



CLINICAL SCHOLARSHIP

The Lived Experiences of People With Chronic Obstructive Pulmonary Disease: A Phenomenological Study

Yi-Ya Chang, MSc, RN^{1,2}, Yu-Tzu Dai, PhD, RN³, Nai-Hui Chien, MSN, RN^{4,5}, & Hui-Ya Chan, MSN, RN^{6,7}

1 Lecturer, Department of Nursing, Chang Gung University of Science and Technology, Taoyuan City, Taiwan

2 Doctoral Candidate, School of Nursing, College of Medicine, National Taiwan University, Taipei City, Taiwan

3 Professor, School of Nursing, College of Medicine, National Taiwan University, Taipei City, Taiwan

4 Lecturer, Department of Nursing, Chang Gung University of Science and Technology, Taoyuan City, Taiwan

5 Doctoral Candidate, School of Nursing, National Taipei University of Nursing and Health Sciences, Taipei City, Taiwan

6 Registered Nurse, Department of Nursing, National Taiwan University Hospital, Taipei City, Taiwan

7 Doctoral Candidate, School of Nursing, College of Medicine, National Taiwan University, Taipei City, Taiwan

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Correspondence

Yi-Ya Chang, Department of Nursing, Chang Gung University of Science and Technology, No.261, Wenhua 1st Rd., Guishan Dist. 33303, Taoyuan City, Taiwan.
E-mail: yychang@mail.cgu.edu.tw

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Abstract

Purpose: This study explored the lived experiences of people with chronic obstructive pulmonary disease (COPD) following hospitalization for acute exacerbation or pneumonia.

Design and Method: A phenomenological approach was adopted to collect data through semistructured interviews. Fourteen participants were recruited from a medical center in northern Taiwan. Data were collected from January 2013 to January 2014. Giorgi’s phenomenological methodology was adopted to analyze the interview content.

Findings: Three phenomenological themes emerged: trapped in an invisible cage, torments in the winter, and striving for wellness.

Conclusions: This study sought to elucidate the lived experiences of people with COPD, who perceived themselves as feeling an overwhelming sense of confinement. The interviewees displayed positive attitudes, indicating that people with COPD are willing to cope with their disease. Health practitioners should focus on educating people with COPD about their needs, encouraging them to be more positive, and assisting them in engaging in self-management.

Clinical Relevance: People with COPD can cope with the disease and seek alternative methods to improve their health. These positive attitudes could be used to encourage self-management in the future.

Chronic obstructive pulmonary disease (COPD) is a growing threat to global population health because of smoking, air pollution, and population aging. COPD was the fifth leading cause of death in 2002, and it is estimated to rise to the third largest cause of death in the world by 2030 (World Health Organization, n.d.). The burden of COPD is projected to increase in the coming decades.

Earlier researchers emphasized that people with COPD have a prevalence of depression, anxiety, and poor quality of life (Al-Gamal, 2014; Asuka et al., 2013; García-Rio et al., 2011). Pulmonary rehabilitation and self-management were used to improve quality of life by medical practitioners (Billington, Coster, Murrells, &

Norman, 2015; Jácome & Marques, 2014). It is unclear why people with COPD continue to have a poor quality of life and in an unhealthy mood.

Previous qualitative research on the lived experiences of people with COPD focused on their self-care, self-management, or final stage (Chen, Chen, Lee, Cho, & Weng, 2008; Ek, Sahlberg-Blom, Andershed, & Ternstedt, 2011; Hayle, Coventry, Gomm, & Caress, 2013). More evidence and different views of lived experiences other than self-management and life during the final stage are needed for understanding life with COPD. Further, lived experiences of patients may differ under different health care systems, social cultures, and living conditions.

