

The first year experiences of early stage post-surgical lung cancer survivors

Abstract

Background: There are over 220,000 patients diagnosed with lung cancer each year. Although only 15% are diagnosed at an early stage, with the possibility of curative surgery, this population is over 165,000 annual survivors. The purpose of this study was to describe the first year lived experiences of these post-surgical early stage lung cancer survivors.

Research approach: Open-ended interviews

Setting: A large university based surgical cancer center located in the northeastern United States.

Participants: 15 early stage post-surgical lung cancer survivors.

Methodologic approach: Heideggerian hermeneutics interpretive phenomenology

Main research variables: The lived experiences and how early stage lung cancer survivors within their first post-operative year, themes and patterns from these experiences.

Findings: Participants describe a progression of their experiences through 4 themes: 1) thankfulness of an incidental diagnosis, 2) surprise reactions to post-surgical procedures (chest-tubes, narcotics), 3) the annoyance of concurrent symptoms (pain, fatigue, mood disorders, cough, shortness of breath), and 4) acceptance and striving for a new sense of normalcy.

Conclusion: Although patients often did not complain, from diagnosis to survival the surgical experience impacted patients in many ways. Thus, health care professionals should design interventions to alleviate common disturbances related to the entire surgical experience of lung cancer patients, focusing on improving education in smoking cessation, reaction to post-surgical medications and procedures, and symptom management to improve patient's quality of life.

Keywords: lung cancer, pain, symptoms, symptom management, postthoracotomy pain syndrome

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Introduction

The alleviation of pain is an essential component to lung cancer survivors' quality of life from the initial diagnosis, the surgical experience, recovery, to homecare symptom management.¹⁻³ However the role of pain spanning from diagnosis to survivorship is needed. With an expected 220,000 cases attributed to lung cancer, the majority of patient's initial symptoms (blood streaked sputum, chest pain, persistent cough, recurrent bronchitis or pneumonia and voice changes) do not occur until their lung cancer is in its advanced stage.⁴

New initial diagnosis are expected to reduce deaths by 20 to 30% for current smokers, however these new techniques do not help those currently diagnosed.^{4,5} However, for those currently diagnosed cigarette smoking is still the prominent risk factor for this disease with radon, air pollution, second hand smoke and other environmental factors following suit.⁴ Once lung cancer is diagnosed, surgery is still the gold standard for early stage treatment.^{4,6} Yet, lung cancer survivorship remains low, 15% per year, with 54% of these early stage patients expect to survive 5 years or more.⁴ These results project the potential for pain to impact over 165,000 lung cancer survivors annually.⁷

Researchers have noted that regardless of the initial treatment,

the post-treatment period is often full of complications⁸⁻¹² and a stressful time for most lung cancer patients.¹³⁻¹⁶ Postthoracotomy pain syndrome (PTPS) is a common symptom for these patients, with an incidence between 22% and 67%.¹ PTPS is defined as "pain that recurs or persists along a thoracotomy scar at least two months following the surgical procedure that is not related to metastasis or other treatments."¹⁷ PTPS is often associated with post-surgical complications and symptom clusters.^{18,19} PTPS is a common long term syndrome impacting early stage lung cancer patients' quality of life. With little success, several researchers have investigated techniques to minimize PTPS during recovery.^{15,20-22} PTPS may also be influenced by symptoms^{19,23,24} and symptom management homecare.²⁵ PTPS symptom distress^{16,26} and management remains an issue.¹⁸ However the combined lived experience from diagnosis to recovery of early stage lung cancer patients with post-thoracotomy pain syndrome remains relatively uninvestigated.^{27,28} The purpose of this research study was to describe the first year lived experiences of lung cancer patients' with post-thoracotomy pain syndrome.

Materials and methods

Martin Heidegger²⁹ departed from historical hermeneutics, in rejecting the researcher's personal opinion within the writings.

