Lived Experiences of Lung Cancer Patients

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Abstract: Cancer constitutes a major area under the non-communicable diseases and the lung cancer is one of the commonest cancers among them. Objectives: to explore lived experience of patients with Lung Cancer. Methods: explore the lived experience of patients with Lung Cancer using semi-structured interview schedule with a lead question “Describe your experiences in living with Lung Cancer”. Purposive sampling was used till data saturation. A total of 9 patients lived experiences were explored. The average duration of interview was about 40 minutes, where the investigator started with a lead question and encouraged the subjects to give more about via probing questions and via nonverbal cues. The investigator recorded the responses of the subjects with field notes. The entire interview was recorded. The collected data was transcribed and translated into English. Themes were derived and validated. The samples were coded with numbers to ensure anonymity. Results: TheFour main themes derived from are Being in a black hole, Diverted flow of life, Hopeless treatment and Coming into terms. Conclusion: There are different ways to adapt to their life after lung cancer. Providing them with opportunities to narrate their experiences and feelings might be helpful.

Keywords: lung cancer, qualitative research, experience, oncology

1. Introduction

India is experiencing an increased burden related to cancer. Cancer is the third leading among adults in India.¹² Lung Cancer constitutes 6.9 percent of all new cancer cases and 9.3 percent of all cancer-related deaths among males and females. People diagnosed with cancer undergoes various crisis conditions in which everything revolves around life, the disease and death.¹²

In a community-based prospective qualitative study done in 2002, the illness course, need and service use of patients with cancers were noted. 20 patients with inoperable Lung Cancer were interviewed. The major concern of patients with Lung Cancer and their caregivers was facing death, frustration, social isolation, progressive losses, and the stress of following a complex medication regimen. The study concluded that care for people with advanced illnesses is presently focused on diagnosis rather than need. The End of life care should be proactive and modified to meet their needs.³

The experience of living with non-small-cell Lung Cancer was studied using focus group and telephone interviews to explore symptoms important to QoL. The study results showed that the patients reported feeling of fear and shock at diagnosis and also loneliness during the therapy. The study concluded that patients with NSCLC have conflated emotional well-being after diagnosis with symptoms of their cancer and treatment of “adverse reactions”.⁴

Lived experience of 12 patients diagnosed with stage IV lung adenocarcinoma were collected using in-depth interviews with a semi-structured, open-ended question guide and four themes identified were emotional roller coaster, trying to find out causes, adjusting my lifestyle, and cancer fighter. Understanding these experiences of Lung Cancer patients helps in supportive care service and in the development of interventional researches.⁵

A study explored and described the meaning of lived experiences of patients with non-small-cell Lung Cancer treated with curative radiotherapy. Three patients were interviewed 3 weeks after the end of radiotherapy treatment. The main theme was described as “Hope for recovery serving as a compass in a changed everyday life.” The subthemes were: radiotherapy as a life priority, a struggle for acceptance of an altered everyday life, interpersonal relationships and meeting the health care system. The study concluded that hope was essential during radiotherapy and interpersonal relationship is a prerequisite to the experience of hope.⁶

A qualitative study was conducted in the United States in 2016 to describe the first year lived experiences of the post-surgical treatment early stage Lung Cancer survivors. Interviews were conducted among 15 patients and 4 themes were derived such as thankfulness of an incidental diagnosis, surprise reactions to postsurgical procedures, the annoyance of concurrent symptoms and acceptance and striving for a new sense of normalcy. The study concluded that there should be newer interventions to makeup common uneasiness related to the surgical experience of Lung Cancer patients.⁷

The subjective experiences of an individual with Lung Cancer allow the practitioner to understand and gain insight about the patient’s current experience and thus the practitioner can develop strategies to improve coping ability of a cancer patient. The purpose of the study was to explore lived experiences which may eventually lead to deliver holistic comprehensive nursing care for patients with Lung Cancer.