Table 1. Interview Guide

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1. Would you like to talk about how you feel about COPD?
 2. How has COPD affected your life?
 3. How do you feel when you feel breathless or have difficulty breathing?
 4. How do you deal with COPD?
 5. What concerns you the most in your daily life?
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The purpose of this study was to explore the lived experiences of people with COPD following hospitalization for acute exacerbation or pneumonia. This article extends knowledge about what it is like to live with COPD after being hospitalized for acute exacerbation or pneumonia by highlighting the lived experiences of these persons.

Methods

A qualitative approach was designed for data collection through semistructured interviews. A phenomenological methodology was adapted for analyzing the interviews to extract the meaning of the lived experiences of people with COPD following hospitalization for acute exacerbation or pneumonia.

A purposive sample of 17 participants was recruited from the thoracic and geriatric wards of a medical center in northern Taiwan by one of the authors. Three of the 17 participants declined participation, and 14 participants were included in this study. Eligibility criteria were: (a) clinical diagnosis of COPD, (b) had hospitalization due to acute exacerbation or pneumonia within the past year, (c) were over 18 years of age, (d) were Mandarin- or Taiwanese-speaking, (e) were willing to be interviewed and digitally recorded, and (f) were provided informed consent. Exclusion criteria included: (a) lung cancer or pulmonary tuberculosis, (b) heart disease, or (c) cognitive impairment. As no new themes emerged at the 11th interviewee, the results were considered saturated and were stopped at the 14th interviewee in this study.

Data were collected from January 2013 to January 2014. Six of 14 interviews were conducted in clinical settings, and eight took place at the patients' homes. Semistructured, face-to-face, digitally recorded interviews were conducted and ranged in length from 42 to 120 min. The interview guide was developed and modified from previous studies (Chen et al., 2008; Tsou, Lu, Lin, & Maa, 2009), as outlined in **Table 1**. This study was approved by the Research Ethics Committee of the National Taiwan University Hospital (Reference No. 201211017RIC) and related departments before commencement. Subjects who met the recruitment requirements were invited to participate in this study and were informed about the aims and procedures of it in both oral and written form. Before the interviews, all

participants were told that they were free to withdraw from the interview at any time and for any reason.

The data analysis and interview processes of this study were carried out simultaneously. After an interview recording was transcribed, the first author (interviewer) checked for accuracy by listening to the recordings while reading the transcripts. All data were analyzed using Giorgi's (1997) method for extracting the meaning of their lived experiences. This method is based on the philosophy of Husserl. The researcher must "bracket" to analyze a person's phenomenal status (Giorgi, 1997). Procedures used included reading all of the transcripts that described the experiences and listed the feelings described, rereading the description, confirming the lived experiences transcribed in the transcripts, clarifying and carefully connecting related relationships, carefully considering what was mentioned by all the interviewees, translating what was expressed by all interviewees into scientific terminology and concepts, and combining all observations into a meaningful description of their lived experiences. After repeated readings of the transcripts, the researchers grouped similar meaningful experiences from the transcripts into key words. Key words with similar meanings or concepts were then grouped into a subtheme. Lastly, the main meaning behind each of these subthemes was then formed into the theme.

This study adhered to credibility, dependability, transferability, and confirmability (Lincoln & Guba, 1985) for maintaining rigor. Each interview was conducted by the first author who is not a staff member at this hospital and shared no health care provider relationships with the participants. The interviewer is a doctoral candidate who has more than 15 years' experience as a nursing lecturer and who received qualitative research training in her master's and PhD courses. In order to achieve credibility, the interviewer tried to avoid using her experiences and ideas to guide the participants to talk about their minds and feelings. All the transcripts, data coding, and theme formulation were reviewed by another author (first author's advisor). A precise transcription of all interview recordings was read several times and confirmed by the first author to achieve dependability. Transferability was met through a rich description of the context of participants from different levels of severity in COPD. Confirmability was enhanced with a rigorous audit trail of data and procedures.