Heideggerian hermeneutics requires the researchers to focus on and acknowledge that human subjects are themselves self-interpreting beings, communicating through language, and situated in time. Thus, Heidegger requires the researcher to reject personal opinions and turn to the narrative for the interpretation.³⁰

In this study, Heideggerian hermeneutics phenomenology was used to examine early stage lung cancer patient’s narratives depicting their post-surgical experiences from diagnosis to survivorship.^{30,31} This interpretative phenomenology guided the open-ended interviews questions. Patients’ were asked to share their surgical experience, from when they were in the hospital until today, any type of discomfort or symptoms they had from that whole entire period; how it has affected their recovery. Post-consent, all interviews were tape-recorded and transcribed to provide text for analysis. The recorded interviews and transcriptions were reviewed by two researchers for accuracy. Transcriptions provided the textual data which was analyzed using a modified Heideggerian hermeneutics interpretive phenomenology approach. The team reviewed the textual transcriptions, in a reflective and circular process identifying related themes and supported by verbal recordings.³² Discrepancies were classified refereeing to the transcripts. Patterns were uncovered in the texts, to reveal patterns of the patients’ post-surgical situations as lived. In using the hermeneutics process this researcher strived to reduce unwarranted interpretations, and results were focused on reflecting the text.³²

Sample and setting

A prospective sample of 15 early stage (I, II, III a) lung cancer patients was from a cancer center located in the northeastern United States. Of all 15 participants, one was an African American (7%), two were non-smokers (13%), nine were men (60%), nine had at least a high school education and all had early stage lung cancer. Demographics are summarized in Table 1. Participants were selected for this study because of their post-surgical symptom experiences.^{6,18,20,32}

Table 1 Sample Characteristics (N=15)

Variable	Mean	S D	Range
Age	66	10	48-83
Smoking (pack years)	51	33	0-120
Pain	3	3	0-8
Variable		n	%
Gender			
Male		9	60%
Female		6	40%
Education			
High school		9	60%
College		5	33%
N/A		1	7%
Race			
Caucasian		14	93%
African American		1	7%
Employment			
Retired		7	47%
Leave/Unemployed		4	27%

Table Continued....

Variable	Mean	S D	Range
Part-time			2 13%
Full-time			2 13%
Smoking status			
Non smoker			2 13%
Quit			8 56%
Current smoker			5 31%
Years smoking			
0			1 7%
1-30			4 26%
31-60			7 47%
61-90			1 7%
91-120			2 13%

Patients were recruited from a large university based surgical practice located in the northeastern United States. This clinic provided gender, social economic and surgical diversity. Patients were recruited using purposeful sampling and eligibility included: being diagnosed within their first year following surgery, having post-thoracotomy pain syndrome, a diagnosis of early stage/non-metastatic disease (stage I, II or IIIa), with the ability to speak and read English.

Main research variables

Lived experiences and how early stage lung cancer patients interpreted these experiences.

Results and discussion

Four themes emerged that described the PTPS patients’ lived survivorship experiences.

These themes include:

- a. Incidental lung cancer diagnosis.
- b. Reactions to post-surgical procedures (chest-tubes, narcotics).
- c. Concurrent symptoms (pain, fatigue, mood disorders, cough, shortness of breath).
- d. Acceptance and striving for a new sense of normalcy.
- e. Pain was a constant pattern that linked all themes.

Theme : Incidental lung cancer diagnosis, yet not surprising

Several patients’ initial symptom experiences were often described as unrelated and nonspecific to their cancer diagnosis. This patient noted that GERD not cancer was a concern.

“I thought I had GERD, and had a pain and burning in my throat, loss of voice, and I was really concerned about throat cancer. So my doctor ordered a CT scan which revealed something on the lung, possibly pneumonia. So they put me on an antibiotic and he sent me for further study where they discovered “it” was there, and subsequently I had the surgery.”

Some were diagnosed while being tested for a completely unrelated disorder. Patient noted “The discovery of my cancer was such a fluke, which I was very lucky. I went to a podiatrist for pain and he thought I

had a circulatory problem. They did a Doppler, a CT, and other tests I forget. And they said I don't have a circulatory problem, all your tests are negative, but we saw a spot on your lung. Well thanks a lot hunny and here I am." This patient further explained:

"Yep, when I was first diagnosed and I said it was lung cancer, the doctor said you can't jump to conclusions; you got to have proof that it's not cancer before you do anything. And I said well I smoked for 43 years, it has got to be cancer. And I always said right after I quit, if I was going to get cancer, well I've already got it. Because I smoked for so long."

