| Phase of Cancer Trajectory | Themes regarding challenges from lung cancer survivors and caregivers | Illustrative quotes |
|----------------------------|-------------------------------------------------|---------------------|
| Being diagnosed            | Recognition of symptoms as lung cancer           | • *I had a pain in my diaphragm. First I was told it was a pulled muscle; then an infection, and when it didn’t go away, that the wrong antibiotic had been used...I waited 6 months to see the specialist and by then he said he couldn’t do anything. It was too late.* (female patient)  
• *His cough and shortness of breath was dismissed at first. He was not a smoker and we didn’t even think about lung cancer.* (wife, caregiver)  
• *We lost two years treating what everyone thought was sciatica...the tumor was not seen until an MRI was done.* (wife, caregiver)  
• *We were shocked at the diagnosis. We had never even considered the possibility of lung cancer. Lung cancer is a smoker’s disease and he had never smoked.* (wife, caregiver) |
| Timeliness of tests and receiving results | | • *I had a cough and it was treated with two or three antibiotics before anything else was investigated. It was 8 months, I think, before I was really diagnosed.* (female patient)  
• *It took a year to finally make the diagnosis. Looking back, I feel like I really lost out on a year I could have been getting treatment...the first spot on the x-ray was interpreted as having to do with my COPD, maybe scar tissue.* (female patient)  
• *The symptom was really not typical for lung cancer, pain in my back, and it took ages to go through the tests and see what was really going on.* (male patient)  
• *The most frustrating thing for me was how long it took to get diagnosed....once in the system, things went well. It was the lead up that was the concern.* (daughter) |
| Emotional ‘shock’ of the diagnosis | | • *Hearing the diagnosis was a huge shock. It was like getting a life sentence for me. I felt I was close to the next journey of my life...what happens now?* (male patient) |
### Exploring patient and family experiences

| How the diagnosis was communicated | Negative communication                                                                 |
|-----------------------------------|----------------------------------------------------------------------------------------|
| **•**                             | **•** We were completely blindsided by the whole thing; complete and utter shock is an understatement. (wife) |
| **•**                             | **•** There is an emotional aspect to cancer, to be diagnosed – especially when there is a long drawn out process for getting diagnosed. (female patient) |
| **•**                             | **•** There is no doubt that cancer changes you. It changes your life…lung cancer and death have gone together for years in people’s minds. (male patient) |
| **How health care professional communicate the words they use, that is an issue. I would say stay away from using the word ‘palliation’ at the first diagnosis. I had a shock already [with the diagnosis] and then heard the word palliative and had another. He presented lung cancer as a death sentence. (female patient)** | **•** The biggest issue for me is that I am not sure the patients really understand what is being said…I am not convinced that they understand the seriousness of the situation and the benefits of treatment in that situation. Health care professionals really need to be clear in what they tell patients. (daughter) |
| **•**                             | **•** I really think she ought to have been more sympathetic when she told me…I went back a month later and told her I did not appreciate how she told me…we were all so very worried and it was not necessary in the end…She told me to make my will and plan my funeral. (female patient) |
| **Positive communication**        | **•** How health care professional communicate and the words they use, that is an issue. I would say stay away from using the word ‘palliation’ at the first diagnosis. I had a shock already [with the diagnosis] and then heard the word palliative and had another. He presented lung cancer as a death sentence. (female patient)** |
| **•**                             | **•** People need to know it is not an immediate death sentence like it used to be…it’s a different story now. (female patient) |
| **•**                             | **•** Lung cancer is a good news story now. There are plenty of hopeful cases…there are possibilities for a longer life…a productive life…it is not a death sentence. (male patient) |
| **•**                             | **•** There can be more winners now with lung cancer…you can be a winner and survive. (male patient) |
### Exploring patient and family experiences

| Undergoing treatment | Need for information about disease and treatment options |
|----------------------|----------------------------------------------------------|
|                      | • When I was diagnosed, I really did not know much about lung cancer. I was just told the diagnosis and that was it. I was young at the time and had so many questions...so did my family...I really did not know what was happening to me. (male patient) |
|                      | • ...there was not much information around about lung cancer...you are really on your own to find it. (female patient) |
|                      | • It was really a very steep learning curve for me [after the diagnosis]. It was all so new for me...all the words they use are hard to understand. (male patient) |
|                      | • Hearing the diagnosis was a shock...I began to think about all the things I needed to do...what happens now? There were so many things to sort out. (male patient) |
|                      | • You feel bombarded at first, dragged into an undertow, dread about what is going to happen and whether you will survive. (female patient) |
|                      | • For me, I wanted to see the definitive evidence, what treatment approaches were really going to work? What choices did I have? (male patient) |
|                      | • I drove back and forth each day – it was 400 kilometers roundtrip...At first it was OK, but my biggest concern was the fatigue. I worried about falling asleep while I was driving. (male patient) |
|                      | • I lived too far away to go back and forth every day, so I stayed in the city. It gets costly and you are away from your family...I worried about what was happening at home. (female patient) |
|                      | • Sometimes, you feel so overwhelmed, you can forget to breathe. (female patient) |
|                      | • It’s not just one thing, you know, it’s a number of things all happening together. I am tired but the pain means I can’t sleep soundly. I wake up tired and I don’t want to do anything, but I am bored. I’m used to being busy at work, but right now I cannot focus on that and do not have the energy for it. (male patient) |