2. Methods

The qualitative design adopted for the study was interpretative phenomenology. The study was undertaken in selected hospitals of Calicut. Lung Cancer patients admitted to these hospitals with disease or associated discomfort or
taking chemotherapy from Daycare units, or attending outpatient department were taken for study. Patients with Lung Cancer who were disoriented or unconscious, not aware of their illness and unable to communicate to researcher due to physical constraints were excluded. To preclude the issues of confidentiality, a pseudonym was chosen for each participant by the researcher. It was used on all transcripts, data validation of themes, and reported findings. Semi-structured interview schedule with 11 items was drafted. After a brief self-introduction and about the study, the investigator established rapport with the subjects and assured confidentiality of the responses. Prior to data collection, the researcher has done bracketing of his own experiences and viewpoints about the phenomenon under the study. The average duration of interview was about 40 minutes. The interviewer started with the lead question “Describe your experiences in living with Lung Cancer” and then moved on to other questions with the probing technique to elicit more detailed information, depending on answers and meanwhile the subjects were encouraged to give their answers frankly. The investigator recorded the responses of the subjects with field notes. The entire interview was recorded. The collected data was transcribed and translated into English. Themes were derived and validated. The samples were coded with numbers to ensure anonymity. The investigator went through the collected data and divided it into segments and labelled with codes. The codes were collapsed into themes to explore lived experience of patients with Lung Cancer. The identified themes were validated. The analysis was done by using the Colaizzi’s method.

3. Results

Description of each patient with Lung Cancer / Vignettes.

Participant 1
The first participant was a 62-year-old politician and a private employee. He was on treatment for two years since the confirmation of diagnosis. Initially, he presented to a local hospital with complaints of fever, cough and received symptomatic management and later worsening of dyspnea, haemoptysis and generalised weakness made him for the treatment at Medical College Hospital Calicut. He was diagnosed as having Lung Cancer and then referred to Regional Cancer Centre Trivandrum for advanced treatment. He was an ex-chronic smoker. He smoked around 43 years. He had no family history of cancer. Presently he was on the 5th cycle of chemotherapy. He tried alternative medicines and has discontinued it with dissatisfaction. Now he has certain disease symptoms and also has adverse reactions to medicines. He became dependent on the activities of daily living. He was taken care by his wife and two children. He had financial constraints and lost his valuable properties for meeting the expenses of treatment making him in stress.

Participant 2
The second participant was a 62-year-old ex-serviceman who was diagnosed with the disease 1 year ago. He belongs to a nuclear family lives with his wife and two daughters. Initially, he had a mild cough which was neglected and later the cough and dyspnea increased on exertion and sought medical advice. The case was diagnosed as pneumonia in nearby hospital and treated with antibiotics. Later from a higher centre, diagnosed as Lung Cancer and referred to MIMS Calicut for expert management. His father also had cancer. He was a chronic smoker for around 40 years and also a chronic alcoholic. Now he is on his 5th cycle of chemotherapy and suffering from the adverse effects of treatment. Underlying diabetes and liver disease made an increased number of hospitalisations. He was dependent on caregivers for doing activities of daily living. The central government medical insurance is aiding him to meet the medical treatment expenditures.

Participant 3
The third participant was a 64-year-old female from Calicut, who was a retired teacher from a reputed school of Calicut. She was diagnosed with the disease 6 months back. Initially, she had a mild cough and fever and had taken treatment from a local clinic. Then later she was referred to a pulmonology specialist and then to an oncologist. Now she is on treatment from Baby Memorial Hospital Calicut. She had completed her radiation therapy and now only on cancer chemotherapy and supportive care. Her husband passed away 5 years back, lives with his son. The treatment expenses went beyond the earnings and lost all the properties and now she is facing financial crisis situation. Presently she is suffering from the disease symptoms as well as adverse effects of cancer chemotherapy which is leading to recurrent hospital admissions. The only caregiver is her son and she is completely dependent on him.

Participant 4
The fourth participant is a 45-year-old gentleman from Kallai Kozhikode who was a cook working abroad, came back to hometown 2 years back. He belongs to a joint family. He had a cough and weakness and ignored initially and his friends compelled him to seek medical advice. Initially, he consulted a local clinic and later referred to an oncologist at District Cooperative Hospital Calicut. He was a chronic smoker and non-alcoholic, smoked around 25 years. He was non-diabetic and non-hypertensive and had taken radiation therapy as well as chemotherapy. Now he is suffering from disease symptoms and the adverse effects of cancer chemotherapy. He had taken herbal treatment at an earlier period and later discontinued. The financial instability affected his treatment and now his friends are helping him to meet his medical expenses.