This patient's cancer was found during a routine check-up investigating the possibility of a cold or the flu. This patient recalled: "Well, when I was in Florida they found a spot on my lung, I had H1N1 (flu), and the hospital took an x-ray and found a spot on my lung."

Many patients, like this patient are not surprised at their diagnosis due to their long history of smoking. She also noted "I quit about fourteen years ago. I smoked for 43 years about a pack of cigarettes a day. One of your questions on there is 'Smoked or Chewed?' I did both. But, I smoked a pack a day for 43 years and I quit cold turkey. If I knew it was going to be so easy, I would have quit earlier. I had no trouble. People around me smoking doesn't bother me." Even this patient who did not personally smoke, often have a family history or connection to smoking "No, just tried a cigarette when I was in high school, my husband smoked when we were first married, but he quit. My dad had smoked when I was younger, but then he quit when he was in his 20's. So, maybe it was his 30's, but I was very young". These diagnoses often led to surgery.

Theme 2: Reactions to post-surgical procedures, wanting to feel wonderful

Many patients reported unique reactions and descriptions of their surgical and post-surgical process. A few from this study include "The upper 1/3 of the left lobe of my left lung." Or "here is where he "whooped" the lobe." Still another stated "there is a wound there and he had to "loped" that part of the lung and sew it up." These same patients reported post-surgical complications with the majority concerning anesthesia, living with chest-tubes, and chest-tubes dressing changes.

Anesthesia complaints emphasized the need for pre-operative screening for dosing and complementary medications. Thus many patients noted how they themselves, not the surgical team, need to "try to determine whether or not you're allergic to the anesthesia, or to the pain medicine." Patient's expectations to inform the team and avoid side-effects were occasionally successful "I told the anesthesiologist that I would get sick, and he must have given me something because I felt wonderful." Yet, others surgical experiences were not so positive. This patient noted: "I guess there are drugs you can get to from getting nauseas." He later summarized his experience as "I think they need to discuss more about the pain medication and how it may affect people because some people are new at it and will never know. I do know they need to listen to me getting nauseas because I hate it."

There were no complaints about chest tube (CT) insertion, however, there were common complaints regarding either living with CTs or CT removal. This patient noted how CT problems continued at home "Sort of at a 45 degree, but to your right side so, no pressure on your back or your back chest tube sites. And they told you, possibly have chest tubes when you go home?"

Another patient reported distress regarding their CT removal in the hospital. They note "My most pain I had, the drainage tubes (CT), they had in. And it was fine until a Doctor, not my surgeon, picked up the box to look at the amount of fluid that was in the box. He must have twisted the tubes, the pain was excruciating. And when he put it down, you know I hit the button for pain a few times and that always makes me nauseas and didn't help anyways. But, after a while that went away and then they came in to take those tubes out, because I was ready to have them out. But that was the worst pain I've ever felt in my life. The surgery pain was fine. But it was almost as if those tubes had twisted when he picked that box up."

Patients' often went home with two chest tubes. This patient noted "When I first came home I had the tubes and big box, two of them, one for the back and one for the front." This patient noted how having a visiting nurse helped.

"I had a visiting nurse at home; she came once or twice a week, maybe twice a week for I think six weeks. And then she was finished; she was a big help. I had more discomfort than pain from the surgery itself. And she was good about what I could do. I slept in a chair. That was how I was comfortable when I was home. I have a small, a lady size recliner, and that is what I slept in. The bed was not comfortable to lay down in, probably because you're propped up in the hospital type thing. I had oxygen for six weeks which I don't know, I don't think it made a big difference to me, because I did it, so I don't know if I was without it, if it would have made a big difference. But I didn't feel like it was worthwhile. But like I said, if I was without it I maybe would have noticed the difference."

Still another patient reported how her combined in hospital chest-tube and pain medication experience. This turned a patient against taking any home pain medications.

