ORIGINAL RESEARCH

The lived experiences of smokers with lung cancer

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ABSTRACT

Objective: The aims of this research were to learn about the lived experiences of patients with lung cancer who smoke tobacco and to provide nurses with more insights into complexities of people's relationship with their smoking.
Methods: Descriptive phenomenology was used to explore the lived experiences of smokers with lung cancer. An in-depth unstructured conversational style interview was used as a method for data collection. The study was conducted in the inpatient, outpatient, and day care units at the National Center for Cancer Care and Research (NCCCR) in Qatar. Purposive sampling was used to recruit five lung cancer patients who smoke. Colaizzi's (1978) method was used to analyze data.
Results: Participants described three related themes: (a) fate, (b) a socially acceptable addiction, and (c) self-blame and guilt.
Conclusions: The findings of this study are of interest to nurses and physicians who work with lung cancer patients. The findings provide insight into experiences of patients who continue to smoke after their lung cancer diagnosis. Nurses within the smoking cessation clinic will also benefit from patients' descriptions of what they consider useful and supportive in regards to an empathetic, coaching response to their relationships with tobacco. Future study is needed to elucidate nurses' perception on lung cancer patients who continue to smoke.

Key Words: Lived experiences, Life experiences, Perceptions, Descriptive phenomenology, Lung cancer, Lung sarcoma, Cigarette smoking

1. INTRODUCTION

Lung cancer is the leading cause of death among men and women in the USA.[1] The survival rate for lung cancer is very low with an average of 5 years depending on the histology and stage of disease.[2,3] Lung cancer is a disease of the elderly and it is usually diagnosed between the ages of 65 and 84 years.[4] More than 90% of lung cancer patients are symptomatic when they are diagnosed.[5] In Qatar, the rate of lung cancer disease, such as small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC) has increased to 5.9 per 100,000 populations.[6] Lung cancer is associated mainly with smoking related behaviors.[7] El-Hajj et al, 2017 reported that 20.2% of men in Qatar smoke tobacco and that tobacco use is one of the major preventable causes of death and disease in Qatar.[6] Patients with lung cancer who continue to smoke may feel stigmatized.[7] They may also feel self-blame and guilt due to the connection of their disease with smoking behaviors.[8] The feelings of self-blame and guilt can have negative effect on patients' treatment and quality of life. Focusing on modifiable health risk factors among cancer survivors, such as smoking, is considered critical for preventing recurrence of cancer and enhancing quality of life (QOL).[9] Understanding the lived experiences of smokers with lung cancer may reduce the level of self-blame and guilt among these people.

The aim of this study was to explore experiences and perceptions of lung cancer patients who continue to smoke after diagnosis. In particular, the authors were interested in the

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moments of decision to continue to smoke, to attempt to stop, and periods of relapse. The purpose of deepening understandings about lung cancer experiences with smoking was also to provide nurses with more insights into the complexities of people's relationship with tobacco.

1.1 Background

Lung cancer is divided into two categories: NSCLC and SCLC. NSCLC is classified into squamous cell carcinoma, adenocarcinoma, and large cell carcinoma.[4] NSCLC represents 80% of all lung cancers, with adenocarcinoma responsible for 40% of all lung cancer.[5] SCLC is more aggressive than NSCLC and survival rate for SCLC with extensive disease without treatment is often measured in weeks.[4] Treatment for lung cancer patients varies depending on the type and stage of lung cancer.[4] Thus, a diagnostic workup is necessary to identify the specific type of lung cancer, the stage of the disease, and a patient's ability to tolerate treatment. Lobectomy or pneumonectomy is the most effective treatment for NSCLC.[4] The type of surgical procedure depends on tumor location and the patient's comorbidities.[4] Neoadjuvant radiotherapy and cytotoxic chemotherapy provide moderate survival benefit for lung cancer patients and reduce recurrence of cancer.[10] Primary treatment for SCLC includes a combination of chemotherapy and radiation therapy.[10] Surgical intervention is not generally a treatment option for SCLC although it might be done in the rare case when a patient has limited SCLC.[10] Radiation therapy is the best treatment for patients with extensive disease.[10]

