

Original Research Article

Lived Experiences of Patients with Chronic Obstructive Pulmonary Disease in Chitwan, Nepal

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ABSTRACT

Introduction: Chronic obstructive pulmonary disease has a great impact on patients' daily life. Patients' subjective experiences and its management vary based on their illness perception and accessible to health services. The objective of this study was to explore lived experiences of patients with chronic obstructive pulmonary disease in Chitwan, Nepal.

Methodology: Qualitative phenomenological study design was used and four patients were selected from parent population as a nested sample. In-depth interview was conducted among participants in their home settings by using interview guidelines and data was analyzed by using the steps outlined in Colaizzi's method (1978)

Results: The key results were broken down in four themes. (1) Physical health: Chronic obstructive pulmonary disease had detrimental effects on the patients' physical health. Dyspnea was the most troublesome symptom and major cause of disability. All patients experienced limitations on their physical activities. (2) Social health: Most of the patients identified limitation on their social and recreational activities. Despite of all patients reporting adequate support from their family, they still experienced social problems such as feeling of loneliness, isolation, dependent and burden on family members. (3) Psychological health: Patients encountered different emotional feelings such as restlessness, sadness, frustration, helplessness, panic and fear of dying as a result of their physical and social limitations. (4) Adaptation with illness: Patients mostly used inhalers and modified their activities to deal with the problem. Care from family members was a helpful measure for adjustment.

Conclusion: Patients experience different physical and psychosocial health problems in their daily life. Therefore, there is need to establish rehabilitation program including physical and psychosocial dimension of health for the enhancement of quality of life of patients suffering from chronic obstructive pulmonary disease.

Keywords: Lived Experience, Patients, Chronic Obstructive Pulmonary Disease.

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is one of the most common chronic diseases throughout the world. The prevalence of COPD in adults 40 years and

older is approximately 9%-10% worldwide.

(1) This disease is expected to become the fourth leading cause of death worldwide by 2030AD. (2) COPD is characterized by progressive impairment of airflow through

the lungs and airways. This compromised pulmonary function is irreversible and often associated with airway inflammation.

Chronic obstructive pulmonary disease has a great impact on patients' daily life and affects the degree to which the person can be active at home, participate in social relations and experience well-being. (3-5) Breathlessness (3,5-8) and fatigue (3,6) are the most common symptoms which decrease the performance of daily activities and overall quality of life. (4,6) Person reporting low quality of life have various distressing symptoms and impairment in physical functioning. (9) Limitation on physical functioning reduces the patient's ability to socialize and lead to social isolation. (3,5) In addition, patients with COPD describe feeling of frustration, tiredness, anxiety, panic and fear because of their breathlessness. (3)

Patients' need of illness management varies based on their illness perception and accessible health services. Hence, health workers should identify COPD patients need at an early stage and be familiar with how patients experience and cope with the disease so that they can provide adequate support and good care to them. Several studies were done on the experiences of COPD patients in other countries especially western world but limited in developing countries like Nepal. Therefore, this study was undertaken to explore the lived experiences of patients with COPD in order to gain in-depth understanding of the effect of the disease in them and the ways in which they integrated the illness into their lives in Chitwan, Nepal, which will ultimately help to develop and implement context suitable program for COPD patients.

MATERIALS AND METHODS

As the proposed research of this pilot study is sequential explanatory mixed research design (Quantitative Survey→

Qualitative Study), subsequent to the quantitative data collection and analysis, interview guideline was developed for qualitative data collection part. The focus of this study was to explore lived experiences of patients with COPD. In-depth interviews were employed as a primary method of data collection which encourages patients to reflect on their experiences of living with COPD.

In order to explore lived experiences, COPD patients who obtained higher and lower quality of life (QOL) scores in the quantitative survey were identified first. Among them, four patients (two from higher QOL scoring group and two from lower QOL scoring group) were purposively selected from the parent population as a nested sample. Inclusion criteria were: (i) patients aged 40 years and above (ii) clinically diagnosed to have COPD for at least three months (iii) patients participated in the quantitative survey conducted to assess the quality of life.