Participant 5
A 60-year-old gentleman from Malappuram was diagnosed since 1.5 years. The symptoms, chest pain and breathing difficulty presented abruptly on a night and he went to a local hospital and referred to Medical College Hospital Calicut. The diagnosis of Lung Cancer was delayed because biopsy results were negative on two centres and later diagnosed from Aster MIMS Calicut and started cancer chemotherapy. He was suffering from the symptoms and adverse effects of cancer chemotherapy and completely dependent on caregivers. His wife is the caregiver. He belongs to a nuclear family residing with wife, son and daughter. He was a coolie as well as a shopkeeper and belong to a below poverty line family. The medical expenses were covered under his daughter’s ESI insurance and the limit has exceeded recently. Now a local welfare...
Participant 6
He was a 69-year-old Businessman from Mukkam, belongs to a middle-class family. He was married and living with wife and two sons. He was diagnosed with Lung Cancer 1 year back. The symptoms started as cough. Then he went to a primary health centre and from there was referred to medical college. He was not satisfied with the treatment and later went to a private hospital at Calicut. He was discharged against medical advice from there and sought Ayurveda, and Homeo treatment. Once he reached a critical stage, discontinued and came back to Aster MIMS Calicut and started Cancer chemotherapy. Now he suffers from the symptoms and on adverse effects of Cancer Chemotherapy. He was a chronic smoker for last 50 years and a known case of CAD, type 2 diabetes mellitus on medical management. His mother and brother also had Cancer. He has limitations of activities of daily living and his wife is taking care of him and son meeting the financial aspects of the treatment.

Participant 7
She was a 38-year-old female who belongs to a middle-class nuclear family from Palakkad. She lives with her husband and two school going daughters. She was working as saleswomen in nearby textiles. The disease presented with cough and episodes of haemoptysis. Initially, she went to the primary health centre and then referred to Medical college Hospital Calicut. She took some herbal treatment with strict dietary restrictions, which aggravated illness and later she went to Malabar Hospital Eranjipalam, Calicut for the course of chemotherapy. Now she is on her 3rd cycle of Cancer Chemotherapy. The adverse effects and symptoms affected her health and the medical expenditures are beyond the limit of her wealth and her distant relatives support her for treatment.

Participant 8
He was a 74-year-old retired Constable of Kerala Police from a rural area of Calicut. He belongs to an upper-class nuclear family, lives with his wife. He was a chronic smoker for 45 years. His daughter passed away 3 years back with cancer and his son was working in abroad. The symptom presented with recurrent cough and haemoptysis. He went to Baby Memorial Hospital Calicut and diagnosed as Lung Cancer. Now he is on Cancer Chemotherapy. The symptom burden and adverse effects of drugs deteriorated his health and he was completely dependent to caregivers.

Participant 9
The 9th participant was a 57-year-old male belong to a middle-class nuclear family from Malappuram. He was working in a restaurant. He was a chronic smoker for the past 35 years with a positive family history. The disease presented with an occasional cough and dyspnea and went to the nearby hospital and then referred to a pulmonology specialist management and later referred to oncologist at Aster MIMS Calicut and was diagnosed as Lung Cancer 6 months back. He had undergone radiation therapy and then completed the 2nd cycle of Cancer Chemotherapy. The adverse effects affected him very much and not affected self-care abilities. The treatment cost is a major concern for him. The entire expenditure is managed with the support of his friend.

4. Common Themes
Theme 1: Being in a black hole
1.1 Unexpected entry of disease
1.2 Sufferings of life
1.3 Wavering hope

Formulated meanings are:
- Lung Cancer is a chronic disease condition; the condition itself and the treatment will cause multisystem multi-dimensional negative impacts with poor prognosis.
- The conditions start with minor ailments and do not generally recognized in the initial stage of illness and only the expertise advanced investigations needed to the diagnosis. The last stage diagnosis was beyond the effective interventions and becomes disheartening information to everyone.
- The severe pain, the pulmonary as well as systemic symptoms make the patients suffer.
- Patients generally precede their life with a hope of the cure from the disease in the initial treatment period and later the hope wavers and then disappears.