"In the hospital, the pump made me very nausea, and I kinda got sick, so you know, they didn't do anything and I'd get sick so I didn't want to hit the pain pump, because I knew that made me ill. But, when the CT-tube thing, I hit it and I was so nauseated, but I had to do it over again I would have never hit that. And I told him that makes me sick, but they hook you up anyways, because they're not sure and they do send me home with a prescription of pain medicine, even on my most extensive surgery I've never needed it. Because I just don't like to take pills anyways, I did not need it. I took my prescription home last time, but did not buy the prescription, the pills, because I just didn't need it. I figured if I happen to need it I'll have him run out and get it for me." Yet another patient recalls his bad experience at home

"I mean it's not excruciating pain, but I'm already in enough pain why you causing me more, and where it was when they taped the dressing. They would tape it to my armpit hair, so every time they changed the dressing they are tearing out armpit hair which was just was adding fuel to the fire and making a bad situation worse."

Medication may help the patient's pain, however, its side effects once home, can also be an issue. "Oxycodone...lately it's been causing me to itch and... rash on both arms." Another noted "The first couple weeks were painful, the incision was healing well, but the pain ... They gave me Oxycodone. It worked, two of them kept me asleep, I was supposed to take one. One still had me drowsy." Still another "Oxycodone was making me sleep all the time, and I didn't want that he started me on the Neurontin. Now, the Neurontin eased the pain up to where I could tolerate it. Now as opposed to a 10. It is now a 5." and Another "Oxycodone and Vicodin. They do help somewhat, it takes

the pain level from like a constant 7 down to maybe a 3 or 4. It only lasts for an hour or two and its back again.” Another patient noted:

“I did really bad with Dilaudid. I got lucid, I thought my daughter put me in a nursing home, and I was in intensive care, so I was mad at her. It was so real, but, I just gave the machine back one day and said, I’m done, I can’t take this anymore. But I had a nerve block on my back too so. Where the surgery was, there was hardly any pain at all there too.”

Theme 3: Those annoying symptoms (pain, fatigue, mood disorders, cough, shortness of breath)

Many patients did not call it pain, but noted annoying symptoms. Similar to this patient, they noted “I’ve never had pain before, so I don’t know how to explain it. But it’s not pain that I get, and there’s just a funny feeling when I move my arm a certain way.” Still another stated “It’s annoying, it’s intense most of the time, and my left arm is virtually useless, I can’t pick anything up. I can’t reach. Like I couldn’t put a hat on with my left hand.” And that this annoyance impacts their lives “I was a meat cutter. Very physical, demanding job: I can’t do anything. If I empty the dishwasher, I have to sit down for an hour because it hurts so bad.” Another noted “I have restless nights, a lot of restless nights. If you lay wrong you can feel it, where the incision is, and it will wake you up.”

Other patients noted pain with tactile stimulation. A few examples are “It’s kind of a constant pain, tender to touch, something I deal with, it’s very irritating, it’s there, I do the best to try to deal with it.” And “The seatbelt if you’re the driver because it comes across here it hurts because I can’t wear it up here because it hurts here so I’ll go to put it down here, but it hurts here. But on the passenger side its okay.” Or “The pain from the nerve was intense; it was like to the point where I couldn’t put no clothes against my breast, unless it was the real soft “cottony” type material.” A gentle man who worked noted “lifting anything heavy, it aggravates it definitely.” And for woman “Bra, took forever to wear a bra, and then I still can only wear it, like if I’m at home.” Another woman notes “I constantly held my breast in my hand, to keep it from touching my stomach.” Yet another woman states:

“That scar is and goes over, for me it’s from the drain tube. And it does everything, it does what it wants to do, when it wants to do it, from severe pain, to jaggng pain, burning pain, shooting pain, pain for a whole day or two days and you think it’s getting better and it’s back again or it’s doing different things. It does what it wants to do when it wants to do it and it goes away when it wants to go away and comes back when it wants to come back. But it never stops, sometimes it will affect the whole left breast, or the whole thing is totally sore.”