Findings

Fourteen participants (12 men and 2 women) were recruited from a medical center in northern Taiwan. The average age of the participants was 77.1 years (range 63–86), and the mean duration of COPD was 5.8 years

(range 1–11). According to the Global Initiative for Chronic Obstructive Lung Disease (2015) severity classification of COPD, seven participants were in the mild stage, two participants were in the moderate stage, and five participants were in the severe stage. Eleven participants were former smokers, two were nonsmokers, and one was a current smoker. Their lived experiences following hospitalization for acute exacerbation and pneumonia were analyzed to develop subthemes and themes.

Theme 1: Trapped in an Invisible Cage

All participants perceived being trapped in an invisible cage as having a great impact on their daily life after being hospitalized for acute exacerbation or pneumonia. Participants experienced a derailed life because of the symptom of breathlessness. Breathlessness is difficult to avoid and manage for participants, discouraging them from going outside, so they would choose to stay at home for a sense of security. These feelings are linked to debilitation and a sense of confinement.

Derailed life. Their lifestyles changed dramatically and they endured significant differences, especially with respect to exercise capability, sleep patterns, and eating habits. From their descriptions it was obvious their quality of life was affected by COPD: “I used to go hiking before, but I could not go hiking anymore after the exacerbations again and again. All I can do is to walk around my house” (Participant 09). “It is hard to breathe when I lie down in the bed. I like to sit in the chair when I feel breathless at night” (Participant 13). “My appetite was affected by breathlessness. I lost a lot of weight within 2 years because I didn’t eat much” (Participant 13).

Debilitated. Breathlessness is difficult to avoid for people with COPD, which frustrates participants as it becomes difficult to manage. From the participants’ descriptions, it appeared they lacked energy to move around. This is linked to feelings of debilitation. One participant expressed his situation: “I am just like a withered flower. I have no energy to go outside so I choose not to go outside” (Participant 07).

Sense of confinement. Participants became breathless and fatigued easily due to their COPD, which resulted in participants narrowing their range of activities. Participants described their concerns: “I didn’t like to go outside when I lived in the old apartment without an elevator, because it was difficult to return if I went outside. I was locked up in the house all day” (Participant 03). “I used an oxygen machine at home for nearly 4 years. When I

went outside, I had to carry a small oxygen cylinder so I couldn’t go far away from my house” (Participant 02).

Theme 2: Torments in the Winter

Participants suffered torments from unpredictable and uncontrollable pneumonia or acute exacerbations in the winter. Winter acts like a time bomb that could explode and cause destruction to their daily life. They expressed their fears, worries, and concerns. Their airways are sensitive to the low temperature, and acute exacerbation is more likely to occur in the winter. They experienced a great fear of death when they struggled for oxygen. Further, they worried about becoming a burden to their families when they were hospitalized.

Sensitivity to the cold. The low temperature in the winter led to coughing for many people with COPD, which was often quickly followed by feelings of breathlessness. One man described his experiences in the winter: “I have been hospitalized for acute exacerbation in the winter almost every year due to the weather change. When the weather changes in the winter, the breathlessness comes with coughing . . . they never stop” (Participant 04).

Fear of death. The fear of struggling with oxygen was not only related to death, but also the complications or outcome of hypoxia. One participant described his fears: “I couldn’t breathe . . . It was just like my neck was squeezed . . . I was afraid that my heart might stop beating . . . I needed oxygen right away” (Participant 03).

Family burden. When the time bomb of pneumonia or acute exacerbation exploded, it caused not only suffering for the people with COPD, but also for their families. One man described his concerns:

I am in a state of bliss if the next generations show their filial piety. My son came with me when I needed to go to the emergency room because of an acute exacerbation. The daily routine of my son’s family was disrupted . . . I don’t want to be a burden to my son and daughter in terms of medical costs or care. (Participant 03)

Theme 3: Striving for Wellness

Participants suffered from discomfort because of the symptoms from COPD. Participants strived for their wellness by preventing the flu, smoking cessation, and using folk medicine in their daily life to improve their well-being.