1.1 Unexpected entry of disease
Participant 3
I was shocked (says it with facial expression).....It was indeed a shock for me...I feel bad when I think about it. There is no happiness in me anymore. No happiness at all. I feel sad thinking that God has destined me to endure this disease. (crying……wet eyes)

Participant 7
I was disheartened. When I heard it all of a sudden… (Rolling a piece of thread with fingers.). I heard them saying it when they inserted that tube into my body. I felt really bad then… (Silence) They didn’t tell me anything further. But I already knew everything…

1.2 Sufferings of life
Participant 1
I have constipation for the past two days... My bowel movements are not getting normal even after taking medicines... I am also experiencing a burning sensation in the chest. This will aggravate if I take food...... Even a glass of water will cause breathing trouble. Spicy food will also cause difficulties. I can’t sleep when it hurts........This disease and the consequent pain troubles me a lot. I will have to consult the doctor 5 or 6 times because of the recurring pain. Apart from all those visits, I have to consult the doctor 2 or 3 times for regular check-ups.

Participant 2
….It seems my facial skin is quite dry. .....I am frequently feverish, especially in the mornings. That is a huge problem......I will eat the food even if it is tasteless. Since I find it difficult to chew, I have food in the form of juice. I don’t eat rice or chapati. It is quite difficult to eat anything (Clearing voice). Having food has become a difficult chore.
Participant 4
I had a cold and cough...I was bedridden for a while..... I became so tired after being affected with this disease. Because of the tiredness, I became lean like a skeleton....... I am really weak... I have a frequent cough..... Am I losing my voice? (Clearing voice).

Participant 7
I felt exhausted (Lowers voice)... I feel suffocation too, especially when I walk and talk..... (silence). Earlier my bodyweight was 60Kg, now it was only 45Kg. I cannot work with this body. I feel pain sometimes (touches chest). I had a severe headache too...

1.3 Wavering hope

Participant 1
As far as I know, one will recover completely with proper medication and treatment if the patient is in the first or second stage of this disease.... ….. I am 63 years old now. So whatever may happen, I won’t have infinite time to live...

Participant 2
I don’t have any wishes now. I don’t wish to buy land property or anything else. Even if I have it is of no use (Clears voice........silence)

Theme2: Diverted flow of life
2.1 On the wheels of treatment regimes
2.2 Adjusting to imposed restrictions
2.3 Being dependent and incapacitated
2.4 Emotional turmoil
2.5 Struggling and supporting family

Formulated meanings are:
• The disease condition insists the patients to change their usual lifestyle. Imposed restrictions and limitations alter the normal life and they move away from the usual flow of life.
• After the initiation of cancer chemotherapy and radiation therapy, the procedure will be cyclic and the patients have to stick onto the regime. The entire duration will be taken up by the cyclic therapeutic procedures and gain control over the patient’s overall health
• The patient himself adjust to some kind of restrictions in his life to take care of himself and to prevent further complications
• The chronic illness and long-term suffering create psychological distress deteriorate the life of the patients and it alters the physical, social and psychological self. The disease makes them dependent.
• The condition and the treatment have a negative impact on health and it leads to the limitation of activities and individuals become dependent on the caregivers for their even for their basic needs.
• The overall impact of illness and the associated factors creates great emotional disturbances in patients.
• The course of illness and the unproductive dependent stage making the patient think that the family members are struggling.
• The stage of illness, especially in the end stage, patients seeks physical, psychological and financial support from close and distant relatives and it provides a sense of wellbeing.

2.1 On the wheels of treatment regimes
Participant 1
I eat eggs and drink milk and gooseberry juice as told by the doctor... I have to take almost 10 tablets in the morning. I also have rice gruel from time to time.