Data were collected over a month period (27-07-2014 to 27-08-2014) by using in-depth interview guidelines, covering questions on how COPD affected patient's daily life. The date and time for the interview were predetermined with the participants and they were approached by a reminder telephone call prior to interview. All the participants were informed about the purpose of the study both verbally as well as in written form. They were also assured that their participation in the study was voluntary, and the information given by them would be kept confidential and only be used for the study purposes. After obtaining oral consent, the participants were scheduled for interviews at their convenient place and time. Written informed consent was obtained from the participants prior to data collection and they were interviewed separately in their home setting. The researcher also captured the essence of the

interview by recording the interview using audiotape device after obtaining permission from participants. The estimated time for the each interview lasted for 50-60 minutes. Each participant was assigned a code number for the interview to ensure confidentiality of the data.

Data collection and analysis were done side by side. Soon after the data collection, each set of notes were written up by listening audio record carefully along with memos and field notes for the expansion and elaboration of situation. The unedited transcripts and comprehensive notes served as reference tools during the analysis phase of this investigation. Audio records of each interview were transcribed verbatim to produce written accounts. The transcription was done at the end of each day as recommended. The initial interpretation of the transcripts and notes were completed individually to permit researcher more opportunity to study and become familiar with each transcript and its themes. Afterwards, all four interview transcripts were analyzed collectively to discover the emerging themes, ideas, and concerns.

Data were analyzed using the steps outlined in Colaizzi's (1978) method. In the 1st step, the transcripts were read and re-read in order to understand the meaning written within the context of significant words or phrases. In 2nd step, the texts were read several times to obtain a sense of whole things and extract significant phrases and statements. In 3rd step, each significant phrases and statements were read through several times, underlined, condensed, and coded. Then the codes and meaning units

were read several times and compared to context. In 4th step, the codes were grouped together to form concepts and categories. The final categories were examined to ensure a clear difference between them. Then the process of analysis and continuous comparison of data were done and numbers of codes were reduced and finally subthemes and themes were obtained. In 5th step, researcher compared the themes with the participants' original descriptions and texts for validation and themes were incorporated into original text. In 6th step, themes were clearly described and verified with the participants. The individual and collective analysis process initiated a continuous cycle of writing, edits, and revisions to develop a coherent narrative that will sufficiently contributed to existing literature

RESULTS

In total, eight interviews with four participants were conducted by the researcher during a period of one month. To maintain confidentiality, patients name were changed. The patients' socio-demographic characteristics were reported in table 1. Thematic content analysis was done to analyze the data. The key results of qualitative data analysis were broken into 4 major themes: (1) Physical health which contains 2 subthemes: severity and symptom burden and limitation on physical activities. (2) Social health contains 3 subthemes: limitation on social activity, relationship and support system, and social problem. (3) Psychological health contains emotional feelings and (4) Adaptation with illness which contains techniques used to manage their problems in daily life.

Characteristics of Participants

Participants*	Sex	Age in year	Education	Occupation	Marital Status	Duration of Illness in year	QOL Score in Phase I
Sunita	F	71	Illiterate	Home maker	Widow	10	High
Harke	M	72	literate	Agriculture	Living with spouse	20	High
Birkhe	M	72	literate	Priest	Living with spouse	6	Low
Sita	F	80	Illiterate	Agriculture	Widow	15	Low

*Changed name were given

Table 1 presents the characteristics of participants. Out of four patients, two were male and two were female. The mean age was 73.75 years (age range 71-80 years). Two participants were illiterate and two were living with their spouse. The mean duration of illness was 12.75 years. All the participants were on regular inhaler drugs for breathing problem.

Physical Health

Severity and Symptoms Burden:

Participants characterized COPD differently as a non-curable disease, devastating illness and old age disease. Many participants (3/4) accepted that smoking and exposures to indoor and outdoor air pollutions were the contributing factors for their illness.

