

Original Research Article

Experiences of Living with Chronic Obstructive Pulmonary Disease: Patients' Perspectives

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ABSTRACT

Introduction: Chronic obstructive pulmonary disease (COPD) has a great impact on patients' daily life which is mostly subjective in nature and it can only be interpreted by the person experiencing it, despite medical attempts to measure or quantify it. The objective of this study was to explore the experiences of patients suffering from chronic obstructive pulmonary disease in Chitwan, Nepal.

Methodology: Qualitative phenomenological study design was conducted in Chitwan and a total of 22 patients with COPD were selected purposively for the study. Prior to data collection, ethical clearance was obtained from institutional review board of Institute of Medicine, Tribhuvan University. In-depth interview was conducted in the participants' home by using interview guidelines and data was thematically analyzed using the steps outlined in Colaizzi's method (1978).

Results: Seven themes emerged after thematic analyses and they were: Self-inflicted frightening illness, multiple distressing symptoms, modification in activities, altered family relationship, social isolation and loneliness, financial hardship and emotional trauma. Most of the patients perceived COPD as a self-inflicted disease resulting from their smoking behavior. On multiple symptoms dyspnea and fatigue were most troublesome and leading cause of physical disability and psychosocial problems. Patients were struggling with their mobility especially in climbing upstairs and walking, household activities, and bathing. All patients received support from at least one family member; however, half of them were dissatisfied with their family relationship. In addition, they encountered emotional problems such as symptoms of depression and anxiety. Patients acknowledge the importance of family support, treatment modality and awareness about disease and treatment for their improved health status.

Conclusion: Patients with COPD experience multiple physical and psychosocial problems in their daily life. Therefore, there is need to provide holistic approach for the enhancement of quality of life of patients.

Key Words: Chronic Obstructive Pulmonary Disease, Experience, Patients

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is highly prevalent respiratory disease worldwide. The prevalence and burden of COPD are projected to increase in the coming decades due to continued exposure to COPD risk factors and the changing age structure of the world's population.⁽¹⁾

COPD is a multi-systemic nature of illness which affects the patients' physical health, social life and psychological functioning. Dyspnea, fatigue and cough are the often reported symptoms of COPD.^(2,3) Many researchers have described how shortness of breath imposes greatest restrictions on patient's daily life,^(4,5) physical endurance and functional ability,⁽⁵⁾ causes social isolation and loneliness,⁽⁶⁾

emotional fluctuation, ⁽⁵⁾ fear, ⁽⁶⁾ anxiety and depression, ⁽⁷⁾ as well as reduces quality of life. ⁽⁸⁻¹⁰⁾ Barnett (2005) described that patients' functioning ability fluctuated from day to day depending on the weather and degree of the symptoms. As a result, restriction in daily living occurred due to uncertainty about limitations in physical capacity. ⁽²⁾ Habraken reported that the social limitations' evident in patients when they became less mobile as a result of their physical limitations. ⁽¹¹⁾ Balcells et al. explored that the anxiety, depression, and or combination of both were significantly associated with poor health related quality of life. ⁽¹²⁾

Impacts of COPD on patients' daily life are mostly subjective in nature and it can only be interpreted by the person experiencing it. Management of COPD varies based on their illness perception and accessible to health services. Many researchers especially in the western world addressed the situation of COPD patients from the perspective of symptoms and quality of life and very few have addressed the experience with COPD in daily lives. However, there is dearth of information in Nepal addressing patients' experiences with COPD. Hence, this study was undertaken to explore the lived experiences of patients with COPD in Chitwan, Nepal in order to gain in-depth understanding of the effect of the disease and the ways in which they integrated the illness into their lives.

MATERIALS AND METHODS

Qualitative phenomenological approach was adopted to explore the lived experiences of patients with COPD in Chitwan, Nepal. A total 22 COPD patients were selected purposively as a nested sample from 470 COPD patients who visited outpatient department of Chitwan Medical College Teaching Hospital, College of Medical Sciences Teaching Hospital, Bharatpur Hospital and Bakular Tandi Hospital of Chitwan district, and participated in the quantitative survey. Those patients aged 40 years and above,

clinically diagnosed to have COPD for at least three months, and gave consent for the follow up study during quantitative survey were included in the study whereas patients with identifiable mental illness and physical disabilities were excluded from the study.

