

# Living with chronic obstructive pulmonary disease: a qualitative study

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## KEY WORDS

Chronic obstructive pulmonary disease, qualitative study.

## ABSTRACT

### Objective

The purpose of this study is to explore the experience of living with chronic obstructive pulmonary disease, with the aim of gaining an understanding of how the disease affects the patients' lives.

### Design

This study is a phenomenological study.

### Setting

The study was conducted in Atatürk University chest service.

### Subjects

The study consisted of 14 participants who had, had chronic obstructive pulmonary disease (COPD) for at least one year. The participants ranged from 55-81 years of age.

### Results

Breathlessness was identified as the most troublesome symptom leading to panic and fear. Participants also described a feeling of frustration and loss of social activity. This also resulted in loss of roles and led to emotional trauma.

### Conclusion

This study provided valuable insights into how patients view the overall impact and their subsequent degree of coping with COPD from day to day.

## INTRODUCTION

COPD is a chronic, complex, and incurable condition. It may result in declining pulmonary function, decreasing physical ability and loss of health related quality of life accompanied by symptoms such as anxiety, depression, fear, and fatigue. It is a major cause of morbidity and mortality and is currently ranked as the fourth leading cause of death in the world (Pauwels et al 2000; Downs and Appel 2007). Prevalence rates are estimated to be 24 million people in America, 2.7 million people in Germany, 300,000 people in Australian, 200,000 people in New Zealand, three million people in the United Kingdom, 1.5 million people in Spain and 2.6 million people each in Italy and France (Stang et al 2000, <http://www.goldcopd.org/Guidelineitem.asp?l1=2andl2=1andintId=989>). These prevalence rates are thought to underestimate the true prevalence of COPD as many people are not diagnosed with the condition until they become symptomatic (Cross 2005; GOLD 2006).

Several problems are encountered when defining COPD. The first relates to the term chronic obstructive pulmonary disease because this is not truly a disease but a constellation of diseases. According to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) program, COPD is defined as a disease characterized by airflow limitation that is not fully reversible (Pauwels et al 2001). The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases. Traditionally, COPD has been divided into several pathophysiologic entities, each sharing the common physiologic features of airflow obstruction and abnormal inflammatory response. These groups include chronic bronchitis, emphysema, asthma, and bronchiectasis (McCorry et al 2001). The GOLD program standardizes the term COPD by incorporating each entity into the diagnosis of COPD. Additionally, clinicians may experience difficulty in differentiating COPD from asthma, particularly the syndrome of poorly reversible airway obstruction in older patients with chronic asthma (D'Alonzo 2004).

COPD is as a result of a wide variety of environmental, behavioural, and genetic conditions. Approximately 85-90% of all cases of COPD arise from cigarette smoking, with the remaining 10-15% arising from passive smoking, occupational exposure, air pollution, genetic disturbances, progressive and possibly hyper responsive airways (Tzortzaki et al 2005; Downs and Appel 2007). It is considered to be a chronic and not fully reversible disease; thus, treatment is aimed at providing symptom control, supportive care and assistance in disease self-management. The goal of treatment is not to cure the disease, rather, it is to palliate symptoms, maintain physical functioning, and prevent further disability, as well as to decrease unplanned hospital visits and, thus improve health related quality of life (Bourbeau et al 2003; Monninkhof et al 2004; Linnell 2005; Chen et al 2008).

COPD patients must cope with psychosocial changes and functional limitations. The devastating effect of COPD can include a lack of control over daily life activities, restrictions on recreational and social activities, and encounter early retirement, financial stress, role alterations, disruptions in family life, altered self-image, loss of independence, and decreased self-esteem (Kinsman et al 1983; McSweeney et al 1982; Pirgatanio et al 1984; Schier et al 1990; Smeltzer and Bare, 2000; Weilitz and Sciver, 1996; Williams and Bury, 1989).

The aim of this study was to explore the experiences of patients with COPD in order to gain an understanding of how the disease had affected them and the ways in which they integrated the illness into their lives in Turkey.

## METHOD

A qualitative and descriptive design was adopted. In-depth interviews were used to collect the data.

### Design

This study is a phenomenological study. Data were collected in 2008. The first author conducted semi-structured and face-to-face interviews. The interview questions focused on the effect of COPD on everyday activities and relationships, the

emotional feelings associated with the disease and the participants' experiences with dyspnoea. The interviews were conducted in a University chest service. Each interview took between 20-40 minutes and was tape-recorded. After the interviews, the tapes were transcribed by the first author. Interview tapes and transcripts were de-identified in order to ensure participant confidentiality.

### Data analysis

Data were transcribed and analysed using the seven steps outlined in Colaizzi's (1978) method:

1. Reading the transcripts to develop an understanding of what the participants meant;
2. Extracting significant phrases and statements that are meaningful to the experience of living with COPD;
3. Formulating meanings for each significant phrase and statement;
4. Organising the meanings from each interview into themes;
5. Validating themes by comparing them with the participants' original descriptions and incorporating them into the original text;
6. Developing an exhaustive description of the themes; and
7. Verifying with participants that the researchers' conclusions were in agreement with their descriptions.

