) that helps protect one from the challenges of their environment (Salmon, 2000). Participants identified that partners, family members, friends, and health professionals played a vital role in supporting them through their surgical journey and they identified situations where access to “better” support might have resulted in a different experience of recovery.

#### 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 judgment, 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).

#### 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 it varied among participants because individual domestic circumstances varied. One lady commented:

*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... ..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.*

When a person is well, activities of daily living are taken for granted. When a person is unwell, basic tasks become a major challenge. Family becomes very much involved with the ‘illness drama’ (Kleinman 1988, 182). One lady relied on the help and support of her daughter to get her through her struggles.

*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.*

For one participant the experience of pneumonectomy was a shared experience for which careful negotiation was required. His recovery was rough and his partner lived the challenges of that recovery with him. He was able to rationalize the situation and conclude that he was coping poorly but avoided confronting the real problem. His partner said:

*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 and it seems one copes by “bearing it”. Rollin (1976, cited in Dewar and Morse 1995, 957) asks, “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?”

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).

### Professional support

Patients measure the effectiveness or appropriateness of their support by the amount of stress they are subjected to while under professional care. Participants found support came from the local medical officers, respiratory physicians, surgeons, and nursing staff. One participant felt the professional support he received was impeccable and so voiced his confidence about the overall professional care that he received.

*I had a lot of confidence in him [the local doctor] um. He was a nice chap to talk to..., .... 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.*

Having access to a contact person would have been beneficial:

*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.

*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.*

Another participant commented:

*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.*

One male 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.

Another participant struggled to find the support he needed and believed the professionals failed him. 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.

*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. ... ..*

*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 f....*

Usherwood (1999, 27) said, 'We all know doctors who, while knowledgeable and technically competent, succeed in alienating their patients'.

### 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 by the brief time that patients spend in hospital, however, it is possible for nurses to make even brief relationships meaningful and supporting. 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).

There were occasions when nursing support was absent and or uncaring. One participant, a registered nurse said:

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

Another female reported that the nurse told her:

*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....*

These comments indicate that the ladies expected more “care” from the nurses and that there were no meaningful relationships established.

### Support groups

A number of participants made it very clear during their interview that support from another person who had experienced recovery after pneumonectomy would have been very beneficial. They felt that knowing what others had experienced and how they had managed recovery would have been helpful to them. Unlike patients recovering from mastectomy or living with emphysema, there is no formal support group for pneumonectomy patients. A number of participants offered to talk with new patients facing this surgical journey and their offer has since been taken up.

### ***Summary of the study findings:***

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 aiding their 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.

#### 4 MY FINANCIAL SECURITY IS THREATENED

Most people take for granted good health and a comfortable lifestyle but in the twenty-first century ones lifestyle is dependent on their capacity to earn money. A diagnosis of lung cancer and major surgery threatens their ability to work and therefore also threatens their financial security.

##### Experiences in returning to work

Initially, two issues appeared to be the main threat to the financial security of participants in this study - the age of the participant and their need to return to work. There seemed also to be two categories of participants: 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 organize 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

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: those who performed light or office-type work to which they were able to return, those performing heavy or demanding work and were able to change to lighter work and those who performed heavy and physically demanding work but were not able to return to that work nor change to lighter 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. One lady said:

*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.*

A male in the public service said:

*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.*

Another participant said:

*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.*

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.

*Well, I used to be a senior (person) down there. They kicked me out of there because they thought I wasn't fit enough. ... .. 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.*

Another self-employed male said:

*I mean there is 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 because the work 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. Lifting was the main physical activity that challenged the ability of participants to perform heavy work. They therefore 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.

*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.*

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 as these comments suggest:

*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.*

There is no literature reporting the experience of patients returning to work after lung surgery but Berry (1993) reports 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). Berry also found that the time people were absent from their work was important and 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). Interestingly, one of the participants in the Berry (1993) study reported the lifting as an issue, he said, 'I'd go back [to work] tomorrow if I didn't have to do all that lifting...' (909).

### Return to work and power

Returning to work is said to represent positive change because it provides one 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. The control and power that some employers had over some participants left the participants disempowered and with feelings of anger, uselessness, worthlessness, and degradation. 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.*

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).

### ***Summary of the study findings:***

The return to work experience of participants revealed that the theme *my financial security is threatened* was a real threat to participants because returning to work gave them back their financial security, social freedom, and pre-surgery lifestyle. For some participants' 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 type of work determined the likelihood of participants returning to their pre-surgical work.