Prior to data collection, ethical clearance was obtained from the institutional review board of Institute of Medicine, Tribhuvan University and data were collected over three months period from 15-02-2015AD to 13-05-2015AD. The researcher chose the local person as an assistant and trained for tape recording and note taking appropriately. Type of patients, their addresses and contact numbers were identified from the filled up interview forms of quantitative survey. The researcher contacted the participants individually to ensure their consent for participation. The date and time for the interview were predetermined according to the convenience of the participants and they were approached by a reminder telephone call on the day of interview. Written informed consent was obtained from the participants prior to data collection and data collection took place in the participant's home. In-depth interviews were employed as a primary method of data collection by using interview guideline. The main areas covered during interviews were general health status, impacts of COPD on physical, social, and psychological health and coping strategies with COPD. Grand tour questions were posed to encourage the participants to express their feelings and experiences about their situation. Each interview lasted for 40-60 minutes in one visit and interview was audiotaped on a digital voice recorder to obtain a true account using the participant's own words. The digital voice recording was downloaded to password protected personal computer and transcribed verbatim by the researcher at the end of each day. On the day of subsequent interview, reminder call was given to the participant and asked for consent. Data collection sessions were carried out until data get saturated.

After transcription, data were analyzed thematically using the steps outlined in Colaizzi's (1978) method. Seven steps were: (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) Organizing 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 if the researchers' conclusions are in agreement with their descriptions. During data analysis, individual meaning was coded and when patterns began to emerge, these were combined and consolidated into common themes. Pseudo names are given to the participants instead of their real name to maintain privacy and confidentiality of the information.

RESULTS

Socio-demographic Characteristics

Nine man and 13 women participated in the study. Age of the participants ranged from 50 to 85 years. Half of them were married and half were widow or widower. All the participants except one were staying with at least one family member and fifteen belonged to joint family. Seventeen participants were illiterate and the major occupation among the participants was agriculture (13/22). The mean duration of illness was 6 years. Seventeen participants were under regular medications however only half of the participants were going for regular follow-up visits. Onsmoking status, seventeen participants were ex-smokers, four were never smokers and one was still smoking. Eleven participants had other co-morbid conditions and hypertension (7/11) was the common comorbid condition among them.

Experiences with COPD

Seven themes emerged after thematic analysis of narrative descriptions of the participants' experiences with COPD. They were: (i) Self-inflicted illness with hidden disability (ii) multiple distressing symptoms (iii) modification in activities (iv) altered relationship (v) social isolation and loneliness (vi) economic hardship (vii) emotional trauma.

Self-inflicted Illness with Hidden Disability

COPD participants under this study perceived their illness differently. Each gave their own description of illness such as self-inflicted disease, disease with hidden disability, frightening illness with insecure life, and chronic illness that needs regular treatment. Birbal, 79 years old man described his feeling of guilt due to self-inflicted disease resulting from his smoking behavior as "*I invited this problem to myself. As I was not aware of its effect on health then, I kept smoking indiscriminately and when I learned its adverse effect, it was too late to avert*". Other 65 years old man [Rishi] expressed his perception towards COPD as "*It is a deadly disease which has killed me even before I am dead ('Jiudomurda' in local language). I can just sit and watch things normally but not able to go around freely*".

Participants tried to make a sense of how they had developed breathing problems, with many of them reporting more than one factor responsible for their disease causation. Smoking behavior (15/22) and prolonged exposure to indoor and outdoor air pollutants (11/22) were common contributing factors of COPD. Moreover, few participants linked their current illness with weak health resulting from childhood pneumonia (3/22), advancing age (2/22), and family history of COPD (2/22). However, three participants (3/22) had misconception about causes of COPD and still believed that the illness resulted from their ignorance on diet rather than their smoking habits and exposure to air pollution. Two participants expressed their difficulties to avoid exposure to indoor

air pollutants (biomass fuel) due to financial constraints.

