RESEARCH ARTICLE

Lived Experience among Patients Newly Diagnosed with Lung Adenocarcinoma Stage IV within One Year

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Abstract

Background: lung cancer (LC) is the fifth of the 10 leading causes of death in the world. LC is in first place for cancer-related mortality for both males and females in Taiwan. It is one of the most difficult cancers to treat and is often diagnosed at a late stage. Patients with stage IV are often unprepared for the diagnosis. Materials and Methods: To explore lived experience among patients newly diagnosed with lung adenocarcinoma stage IV within one year. Results: Twelve participants were recruited in this study. Content analysis of the interviews revealed four themes: (1) emotional roller coaster, (2) trying to find out causes, (3) adjusting my lifestyle, and (4) cancer fighter. Conclusions: This study provides new insight into the experiences of lung cancer patients y with newly diagnosed lung adenocarcinoma stage 4. These results will inform future supportive care service development and intervention research for patients with advanced stage cancer.

Keywords: Lung cancer - adenocarcinoma - advanced stage - qualitative experience - Taiwan

Introduction

According to World Health Organization (WHO) statistics, lung cancer (LC) is the fifth of the 10 leading causes of death in the world (WHO, 2015). Lung cancers (along with trachea and bronchus cancers) caused 1.6 million (2.9%) deaths and contributing 13% of the total number of new cases diagnosed in 2012, up from 1.2 million (2.2%) deaths in 2000 (Ferlay et al, 2014). In Taiwan, cancer is the leading cause of death. In 2013, 29% of people died from the ten leading causes of death in Taiwan. Among them, LC is the first place of cancer death for both male and female (Health Promotion Administration, Ministry of Health and Welfare , 2015). LC is considered a serious public health problem that is primarily associated with smoking. WHO estimates that in 2030, the number of deaths due to tobacco consumption will reach 100 million, with part of this figure due to an increased incidence of LC (Xie and Minna, 2008).

The main primary types of LC are small-cell lung carcinoma (SCLC) and non-small-cell lung carcinoma (NSCLC). NSCLC accounts for approximately 85% of all cases of lung cancer (Navada et al., 2008). The most common subtypes of NSCLC are adenocarcinoma, squamous-cell carcinoma and large-cell carcinoma (Horn et al., 2012). Nearly 40% of lung cancers are adenocarcinoma, which usually originates in peripheral lung tissue (Lu et al., 2010). After the initial diagnosis of NSCLC, the determination of stage is crucial for appropriate therapy. NSCLC is broken down using the TNM (T-tumor, N-lymph nodes, M-metastasis) staging system into four stages: stage I, the cancer is localized within the lung and has not spread to any lymph nodes; stage II, the cancer has spread to lymph nodes or the lining of the lungs, or is in a certain area of the main bronchus; stage III, the cancer has spread to tissue near the lungs; stage IV, the cancer has spread to another part of the body. In 2007, the International Association for the Study of Lung Cancer (IASLC) initiated the IASLC Lung Cancer Staging Project about lung cancer on more than 81,000 patients from 19 countries between 1990 and 2000(Goldstraw, Crowley, Chansky, Giroux, Groome, Rami-Porta, et al, 2007). The study gave the following statistics about survival for non-small cell lung cancer: For stage I, 43 - 73% of patients will survive for 5 years or more after diagnosis. For stage II, 25-46% of patients will survive for 5 years or more after diagnosis. For stage III, 7-24% of patients will survive for 5 years or more after diagnosis. For stage IV, the most advanced stage of lung cancer, the survival statistics are very low and about 2-13% will survive for 5 years or more after diagnosis. According to Koo Foundation Sun Yat-Sen Cancer Center's research in Taiwan, Taiwanese patient's surviving 5 years from the time of diagnosis of LC for each stage from 1990 to 2009 were stage I - 69.5%, stage II - 44.2%, stage III - 13.8, and stage IV - 5.4% respectively (2015). This statistics of the reports coincided with IASLC reports.

Most lung cancers do not cause any symptoms until they have spread too far to be cured, but symptoms do occur in some people with early lung cancer. The most common symptoms of LC are persistent cough and coughing up blood. Other symptoms include hoarseness,

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weight loss, malaise, shortness of breath, loss of appetite, wheezing, and chest pains (Beckles et al, 2003; Horn, et al, 2012). Lung cancer is often first suspected when chest x-ray showed abnormalities. The procedures used to confirm NSCLC include history, physical examination, routine laboratory evaluations, sputum cytology, chest CT scan with infusion of contrast material, and biopsy.