1.2 Quality of life and smoking cessation

Lung cancer patients who continue to smoke experience high rates of recurrence and metastasis, which also has a negative impact on QOL.[11] When lung cancer disease with a history of smoking is diagnosed at an advanced age, the overall survival is poor and most of the patients die within the first year of diagnosis.[12] Patients with lung cancer who persisted in smoking following the completion of treatment had worse appetite, fatigue, coughing, dyspnea, symptomatic distress, and reduced overall QOL compared to those people who had never smoked.[13] Moreover, smokers with lung cancer have more mental health problems and psychological distress than non-smoking patients.[11] Smoking had a negative impact on small cell lung cancer survivors' QOL.[14] These researchers found that smoking cessation at the time of lung cancer diagnosis improved long-term QOL and symptoms. Lung cancer patients who participate in smoking cessation programs are more likely to quit smoking and thus improve treatment efficacy, QOL, and survival rate.[15]

1.3 Literature on experiences of people with lung cancer who smoke

Prior literature on smokers with cancer has been generated around an interest in identifying the factors that influence lung cancer patients' continued smoking. These have been found to be related to low income, tobacco advertisement, limited education, negative consequences of the cancer experience, loss of control, fatigue, social isolation, and lack of knowledge about causes, characteristics, and prognosis of the disease.[16] As well, research interest has been focused on the stress that lung cancer patients experience with findings of high levels of distress due to poor prognosis, with an accompanying sense of responsibility for the cancer, and the stigma associated with their disease as an illness of smokers.[17] Lehto (2014) also identified stigma among friends, family, and health professionals for people with lung cancer because the disease is so closely connected with smoking.[7] According to Cataldo et al.,[18] stigma among lung cancer patients can lead to negative outcomes including increased level of depression and diminished QOL. Lathan et al. (2015)[16] used a qualitative approach to interview lung cancer patients and identified that negative thoughts and emotions, such as guilt, self-blame, and self-deprecation are common in this population. Similarly, Raleigh[8] found smokers with a lung cancer diagnosis often feel depression and guilt because they think that they are a burden to their families and friends. According to Dirkse et al.'s study,[17] the self-blame and stigma associated with smoking cause distress for smokers with lung cancer and prevents them from communicating with their partner and families. These authors suggest that open communication helps smokers with lung cancer to adapt to cancer and to experience less distress throughout their illness. These perceptions and experiences are many features of the complicated landscape of experience that all lung cancer patients may suffer.

2. METHOD

Descriptive phenomenology was method of research, which used to describe and understand beliefs, assumptions, and feelings of lung cancer patients toward smoking. The method provides the opportunity to generate empathetic connections to share with nurses and physicians that provide insight into why some lung cancer patients do not give up smoking after their diagnosis. Interview questions in this research include: What are the actual experiences of smokers with lung cancer at those moments of decision, quitting, not quitting, and relapse? Are they aware of the complications of smoking and its impact on QOL? Are they aware of how to access smoking cessation clinics? Are they receiving education about pharmacological smoking cessation interventions that

are linked to smoking cessation programs? Why do lung cancer patients relapse back to smoking after quitting? What are their experiences with stigma and self-blame?

2.1 Setting and participants

The study was conducted in the inpatient, outpatient, and day care units at the National Cancer Care Center Research hospital (NCCCR) in Qatar. Purposive sampling was used to recruit five lung cancer patients who quit or continued to smoke after their lung cancer diagnosis. The selection criteria for inclusion were adult patients with lung cancer who smoke. The participants who volunteered were from different nationalities and cultures including, British, Pakistan, Indian, Qatari, and Palestine. They included three men and two women above 40 years of age. Three of the participants quit smoking within three months following their lung cancer diagnosis, one quit one and a half years after the diagnosis, and the other one continues to smoke.