Participant 8
Yesterday, they injected medicines worth 2500/-… two days before, medicine worth 3000/- Upon injecting medicine, my blood level will go down. The same will happen if I undergo chemotherapy too. By the time it becomes alright, it will be the time to inject the medicines again.

2.2 Adjusting to imposed restrictions
Participant 9
I spend time at my home, I don’t go outside... I feel that, I became a patient... I do not go outside much. I have coughing fits. So it is better to avoid dust. So I generally avoid all kinds of meetings and marriage functions.

Participant 8
I used to drink alcohol. I smoked cigarettes too. But now I don’t do either. I started gaining weight when I quit smoking. I was lean earlier. I started eating a lot when I quit smoking.

2.3 being dependent and incapacitated
Participant 1
I was an active participant in social activities. Nowadays I could not engage in politics. My direct involvement in the social activities came to an end. My brothers visit me almost every day. They support me financially too.

Participant 3
My son will prepare breakfast at morning. I will have it at 11. He also prepares lunch for me. I am not able to prepare good food for my son and take care of him. I can’t take care of my pets now as before... I had many pets- dogs and monkeys. I love them. I love taking care of them and gardening. But now I am a bit unhealthy.

Participant 7
I can’t-do anything now. I have to depend on others for everything (pause …clearing voice). I cannot work with this body. I can’t even do household chores. I can’t even go to the bathroom alone. I was part of an “Ayalkoottam” (neighborhood group). But now, I am inactive for the last one and a half years.

2.4 Emotional turmoil
Participant 1
We can’t control our temperament when we have this disease. I will lose my temper if someone interrupts what I say. Afterwards, I will regret on my response...When I see kids with one and a half or two years with this disease, my heart will break. I can’t even imagine the pain they undergo. When I compare my condition to them, I think mine is much better.
Participant 3
My own family plunged me into grief. They do not let me be at peace. They want me to do the partition of our family property saying “we want this; we want that”.

Participant 7
I am worried whether there will be anyone for us if something happens to me (crying)… I myself have to take an effort to be relaxed when I become tensed. I feel bad when I see others. I will feel breathing trouble. Then I have to relax. I will tell myself that I will be fine (lowers voice…. can’t make outsentences…crying)

2.5 Struggling and supporting family

... My wife is very considerate and caring. She can’t sleep well when we are at the hospital. She won’t sleep even when I sleep. She struggles a lot for me...

Participant 2
My family members are sympathetic to me. It is just like that. All of them are really supportive. They will come to my assistance promptly when I need their support to go to the hospital. There are no problems at all...

Participant 5
All that I have the result of my hard work... Now my son has to deal with all the expenses. We had to spend lakhs and lakhs of money. They never let me bother about it. It was a great help for me. Otherwise, I would not be able to deal with my condition...

Theme 3: Hopeless treatment.

3.1 Agonising reactions of treatment
3.2 Delay in identification of disease
3.3 Ineffective alternative treatments
3.4 Money is a matter

The formulated meanings are:

- The adverse effect of the treatment creates agony among patients.
- In the initial stages, the disease mimics other common respiratory diseases such as lower and upper respiratory tract illnesses and there is a delay in early detection.
- During the course of illness, patients seek a rapid recovery. The physical, psychological impact of the illness, financial constraints and opinion from others gives a hope in alternative treatment modalities. Later identified as it was ineffective.

3.1 Agonising reactions of treatment

Participant 1
When I started taking medication, I found it difficult to tolerate even the smell of food... I used to tell others to keep the door of the kitchen closed. It was like that in the initial stage of treatment and then for a while I was OK with odours. After some days, that problem resurfaced... It will reoccur with the intake of medicines.

Participant 3
I have to take chemotherapy too ...I vomit if I eat anything at all...I vomit and vomit and vomit. It feels like I am dying. I want to rest always. I will be able to rest peacefully only after my body is cleared off the side effects of this medicine (pause).... I am also undergoing treatment to increase my blood level (silence….closing eyes)

Participant 4
I feel weak because of the effect of the medicines that I take. (Clearing voice). When medicine is injected, my voice will turn feeble for a while. A few days back, my voice was not even audible this much. It sounded like the chirping of a bird. Nobody will understand what I am saying.....When I started medication, my whole hair fell down (touches scalp).