Lung cancer is one of the most difficult cancers to treat. It is often diagnosed at a late stage. Stage IV non-small cell lung cancer is the most advanced stage of lung cancer. Nearly 40% of people newly diagnosed with lung cancer already have stage IV disease (Ellis and Vandermeer, 2011). This stage of lung cancer is not curable, but it is treatable, and many clinical trials are in progress looking at new treatments to improve survival. Lung cancer if left untreated can spread beyond the lung into nearby tissue or other parts of the body. Treatments of NSCLC can include surgery, chemotherapy, targeted therapies, radiation therapy, or a combination of these and it depends on patient's stage. For instance, surgery can be used for patient in the early stage. Currently, patients with stage IV are considered for nonsurgical treatment such as chemotherapy and molecular targeted therapy. The major physical side effects identified for chemotherapy and molecular targeted therapy were emesis, nausea, and hair loss (Carelle et al., 2002; Widakowich et al., 2007).

A number of factors may increase risk of lung cancer, such as smoking, exposure to secondhand smoke, exposure to radon gas, exposure to asbestos and other chemicals, and family history of lung cancer (Molina et al., 2008; Noronha et al, 2012). Risk of lung cancer increases with the number of cigarettes each day and the number of years of smoking. The patterns in lung cancer incidence are influenced by past trends in exposure to tobacco smoking, which is the overwhelmingly predominant cause of the disease (Alberg et al., 2007; Kamangar et al., 2006). If one person exposed to secondhand smoke, the risk of lung cancer increases. Although cigarette smoking is the primary cause of LC, not all smokers develop this disease, whereas a fraction of lifelong nonsmokers die from it. According to a systematic study showed that about 10-15% of cases occur in people who have never smoked (Thun et al., 2008). Thus, in addition to environmental factors, genetic background has been recently implicated as a cause of differences in LC susceptibility. Radon is produced by the natural breakdown of uranium in soil, rock and water that eventually becomes part of the air you breathe and is the second cause of adenocarcinoma of lung. In Turner's dissertation, there were significant positive associations between ecological indicators of residential radon and fine particulate matter air pollution (PM2.5) and lung cancer mortality (2012). Previous tuberculosis history was found correlated with an elevated risk of squamous/small cell carcinoma and adenocarcinoma for male patient. For female, the use of range hoods in the kitchen and the habit of waiting to fry after the fumes emitted were attributed to squamous/small cell carcinoma and adenocarcinoma (Lee et al, 2001). In addition to above risk factors, lung cancer incidence was associated with low educational, occupational, and income-based socioeconomic position (SEP) (Sidorchuk et al., 2009).

Previous reports have shown that most lung cancer patients are diagnosed at an advanced stage (Little et al., 2007). Not unexpected, since 65% of people have already progressed to stage IV lung cancer at the time they are diagnosed (Yang et al., 2005). Patients with advanced cancer stage in a shorter time of their diagnosis revealed more impact on their psychological distress. Unfortunately, little information is available regarding experiences among patients newly diagnosed with lung adenocarcinoma stage IV. The purpose of this study was to explore lived experiences among patients newly diagnosed with lung adenocarcinoma stage IV within one year. The findings could provide the basis of an improved supportive care for these patients.

Materials and Methods

Data of this research study were collected from in-depth interviews. A semi-structured , open-ended question guide that was designed by the researchers according to research aim and relevant literature was followed when one-to-one interviews were carried out. The subjects were identified by purposive sampling with the following criteria: (1) more than 18 years old; (2) diagnosed with lung adenocarcinoma stage IV; (3) ability to communicate clearly in Mandarin or Taiwanese; (4) no learning, hearing, or communication difficulties; (5) willing to participate in this study. Patients who were too ill to be interviewed were excluded in this study. Twelve participants were recruited in this study.

The constant comparative method was used to collect data by newly collected data comparing with previous data that was collected on one or more earlier studies (Strauss and Corbin, 1990). It is a continuous ongoing procedure. No pre-established conceptual framework or theory was used to guide the analysis. Data analysis involved coding and classifying data, also referred to as categorizing and indexing and the aim of context analysis was to make sense of the data collected and to highlight the important messages, features or findings. Rogor standards of the data were established by using the criteria of Lincoln and Guba (1985): credibility, dependability, confirmability, and transferability to make sure of reliability.