All participants experienced symptoms gradually over the time period and perceived that it was worsening over time. Some participants experienced symptoms frequently while others were experiencing during chest infections only. All participants reported that they were more troubled from dyspnea and cough which reminded them about their disease and death. Sita, 80 years old woman expressed her feeling as: I had bad cough and difficulty in breathing frequently which was pretty troubling at times. Sometimes, I feel like dying due to bad cough and breathing difficulties.

Some participants experienced dyspnea all the time whereas others were experienced dyspnea during their moderate and strenuous activities only. Dyspnea imposed the greatest restrictions on daily life and caused intense fear. They had changed their priorities area and were being addicted with inhaler drugs. Sunita, 71 years woman confirmed this as: I have been experiencing shortness of breath on a daily basis which is relieved with the help of inhaler only. When I remained sedentary (sitting at home, speaking on phone, and walking inside home) I can breathe easily however,

running, brisk walking and little exertion caused shortness of breath.

Another participant, Sita, 80 years women expressed her experience as: I had shortness of breath during sedentary state (sitting, speaking) or even at rest. My symptoms gradually increased in the last 5 years, so I stopped doing all moderate and strenuous activities. Since last year, I am on regular inhaler drugs and have stopped doing even minor work and stayed at home.

Participants who had lower score on QOL in quantitative survey were experiencing dyspnea even during minor work and even at rest also, whereas participants who had higher score on QOL scale in quantitative survey were experiencing dyspnea during moderate and heavy activities only. Participants with high QOL score in quantitative survey were experiencing bad cough occasionally whereas participants with low QOL scores were experiencing bad cough frequently.

In addition to dyspnea and cough, all the participants (4/4) reported that they used to get tired with varied intensity. Some reported that they get tired with minimal work while others reported that they get tired without doing anything. Harke, 72 years male indicated such tiredness as:

I get easily tired even without doing any work, so I quit my job and stayed at home most of time.

Likewise, Birkhe, 71 years male participant described his tiredness as: I feel fatigue and weak most of the time even while I am not doing anything in the last 2 months. That's why, I am taking vitamins regularly.

Other symptoms reported by two participants (2/4) were sleep disturbance due to the shortness of breath and burning sensation on leg, loss of appetite and physical pain. Sita, reported her experience of pain as: I am suffering from back pain so much so that I couldn't sit or stand easily and hence, I am using back support (by a

piece of cloth known as patuka in local language) since last month. I can hardly sleep for few hours (3-4 hours at night) and wake up in the middle of the night (2-3 am). Likewise, Birkhe, stated his disturbed sleep as: I am suffering from burning sensation on legs which interferes my sleep almost whole night. Last night, I had difficulties falling asleep due to the attacks of shortness of breath.

Another participant, Sita reported her loss of appetite as: I am taking very little semi liquid diet (dal and jaulo) to survive since last month. Please teach me how to increase my appetite.

While comparing the differences between high and low QOL groups, both groups had tiredness and fatigue but burning sensation, pain, sleep disturbance and loss of appetite were more common among low QOL scoring group.

Limitation on Physical Activities:

Many participants described that they had once lived an active life but now have to exclude some of the activities due to their illness. All the participants (4/4) experienced certain limitations in their physical activity such as walking, climbing up and performing their usual activities of daily living due to dyspnea and lack of physical strength but limitation varied among participants. Two (2/4) participants were performing their daily activities with the help of inhalers and little modification on their life styles while others (2/4) were curtailing their usual activities and became housebound these days. One, male, Harke, stated that he is managing his low intensity physical activities as: I can do my daily activities like eating, clothing, washing my face, dressing, bathing, and walking around the house but I am not able to perform other activities such as running, gardening, and raising cattle and selling the milk in the market.

Other, woman, Sita, reported that she become dependent on others for her activities of daily living as: My activities are quite affected. Nowadays, I am not able to walk inside the house and even using toilet is not easy task for me. My family members are helping with my activities such as bathing, preparing food, washing clothes and visiting physicians etc. I can't even answer the phone due to shortness of breath.