Participant 7
When they draw blood from my body, a black colour will spread over that place. See fingers have gone black. It became like these when I started taking chemotherapy. Why does it happen to my fingers only? Black colour will spread wherever they put the needle on me, even where they injected me to give me glucose. It started after the third session of chemotherapy. My body shivers too (Pause).

3.2 Delay in identification of disease

Participant 1
When I consulted a doctor of the nearby hospital, he said it is because of breathing trouble and there is nothing to worry. He asked me to take an antibiotic injection. It was because of a fever that I went there. The injection administered was for fever and breathing trouble. When I went to Trivandrum, I was told to take three injections. I have taken 17 injections to this day...Now, I have cancer (Shows his neck), Cancer was identified after testing blood from here. (Showing neck).... My disease is in its third stage now...I lost almost one month on account of a doctor whom I consulted earlier..... If I had come here then, it would have given me sufficient time to do a proper treatment.

Participant 2
.....I was on treatment for pneumonia. I had an infection. I was admitted to a hospital at Allahabad... (Silence)....Occasionally I suffer from cough for the past 10-35 years, but I never took it seriously...When I felt hyperventilation and bloody sputum, I consulted a doctor. They took an X-ray. Then they admitted me to conduct Bronchoscopy and identified my disease.

3.3 Ineffective alternative treatments

Participant 1
.....Initially, I took herbal medicine for three months and by the time there weren’t any improvements much to say... When I developed breathing trouble, the doctor told me to stop taking other kinds of medicines while undergoing allopathic treatment. Ayurveda doctor allowed me to continue allopathic medicine along with their mode of treatment. But we did not pursue it by the fear of worsening the health condition. They instruct us to eat and drink only cold foods. But when we are taking allopathic medicine, we are not allowed to take cold foods.
Participant 7
I have tried Ayurveda and herbal medicines. I took Ayurveda treatment for 10 months. I had to follow a strict diet along with a liquid medicine prepared out of leaves... I had to avoid non-vegetarian food completely. Because of that, I stopped eating most of the things and as a result, my body became weak.... I couldn’t even drink tea then. That “vaidyar” was from Cherthala. They told me that I had fluid inside my chest. They do not go through any other results. I took their medicines for 6 months. Then it aggravated and I had fever. Then I consulted another Ayurveda doctor in a hospital. He went through the results and told me not to worry and that it has affected only 20% of the organ. I took medicine for 4 months from there and later stopped and came to Kozhikode. I was really sick by then-really tired.....

3.4 Money is a matter

Participant 1
I have to consult the doctor 2 or 3 times for regular checkups... Doctors demand so much money. We have to give them money whenever we consult them... The treatment charges are too high. It is difficult for the common man to meet these expenses. For each visit to the hospital, I have to spend more than 3000/- per month. Together with all the medicines that we have to buy, the expense exceeds around 20000.

Participant 3
I spend my earnings very carefully, little by little for my treatment. When it gets exhausted, what will we do? I need money for my son’s education... I need money for medicines and for this and that tests...... Can I ask you something? Could you help me to sell one-acre land? Is it possible for you? only one acre...... I will be able to get out of my financial trouble by selling it... I have borrowed a huge sum of money. If I could pay it off, I will feel better........

Participant 6
Cancer will eat the man affected with cancer. Hospitals will eat their money. Treatment costs are really high. So, most of the people will decide not to do any kind of treatments. It is a terrible disease...

Theme 4: Coming into terms

4.1 Wish to become better
4.2 Godly destiny
4.3 Death-a natural process

The formulated meanings are:

- The wishes to fulfill are formulated by the patients as per perception of their stage of illness and prognosis and they expect to become better.
- The painful adverse incidents on which we have a little, hardly or no control are blending with spirituality and creates its own meaning.
- The view towards death change from the never happening to an inevitable phase of life.

4.1 Wish to become better

Participant 1
It is natural for a man to have desires. I want to arrange a marriage for my son. I want to complete the construction of our house. My sons are building a new house; I want to live in that house happily with all of them. That is what I wish for. Nothing else matters.