Preventing the flu. Participants were afraid of contracting the flu because of the complications that could immediately arise. Participants have their own methods for preventing the flu in their daily life. One participant shared his experience: "I am afraid of contracting the flu. In order to avoid contracting the flu, I receive a flu vaccine every year and I prefer to stay at home most of the time when the cold weather comes" (Participant 01).

However, one participant described the uncomfortable experience of wearing a mask: "It is suggested to wear a mask. However, I am not used to wear it because it is difficult to breathe when I wear a mask" (Participant 03).

Smoking cessation. It is hard for people to quit smoking. A patient's motivation determines if he or she is successful in ceasing smoking. It is important to know why people with COPD stop smoking. One man described his reason for stopping smoking: "My physician suggested that I stop smoking to live a longer life. I want to live longer so I decided to quit smoking. I quit smoking without any help from smoking cessation outpatient services" (Participant 07).

Using folk medicine. In Asian culture, there is a belief that "medicine and food are from the same source." This belief encourages traditional medicine to be combined with daily food intake. Participants in this study also followed this ideology in their lives. They paid particular attention to the properties of their food to reduce COPD symptoms. Experiences shared by participants include the following: "I found that I have more sputum within 2 days after eating more tomatoes. Therefore, I am eating fewer tomatoes now" (Participant 09). According to Chinese medicine, swallows' nest soup has beneficial properties for healing the lungs. A subject described her hope: "I eat swallows' nest soup with chicken stock every day. I think it will be helpful to combat my breathlessness" (Participant 11).

Discussion

This study presents participants' subjective feelings about their lived experiences as people with COPD following hospitalization for pneumonia or acute exacerbation. Our participants felt that they were trapped in an invisible cage and their lives were no longer the same after suffering from COPD. Previous research revealed that persons with COPD who were severely ill at home with oxygen therapy built their lives around limited space during their final stage of life (Ek et al. 2011). We found that participants had a tendency to narrow their range of activities. However, in our study, participants were not

seriously ill during their final stage of life, indicating that people with COPD following hospitalization for acute exacerbation or pneumonia would be limited mainly to their home, regardless of their stage of disease. Health practitioners can focus on working towards educating and serving people with COPD on how and what to use to deal with breathlessness for increasing their sense of security to go outside and be able to extend their range of activities. Portable oxygen systems are more regularly used in some Western countries. In the present study, the participants who required oxygen used nonportable oxygen, which is one reason why people experienced restricted activity areas.

Influenza has been predicted as a risk factor for the exacerbation of COPD (Montserrat-Capdevila, Godoy, Marsal, Barbé, & Galván, 2015). The highest number of admissions for patients with COPD occur during winter, as exacerbation and temperature are related to the number of COPD hospitalizations (Almagro, Hernandez, Martinez-Cambor, Tresserras, & Escarrabill, 2015; Tseng et al., 2013). Our study supports these findings, as the participants described their fears of contracting the flu, which could progress to acute exacerbation or pneumonia, and in turn could lead to hospital admission. Therefore, our interviewees were particularly wary of the need to keep warm on a daily basis to reduce the chance of acute exacerbation. This is also a reminder to all health practitioners to advise people with COPD to stay warm, as well as to supply information on how to avoid contracting the flu. In addition, this study revealed that people with COPD who experienced breathlessness found it more difficult to breathe after wearing a mask, which was uncomfortable. Alternative methods are needed for preventing respiratory tract infections and protecting against respiratory pollutants.

A previous study found that the Chinese cultural ideology of filial piety and the modernization of society placed the family caregivers of people with COPD in a caring dilemma situation in Hong Kong (Yu, Lee, & Wu, 2007). Taiwan is similarly a place of Chinese culture. We found that when children helped take care of their parents with COPD, parents felt that there was sufficient respect from their children. However, parents with COPD were worried about their children bearing too much of the burden if they were to be hospitalized. These results show that people with COPD were also in a dilemma—while they appreciated being respected by having their children visit and care for them in the hospital, they also worried about increasing the burden on their children. Therefore, health practitioners need to evaluate the mental support needs of people with COPD.