Walking was the most common mobility problem reported by all participants in the study and their experiences were varied for long and short walk. Some participants reported that they were managing their mobility problem by curtailing their outdoor activities; and hence, became housebound whereas others changed their life style. Harke, 72 years male participant said: I am alright while I am sitting or walking around the house but I cannot walk very far without experiencing shortness of breath. So while walking long distance for example, going to my daughter's house, I have to take extra dose of inhaler drugs and take break in between.

Climbing up stairs or hills was another common problem reported by clients with COPD. All participants (4/4) have problem of climbing up the stairs because of shortness of breath. Many (3/4) participants were managing this situation while one participant (1/4) was avoiding the situation altogether. Birkhe, 71 years old man, stated as: I cannot climb up the stairs in one go. I have to stop half way to get my breathing smoothly; I can then carry on for a bit more before I need to stop again at the top of the stairs.

Other Sita, 80 years old woman, stated: I am not able to climb the stairs up at all, so my room is shifted to ground floor since last year.

While comparing activity limitation among higher and lower QOL scoring group in survey, participants from high QOL

scoring group managed their activities of daily living with the help of inhaler drugs however, participants from low QOL scoring group were not able to perform their activities of daily living even with inhalers i.e. activities limitation was highly prevalent on low QOL scoring group.

Social Health

Limitation on Social Activity:

All participants stated that breathlessness stops them from doing social activities, which further reduces their independence and contact with friends and neighbors. They described their diminished social and recreational activities within their family and society. Despite their limitations, some (2/4) participants maintained their social activities with the help of inhalers. Harkhe, 72 years male participants said: I experience shortness of breath while going to participate in social work but still i manage it by taking inhaler.

While others (2/4) participants eventually became housebound and socially isolated as a result their limited physical activity. One 71 years old man [Birkhe] said: Until 2 months ago, I used to visit religious rituals and relatives home. Nowadays, I am not able to visit those places and do such a work. I rarely go out from home.

Relationship and Support System:

Though participants were unable to socialize and enjoy a normal life, all the participants (4/4) accepted that they were getting adequate support from their family members during illness and they are satisfied with them. One 72 years old man [Harke] said: I am happy with my family (spouse, son, daughter in law and daughters) because I am getting care and monetary support as per need. My wife is there to take care during my illness. My son and daughter in law are very supportive too. Daughters are also staying nearby and they are always ready to help me.

Likewise, most of the participants (3/4) reported that they had good relationship with their neighbors and relatives and they were receiving adequate support from them. As one 72 years old woman [sunita] claimed: Last time when I was ill, nobody was at home because my grandson had just left for abroad. At that time, my cousin helped me to take me to hospital and relatives were providing support to me. Up to 3 days, my relatives, who were staying nearby, were giving cold sponge (pani-patti in local language) turn by turn to me.

However, Sita, one 80-years old woman participant expressed inadequate support from her relatives as: I am staying at home since last year. In the beginning, friends and relatives used to visit but nowadays, nobody are coming to meet me.

Social Problems:

Despite close relations and social support system, some (2/4) participants described feeling of loneliness, isolated, dependent and burden on family members. These were often exacerbated by limitations on physical activities. One 72 years old man [Harke] expressed: Although I have very loving family and friends, I used to get feeling that I am useless for my family members as I can't help my son physically in raising cattle and selling milk in the market which I used to do in the past.

Likewise, another eighty year old woman [Sita] said: I am not able to involve in any social work, visit friends and relatives and religious places since last year and nobody are coming to see me these days. While I am alone at home during day time, I feel lonely. Sometimes, I feel that I am burden to my children because they need to take leave from their work if I get sick.

Patients scoring higher and Lower QOL scores on survey reported that they were receiving family support and caring behavior irrespective of their health status.

However, lower QOL scoring group had faced more social problems.

Psychological Health:

Participants reported that they encountered different emotional feelings such as they became restless while staying at home, feel sad when they had to limit their activities, frustrated due to their inability to make the events that their colleagues were able to do, helplessness while inhalers were not able to control dyspnea, panic and fear of losing their breaths during the exacerbation of symptoms. Sadness or frustration (3/4) was common emotions experienced by the participants as a result of inability to perform their task or activities as before. Harke, 72 years old man expressed his feeling of emotion as: I am rather frustrated because of the fact that I cannot make to the events that colleague of my age are able to.