| Dealing with the demands of treatment (driving every day, symptoms and side effects, ) | |
|------------------------------------------|----------------------------------------------------------|
| • I drove back and forth each day – it was 400 kilometers roundtrip...At first it was OK, but my biggest concern was the fatigue. I worried about falling asleep while I was driving. (male patient) |
| • I lived too far away to go back and forth every day, so I stayed in the city. It gets costly and you are away from your family...I worried about what was happening at home. (female patient) |
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| • It’s not just one thing, you know, it’s a number of things all happening together. I am tired but the pain means I can’t sleep soundly. I wake up tired and I don’t want to do anything, but I am bored. I’m used to being busy at work, but right now I cannot focus on that and do not have the energy for it. (male patient) |
| Exploring patient and family experiences |
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| **Not being able to work/do usual activities** |
| - I had shortness of breath; gained approximately 45 pounds during treatment; ended up with neuropathy in my feet and legs; difficulty walking, especially up and down stairs. I also ended up with tendinitis in both ankles and was told not to walk for 6 months or I would end up with casts since it was so severe. Trying to tackle housework and prepare nutritional meals was impossible because I was so tired. I felt help could of, should of been available. *(female patient)* |
| - I eventually got the help I needed for the pain, but a lot I figured out on my own. *(female patient)* |
| - Especially if you live alone, you get so very, very tired with treatment, you need someone to check in on you and to help with the practical things, like getting the groceries. I could go to the store if someone drove me, but then I couldn’t lift the bags of groceries. *(female patient)* |
| - I really could not do my usual things around the house or the yard, I just did not have the energy for anything. *(male patient)* |
| - There needs to be some sort of infrastructure supporting the family...they need to know how to help...I felt like a burden to them. *(male patient)* |
| - Probably the toughest thing for me was not working...and wondering if and when I go back. *(male patient)* |
| - I had to stop working for a while and took a hit financially as I am self-employed...found it hard to get back on my feet again when I went back...even now I am not at my old level *(male patient)* |
| **Finding support services/groups** |
| - It’s so frustrating. There were times when I wanted to talk with someone about lung cancer and there was nowhere to turn...no one to talk to. *(female patient)* |
| - I did not have anyone to talk to about what was happening, not even social work was offered to me. *(Female patient)* |
| - A major gap is that there are no groups for lung cancer patients...you feel so alone and have nowhere to turn...I |
Exploring patient and family experiences

| Facing the stigma of having lung cancer | attended a support group when I had breast cancer and I know how helpful it can be. (female patient)  
• There was no one else my age in the cancer centre...when I went to a retreat and met others my age, it was eye-opening...I could relate...share experiences with each other...it changed my perspective completely. (male patient)  
• There are few supports for lung cancer patients and none for families. They are coping too and trying to help a loved one get through a tough time. They need support too. (Male patient)  
• So many patients do not know what resources exist and feel so overwhelmed with all the appointments and stress. They need help to connect with the services in the communities. (Female)  
• I was not always sure how to get the help we needed or who to call? (daughter) |
| --- | --- |
| Once treatment is finished... surviving lung cancer | The first thing everybody seems to ask is did I smoke, you know, when they hear it is lung cancer. And I never smoked a day in my life!  (female patient)  
• You are given a horrific diagnosis and now have to deal with the stigma...now you are being judged by everyone...not asked how you are doing, but did you smoke?...it really adds to the burden you feel...it is the biggest issue for me. (female patient, non-smoker)  
• It’s like you deserve to have lung cancer...it’s like they think, what did you expect if you smoked?...so you are embarrassed to tell others. (female patient)  
• There really is a difference in the way people react to you if you have breast or prostate cancer and if you have lung cancer...You get so you hesitate to volunteer the information that you have lung cancer or reach out for help because of the reaction you get. (female patient) |
| Dealing with long term effects of treatment | The team at the cancer centre was wonderful. They were so supportive when I went there, asking me how I was doing...once I finished there I felt a little disconnected. (female patient) |
| Exploring patient and family experiences |
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| **Getting back to ‘normal’** |
| **After months and months of surgery, chemotherapy, radiation, visits to cancer Centre that it ended abruptly, and I was just sent back to my life again. I was fearful and felt there was no one to talk to about it.** (female patient) |
| **There are side effects that come a few years after treatment that affect your quality of life. And they depend on which treatment you had, targeted therapies or chemo: edema, forgetfulness, memory loss, weight gain, arthritis, skin rashes, digestive changes...you have to learn to live with the disease after treatment...figure what it all means, what to expect, what questions to ask, what you need now.** (female patient) |
| **My biggest challenge was trying to determine who is coordinating my care following surgery! Who do I call when I am feeling hopeless, depressed, & just having “bad day”. I was not provided any support resources. Lack of emotional support for returning to work. Making self-referrals for post op complications, (physio, footwear, etc.)** (female patient) |
| **Dad started on [name of medication] and he was like a new man – he had a new lease on life. He and Mom went travelling, it was unbelievable to see the difference. He had a wonderful 5 years.** (daughter) |
| **Getting back to normal afterwards – you thought you had a death sentence and now the treatment was a success and now you have to come back, to adjust...both you and your family...it’s not so easy...you’re entire world turns upside down...life is on hold for a while...and it’s hard to get back to it all.** (male patient) |
| **You are walking around and looking healthy; people hardly can believe that you have lung cancer.** (male patient) |
| **No direction as to potential way to reduce the chance of the cancer returning & what to do, how to navigate** (male patient) |
| **Trying to go back to the person I was but really didn’t exist anymore & realizing that would never happen. It changes who you are & how you look at the world & life.** (female patient) |
| Exploring patient and family experiences |
|------------------------------------------|
| **I was lost and scared. You spend all your energies on treatment. When it was over I felt overwhelmed not knowing what to do. (female patient)** |
| **I was trying to plan my life and, to make a long story short, I was trying to figure out if I should invest my time in rest and healing with focus on the long term or stay very active and make memories for my family in the short term. I’m a realist and I want to balance my life according to both possible outcomes. This all related to my poor yet very vague prognosis. (male patient)** |
| **Getting back to a new normal. Things have changed regarding my memory and attention span so I’ve had to adapt my life to these changes. I’m also a lot more emotional. When I think back to what I’ve been through gets me teary-eyed. (female patient)** |
| **You have to adjust to a new way of breathing. I never felt my lungs before…I have to think about breathing now…I had to learn new ways of breathing and doing activities, even like speaking. (male patient)** |
| **Some days you can sort of forget about it and go on with whatever you’re doing. Other days not so much. You hear a news story or someone tells you about someone who was just diagnosed and it all comes rushing back…you feel a little like you cannot control it. You just have to learn to live with it, with the uncertainty. (female patient)** |
| **The mental challenge of accepting that the cancer was gone and was not coming back, the constant fear of it returning.** |
| **I am going to focus on getting the house remodeled as it will help with the eventual resale. (female patient)** |
| **I can see how finances would be a worry for some patients, especially after while if they are not able to work or do not have a coverage plan of some sort there could be a drain on the family finances. (male patient)** |
### Living with advanced disease