Results

A total of 12 patients recruited in this study with 7 males and 5 females ranging from 39 to 70 years old with an average age of 59. Among these patients, 3 males and 4 females had never smoked, 3 males quit smoking, and one male and the other female smoked 2 packs a day for more than 30 years. The average time of interview after diagnosis was 3.8 months. At the time of interview, 6 patients were accompanies by their spouses, 4 by their children, 1 by his father, and 1 by his brother.

From transcript data, which were carefully coded and categorized, four themes were identified, namely: *(i)* emotional roller coaster, *(ii)* trying to find out causes, *(iii)* adjusting my lifestyle, and *(iv)* cancer fighter. Individual themes were explained more detail into sub-themes below, using direct quotations from participants as much

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as possible to ensure a sense of authenticity, and further attempt to demonstrate the credibility of interpretation of findings.

Emotional roller coaster

Since most of the patients were misdiagnosed at the beginning and often diagnosed at a late stage, their emotion moved up and down along with examinations and treatments. There were four sub-themes: why me, complaint of delay of diagnosis, sentenced to death, and accepting the truth reluctantly.

(i) Why me: Most of lung cancer patients only have mild symptoms such as chronic cough. So, when they were diagnosed of lung cancer at the late stage, they could not accept this result. One patient said, "I don't smoke or drink. I live a healthy life. There is no reason I got this disease. I am so unlucky." Another patient stated, "People around me such as my co-workers and friends they do smoke as me, then, why only me? Why? It's unfair."

(ii) Complaint of delay of diagnosis: At the very beginning, patients thought it was cold and went to private clinic and there, they were treated as cold as well. After certain period of treatment without any improvement, they started going to hospital for help. One patient said, " I coughed for a long time and doctor suspected chronic rhinitis and then pneumonia, and at last lung cancer. What a joke." Another patient stated," Is it very difficult to diagnose lung cancer? I've never stopped coughing, so I visited both traditional medicine clinic and Chinese medicine clinic for a period of time and in vain. I was treated as cold, pneumonia, tuberculosis, and finally diagnosed as lung cancer. It's a long journey for me to find out what's going on with me. Now I know whenever you are sick, go to a big hospital and find a good doctor so you don't waste time and get wrong diagnosis."

(iii) Sentenced to death: Stage IV NSCLC is the most advanced form of this disease. In this stage, the cancer has metastasized, or spread, beyond the lungs into other areas of the body. It is not curable but treatable. One patient stated," To me, it's like sentenced to death. I know I am clutching at straws with little hope now." Another patient said, "To me, the doctor's announcement of my diagnosis is like sentenced me to death. This is a very advanced stage. I am not mentally prepared."

(iv) Accepting the truth reluctantly: Since there is no severe symptom for lung cancer, it was hard for patients to accept it. One man said," I have no choice but to accept it. Another patient revealed, "There is no way to blame the gods. Such being the fact, I have to accept it."

Trying to find out causes

There are many risk factors for getting lung adenocarcinoma. Most of people know that cigarette smoking is the primary risk factor but some of the patients had never smoked. There were two sub-themes: trying to get answer from physician, and trying to reflect from self.

(i) Trying to get answer from physician: most of patients were uncertain of the cause of getting lung cancer, so they tried to get answer from physician. One patient said," there is no reason that I got lung cancer. I don't smoke. I asked my doctor why I still got lung cancer."

Another patient stated," I asked doctor if this was from gene because I happened to watch from the news. I had never smoked before." The other patient responded, "I don't smoke. I am a housewife and I cook everyday. I asked my doctor if my lung cancer is due to smoke from cooking.

(ii) Trying to reflect from self: Especially for those patients who had never smoked. Most of Chinese worship their gods at home by burning incense and gold money and this produced smoke. One female responded," I don't smoke and neither of my family. I don't cook but my mother burned incense and worshiped the god every day. I strongly suspected the incense was the cause of my lung adenocarcinoma because I smelled the particular smell every day and it might contain toxicant. I knew one of the sincere monks also had adenocarcinoma. Now, my mother stopped it." The other female stated, "I just realized that my cause of lung adenocarcinoma might be from the radon gas because I moved into a new house with marble floor and kitchen, new furniture, and paintings a few years ago. I am a housewife and I rarely opened my windows all year around. My close friend told me that was the reason why I got cancer because the environment I was in was very toxic. Now I tried to open the windows even in the winter and I also used air cleaner." Another female said, "None of my family smoked and I searched the paper and knew that we as oriental women have higher possibility to get lung cancer. I think it is gene."