2.2 Ethical considerations

Ethical approval was obtained from the University of Calgary Ethical Review Board, the NCCCR Hospital Research Committee and the Medical Research Center at Hamad Medical Corporation in Qatar. A verbal consent and written consent were obtained prior to commencing each interview. The informed consent included information about the study, its purpose, the participant's right to withdraw at any time, participant privacy, and confidentiality.

2.3 Data collection

Data was collected over three months period and utilized in-depth unstructured conversational style interviews. All interviews were conducted in English. The interviews were conducted in a private room at the hospital, which was identified by the participants as the most convenient. The duration of the interviews lasted 20 to 45 minutes, depending on the participant's energy and availability. Interviews were audio-recorded and transcribed. Field notes were added immediately following each interview. The field notes were written to capture observations of general responses to the interviews, including nonverbal interactions, context, and the interviewer's impressions. Saturation was reached once the researchers were able to use the data to get a clear picture about perception of lung cancer patients who smoke in order to answer the research question.

2.4 Data dnalysis

Collaizzi, 1978 method was used to analyze the data.[19] The interviews were transcribed verbatim and the handwritten field notes were added to each transcript. Transcripts were reviewed and analyzed by all three authors to identify preliminary key themes which were then subjected to an intuitive reading. The intuitive reading included revisiting the original data with an emphasis on the sensing, thinking, and feelings evident in the texts with a goal uncover a deeper understanding the complexity of the phenomenon. Participants' quotations were closely examined as an individual experience and also for what they contributed to the growing awareness of the "essence" of the experience being studied. Qualitative criteria for rigor were maintained by assessing credibility, dependability, confirmability, and transferability. This was done by the use of triangulation with co-authors, member checks, and keeping an audit trail of the developing description being generated from the data.

3. FINDINGS

As a result of interviews with the participants three themes emerged. These themes included fate, a socially acceptable addiction, and self-blame and guilt. These three perceptions and experiences were at the core of the relationship with smoking and their lung cancer and how the participants made meaning of their life world.

3.1 Fate

During the course of the interviews, the causes of lung cancer were prominent with emphasis that smoking is not the only cause of lung cancer. The participants knew that some patients were diagnosed with lung cancer without a history of smoking. They believed other environmental agents or lifestyle factors could also cause the disease. This seemed to be important for the smokers. The participants knew there might be a connection between personal smoking behaviors and developing lung cancer, but also knew there are other reasons for getting the disease. The participants seemed to come to terms with their smoking and their cancer diagnosis by attributing their cancer to fate and to God's will.

Ms. M believed that everything happens in life because God plans for it. She believed that illness was a sign from God for her to think about death. She said, *"We do not know what God's plan is for us. You have your life until you have your life. What has to come in your way has to come whether you smoke or whether you did not smoke. I just feel that one has to die."*

Mr. R stated, *"Who is to say that smoking cause lung cancer? Smoking is not the cause of the lung cancer. People who never smoked have lung cancer so it is not smoking. They cannot just say because I smoke cigarettes that is why I have lung cancer."*

Ms. N expressed her feeling and said, *"People who have never ever smoked have lung cancer. I feel sorry for them. It*

may be because I smoked; it may not be. It could be for a million reasons that I have lung cancer. I do not believe that 100% smoking can cause lung cancer."

Overall, participants' expressions of the knowledge that even those who do not smoke get lung cancer appears to be a way for them to come to terms with their own fate regarding the diagnosis. Attributing the disease on fate or God's will was a way to make meaning from their past and present smoking behavior. It addressed some of the guilt and regret that they also expressed. Fate seemed a paradoxical juxtaposition with the concurrent theme of self-blame. The above quotes reflect the participants' needs and sense making of their illness. It seemed to be a way of contemplating their smoking and the enormity of their lung cancer.