#### Dealing with symptoms

|   |   |
|---|---|
| • | *I find I have to pace myself when I garden. I cannot lift things the same or stay out as look without a break. I get tired and short of breath. (female patient)* |
| • | *“It’s a good thing I do not have to work right now, I could never hold a [work instrument] with these hands or stand all day with these feet. I am really unsteady when I walk and when I stand, it takes me a little time before I can get going. (female patient)* |
| • | *Targeted therapies can be ‘healthy’, let you live life and do things, have a full life. You just have to watch your energy levels and what you want to do each day…I really have no symptoms and feel like a million dollars now. (male patient)* |

#### Obtaining information about and access to services (especially for care and support at home)

|   |   |
|---|---|
| • | *Dad really wanted to stay at home and not go to hospital and we wanted to make sure that happened. But it was hard on all of us, but especially on Mom. She was pretty isolated from her friends and normal activities. (daughter)* |
| • | *He just kept right on living despite everything that was happening…he was determined. (wife)* |
| • | *Mom was the main caregiver and she was there almost all the time. She was worn out. We were not sure what help we could get for her. (daughter)* |
| • | *She is at a point she really cannot stay by herself any more. Her reactions are really slow and she is not thinking clearly. I am afraid she will fall and not be able to get up or something else will happen…we have to organize the family because it is a weekend and we can’t get other help right now. (sister)* |
| • | *Dad is deteriorating now and I think we need more support, but I am not sure how to get that help. Who do I call? (daughter)* |
| • | *The family takes the brunt of the burden…and it is huge. And sometimes the services do not match what you need when you need it…for a whole year my Mother’s life went on hold. You can’t leave the house. (daughter)* |
| • | *Caring for someone at home [who is dying] is 24/7. It’s like having two full time jobs. I couldn’t have managed work and* |
### Exploring patient and family experiences

|                |                                                                                                                                  |
|----------------|-----------------------------------------------------------------------------------------------------------------------------------|
| **Looking after him on my own if my daughter had not moved back home.** (wife, caregiver) |                                                                                                                                 |
| **Navigating the system** |                                                                                                                                  |
| • | We just don’t have those services easily available where we live in a small town...Once, the family doctor was away and the covering doctor did not seem to know what to do, so we took Dad back to the city to see the specialist. He knew right away what was needed to get the pain under control. (daughter) |
| **Balancing life situation/demands** |                                                                                                                                 |
| • | I went to a program and learned a lot about breathing exercises and pacing myself. (female patient)                             |
| • | Balancing my life, with my children and my household and my work, as well as supporting Mom and Dad and meeting their needs for care, it was a real balancing act. (daughter) |
| • | It’s taken a year for my mother to get back on her feed. She was the main caregiver at home and it was hard on her. (daughter)   |