Adjusting my lifestyle

Most of the patients expressed that even the diagnosis was at a late stage, they still hoped to adjust their lifestyle to prolong their lives. There were three sub-themes: avoiding risk factors, searching for nutrition good for me, and having regular exercise.

(i) Avoiding risk factors: One patient said," I used to smoke a lot and stopped after I was hospitalized. I knew it was kind of late but I wanted to live longer. I want to behave from now on." Another patient stated, "I tried to avoid the places with smoke such as temple and barbecue restaurant, and I tried to cook with boil technique and avoid frying".

(ii) Searching for nutrition good for me: one female responded, "I know broccoli was a magical natural food and good for anti-cancer. Other cruciferous plants such as cauliflower, cabbage, and radish were also good for your body". The other man said," I used to live an unhealthy life with fry food, sweet food such as ice cream, cake, and chocolate. Now I quit eating those junk foods." Another patient responded, " I drank the five elements vegetable soup and brown rice tea every day and they were actively promoted by the Japanese Cancer Association. These five elements were green - leaves of daikon, red - carrot, yellow - burdock, white - daikon, and black - black mushroom. These healthy foods can increase the immune system of the body and decrease the chance of getting cancer. If you were interested in this, you could buy the book written by Japanese doctor Kazu Tateishi. There were no side effect in a long run and can improve immune system." One patient said," the side effect of target therapy was liver damage and my sister suggested me drink essence of clam

for robust liver health and I did. What a surprise that my liver function got better after I drank for several times. It's amazing. During chemotherapy, I tried to eat high protein and high calories foods and also ate L-Glutamine for my mouth ulcer."

(iii) Having regular exercise: One patient responded, "I stayed late all the time and barely exercise and now I've changed all these bad habits. I woke up at six thirty and started to do walking for 20-30 minutes for 2-3 times a week. I tried not to stay late. My wife reminds me every day." Another patient stated, "A lot of reports revealed that regular exercise can reduce the risk of getting cancer. I tried to exercise whenever my energy is better. I wanted to build up my immune system so I can conquer this disease."

Cancer fighter

Most of people were shocked when diagnosing with lung cancer. Since some of their conditions allowed them to participate aggressively in all treatment, they expressed the willingness to fight for cancer. There were three sub-themes: where there is life there is hope, searching for beneficial resources, and support from family and friends.

(i) Where there is life there is hope: One patient stated, "I don't like to muddle along with my life with ignorance of it at last. I don't like to grumble against god and lay the blame upon other people. I know what I have lived for. So, I would make every effort and fight for it." The other patient said, "After sobbing wildly, I convinced myself not to show too feeble. Then, I dried my tears and was ready to prepare for a long-term anti-cancer life." Another patient responded," Let by gone be by gone. I confidently told myself to be positively facing this disease. I hoped these bad cancer cells could be changed to good normal cells."

(ii) Searching for beneficial resources: One patient responded, " I incidentally watched TV regarding immunization therapy in other country. A woman with stage 4 lung cancer underwent immunization therapy after chemo-therapy in vain and showed improvement. I was hoping I can have this treatment someday." The other patient said," I searched website and found out a book "Anticancer: A New Way of Life" by David Servan-Schreiber stating eating more foods with Omega-3 to reduce inflammation and metastasis of cancer cells. Taiwanofungus camphoratus and Flaxseed are other choices for anti-cancer food." Another patient stated, " I've tried Chinese medicine such as acupuncture to relieve my pain and ease cancer treatment side effects such as nausea and vomiting. "

(iii) Support from family and friends: Family and friends support are important to patient when facing cancer treatments. They are the motivation for these patients to live as well. Family and friend can provide the practical support patients need, such as helping take care of the house or serving as emotional support. The patient responded, " I am so lucky to have my family around me. My husband would search a lot of information from website and gave me a lot of information such as taking L-Glutamine for mouth ulcer while doing chemo-therapy and eating anti-cancer foods." Another patient said, " My husband always remind me to cut out the non-essential tasks from my day so that I can save my energy for what

needs to be done. " The other patient states, " One of my close friend provided me with lot of information regarding healthy foods and anti-cancer goods such as the five elements vegetable soup. My husband is always by my side and is willing to listen to me talk about my hopes and fears."

Discussion

The purpose of this research was to gain insight into lived experiences among patients newly diagnosed with lung adenocarcinoma stage IV within one year. The main themes that explained study participants' experiences were revealed both in psychological and physiological perspectives. The results of this study showed that even patients were in the stage IV of lung cancer and experienced tough time they have being through, they still wanted to fight for cancer. As long as there is hope to live, they want to try.