### Setting and sample

The sample consisted of 14 participants who had had been formally diagnosed COPD for at least one year. According to the GOLD (2009) classification of COPD (table 1), three participants were in the mild stage, seven in the moderate stage, three in the severe stage and one in the very severe stage.

Three women and eleven men participated in the study. All of the participants were taking bronchodilators, mucomyst and antibiotics. The age range of participants was 55-81 years old with a mean of 67 years. Twelve of the participants were married, two were widowed. All had informal support from their families and friends.

**Table 1: Spirometric classification of chronic obstructive pulmonary disease.**

Severity	Characterised by airflow limitation
Mild	$FEV_1/FVC < 0.70$ , $FEV_1 \geq 80\%$ predicted
Moderate	$FEV_1/FVC < 0.70$ , $50\% \leq FEV_1 < 80\%$ predicted
Severe	$FEV_1/FVC < 0.70$ , $30\% \leq FEV_1 < 50\%$ predicted
Very severe	$FEV_1/FVC < 0.70$ , $FEV_1 < 30\%$ predicted or $FEV_1 < 50\%$ predicted plus chronic respiratory failure

$FEV_1$ , forced expiratory volume in 1 second; FVC, forced vital capacity (GOLD 2009).

### FINDINGS

The participants gave vivid descriptions of their lives with COPD and how the illness influenced every aspect of their daily activities. Three themes were identified: symptoms control, functional disabilities, emotional trauma.

#### Symptoms Control

The symptoms which all study participants complained about most were: dyspnoea, coughing, and phlegm. Dyspnoea causes patients with COPD to experience intense fear, change in priorities, increase in the addiction status and intense anxiety.

Patient no 3: *The worst thing is, probably, not being able to breathe. When I'm unable to breathe, I think I will definitely die.*

Patient no 12: *I postpone everything to prevent gasping for breath. Housework, cooking, going out...*

Patient no 5: *When I'm out of breath, I think I will die at that moment. It is very difficult to experience this continuously. Before, I used to force myself too much and panic. This caused me to be more out of breath.*

Patient no 8: *To avoid gasping while I am doing housework, I try doing the work without bending down to the floor as much as possible.*

Patient no 14: *They taught me lip breathing (pursed lip breathing) in order to breathe more easily. I am using these (pursed lip breathing and diaphragm breathing). But I don't think they are useful.*

Patient no 13: *I can't possibly tell how inhaler drugs comfort me. They didn't use to work at all when I first used them, or I was not using them correctly but now, I never leave without them.*

Patient no 4: *I am always coughing. I am using antitussives but my cough doesn't stop.*

Patient no 12: *Sometimes I expectorate while coughing. It's awful to cough continuously and expectorate in public. I'm making everyone sick. I'm aware of this. My wife and daughters got used to this but expectorating in front of my relatives and neighbours embarrasses me.*

Most of the patients who participated in this study (nine patients) had an unplanned admission to the hospital for an exacerbation of their COPD symptoms, with a hospitalisation period of one to three months.

It was determined the patients tried to use drugs regularly and learned pursed lip breathing and effective coughing techniques mostly with their personal experiences. However, it was found they did not exercise and used diaphragm, pursed lipped breathing.

Patient no 4: *It appears that I was not using my breathing drugs (inhaler drugs) correctly. I used to inhale its (drugs) but no air would come in. I learned how to use them later. I am not literate, so, they explained it to me at the hospital.*

Patient no 1: *I am trying to breathe by pursing my lips. I was given a booklet at the hospital. I had learned from that booklet. However, I don't know anything else to relieve my breath.*

Patient no 7: *Never mind about the drugs my friend, they are not working. Who can tell these (effective breathing techniques) would work...*

### **Functional disabilities**

COPD patients stated they experienced a loss of function and as a result, their life-styles changed and life standards decreased. They expressed the difficulties of being dependent on somebody else.

Patient no 6: *I can manage none of my works. I'm always asking for help from my spouse. She is also*

*elderly. They are difficult for her as well. There is nobody else at home with us...*

Patient no 4: *I can't manage long walks. Especially when I climb uphill, my breathe gasps. If the weather is fine or if I'm going somewhere near or downhill, I walk. Even my five year old grandchild walks faster than me, and says "Come on grandpa, how slowly you're walking".*

Patient no 13: *Winter months last long here. That's why I always have to stay at home. Our house is stove-heated. Living in a stove-heated place is not good for my disease. I know this. I am financially incapable of moving to a centrally heated place. Thus, I always feel unwell and stay in hospital in winter.*

Most of the patients complained about not being able to fulfil their roles and their changed roles.

Patient no 11: *Sometimes even cooking at home happens to be difficult. The steam and scent of the meal irritate me when I put two or three pans of meal on the fire and start cooking. Therefore I sometimes ask for my daughter's help for cooking.*

Patient no 8: *Even taking a bath alone at home becomes difficult. I am having difficulty when I raise my hands up to wash my hair. I rapidly wash up and get out of the bathroom. Sometimes my daughter washes me. The steam in the bathroom irritates me. Therefore, I always leave the bathroom door open. Or I become out of breath.*

Patient no 1: *I used to run a tea shop. I was earning some money though it was a small amount. Then, after I caught this disease, I became unable to run it. There was a lot of smoking in the tea-shop. I was always coughing and becoming out of breath. My doctor had told me that already. For this reason, I sublet my shop. We moved in my son's house. Now, my son is looking after us.*

### **Emotional trauma**

Most of the patients feel uncomfortable about being dependent on their relatives because of the symptoms of COPD. They also stated they could not be in crowded places and so they postpone their social lives.