Multiple Distressing Symptoms

Participants talked about multiple distressing symptoms which were progressive in nature and became severe slowly over a period of time. In the beginning, they experienced occasional cough and cold, throat discomfort as well as shortness of breath during strenuous activities but they did not recognize these as signs of COPD. Hence, some of them did not consider seriously or overlooked them thinking that they were just upper respiratory tract infection. They unknowingly reduced and or avoided the activities involving exertion to get rid from those problems, which can eventually lead to disability. Later when they experienced symptoms such as cough, wheezing ('GhatiKaraune' in local language), early morning tiredness, severe attack of dyspnea frequently or experienced disturbance on their usual activities then only they consulted health worker and were diagnosed as a COPD.

Dyspnea was the most distressing symptoms and the common cause of physical disability among the participants. Severe episode of breathlessness triggered psychological distress such as frightening feeling of dying due to suffocation, hopelessness, helplessness, and being dependent on medications. One 79 years old man [Birbal] shared his experience of severe episode of breathlessness as "*Oh! Breathing attacks....it is so terrible. It feels like I am chocking or something's stuck up in my throat which could not be relieved through coughing. Breathing can suddenly go and I get almost unconscious*".

Cough was the second most common and distressing problem described by seventeen participants. Severe attacks of cough sometimes contributed to breathlessness, sleep disturbance, sudden feeling of dying, panic attacks and fear of impending death among the participants with COPD. Rani, 65 years old woman narrated her experiences as "*I have dry*

cough almost every day and it is getting worse from the last 2 months. Each episode of cough is very frightening and painful. It troubles me for nearly half an hour. My husband was hospitalized several times for worsening cough and eventually passed away.... I fear I will have the same fate".

Fatigue was the third most prevalent physical problem among fifteen participants with COPD but the intensity of fatigue was varied among them. They described fatigue in various ways such as feeling of weakness, lack of strength, lack of energy, lethargic and giddiness. Fatigue hampered the participants' daily activities including routine work, mobility, and social life as well as contributed psychological distress among them. One 85 years old man [Ram Bahadur] stated his experienced of fatigue and associated difficulties as "*Nowadays, I feel powerless because breathing problem attacks quite frequently like a wimp dog gets bullied by stronger ones due to lack of energy in my body. If there is energy, I can talk and move but being a powerless man, I am unable to do anything*".

Participants also reported other problems such as sleep disturbance (14/22), loss of appetite (10/22), physical pain (8/22), dry mouth (6/22) and wheezing (4/22). One 59 years old woman [Patali] described her diminished digestive power due to ill health as "*I could easily digest food (e.g. 4-5 mana roasted maize and 2-3 manamohi in local language) then but I hardly take food nowadays. It's all due to decrease physical strength*". Similarly, Rebat, 61 years old woman expressed that burning sensation usually disturbed her sleep pattern. She narrated "*I am experiencing burning sensation especially on legs which disturbs my sleep almost every night. I keep handkerchief soaked in cold water and place it over the legs but in vain. I sit up and bend on bed throughout the night, but still no sleep*".

Participants used various techniques such as medications, alteration in positions, alteration in breathing techniques to manage their symptoms and to avoid the risk of

recurrence. The most common technique reported by participants was use of inhalers. Patali, 59 years old woman reported that she frequently used inhalers to manage her shortness of breath as "*During breathing attacks, I use nebulizer 4-5 times; otherwise 2-3 times are enough. Aside from that, I use cough syrup whenever I have cough and use nebulizer too.*". Only three participants reported the use of breathing technique (deep breathing or purse lip breathing or breathing through mouth) on dyspnea management. Rishi, 65 years old man stated his experience as "*If I get shortness of breath on the way, I just sit over there, inhale air from one nostril and exhale from another on regular interval as Ramdev teaches for 10-15 minutes. It is really helpful for me because I feel relax after sometime.*". Aside from that, participants consulted the health worker immediately in case of exacerbation of symptoms or failure of usual measures to control the symptoms.