Clancy, Hallet, and Caress (2009) found that COPD patients shared very negative experiences. Our study

supports this finding since most participants had very negative feelings towards having COPD. However, some participants tried hard to be healthier and show a positive attitude, suggesting people with COPD can cope with the disease and seek alternative methods to improve their health. These positive attitudes could be used to encourage self-management in the future. This research showed that participants believed eating functional foods was very important to them, but they also suffered from a poor appetite, malnutrition, and weight loss. Therefore, health practitioners should try to introduce evidence-based nutritional information to people with COPD and find ways to improve their appetites. This study also revealed that participants tried to avoid all foods that had “cold” and “cool” attributes. According to traditional Chinese medicine, foods have four different attributes not defined by their temperature: cold, cool, warm, and hot. From a modern medicine viewpoint, foods with cold and cool attributes can reduce body metabolism, while foods with warm and hot attributes can increase body metabolism (Chen, 2000). Many interviewees believed that foods with “cold” and “cool” attributes, such as melons, radishes, and tomatoes, would increase mucus production. This resulted in reduced intake of these vegetables by the interviewees. We suggest that a randomized controlled trial be performed to investigate if avoiding these vegetables can control COPD symptoms to provide a more scientific basis for this belief.

Chen and Wang (2011) found that the quality of sleep for COPD patients was not ideal. Our study supports this finding, since our participants mentioned that they experienced breathlessness, increased mucus expelling, and coughing, leading to poor sleep quality or an inability to sleep. Except for the recommendations of noninvasive ventilators and medicines for sleeping, the literature or educational brochures lack information on ideal sleeping positions, which healthcare experts need to address and further research is needed to explore.

Furthermore, the majority of participants were ex-smokers (11 of 14, with 1 current smoker and 2 non-smokers). This indicates that people with COPD in this study were more successful at quitting smoking than a previous qualitative study showing that two out of three COPD interviewees were unable to quit smoking (Schofield, Kerr, & Tolson, 2007). Participants in this study indicated that they did not receive any treatment to help them quit smoking. Coughing and breathlessness contributed to these people successfully quitting smoking, as did consistent encouragement from health practitioners. The reason and process behind the high success rate in Taiwanese people with COPD in quitting smoking without any treatment should be explored further.

This study also showed that it was very helpful for health practitioners to correctly remind people of the need to quit smoking.

Study Limitations

The results of this study only presented the experiences of people with COPD who were hospitalized at a medical center in northern Taiwan. People in other parts of the world may experience living with COPD differently. The participants in this study were only interviewed on one occasion, and the data were not sought from multiple sources. The findings may be unable to describe the phenomenon to a full extent, and it is difficult to interpret participants' experiences about the changing process of the disease without further follow-up.

Conclusions

This study described the lived experiences of people with COPD following hospitalization for acute exacerbation or pneumonia. Participants described their experiences on how to live with COPD. These participants went outside less because of their fear of breathlessness. They felt insensibly trapped in an invisible cage. Health practitioners can focus on working towards educating and serving people with COPD on how to deal with breathlessness and offering information to assist them to choose a more suitable oxygen delivery device for improving their activities. In addition, people with COPD found that wearing a mask actually increased their breathlessness, so alternative methods are needed for preventing respiratory tract infection and protecting against respiratory pollution. The positive attitudes observed in some people indicated that they were still willing to cope with their disease. Health practitioners should encourage people with COPD to be positive and responsible by educating them to self-manage.

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Clinical Resources

- COPD Foundation: <http://www.copdfoundation.org/>
- Self-management tools: <https://www.blf.org.uk/Page/Self-management-tools>

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