3.2 A socially acceptable addiction

Most participants described the relief from stress and anxiety that their smoking provided. They felt a certain calm and relaxation when they smoked. This was especially true during stressful situations. In the face of the stresses of cancer and its treatments smoking relieved feelings of tension and fear that the diagnosis generated. Several of the participants compared the stress of cancer to the stress of work. They said that when they struggled with work pressures, these pressures were relieved when having a cigarette. Smoking was consciously framed by the participants as an addiction and yet, they seemed to have a positive view that their smoking was experienced as an important coping mechanism. It was a craving and a response that was beyond their control, but it had benefits. The participants justified their continued use of tobacco through the lens of stress and relaxation, the way they had enjoyed their habit prior to their diagnosis influenced how they experienced their need to smoke after the diagnosis. Smoking was a form of a fate; a socially acceptable addiction/craving that is integral to the participants' life world.

Ms. N stated, *"We grew up with cigarettes being okay. We became highly addicted to cigarettes and most of us smoke. I only smoke now if something is annoying me. I go back to what I used to be before, but I would only have one cigarette and it would make me feel wonderful to be honest. It makes me feel better. It will just de-stress me."*

Ms. M stated, *"It was a very bad habit. Actually, you could say that it is a kind of a drug because you get addicted to it. But I can tell you one thing that under stressful circumstances, cigarettes did help. They do help. Now, also sometimes if I am stressed out, I do get the urge to have a cigarette. I used to be fine. I used to feel relaxed and calm. It is a drug. It is kind of a drug."*

Mr. B described how the enjoyment one feels during smoking leads to a feeling of satisfaction, which in turn leads him to smoke more. He said, *"Cigarette is a habit and it became something like a routine and it makes you relaxed, calm, or sometimes happy."*

Mr. R believed, *"Smoking keeps me calm, with my work pressure and everything, I will have the cigarette and they go away."*

MR. I expressed, *"smoking is something like you use it every day like food, drinks. It is just when we put the cigarette in the hand, we will feel something else, I do not know. It is just like enjoying."*

A tobacco addiction has many subtle nuances and is a powerful thing. Statements from the participants reflect the need to be heard. The data expresses their experiences about why they continue to smoke, even in the face of cancer diagnosis. Their insight into addiction suggests a need for some explicit interplay between smoking cessation, pharmacological supports, and patients' experiences of their prior stress management practices.

3.3 Self-blame and guilt

Self-blame and guilt were evident during interviews. The participants described how hard it was to act on the advice they were being given to give up smoking. They needed to reconcile the messages being communicated by nurses that they had caused their disease. In this component of the experience, it was as if blaming oneself contributed to how participants could make meaning of their continued smoking.

Mr. B said, *"I am going to blame myself. No one forced me to smoke; it was only my mistake to have a cigarette."*

Mr. I expressed his feeling and said, *"I blame myself. I was smoking for 30 years. I blame myself after I become sick. I told myself now, when I wake up, I say I was a stupid smoker for 30 years really. That is the truth."*

Ms. M stated, *"I blame myself. I do not blame anybody because whatever your action or your doings are, they are yours. Nobody else can make you do it."*

Mr. R mentioned, *"I blame myself. I do not blame anybody. It is my decision. I really like to smoke."*

Paradoxically, despite that participants expressed their understanding that the diagnosis of lung cancer may not be related to their smoking, the participants blamed themselves for having lung cancer. This was evident in their expressions of the guilt that they felt about smoking. Overall, smoking as a coping mechanism, understood as a socially accepted addiction, reflects the ambivalence that felt by the partici-

pants as they struggled with the enormous sense of guilt that they felt from either their prior smoking or their continuing to smoke in the face of their diagnosis. It also reflects the fact smokers do not want to blame the onset of the disease to the actual cigarette. The paradox unfolded as though the participants were protecting a friend, because that is what their smoking had become.

4. Discussion

There is an uncanny lucidity to how the participants blamed themselves and not the cigarettes. This seemed to be central part to how they could hold onto the competing and contradictory descriptions of smoking is not the only cause of cancer, smoking is an addiction and socially acceptable that offers a relief from the stress of cancer, and I have only myself to blame. Somehow, these core features of their life world seemed to help smokers with lung cancer to come to terms with their fate. Ambiguity and ambivalence seemed to be the essence of their experiences. They wanted to believe that they had not caused their cancer, but at the same time, they felt significant guilt related to their smoking. They understand their smoking as an addiction but they also believe that their decision to smoke is a choice.