Participant 3
How long has it been since I prepared food for my son? I just want to do it.

I want me to be okay just to do it. Nothing else matters to me… I have a lot of work to do when I recover from this disease. I will finish all of them. I have taken a few loans. I want to pay them back. I want to lead a good life. I want to teach my students at the school. There is nothing like teaching that can soothe your mind. I have a lot of craft objects to make if I get better in three or four weeks - clay models, decorative pieces, statues of Christ….I love to do it. I want to design dress materials

Participant 5
I should arrange a suitable marriage alliance for my daughter, that too before I die (tears…) I really wish to walk around. I don’t want to earn wealth or land for myself.... I should lead the rest of the life without being a burden to others

4.2 Godly destiny

Participant 2
I don’t think much now a day. I am not even scared now. Maybe God has destined me to experience this. What else can I say? I can't-do anything about it. Such things are not under our control. (Makes a sound as if he is under distress).... It is my fate. Yes, I used to drink and smoke. There are people who drink and smoke a lot. But they don’t have any health issues.....

Participant 3
Godly destiny

My son…. He supports me a lot. I really hope that God will protect my son (crying).... (Singing a prayer song.). I pray to God now and then. Those prayers have been a part of my life since my childhood. It soothes my mind (pause………closing eyes).

Participant 4
God destined me to have this illness. God has already stipulated the years we may live on this earth. After that, we will die. Everyone tells me not to get worried. I am not worried (looks far). It is just an illness. God himself will cure it... I do not forget to do “namaaz”. (The praying method among Muslim community)

4.3 Death: a natural process

Participant 3
None of us can live forever. Life is too short. Be happy as long as you live.....

Participant 6
I am not afraid of death. As long as we are not afraid of death, we can live bravely. Once we succumbed to fear of death nothing further can be done…. It is a terrible disease. If it continues like these it is better to die. At least you won’t
lose your hard earned money. What else is there? We all will die one day...... Many doctors themselves have died of it. Medicine will help you to live a little longer. I only think about how much longer I can live…

Participant 9
I never think about how I will die…. We have to step aside for others. What will happen, if we die suddenly? God must have decided everything when he decided to create us- when we will die, how we will live, where we will reach, what kind of disease may or may not affect us..

5. Discussions

The present study findings have been supported by a qualitative study by Joanne B, Christopher G et al to explore the experience of living with nonsmallcell Lung Cancer (NSLC) of 31 patients from 2 cancer advocacy and patient education/support organizations in the United States. The study revealed that, patients reported feeling of shock and fear on diagnosis and also loneliness during the therapy and conflated emotional well-being after diagnosis with symptoms of cancer and treatment to adverse reactions toxicities. (4).

This experience was similar with the present study participant who verbalized it as”I was shocked. It was indeed a shock for me...I feel bad when I think about it…There is no happiness in me anymore…. no happiness at all. (Crying…….wet eyes). We were leading a happy life (pause…..silence….closing eyes).

The theme diverted flow of life shows that the life of the patient with Lung Cancer has changed and the main focus of life shifted towards the health and illness. The lifestyle of the patient changed more towards the health and prevention of complications.

The study findings were supported by a qualitative study conducted by Whei-Mei Jean Shih et al in Taiwan to explore lived experience of patients with stage IVth stage lung adenocarcinoma. The study was conducted among 12 patients via semi-structured, in-depth interviews. The derived themes were: (i) emotional roller coaster, (ii) trying to find out causes, (iii) adjusting my lifestyle and (iv) cancer fighter. (5)This supports the subthemes derived in the present study, where the affected people were on the wheels of the treatment regime and had emotional turmoil. It showed that the illness causes a variety of emotional problems for the patients. Some patients experienced increased anger, sadness and frustration about their condition. One participant said “I am sad because I can’t go to work even if I have lots of work to do...I will feel really angry after they inject medicine into my body... I will lose my temper easily even if somebody tells me something, I will get angry at my children. I feel bad when I have to depend on others for my personal needs. That makes me really worried. Because of the effect of medicines, I will shout even at children.”