Modification in Activities

Participants expressed how over the years, their breathing problems had become severe, and they were forced to decline their activities and change lifestyles in spite of their wish to continue it. All participants reported that their illness especially breathlessness and fatigue made them hard to maintain their usual activities independently. In addition, environmental triggers (cold weather, dusty environment) put additional difficulties in their activities. As a result participants' modified their lifestyles by adapting certain behaviors such as avoiding, quitting and reduction in activities knowingly or unknowingly to minimize the effect of illness and to maintain their life as normal as possible. Eight participants dropped their activities due to lack of physical stamina and breathing difficulty whereas two participants avoided their activities with the fear of worsening of the symptoms. As a result they became housebound. Rishi, 65 years old man talked about the effect of illness on his physical activities resulting from diminished physical strength and

breathlessness. He felt difficult to engage in energy requiring activities and hence became housebound. He narrated his difficulties as "*It has been almost a year that I am staying at home due to breathing problem. I could do nothing that requires energy. I could not walk far. I have to take rest in between while even walking around the house. I cannot climb up stairs without being breathless. It is hard even to talk sometime.*"

However, twelve participants were still struggling even to maintain their simple household activities with the help of medications. Patali, 59 years old woman described that she had led a very active life in the past. But after suffering from illness she became unable to continue her previous activities. She stated her functional disability and associated emotional changes as "*In the past, I used to finish off work by myself that could have otherwise taken two people to complete. I used to carry 50 kg heavy sack of food from my village to the city without taking rest but now I cannot carry even a single kg of things without breathlessness. It makes me quite sad. Nowadays, I feel discomfort during climbing stairs and cannot manage long walk. However, I am doing household chores whenever I feel easy but I do work in slower pace.*"

Most commonly restricted physical activities were mobility, performance of household work, washing or bathing, and lifting or carrying things. All the participants experienced some restriction in their walking ability and the major causes reported were breathing difficulty and fatigue. However, they made an effort such as they lowered their speed, took rest for a while and shortened the distance of walking based on their condition to maintain their life as normal as possible. One of the participants [Fulmaya] narrated her struggle to manage her mobility as "*I used to remain comfortable while sitting or walking around house on plane surface, but could not walk long distance and climb stairs without shortness of breath. Hence I walk slowly.*"

Difficulty in household activities was reported by twenty participants with COPD. Among them, ten quitted their activities due to fear of worsening of symptom. However, remaining ten participants still made an effort to maintain their household activities by altering their activity level and using inhalers despite of their difficulty. They also talked about their wish to continue household chores. One 62 years old woman (Makhmali) shared her adjustment with her limited activities as "*I prepare meals (especially rice and dal) but leave cooking part of vegetable ('Curry' in local language) to my daughter in-law because steam and smokes especially from cooking vegetables irritate me and induced cough and shortness of breath. I am not hopeful of doing things as in the past. I will be happy if I am just able to cook food*".

Bathing was a particularly difficult task mentioned by seventeen participants with COPD. Nine out of seventeen were frightened to have a bath due to the fear of losing their breath or could not get out while other eight were unable to take bath on their own due to difficulty in lifting arms to wash the hair or bending to dry feet. As a result, most of the participants decreased their frequency of bathing and did just fresh-up or changed their clothes daily, used warm water during bathing and used inhalers immediately after bath to deal with their bathing problem. Bhima, 57 years old woman supports this in the following statement "*I used to bath every day, which I have really missed. Nowadays, I take bath every 10-15 days with warm water because of the fear of catching cold. Few days back when I took bath, I developed cough and shortness of breath which was not controlled with usual inhaler and hence, I visited hospital and took extra dosages of medicine for the pneumonia*".

Difficulty in lifting and carrying things was also a difficult task reported by seventeen participants with COPD. Seven participants had problem in lifting or carrying heavy objects whereas ten participants were unable to carry even light

objects without breathlessness. As a result they avoided those difficult situations as to maintain their breathing within normal range. One 70 years old man (Laxman) expressed frustration associated with his inability to carry things as "*When I was in army, I could run carrying the load of 25kg on the shoulder, but now it is difficult even to carry a bag of 2 kg. I think there is no point of recalling the past*".

In addition, social and recreational activities were diminished among cent percent of participants due to breathlessness, fatigue and fear of getting ill from environmental triggers. As a result eleven participants isolated themselves from their social gathering and activities due to the adjustment problem with limited capacity. Sashi, 62 years old woman expressed her reduced social participation as "*I do not want to go out very often, as I cannot eat food outside because of the fear of getting illness. Last time I went to attend a wedding ceremony of my relatives and became ill after taking some foods. Then, I had to take medicines and I have not still recovered. Whenever I go to my previous place for some events like birth and mourning ceremonies, I usually fall sick*". However, eleven participants made an effort to maintain their social activities by using certain measures such inhalers, available vehicles, as well as modification in their activities. Man Maya, 70 years old woman reported her social participation as "*I go around the neighborhood slowly but while going relatives' houses situated in far places, I use rickshaw or public transport. I participate in death ceremony, wedding ceremony and other religious events*".