Symptoms of lung cancer do not usually occur until it is advanced, and may include persistent cough, sputum streaked with blood, chest pain, voice change, worsening shortness of breath, and recurrent pneumonia or bronchitis (American Cancer Society, 2015). Most people are less likely to see their doctor urgently if they display symptoms such as a constant cough or voice change. A prolonged delay is thought to take place between patients noticing symptoms and reporting them to a doctor (Tod, Craven, and Allmark, 2008). Only 15% of lung cancers are diagnosed at a localized stage, for which the 5-year survival rate is 54%. More than half (57%) are diagnosed at a distant stage, for which the 1- and 5-year survival is 26% and 4%, respectively (American Cancer Society, 2015). Therefore, early detection or diagnosing lung cancer may have a minimal effect on reducing mortality as people do not develop symptoms until the cancer is at an advanced stage. It is of importance to increase public awareness of cancer symptoms and promoting early presentation. As far as in helping cancer patient's emotional responses, the first step for health care professionals is to know that the usual defense mechanisms among oncology patients are regression, denial, projection and suppression (Gregurek, Braš, Đorđević, Ratković and Brajković, 2010) then provide proper care according the different emotional responses.

Risk factors of lung cancer are cigarette smoking, secondhand or passive tobacco smoking, alcohol, air pollution, cooking and heating fumes, occupational exposure such as Crystalline silica and chrysotile asbestos, lung cancer susceptibility genes (Couraud et al., 2012; Molina et al., 2009). Based on reports from Ministry of Transportation and Communications, there were 7.3 million of vehicles and 14.1 million of motorcycles in 2013. PM2.5 in some areas was above 3-4 times of WHO standard. Another research conducting by National Health Research Institutes in Taiwan revealed that cooking fume exposure was a risk factor of lung cancer in Chinese women nonsmokers (Chen et al., 2013). Quite often, Buddhism and Taoism believers worship their god by burning incense and gold money at their home. According to Taiwan 2013 international religious freedom report,

Buddhism and Taoism are major religions in Taiwan which representing 35% and 33% respectively. These factors are considered risk factors in addition to cigarette smoking in Taiwan. Therefore, educating public in taking public transportation, wearing mask when encountering high PM2.5, and cooking food with low grade of heat is of importance to reduce risk factors common seen in Taiwan.

Based on the recommendations from American Lung Association (2015), nutrition is a very important part of lung cancer treatment. Eating the right kinds of food can help patients feel better and stay stronger. Other diet such as dietary fat composition, amino acid supplementation, grapes and grape-based products are excellent sources of various anticancer agents (Kaur et al., 2009; Robinson and Lindsay, 2000). In Taiwan, Taiwanofungus camphoratus, an indigenous mushroom, is commonly used as an anti-cancer herb. It is a kind of rare medical fungus that only grows in Taiwan. Study showed that Taiwanofungus camphoratus was a potential anticancer agent to make cancer no longer a frightening nightmare (Chen et al., 2010). Therefore, some patients would try this Chinese medicine for their cancer. As for support system, family and friends are crucial for patients in both psychological and physical. Study revealed maintaining contact with family and friends for support was important for their quality of life (John, 2010; Eustache et al., 2014). Several strategies such as changing expectations, maintaining positivity, avoiding illness-related thoughts, religion, budgeting time and energy, exercise, relaxation are helpful for cancer patients (John, 2010; Adamsen et al., 2012; Mosher et al., 2015).

Lung cancer is a devastating disease. Maintaining quality of life should always be considered. Appropriate lung cancer care is affected by socio-demographic factors. Greater attention to social and health programs is recommended to improve the timeliness of diagnosis, the staging of potentially resectable patients, and to implement more comprehensive multidisciplinary evaluations of those who may benefit from curative treatments (Pagano, et al, 2010). A diagnosis of late stage of lung cancer is frightening and patients may feel very alone. Health care professionals should encourage patient's loved ones to support them as possible. Family or care givers have no idea how to react toward someone who is diagnosed with cancer especially with advanced stage. Letting people know specific things they can do to help may ease their anxiety, as well as fill their need for extra support at this time.

In conclusion this study demonstrated the lived experiences among patients newly diagnosed with lung adenocarcinoma Stage IV within one year. These results will inform future supportive care service development and intervention research for patients with advanced stage.

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Newly diagnosed without treatment