Still other patients have persistent tales of pain, after having their CTs for months. This patient reported “I still have pain, everyday. My left arm, to go this much (to my side to raising it just level with my shoulder) agonizing under my armpit, and throughout the breast region over to the sternum.” And another:

“You couldn’t sit in the automobile because of the tubes in the back you had to lean forward. So, then when you’re constantly leaning like this, next thing you know your back starts hurting, your lower back, because you’re like this 20 hours a day. Standing up I was fine.” Pain often accompanies other post-operative symptoms. This patient notes pain and insomnia “I have restless nights, a lot of restless nights. If you lay wrong you can feel it, where the incision is, and it will wake you up.” For this patient.

“It’s the pain with the shortness of breath and then you get frustrated because you can’t do the things you normally do. Because I found myself saying if I’m cleaning up my other room I’ll grab up some things, let me run these upstairs, like normally, and then I realize after I get to the top I got to sit down and squirm around like a fish out of water to get air. So, now they got me where they want me to take the oxygen up the steps with me.” Many lung cancer patients experience breathing complications due to a history of COPD, asthma, bronchitis or emphysema. These patients often need medication changes. One patient proclaimed:

“I noticed one thing, after a while, I noticed my breathing wasn’t as great as it used to be, it wasn’t bad, but I started using an inhaler, Spiriva, and that helped me out a little bit. At first I couldn’t tell any difference as far as my breathing goes, but as it went on I could tell I little bit because I did more activity.”

Another noted “I use Advair 250/50 they always want to throw 500 at me, but 250 does me well. And I use actually 3, I use the quick n’ light inhaler, but seldom do I need that, and I keep it in cars just in case. And I use Spiriva once a day.” Yet, patients strive to see the best in things.

“Before the surgery, I still carried a preventable inhaler, and before the surgery, I was using that 3-4 times a day, and since the surgery, I don’t think I’ve used it a half-dozen times. The doctor, I was on Advair, the doctor added Spiriva. I don’t know if the removal of the cancer or the Spiriva, or the addition of the Spiriva, or the combination of the two has improved the asthmatic condition. But, there’s definitely an improvement there.”

Others experienced the need to go home on oxygen and this can influence their pain. “They wanted my home oxygen on at one and a half. I didn’t like it at one and a half. As soon as I felt well enough I turned it down to one. I felt like one and a half was too much for me. I’m not supposed to get over two liters, because it will collapse my lungs.” Home oxygen also requires an education process for the patient to wean off it. This patient discusses his pain and difficulties in weaning off oxygen.

“I need it more on exertion. Always when I bend over and squeeze together you’re definitely cutting off your air suction there, and you have emphysema and everything is pressing on everything and your lungs are. so when I come up yeah I need oxygen, like when I’m bending over to clean or something.”

Coughing may also potentiate pain. One patient noted “coughing. Just once in a while, usually in the mornings after resting, like, it’s like if I get up... I don’t lay flat, I sleep in the chair.” While another stated “The cough is my big thing...Coughing) Right after surgery... Sometimes I get, it’s the flam I think, and if I get a coughing spell as they call it, I can’t stop.” Still another patient coughs yet, has found her solution “for the cough. I’m a tea drinker, I tried the green tea, I drank it for a while, but I don’t like it anymore. I’m on apricot tea. It’s very good. But I do like it. Maybe some hard candy once in a while.”

Anxiety is a common issue. This patient noted “I just get down in the dumps sometimes because I feel like something is in my left lung, but I’m not sure.” Another acceptance of her anxiety and the using medications helped “Celexa, which is an antidepressant which is really helping.” Still another noted a complicated history of anxiety. She denotes a constant battle when anxiety is combined with her other ailments.

“I take Prilosec. I take Mirapex, I have of all things to add to my little list of things, I have restless leg syndrome. I don’t know if that’s a combination, and I just started on Allegra, thinking this is allergy season knowing I have allergies. I don’t think that’s doing any good either.”

Fatigue with walking is common. One patient noted “I can walk, like that one day we went to the mall and I had to walk like a 1.8 of a mile, I was shot, just totally shot. That’s what I mean by shot, I was so tired, and I was out of breath, and it was just. I don’t want to go to the mall. And the next day, it takes you a whole day to recover.” Another noted “If I walk a flight of steps, like 12 steps I have to sit down” Fatigue is often described as a lack of energy. This patient has a tale of her fatigue impacting her beloved garden.