Altered Family Relationship

All the participants under this study received support from at least one family member however; limited roles within family affected the harmony of relationships within family members and their satisfaction was diminished. Ten participants expressed their dissatisfaction with their family members especially due to lack of concern and accompany from them

during their illness. As a result, they experienced the feeling of being neglected and burden on family members. The following statement reflects such situation as "*My daughters' in-laws get irritated with me over little things and they act like they do not need me. If I was disease free, I could have done the works of my two daughter in-laws by myself*".

Social Isolation and Loneliness

Physical disability resulting from breathlessness and fatigue, fear of worsening of symptoms resulting from frequent exacerbations, and reduced interest of engagement in social activities contributed the feeling of social isolation among thirteen participants with COPD. One of the participants (Makhmali, 62 years woman) reported that she avoided participating in social activities, which she used to get involved in, due to fear of getting ill from the food over there. She narrated her problem as "*I don't like to go to social functions in the neighborhood, because when I go there, I get tempted to eat food which eventually makes my health bad. I let my family members go there instead*".

Reduction in social engagement and lack of accompany from children and friends contributed to feeling of loneliness among twelve participants with COPD. Following statement reflects the situation as "*I am living alone as all my sons and daughters are staying in their own houses. I have no one to look after as my husband passed away four years back and there is no body to shed tears at my death*".

Economic Hardship

COPD patients lost their jobs or income generating sources due to physical disability resulting from symptom burden. They experienced frequent exacerbations leading to hospitalization due to the progression of illness. Besides, they had to use different medications regularly for the control of their symptoms which were costly and therefore hard to afford with their limited financial resources. In addition, lack

of regular income or pension and minimum old age allowance means inability to afford the cost of treatment. As a result they experienced financial difficulties in their daily life.

Eight out of twenty two participants experienced economic difficulties for the management of their illness due to limited financial resources and loss of income generating source. Except one all participants (7/8) were previously engaged in agriculture or own work but recently depended on family members for their treatment and medications. Moreover, participants reported disharmony resulting from economic difficulties in their daily life. Rebat, 61 years old woman narrated her problem and requested the government to provide free treatment and medicines as "*....Illness made me helpless. Neither I can die nor can I live happily. It's been two months and I have not visited hospital. I am not able to afford money for regular follow-up visit. .. I just buy medicines from drugstore nearby. Nothing is possible without money. Whenever I become sick, sons take me to hospital but unfortunately they start arguing with each other on the expenses they have to share for my treatment. I wish government would provide the treatment and medicine for free*".

Emotional Trauma

Participants with COPD encountered different psychological problems such as symptom of depression, symptoms of anxiety and memory problem in their daily life. Sadness was the common depressive symptoms reported by eleven participants with COPD. They linked sadness with their restricted physical activities and lack of company of children. Shova, 50 years old woman reported her feeling as "*I am rather frustrated because of the fact that I cannot make to the events that my colleagues are able to do. I regret for not being able to work*". Similarly, feeling of helplessness was evident among eleven participants with COPD which resulted from physical disability, failure of usual measures to control symptoms during breathing attacks,

fear of the progression of illness and feeling of diminished control over life. A 61 years old woman [Rebati] described her feeling of helplessness due to physical inability resulting from breathing problem as "*So pitiful life it has become that neither can I walk nor can I take whatever I like to without being symptomatic. Who will take care of me if I get bedridden and unable even to use the toilet? If only I was disease free, I could have done all the works that a young lady could do, but that has just became a wishful thinking now.*". Feeling of hopelessness was reported by nearly one half (10/22) of the participants with COPD. They became hopeless when they were not able to do their activities, when they suffered from breathing attacks, when usual measures fail to control symptoms, and when they thought about the progressive and uncertain nature of illness. Fulmaya, 73 years old woman stated her feeling of hopelessness experienced during breathing attacks as "*I used to get breathing attacks quite often but they were manageable with the injection, nebulizer and medicines given by health worker. But two attacks were terrible for me on which I lost my hope of living and for which I was hospitalized eventually.*". Moreover, ten participants were worried about their future regarding disease progression and suffering. In addition, disturbing repeated thought in mind, guilt feeling and worthlessness were also reported by the participants.