Similarly, 71 years old man [Birkhe] stated his emotions: I feel sad because I am not able to visit those religious shrines where I used to go before with my wife since last 2 months. I become restless and tense while staying home without doing any work.

Likewise, 80 years old woman [Sita] expressed her emotion as: I am afraid of being left alone at home. Sometime I feel cold and sometime hot and even have to sprinkle water all over my body. I feel anxious and cannot stay inside the room alone.

Other emotions frequently reported by patients were panic attacks, helplessness and fears about dying because of respiratory distress associated with breathlessness. One 72 years old man [Harke] described his experience on panic attacks as: Three years back; I went to chatara, Dharan for 'kumbhamela' with my friends. I had to walk 8-9 km and the road was dusty. At that time, I had very hard time walking and I had to stop and sit down in between; suddenly I had intolerable shortness of breath which

was really frightening.....I really thought I was going to collapse.

Likewise, two patients (2/4) described his fear associated with breathless at night. Birkhe, 71 years old male expressed his fear as: Last night I had severe dyspnea which was really frightening.....I didn't feel comfortable even after using inhaler four times. I thought I was going to die.

Two patients (2/4) expressed that they were happy in their life though they were living with the problem of COPD. The reasons behind this were their familial support and good relationship with family members. One 72 years old woman [Sunita] said: I am happy because all of my sons and daughters are doing their best. I am not worried and nothing had bothered me. I get involve in different enjoyable activities with my friends and neighbors whenever possible.

Patients were facing psychological problems irrespective of QOL scores on survey however, lower QOL scoring group had faced more psychological problems compared to higher QOL scoring group on quantitative survey.

Adaptation with COPD:

In spite of having certain limitations on their daily activities, two participants (2/4) felt that they had better quality of life while others reported worse quality of life (2/4). The reasons behind this may be related to frequency and severity of symptoms they experienced with COPD and their abilities to cope with limitations.

All participants adopted different measures to deal with their breathing problem such as regular follow up visit, regular use of inhalers, taking extra-dose of medicine, pacing of activities and avoidance of situation that worsens their symptoms. The most common dyspnea management techniques reported by the participants (4/4) were use of inhaler drugs and pacing of activities to conserve the energy. As one 71 years old man [Birkhe] stated that he

stopped all those activity which caused breathlessness as: Nowadays, I get breathlessness most of the time and I couldn't breathe without inhalers. Though doctor advised me to take twice a day, I need medicine every 2 hourly. I reduced those activities which caused shortness of breath and I even started to pray at home instead of going out to temple. While climbing the stairs, I walk slowly and take rest in between as per need.

Another 72 years old man [Harke] reported that he deliberately avoid the situation due to fear of catching illness as: I rarely go for long walk and field to get away with flare ups of the disease and I don't even go to kitchen because of cooking fumes which triggers shortness of breath.

DISCUSSION

This study focused on exploring the experiences of living with COPD. The impact of COPD was significant and invaded almost every aspect of patients' lives. The patients in this study described dyspnea as a more severe symptoms that caused major limitation in their physical activities and social roles. Limited physical and social activity altered patients' psychological health.

In this study, limitation on physical activities associated with COPD was clear in the patients' narratives and confirm findings by other researchers. (3-5,10) One study in Sweden (11) reported that patients expressed their change in physical ability as a loss of energy, a feeling of fatigue, or of becoming physically restricted compared to others.

Participants had no obvious symptoms or restrictions in their physical activities in the beginning and appearance of symptoms was an indicator of disease progression, (11) which is consistent with the current study finding which found that the symptoms or limitation on physical activities in patients with COPD were not

obvious in the beginning and they progressed over the time. The most troublesome symptom described by the patients in the present study was difficulty in breathing which imposed the greatest restrictions on individual's physical functioning. This finding is supported by the study conducted in Sweden (5) which found that the symptom described as most difficult to handle and to endure was breathing difficulties which reminded the participants about their disease bodies and death.