“Not having any energy. I don’t mind slowing down; everybody has told me I should slow down a long time ago. I love to garden, I would go out and pull weeds from 9 o’clock in the morning till dinner time fix flowers, do whatever, and I loved it, but I can’t do it, and that bothers me. Although I do have a little garden down in (location) that I futz with. I had a pond, I did lots of things. I’m a cleaner. My friends say, forget the house (name), I said I should be, but I have to have it done, it’s just me, but I’m slowing down a little bit, I’m getting to the point that I don’t mind, as long as it looks good.”

Yet, one other patient simply stated fatigue as “Yeah I get tired easy.” Another “Usually tired, but no effects on sleep.” And a third “I still don’t have my energy, which really, really bothers me. I’m a go doer person. I just can’t, I cry, I really do. I said to my husband I can’t do it anymore, and it’s very upsetting to me. And I’m going to be 75 in July and you can’t go from still being this energetic person and then have it a drop.” Another noted “I can’t do everything as once before, use to be energetic, not anymore. I wasn’t sure who to go speak to about the way I was feeling and my tiredness.” Yet another strives for normalcy “Both, because you’re up and down. Dusting sounds like a real easy job, but if you get into real dusting it is not.” Fatigue is often associated with insomnia and other symptoms. This patient noted that “Too often I lay in bed, trying to nap and then after I nap, I lay in bed after waking up, and so I’m giving up 2 to 3 hours per day to my afternoon nap and it’s putting a dent in what I get done and more specifically what I don’t get done.” Another noted “I think I mentioned sleep problems and fatigue problems, I believe, my memory is not what it used to be.”

Theme 4: Acceptance and striving for a new sense of normalcy

Many noted that they just could not be the same. “Work has changed...because I am not able to do what I used to do.” A golfer noted “Pain is affecting my golfing, because I used to golf four days a week. But I haven’t been able.” A business owner notes his “working ability, just unable to do certain things as I used to...My construction business, any heavy lifting, steps, moving ability, it’s so many things.” Another worker noted.

“Since the surgery SOB’s gotten worse, because it’s terrible now, I wasn’t, I’ve never seen myself being short of breath before the surgery, I’ve worked two jobs and I was hardly ever home, 7 days a week two jobs... now I am part-time.”

Yet, striving for normalcy after cancer is a common goal. This patient chimes “I had surgery last year, my recovery has been steady. Especially in the last 6 weeks or so, the pain, feels more like where he

“whooped” the lobe, rather than the incision, and that’s where the pain has mostly been. It has been subsiding in the last 6 weeks, 2 months I would say.” Another noted that “Every once in a while you would get a pain. It would be in different on your chest, if I breathe deep, take a few deep breaths, it seems to help and go away. It’s not a serious pain; it’s just a inconvenience.”

Family life often changes after surgery. As this patient notes “My husband has been a dream, he does all the cooking. He didn’t just put meat and potatoes. He did the French beans with maybe pine nuts and roasted them.” She continues.

“He’s always been a good cook. I mean he just, the whole thing is, he would make this beautiful meal and bring it to me, and I would be overwhelmed because it would be too much on the plate. And so I would try and eat it, and all I did was gain weight, which I think he was worried I was going to get skinnier or fade away, I don’t know. (Laughing) That’s still a problem; I can’t eat a big meal. He eats breakfast and he eats dinner, and he eats a big breakfast and then he doesn’t eat anything. But I have to do the”.

Another patient notes how she copes with changes at home. “So, I’m generally pleased in my recovery, the big difference and this is complicated, is fatigue, but the fatigue is very much tied up to the fact that I have trouble sleeping at night. I have to take a nap; I have to lie down every day in the afternoon. But it’s not clear to me that I can attribute that to the surgery. So, yea, there are other things going on, in my life. My daughter was disabled at a troublesome time last year; we’re looking at retirement and things in the process of sorting things out there.” This gentleman has also adjusted to his daily work situation.

“I am a courier, a driver for a courier company; well I used to work five 10 hour days. Well, I’ve cut back to four 8 hour days. So, well, that’s part of the picture. Yea, I’m a part-timer now.” Another patient discusses life style changes “try to build my health up, my nutrition, eating, exercising, and going to therapy and stuff like that.” Still another noted how he copes. “I went back to work. My surgery was August [Date], and I went back in September, part time and then I went back full time and I have been working ever since. The only thing is I can’t do as much as I used to, like raking the lawn, I get tired easier, I can’t catch my breath, so I stop and take my time.”