‘Survival is the phase that each cancer patient enters when disease, diagnosis and treatment are over’ according to Little et al. (2001, 9). For lung cancer patients, surviving is a milestone achieved by only a few. There is no literature about survival after lung cancer surgery but survivors of other cancers have feelings of uncertainty about the course of their disease and how it might threaten their survival.

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, 1991). A major struggle for the study participants was the daily fear that the cancer would return.

### Participants’ experiences

Fear was a constant reminder of the uncertainty of their continuing presence in this world, and the reality that they could lose their life. Participants had 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.

*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.*

Another participant had this view:

*...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.*

And another:

*It was all [happening] quickly. It was not something that takes long or over months. ... .. I was not scared. I think I am more scared now than then.*

Fear of discovering recurrent or metastatic disease is always present in the minds of cancer patients and the study participants were no different. Anxiety levels often rose around the anniversary of their operation.

*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.*

If the patient is not fearful then usually another family person is!

Partner: *You see I always worry too about if it is going to come back again.*

Participant *What? The cancer?*

Partner: *Yes! [I worry], whereas [he] doesn't.*

Participant: *It's because I have no control over it [the lung cancer] whatsoever, so I just don't worry about it.*

Fear and hope are two emotions commonly felt by individuals whose lives are threatened by cancer (Fredette, 1995; Nelson, 1996; Breaden, 1997; Shin, 1999). The following comment demonstrates not a fear of dying but 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].*

And another lady 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...*

Most patients live with a suspicious feeling and some participants in this study verbalized their suspicion in the following statements:

*And when something goes wrong you think, "Oh it's there again, eh."*

One participant said:

*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.*

Wife... *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.*

Participant... *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?*

Another lady expressed this view:

*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.*

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....*

Finally, participants saw that they were lucky to be alive on a number of fronts. This participant's wife voiced how lucky she felt that she and her husband were:

*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.*

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).

### ***Summary of the study findings:***

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 in the study were similar to the experiences of other cancer patients reported in the literature. Fear was slowly overtaken by hope — hope to live and survive and see their families grow. Participants told me that doctors were reluctant to use the word “cure” during early follow-up consultations and this made them at times feel uncertain about their future. This theme reinforced the fact that recovery after pneumonectomy is a slow and progressive process and part of that process is facing and dealing with fears and uncertainties about one's life.

## 6 I WISH I HAD KNOWN MORE

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 one to understand what is happening to them, enables them to make informed decisions and it helps them to make sense of any symptoms they feel. Information reduces stress and anxiety – not knowing creates stress. Furthermore, information is especially important when an illness is related to cancer (Key, 1985; Galloway, Bubela, McKibbin, 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).

The need for participants in this study to have had more information about their illness and recovery became apparent very early during the interview process. They asked many 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. They seized an opportunity to learn more about what they had been experiencing and living through.

The need for knowledge amongst participants' varied considerably. 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'. Most participants relied on information from their medical team but the following quotes highlight some of the variations.

*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.*

*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.*

*..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.*

### 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).

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 their concerns might have been relieved and an enormous amount of stress and worry avoided. 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.*

One male 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?*

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 21<sup>st</sup> century will not suffer the same experience of not knowing.

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 hospitalization 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.

## ***Summary of the study findings:***

Underpinning all of the 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, emphasized the crucial role of information in informed decision-making, and reinforced that information helps patients make sense of the things they experience.

## **DISCUSSION**

This study explored the experiences of only a small group of people whose experience took place some years ago. Readers should be mindful that many patients experience a positive recovery and enjoy a full and active life after pneumonectomy. 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’. A recovery after pneumonectomy experience is similar to a pain experience in that how people perceive their recovery depends on many 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 all grateful for any opportunity to regain their lives by surviving lung cancer.

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).

There has been a growing interest in the needs of patients following thoracic surgery (Galloway et al., 1993; Goodman, 2000). This study adds to this knowledge base and has 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 getting back to a “normal” lifestyle. We need to remember that ‘There is no profit in curing the body if in the process we destroy the soul’ (Sam Golter, cited in Ferrell 1995, 610).

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 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.

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 (breathing) that was required for recovery, always knowing that death was a possible outcome. Patients in this study 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, and uncertainty. The words *hard work* describes this process and they describe the phenomena uncovered by this study.

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