In addition to breathlessness, lack of energy or physical strength is another common problem experienced by patients with COPD in the present study which affects the patients' physical functioning and social life and it often resulted in being forced to give up activities which they actually wanted to participate in and which reflected what was important to them. This finding can also be seen in the study conducted in Sweden which reported fatigue or lack of physical strength as a highly prevalent symptoms (12) as well as it has significant impacts on patients physical (5,12), cognitive and psychosocial functioning. (12) Similarly, study conducted in UK found that the patients with COPD had significantly worse activities of daily living and physical, social, and emotional functioning than the patients with lung cancer. (13)

Functional impairment and frequent experience of symptoms place considerable burden on patients' social health. In this study, patients reported feelings of loneliness, socially isolated, dependent and useless for others because of their breathing problem which can also be seen in other studies. (3-5,7)

With the physical problems and social limitations related to COPD, patients expressed vivid emotions such as restlessness, sadness, frustration, helpless, panic, and fear of losing their breath. This finding were supported by the other studies

findings which reported that the participants became sad when they had to forgo so many activities, ⁽⁵⁾ frequently spoke about fear they experienced in relation to fear of losing their breath, ^(3,14) and became panic with the fear of getting dyspnea. ⁽⁴⁾

While living with COPD, patients mentioned some strategies for handling the disease or dyspnea. The successful technique for dyspnea management or coping with COPD as described by the participants in others studies ^(4,7) included using inhalers and nebulizers and modification on life style or daily activities. Patients adopted certain strategies such as adjusting an activity (slowing down the speed and intensity, sitting down instead of walking, and taking rest in between the work) and avoiding or giving up activities (avoiding/ quitting moderate and heavy energy needed activities) to avoid dyspnea. This finding is supported by other studies as well. Arne et al. (2007) in Sweden found that the patients with COPD avoid or give up physical activity to cope with symptoms, especially connected to physical activity ⁽¹¹⁾ whereas Barnett (2005) in UK described that the participants restricted their physical activities to avoid breathlessness. ⁽³⁾ Similarly, Avsar & Kasikci (2011) found that the participants adopted strategies such as pacing activities and learning to conserve energy and daily tasks such as sitting down to complete tasks in kitchen, washing and dressing by trial and error. ⁽⁷⁾

Acceptance of loss can be just important in the psychosocial adjustment to acquire disease or disability. Circutto et al. (2004) noted the importance of support from family and friends to manage COPD. ⁽¹⁵⁾ In spite of having certain limitations on their daily activities, half of the patients in this study felt that they had better quality of life while others reported worse quality of life. The reasons behind this may be related to frequency and severity of symptoms they

experienced with COPD and the support they are getting from family members. In this study patients felt that their spouse, other family members and friends understood their condition and they are satisfied with their supports. This finding is also supported by the study in Turkey ⁽⁷⁾ in which participants described that their family members and friends understood the condition and limitations.

The finding of this study has to be considered in reference to its study limitations. Patients who visited in the outpatient setting of a private hospital were recruited for the study; hence it could not be generalized to other settings. This study was conducted among four COPD patients only. Therefore, it might not represent the COPD population at large.

CONCLUSION

This qualitative study identified many physical, social and psychological health problems of COPD patients. Dyspnea is the most troublesome symptom and major cause of disability in patients with COPD. Limitation on physical activity is common for all patients. The commonly affected activities are performing usual activities of daily living, walking, and climbing up stairs or hill. Patients social activities are greatly affected due to frequent symptom burden and limited physical activity. Patients are getting needed support from their family members and they are satisfied with them. In spite of this, social problems such as feeling of loneliness socially isolated, dependent and burden on family members are common among them. Psychological problems such as restlessness, sadness, frustration, helplessness, panic and fear of dying are also common among the patients which results from their restricted physical and social activities. Adjusting activities and avoiding strenuous activities or quitting up an activities are the common measures

adopted by patients to deal with breathing problems. Likewise, social relationship and support system are helpful for the patients during their process of adjustment with illness. Those patients who are able to involve in activities and experience minimal symptoms have better quality of life. 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.

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