Symptoms of anxiety such as restlessness, frightening feeling, and panic attacks were reported by one third of the participants with COPD. Breathing attacks, loneliness and uncertain nature of illness contributed those feelings among the participants. A 79 years old man [Birbal] expressed his feeling of restlessness as "*I cannot stay in same place for long because I get restless. I keep walking except in serious condition.*". Laxman, 70 years old man explained his feeling as "*I used to do physical exercise in the morning, but I get panicked to go out these days. I can't remain alone inside a locked room and I let*

the toilet door unlocked due to fear of suffocation".

Memory impairment such as recent memory problem was observed among four participants with COPD. They stated that they forgot the things or work quickly that they were supposed to do. One 59 years old woman [Patali] described that she had recent memory problem. She said "*I am starting to forget things quickly. At times, I look for things in and around home that is in my hand already and sometime, I suddenly forget what I was supposed to do next*".

COPD participants attempted to develop various coping strategies to deal with their symptoms and disabilities to lead as normal lives as possible. The commonly identified approaches were symptom management, coping with physical limitations, dealing with environmental factors and emotional coping.

DISCUSSION

The impact of COPD was evident in almost every aspect of patients' lives and they were troubled by multiple physical and psychosocial problems. Patients linked their causes of COPD with smoking habit and indoor and outdoor air pollutants. Some of them perceived COPD as a self-inflicted disease and expressed guilty feeling about their smoking behavior. This finding is consistent with the study conducted in UK in which patients mentioned lifetime smoking habit as their causes of illness as well as they express their guilty feeling of being responsible for having such disease in their lives.⁽¹³⁾ In addition, one sixth of never smokers had COPD due to indoor and outdoor air pollutants arising from the use of biomass fuel, paddy planting and harvesting. These findings are supported by one article in India which noted 15% of COPD cases worldwide are due to nonsmoking causes but developing countries have higher prevalence due to indoor air pollution arising from the use of biomass fuel.⁽¹⁴⁾

In this study, commonly experienced symptoms of COPD were dyspnea, cough, sleep disturbance, physical pain and diminished appetite but most distressing symptom was dyspnea which affected patients physical and social functioning, and contributed the psychosocial problems such as the feeling of social isolation, financial difficulties for treatment and psychological distress among them. These findings are consistent to other qualitative studies which found breathlessness as the worst symptoms and the acute episode of breathlessness is associated with the feeling of helplessness, panic, frightening feeling associated with fear of chocking, suffocation and death.^(2,3,5,15) Frasel et al. in USA noted that the dyspnea affects both physical endurance and functional ability of the patients as well as emotional fluctuations often associated with the physical impact of disease.⁽⁵⁾ Similarly, Seamark et al. reported that the participants frequently described fear and anxiety particularly associated with dyspnea⁽⁶⁾ and Hesselink et al. found the association of more dyspnea and frequent respiratory symptoms with a decline in HRQL.⁽⁸⁾ In addition, Janson and colleagues found dyspnea as an important determinant of a low physical and mental health component scores.⁽¹⁰⁾ Fatigue was another troublesome symptom which was responsible for the limitations on physical activities and social functioning. This findings is consistent with many other studies which explained that the fatigue had significant impacts on patients physical,^(4,16) cognitive and psychosocial functioning.⁽¹⁶⁾ Stridsman, Lindberg, & Shar in Sweden concluded that fatigue in COPD is multidimensional symptom strongly connected to dyspnea, always present feeling that involved whole body and caused the feeling of hopelessness, fear and anger.⁽¹⁷⁾

The combination of breathlessness and fatigue severely restricted the patients' daily activities such as mobility, household chores, social and recreational activities hence patients avoided or curtailed their daily activities to manage their limitations.