Catherine E et al conducted a qualitative study conducted in Indiana University to identify coping strategies with various physical and psychological symptoms among 21 advanced, symptomatic patients with lung cancer and their primary family caregivers. Individualized semi-structured qualitative interviews were conducted and the study found that patients and caregivers reported maintaining a normal routine and turning to family and friends for support with symptom management. The support from healthcare professionals and complementary and alternative medicine were viewed favourably, and several cognitive coping strategies were used such as changing expectations, maintaining positivity, avoiding illness-related thoughts and religious coping strategies.6 This supports the findings from the present study which identified subthemes as adjusting to imposed restrictions, struggling and supporting family.

Tod AM et al conducted a qualitative study was in South Yorkshire, to identify the factors influencing in delayed reporting of early symptoms and factors that facilitates earlier reporting of symptoms of Lung Cancer. The data collection was via a combination of semi-structured interviews with 20 Lung Cancer patients and survivors and a focus group of eight Lung Cancer nurses and two lay representatives. The study derived six themes to explain the barriers in reporting symptoms such as (i) experience of symptoms, (ii) knowledge, (iii) fear, (iv) blame and stigma, (v) cultural and (vi) hospital services. (10).This supports the findings from the present study which identified one subtheme as delay in identification of disease, one participant reported as "My disease is in its third stage now...I lost almost one month on account of a doctor whom I consulted earlier..... If I had come here then, it would have given me sufficient time to do a proper treatment.”

The study findings draw that there are alterations in the balance of the client and the root cause was financial instability that disrupts the social and psychological balance of life.

Crane et al conducted a mixed method study in Australia to investigate knowledge, attitudes and beliefs which may influence behaviours in relation to lung cancer symptoms, diagnosis and treatment. The qualitative data collected via 16 focus group interviews and quantitative data was collected via cross-sectional survey with the instrument Lung Cancer Awareness Measure (Lung-CAM). The study found that, hemoptysis was the only symptom creating a medical urgency, the 'wait and see' attitude creates health deterioration. Perceived risk was low amongst those at risk, smokers deny their risk and former smokers were unaware about ongoing risk. In quantitative findings, hemoptysis and dyspnea were the most recognized symptoms. (11). This supported by the present study, one participant reported “I do have cough for the past 10-35 years. But I never took it seriously...When I felt hyperventilation and bloody sputum, I consulted a doctor. They took an X-ray. Then they admitted me to conduct Bronchoscopy and identified my disease”. Another participant said “I was sleeping after dinner on 22 October 2016. Suddenly I started coughing. Then it grew worse and I started spitting blood... Cancer has affected a region where it is difficult to do anything...”

Murray et al conducted a prospective qualitative to compare the illness trajectories, needs and service use of patients with cancer and those with advanced non-malignant disease among 20 patients with inoperable Lung Cancer and among
20 patients with advanced cardiac failure and their main informal and professional caregivers. The study found that the major concern of patients with Lung Cancer and their caregivers was facing death, frustration, social isolation, progressive losses, and the stress of following a complex medication regimen. More health and social services including financial benefits were available to those with Lung Cancer, although they were not always used effectively. The findings supports the present study. The subtheme death a natural process, one participant stated “None of us can live forever. Life is too short. Be happy as long as you live” The present study shows that at the last patients accepting the facts that being affected by the terminal illness there is no complete cure and the only possible way is to live with a positive attitude.

Sigridur H et al conducted a phenomenological study of patients having cancer. The data were collected from 9 patients and analyzed using Colalzzi’s method. The findings showed that the main derived theme was experiencing the existential changes with five subthemes namely uncertainty, vulnerability, isolation, discomfort and redefinition. This supports the present study findings, one participant said: “God must have decided everything when he decided to create us- when we will die, how we will live, where we will reach, what kind of disease may or may not affect us.”

6. Conclusions

The formulated results can aid the supportive care services to develop new interventional research to prevent the illness to promote the health and to alleviate the suffering. There are areas to be researched in the promotive as well as restorative healthcare practices for patients with different stages of cancers including Lung Cancer.

References