This somewhat conflicted reasoning underlies their experiences of continuing to smoke. Our description of this experience suggests that nurses must come to appreciate this conflicted lived experience in order to support smoking cessation. Each participant seemed to acknowledge their experiences of being addicted to "smoke" and its physiological and psychological effects. They also believed that smoking is a natural thing and it is something they have lived with as a way of coping for many years. The participants acknowledged they smoke, and generated compelling reasons for continuing. It is this essence of their lived experience that health professionals need to understand and validate. Nurses must work with empathy and respect when they endeavor to support patients to quit smoking. Their work is to both acknowledge their pleasure in smoking while at the same time convincing them about their potential for an improved quality of life as non-smokers. This is complex work that requires nurses to acknowledge patients' beliefs and desires to grasp onto their addiction as a familiar and effective pattern of coping.

This phenomenological description reflects some of the previous research focused on lung cancer patients who smoke. Lehto, 2014 also reported that some lung cancer patients refute a connection between smoking and lung cancer to avoid self-blame and stigma. The participants in our phenomenological study made strong statements about their beliefs that smoking did not cause their cancer; however, their sense of guilt was incongruent with their expressions of fate and God's will. Even though they talked about other factors, such as lifestyle and environmental factors like pollution, chemicals, and contemplated whether these factors play a significant role in causing lung cancer, they understood that their smoking was bad. However, they concurrently experienced cigarettes as a source of enjoyment and pleasure. Smoking had been a friend in the participants' life for a long time. Reconciling that their friend is the possible cause for their disease created deep feelings of ambivalence. Raleigh, 2010 findings are similar to our description of participants' lived experiences. Raleigh also found that lung cancer patients reported that their disease was caused by other factors in order to deny the association between smoking and lung cancer in order to avoid feelings of guilt for having smoked. In some regards, this is an important form of protection. Participants' desire to protect themselves was a notable part of the experience that our phenomenological research uncovered. Participants were ambivalent about the cause of their diagnosis, and it was as though they simultaneously understood but were in denial about the addiction. This denial might be an important coping mechanism for participants. Folkman et al. (1985)[20] defined coping mechanisms as "constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised or taxing" (p. 151). Nurses who can empathize with the essence of the internal and external demands that face people with lung cancer who smoke will be more capable of establishing trusting relationships where patients feel cared about and not blamed. It is within these sorts of relationships that nurses will be better equipped to assist smokers to consider other ways to reduce and to cope with stressors. Cooley et al. (2008)[21] described the careful, caring attitude necessary to bring patients into a point of willingness to quit smoking. Halding et al. (2011)[22] made similar claims about smokers' motivations. Participants in our phenomenology acknowledged smoking as unhealthy with a negative impact on their health, but they smoked anyway, for social reasons, pleasure, habit, and relief from stress.

The findings of this phenomenological description suggest that smokers with lung cancer deny the relationship between smoking and lung cancer because of their addiction to cigarettes. Addiction is defined "as a persistent recurring compulsion to use a substance, such as alcohol, drugs, and nicotine with harmful consequences to the person's health, mental state, and social life" (para. 1).[23] Nicotine is highly addictive, and tobacco dependence is considered to have features representative for chronic diseases, such as recurring stages of vulnerability, relapses, and remissions.[24] It is important that nurses who work with smokers understand

addiction. These sorts of understandings aid in nurses' capacity to validate patients who continue to smoke in the face of cancer.

Our research suggests that patients' experience of feeling supported by empathetic professionals is rare. This is congruent with other literature that suggests lung cancer patients report high levels of perceived stigma and self-blame.[24] These messages likely add to the experiences of self-blame and guilt our participants described. It is this experience of culpability that nurses must also understand and validate, as a foundational part of care. Smokers with lung cancer may be embarrassed and not willing to disclose their smoking status because of the stigmas, blame, and pressures to quit that are associated with smoking behavior and their diagnosis.[25] This was obvious in a discussion with one participant who reported to her physician that she stopped smoking, but she continues to smoke. She did not tell the truth in order to be treated non-judgmentally.