Others use unique ways to deal with pain “cell phone to play that ‘60s trivia game ... concentrating on other things I don’t notice the pain as much.” For this patient: “You know, just deal with it. Get something for the pain, and hopefully they won’t interrupt no nerves, or you won’t need the Neurontin, that burning pain, you will definitely need some kind of medication, because you’re not going to be able to tolerate it.”

And for this patient “The first couple months were difficult, ah, after three months I was going back to work, ah, it’s been steady every since. I don’t know when you get to the point where you say everything’s back to normal, but it was shortly, within six months of surgery.”

Surgery is the gold standard and one patient notes “without the surgeries that I’ve had, I’m sure I wouldn’t be around at this time, this goes back 15 years now. So, I’m very thankful that they could do something like that. “Finally, one patient smiled and noted “I’m 100%.”

Additional findings: Patients were asked “Is there any advice you would give?”

One notes to wait then exercise “Well, the main thing is, I was pretty active, I couldn’t do no golfing, swimming for a month, once after about 6-7 weeks, I took another MRI and send it up here, and he said I was cancer free I start doing some exercise to the day I come up here I was walking and exercising.”

Some discussed smoking cessation. One simply stated “not to smoke. I quit 7 years before I got this because both my bosses, my boss and his wife both got lung cancer, and that’s the reason why I quit. But no, I would never smoke again; I wouldn’t recommend that to anybody, that was a terrible thing to quit.” And “Get off that cigarette. That you never listen about. It took me to go to a ventilator to stop, I was left for dead actually. So that’s the biggest thing, if I only listened.” The final word was to have faith. “I would tell them to have a lot of confidence in their doctor, which I did. And uhm that things are going to get better, not worse. And let them put you to sleep, because you will wake up and not know anything that is going on, and that’s a little mind alleviating.”

Conclusion

These findings reflect only the stories of early stage lung cancer patients who provided their views during recordings which were then transcribed and analyzed. The analysis of themes and patterns provided insight into understanding the lived experiences of post-thoracotomy from diagnosis through their first post-operative year. Their experiences gave insight to both the successes and failures of the nursing process.

There are many concerns for these newly diagnosed patients with lung cancer.^{3,33,34} Researchers have noted the initial surgical experience is often a stressful time for most lung cancer patients.¹³⁻¹⁶ Similar to other studies, our studies patients often did not complain during their experiences with lung cancer, even though these experiences may impact patients in many ways.^{33,35}

Almost all of our participants smoked, many quit smoking years before being diagnosed, and still others lived with smokers. Regardless of their smoking history all lived in an environmentally high risk region, of the country. The opinion of these patients, regarding their risk of lung cancer diagnosis, varied widely. This was similar to what other researcher have found among smokers^{13,36,37} and non-smoking individuals in environmentally high risk areas.^{38,39} Yet, both the smokers and prior smokers often experienced the shame and stigma of their past habit.^{13,36,40}

Many of our patients are over the age of 65 and had surprising reactions to their hospital stay, with their only preoperative complaint being their experiences with both anesthesia and the anesthesiology team. Anesthesia is a requirement for lung cancer surgery and many patients expressed expectations to feel wonderful after surgery. Many did, however, all too often patients expressed their frustrations about their post-anesthesia experiences of nausea or unrelieved pain. The entire pre and post – surgical team have a responsibility to talk with the patient’s and ensure that both nausea and pain are minimized.^{16,20,41,42}

Several researchers in nursing,⁴³ anesthesia⁴⁴ and surgery⁴⁵ have noted the lack of standards in chest tube care and this is the center focus of our patient’s in any hospital stay. Several of studies patients’ were surprised and disappointed regarding chest-tube care

and removal. One male patient gave graphical descriptions of his painful experience, when chest tube tape being torn from his body. The majority of lung cancer patients receive chest-tubes and the pre-operative removal of body hair at the chest tube site(s) would reduce or eliminate this pain. A second patient graphically described their pain during the twisting movement of his chest tubes, while a doctor was assessing his chest tube site and drainage. Finally a third participant described that they were neither pre-medicated nor was lidocaine used, resulting in the painful removal of their chest-tubes.