As a result their activities were diminished and lifestyles changed. This finding is also corroborated with other qualitative studies.^(4,18,19) The commonly restricted activities among the COPD patients of this study were walking, household chores, cooking, bathing, lifting or carrying things, visiting to friends and relatives, leisure time and recreational activities and this is similar to the findings in a systematic review.⁽²⁰⁾ Likewise, Elofsson and Ohlen found that the participants experienced difficulties to perform household or leisure activities, they required strength to get up in the morning, get dressed and move from one room to another.⁽¹⁹⁾ Hu and Meek identified that the reduced activities of daily living and physical impairment had significant impacts on the physical health components of quality of life.⁽⁹⁾

Limitation in the activities and multiple distressing symptoms placed considerable burden on patients' social life and their family. Patients reduced or dropped their usual activities to minimize risk of worsening of symptoms and to maintain their life as normal as possible in limited sphere. As a result they lost their jobs, became unable to perform their roles and responsibilities, developed dependency on others, and remained detached from their social and work contacts. Changing roles and circumstances contributed the feeling of social isolation, loneliness, dependent, burden, and neglected as well as financial hardship on treatment in spite of their joint family structure and support from at least one family member. These findings are consistent with the study conducted in USA⁽²¹⁾ which found that the participants experienced reduction in social activities due to the symptoms associated with COPD and other chronic conditions. Barnett in UK found the altered roles and harmony of relationship within the family, financial hardship and feeling of being burden on the family among COPD patients.⁽²⁾ Similarly, studies conducted in New Zealand,⁽²²⁾ Sweden,^(4,19) Chicago,⁽²³⁾ USA⁽²¹⁾ and UK⁽⁶⁾ identified the social isolation and

loneliness among the participants with COPD resulted from symptom severity and their inability to engage in physical and social activities. Fraser et al. found the increased level of dependence to other, feeling of social and emotional isolation, and poor quality of life resulted from disease progression among the COPD clients.⁽⁵⁾

Psychological problem was also marked in the patients due to distressing symptoms, and physical and social limitations. Almost half of patients with COPD reported the symptoms of depression and anxiety during their interview. These findings are supported by other studies^(3,23) which found that the symptoms of depression and anxiety are common among COPD patients. The most common symptoms of anxiety and depression of patients in the study were feeling of hopelessness, helplessness, sadness, worrying for future, frightening feeling, panic attacks. These findings were supported by the other studies which reported that the participants became sad when they had to forgo so many activities,⁽⁴⁾ frequently spoke about fear they experienced in relation to fear of losing their breath,^(2, 24) and became panic with the fear of getting dyspnea.⁽⁵⁾ Miravitles et al added that depressive patients frequently have lower level of physical activity, more cognitive impairment, suicidal thoughts and worse quality of life.⁽²⁵⁾ Moreover, review article in UK noted that the co-morbid anxiety and depression are associated with increased mortality and health care utilization and impact upon functional disability and quality of life. Despite these negative consequences, the identification and management of anxiety and depression is inadequate.⁽²⁶⁾ COPD patients with more positive view of illness and fewer depressive symptoms had a better quality of life.⁽²⁷⁾

Following limitations would need to be considered when utilizing the findings of the study. COPD patients who visited the medical outpatient department of the

selected hospitals and participated in the quantitative survey were recruited for the study; hence, it might not represent the COPD population at large. All the interviews took place in the patients' residence where the circumstances surrounding the interviews and motivations for the participation in the study might have affected the responses in unknown ways.

CONCLUSION

This qualitative study identified multiple physical, social and psychological problems of COPD patients. Dyspnea is the most troublesome symptom and major cause of disability. In addition, fatigue is another symptom which greatly influences patients' activity. They have difficulties in their daily physical and social activities' performance due to frequent symptom burden and physical disabilities. Most of the patients are staying in joint family and they are getting support from at least one of the family members. In spite of this, patients experience the feeling of social isolation and loneliness, neglected, and burden on family members. In addition, depressive and anxiety symptoms are also common among the patients but none of the patients are receiving antipsychotics. Some of the patients make an efforts to maintain their life as normal as possible by using different coping strategies such as symptom management, adjustment with limitations, control of environmental factors and emotional coping. Those patients who are able to involve in activities and experience minimal symptoms have better quality of life compared to patients who became unable to participate in the activities and experience multiple symptoms. Therefore, there is need to establish rehabilitation program with more focus on physical and psychosocial dimension of health for the overall enhancement of quality of life of patients suffering from COPD. Treatment facilities especially medications and oxygen therapy need to be provided in minimal cost to minimize their financial difficulties.

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