According to Else-Quest et al. (2009),[24] self-blame is associated with poorer psychological adjustment in lung cancer patients. Lehto (2014) found that smokers with lung cancer who blame themselves and feel personally responsible for the disease are more likely to be depressed, have lower levels of confidence, and have negative coping mechanisms thus leading them to smoke more. Lehto (2014) findings fit with the experience of one of our participants who said he was very depressed when he was diagnosed with lung cancer, blamed himself, and continued to smoke. This participant delayed seeking medical advice for his depression until he became critically unwell. This experience could have been prevented by a closer and more validated relationship with his cancer care team.

5. Conclusion

This research described the lived experiences of smokers with lung cancer in Qatar. The findings of this study provide insights for nurses and physicians to better empathize with patients who continue to smoke after their lung cancer diagnosis. It is important to understand the lived experiences of smokers with lung cancer, not only to help them to quit smoking, but also to validate their suffering and the essence of their relationship with smoking and cancer. It is only through this knowledge nurses can truly understand the importance of fostering therapeutic relationships with these patients. Nurses working with patients towards smoking cessation would likely be more effective if they connect more genuinely with the lived experiences of lung cancer patients who continue to smoke, especially the feelings of guilt and self-blame that these patients feel. Having a clear sense of patients' psychological journey is necessary in order for nurses to work with and promote positive encouragement toward success within patients. This success may not be quitting smoking. Success must be judged by whether or not a smoker with lung cancer has better resources to meet their fate with acceptance and less turmoil.

The findings from this phenomenological research are important for nursing because nurses are expected to provide an integrated approach to care for their patients. The nursing care of smokers with lung cancer must not place additional burdens of shame and guilt that could have a negative impact on patients' QOL. Nurses must establish advanced communication skills in order to avoid criticizing smokers with lung cancer. It must be a conscious effort to avoid triggering a patient's negative feelings about themselves that is balanced with resources and tools that respectfully guide patients towards smoking cessation.

5.1 Limitations

Although it is common in phenomenology to only interview a small number of participants, this study, with only 5 interviews presents limitations for ensuring the fullest description that would have been validated through more interviews. Recruiting was a sensitive process in this study. Three people who had agreed to be interviewed died prior to the scheduled interview. Most participants were diagnosed with lung cancer in the later stages of the disease, this may have impacted their motivations and experiences regarding their tobacco use and disease. Participants' interviews were arranged to coincide with their scheduled medical appointment times. Issues with transportation and parking made this the most convenient. Thus, interviews were undertaken one hour before or after patients' visits to the hospital. The participants were anticipating pending appointments to receive chemotherapy drugs. These circumstances may have limited the depth of the phenomenological interviews.

5.2 Recommendations and implications

Nurses must concern themselves with their patients' lived experiences and lung cancer patients' relationship with tobacco should be integral to empathetic care. There is dual heartbreak in facing a serious diagnosis that is judged to be self-induced. The specter of losing a lifelong coping strategy (smoking) whilst also coming to terms with a terminal diagnosis produces enormous ambivalence. Lung cancer patients need nurses to empathize with these tragedies of their fate. Patients could be better supported when they reflect on the reasons why some people do or do not get cancer. This reflection on fate seems to offer solace. However, smokers' strong claims that it may not be their smoking that has led to their cancer seems to taint the way smokers are perceived by

nurses and thus may lead to unsupportive relationships. The findings of this study might help nurses to understand the lived experiences of smokers with lung cancer and provide insight into how to communicate. In sum, nurses should respond with empathy and insight to those lung cancer patients who display readiness to quit smoking, provide appropriate counseling, and do regular follow-up to celebrate success and be unconditionally accepting of relapse. Nurses need to consciously work to reduce feelings of guilt and self-blame by establishing good relationships built on careful listening. It is our impression that smokers with lung cancer are a group with distinct needs. Future study is needed to elucidate nurses' perception on lung cancer patients who continue to smoke.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest.

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