During a patient’s hospital stay, adequate pain control is a nursing measure.⁴² Research has shown the dosing requirements of pain medications in the elderly should be reduced both in the hospital⁴⁶ and at home.⁴⁷ This is supported by our study with an average age of 66 years Table 1 and several of them reported getting sick or nauseated, while either on the pain pump or recovering with pain medications at home.

Finding of this study agree that symptom monitoring is vital.^{16,48} This study also agrees with researchers whom have noted the common and concurrent symptoms for lung cancer patients include pain, fatigue, mood disturbance and shortness of breath.^{19,49-51}

Several researchers have investigated techniques to minimize PTPS: from pre-operative anesthesia to surgery,²⁰⁻²² recovery^{2,50} and home therapies,²⁵ with little success.^{1,2,28} Many patients in this study, as in prior studies note their PTPS symptoms may be influenced by multiple and concurrent symptoms.^{19,23,24,52} PTPS symptom distress^{16,26} and management remains an issue.^{18,53} Similar to Ballantyne²⁵ & Chapman¹ our patients have noted the advantages of using neuropathic pharmacological techniques in the symptom management of PTPS. Still the combined lived experience from diagnosis to recovery of early stage lung cancer patients with post-thoracotomy pain syndrome is relatively uninvestigated.^{27,53}

Interpretation for nursing

Nurses and health care professionals should be aware of their potential in alleviating common disturbances related to the entire surgical experience of lung cancer patients, focusing on improving education in smoking cessation, reaction to post-surgical procedures, concurrent symptoms and quality of life.⁵⁴

Nurses should be aware that patients with a long history of smoking or smoke related factors and lung cancer often bring additional psychological factors due to their personal history. Nursing is on the front line of how smoking may impact patients’ perceptions of lung cancer, PTPS and other symptoms.^{1,55,56} Nurses should educate patients by promote smoking cessation, from diagnosis and throughout the patient’s treatment process.⁴¹

Pre and post complications impact patient’s quality of life.^{12,57} Nursing should vigilant in looking for complications as they assess and monitor the patients.⁴⁸ Nurses have a duty to inform anesthesia of pain and other complications, ensuring all patients have a wonderful experience after surgery.⁸ In particular patients should be screened for prior anesthesia and opioid allergic reactions and side effects.⁵⁵

Although there are no national chest tube care standards, nurses should be aware of the protocols and standards at their institution. Nursing and clinicians should strive to minimize the possibility of complications, the insertion of chest tubes either during or after a thoracotomy is a common practice.⁵⁸ Although chest tube protocols often vary, Lidocaine (1%-2.5%) is typically ordered for chest tube

insertion and removal^{43,44} and nursing should see to the appreciate administration of this pain saving agent. Nurses should also be aware that Morphine or other opioid are recommended for patients with moderate to severe pain during removal⁴³ may cause issues in the elderly.⁴⁶ Chest tube management involves measuring output and dressing management and changes.^{44,45} Similarly, nurses should be vigilant that symptom distress is common following lung cancer surgery^{15,16,52} and pain is often called the “fifth vital sign” and must be assessed during each post-operative visit.^{56,59,60}

Our patients experienced fatigue, dyspnea, pain and other symptoms similar to other research studies.^{49,61,62} Nursing should also remember that PTPS may not present as pain but neuropathy^{55,56,63} with acute^{1,64} or chronic symptoms.^{1,65,66} This study shows that as patients strive for normalcy,³³ nursing care continues to play a vital role in the QoL of lung cancer survivors.⁶⁷

Summary

Throughout these interviews we have noted, as have many researchers that symptom management should remain a nursing priority throughout the entire first year of lung cancer,^{52,68} impact quality of life.⁵⁰ Additionally, we have noted that a complete assessment is necessary to identify, neuropathic symptoms acute and chronic are common after surgery.^{64,69}

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Conflict of interest

The authors declare no conflict of interest.

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