Patient no 11: *I am fed up with asking for help from others. I am continuously asking for help from my spouse, my daughter, my son, even from my grandchild. Though they are my very close relatives, I feel myself miserable. They (the relatives) do not mind helping me. But I guess, after some time, I'm going to be a burden on them.*

Patient no 3: *All of my friends are retired, like me, and we usually come together in a coffee house. I used to enjoy chatting, drinking tea, and smoking together with them. After I caught this disease, I kept going there for some time. However, after a while, I could not stay in there (the coffee house) for there were lots of people smoking. My friends are still gathering in the coffee house. They used to come to visit me often in the beginning, but they are not coming any more. I was so upset about this at the beginning, but then I got used to the loneliness.*

Patient no 2: *Being dependent on somebody used to make me upset in the beginning. Sometimes, although I was forcing myself to the limits not to ask for help, I was trying to manage my own work. But now, both me and people around me got accustomed to this disease.*

Patient no 12: *We have a very big family. We always used to see my relatives, but I can't visit them now, like I used to before, I can't get into crowded places. What should I do, I can't help it...*

## DISCUSSION

The findings of this study suggest living with COPD is a complex and dynamic experience. The impact of dyspnoea was significant and invaded almost every aspect of participants' lives. Participants made changes in activities due to shortness of breath, and this is similar to findings in other studies (Jonsdottir 1998; Russell 1998; O'Neill 2002; Cicutto et al 2004).

The phrase 'living with COPD' may be synonymous with living with dyspnoea, particularly during the severe stage of the disease. Many participants described them as frightening experiences, which were associated with fear of choking, suffocation,

and death. Successful techniques for dyspnoea management in this study and others (O'Neill 2002; Cicutto et al 2004) included using inhalers and concentrating on breathing slowly and not panicking. Participants adopted strategies that they had tested by trial and error. This involved pacing activities and learning to conserve energy and adapt daily tasks such as sitting down to complete tasks in the kitchen, washing, and dressing.

Chronic illness places considerable burden on patients, spouses and other family members. Because of the illness, roles within the family alter which may cause difficulties and affect the harmony of relationships within the family. These changing roles and circumstances may result in miscommunication within the family or even conflict (Rabinowitz and Florian 1992). In this study most participants felt their family and friends understood their condition and limitations. Leidy and Haase (1999) characterised some of their participants with COPD as struggling to maintain a sense of personal integrity, with feelings of decreasing effectiveness and connectedness with others. The importance of sufficient formal and informal resources, particularly in support from family and friends, to manage COPD has also been noted by others (Cicutto et al 2004).

Emotions ranging from irritation to depression were found in the study. Williams (1993) also noted feelings of frustration and depression were common among those with COPD. Kara and Mirici (2004) also found reactions to COPD included depression. Although depression was not mentioned frequently in this present investigation, some participants described a feeling of 'down' or 'low'. Moreover, the emotional ups and downs they described were frequently associated with their physical ups and downs. Themes that included both physical and emotional aspects of COPD were identified in several other qualitative studies (O'Neill 2002; Robinson 2005). Feeling poor emotionally was frequently linked to feeling poor physically, with each contributing to the other. This suggests living with COPD is characterised by the interaction between physical and psychological factors.

## STUDY LIMITATIONS

The sample size for this study was small but, because this was a qualitative study, it provided rich data and a culturally sensitive perspective on COPD embedded in Turkish culture. However, theme saturation was achieved and the usefulness of the data is a more important concern than the generalisability of the findings.

## CONCLUSION

The use of phenomenology as a research methodology fulfilled the aim of gaining a greater understanding of the experience of living with COPD. It provided valuable insights into how patients viewed the overall impact and their subsequent degree of coping with COPD in daily life. Undoubtedly, this condition has detrimental effects on participants' daily lives and cause disability. Actively listening to patient's individual accounts is a very important process in developing the services for patients with COPD. Further consideration of the themes discussed in this study may help healthcare professionals to increase their field of knowledge about their patients and add breadth and depth to their body of knowledge on this subject. This increased understanding will enable professionals to select strategies that will enhance patient care and their management and promote the best quality of life possible within the limits set by individual capabilities.

When dyspnoea occurs, patients with COPD will first choose to rest and reduce activity. However, as the disease progresses, the patient will experience dyspnoea at rest. This will cause the patient to become increasingly immobile, resulting in decreased ability to exercise, social isolation and lowered mood states (GOLD 2006). To reduce the frequency and severity of breathlessness, healthcare professionals should teach patients, as soon as possible, controlled breathing, self-medication adjustment and interacting appropriately with healthcare providers (Gosselink 2003; Maher and Hemming 2005).

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