Journal of Population Therapeutics & Clinical Pharmacology

RESEARCH ARTICLE
DOI: 10.53555/jptcp.v30i18.2985

# BARRIERS FACED BY CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) PATIENTS IN SELF-MANAGEMENT AT HOME

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## Abstract

**Objective and Methods:** This cross-sectional study assessed the self-management barriers faced by Chronic Obstructive Pulmonary Disease (COPD) patients. Adult patients (≥ 18 years) diagnosed with COPD for at least six months and engaged in self-care at home were included in this study. Data was collected through in-person interviews using a structured questionnaire and analyzed using descriptive statistics.

**Results:** Response rate was 98% (371/377). Age of the participants ranged from 41-73 years, with a mean of 53.3 (SD ± 9.65) years. Majority participants were men (82%), married (96.7%), laborers (65.5%) and residents of rural areas (90.6%). Above two-third (79%) were current or previous smokers. Main barriers reported by the participants included lack of knowledge about disease and self-management at home. Additional barriers reported were lack of training in exercise, breathing and relaxation techniques, non-affordability of cost of medications and home-base-oxygen therapy, absence of community support and difficulties in accessing and communicating with healthcare providers.

**Conclusion:** This study highlighted multi-faceted barriers faced by COPD patients, emphasizing the necessity for comprehensive, patient-centered interventions tailored to the specific needs and circumstances of these individuals.

**Keywords:** Barriers, COPD, Self-Care, Self-Management, Pakistan

## Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung condition that leads to major disabilities and even death if not properly managed. COPD is characterized by persistent obstacle in lung airflow that interferes with the regular breathing pattern.[1] Contrary to asthma which may be reversed with a variety of medications, COPD is irreversible and gradually damages the airway and air sacs reducing lungs function.[2] In addition to lung abnormalities, COPD also causes systemic effects including weight loss, nutritional instability and abnormal skeletal muscle function which affect individual's overall quality of life.[3] Moreover, COPD is frequently associated with, and may also contribute to a number of syncronized diseases such as heart disease, diabetes mellitus and osteoporosis further aggravating morbidity and mortality in this population.[4]

COPD is the third leading cause of death worldwide, accounting for 3.23 million deaths in 2019 with 90% of those occurring in low- to middle income countries (LMIC).[5] Pakistan, a LMIC with around 233 million population, is confronting huge burden of respiratory illnesses including COPD.[6] Pakistan holds the highest prevalence of COPD (13.8%) in the eastern mediterranean region[7] and given the rising trend in risk factors such as smoking (including second hand smoking), occupational exposure to fumes and dust, indoor and outdoor air pollution, asthma, infections, and low socioeconomic level, the prevalence is likely to rise even more.[8] In Pakistan, the age-adjusted mortality rate linked to chronic respiratory conditions, including COPD, is projected at 138.2 per 100,000 for men and 41.3 per 100,000 for women.[9] This disparity between age-adjusted mortality rates for men and women reflects the smoking rates in the two populations. The disability-adjusted life year from COPD is over 4000 years, with nearly half of this figure being attributable to the years of healthy life lost due to disability resulting from COPD and associated comorbidities.[10]

Since there is no known cure for COPD, medical management focuses on controlling symptoms and slowing the disease's progression by emphasizing patient's self care needs as well as improving their self-care behaviours.[11] Literature supports that adequate self-care enables patients to respond to changing symptoms and make appropriate decisions regarding management of their own condition thereby improving health status and reducing hospital admissions.[12-14] Exacerbations are the primary reason for hospitalisation in COPD patients, which place a financial burden on the patients, their families, and the country's economy. For people in Pakistan, a resource-limited country with already debilitated health care system, self-care management plays a crucial role as it relates to the individuals' ability to detect and manage their symptoms, adhere to their treatment plan and adapt to the life style changes inherent in living with COPD.[15] Self management empowers individuals to manage their minor symptoms / conditions at home and avoid unnecessary hospital admission thereby reducing health care cost and burden on national healthcare system.[16] Self management is also embedded in national clinical practice guidelines for COPD management in Pakistan and focus is being placed on self-management at home to prevent repeated emergency visits and hospitalization.[17] Despite the literature from affluent nations and contextual guidelines pointing to its success, self-management is not incorporated fully into routine clinical care thus, not widely implemented in Pakistan. This is demonstrated by recurrent emergency visits, hospital admissions, non-adherence to medication, low psychological wellbeing and a poor quality of life among patients with COPD.[18]

Although altering behavior is the ultimate goal of COPD self-management, research from Pakistan indicates that doing so is very challenging due to the complex interaction between the patient, healthcare provider, healthcare system, and the community.[19] Self-management of COPD patients in Pakistan varies from person to person, taking into account each person's age, health literacy, psychological, sociocultural, economical and medical needs.[20] As a result, on one side it is influenced by individual-level factors including person's physical, psychological (disease-related depression and anxiety), and socioeconomic status and on the other by healthcare system related factors including access to health services, healthcare providers and healthcare facilities .[21] Effective self-management can only be achieved by addressing the underlying problems at the individual, family, societal and health care system levels. Further, identification of explicit barriers preventing COPD patients from performing self-management tasks, can help designing comprehensive interventions targeting specific barriers. This will further enhance their quality of life, decrease healthcare cost and will benefit the national economy. There is a dearth of contextual information from the patient perspective, only a small number of studies have identified barriers to COPD self-management from the perspectives of healthcare providers.[22] This study is aimed at identifying the barriers faced by COPD patients related to their self-management at home.

## Methods

### Participants and Sampling

The Descriptive cross sectional study was conducted at Liaquat University Hospital (LUH), situated in Sindh Province of Pakistan. LUH is one of the biggest public-sector hospital providing services to Sindh and neighboring province Balochistan. The study was approved by Ethics Review Committee

(ERC) of Liaquat University of Medical & Health Sciences (LUMHS), the first medical university in Pakistan. The eligibility criteria for participation in this study were: Adults aged 18 years and/or above, diagnosed with COPD for at least six month duration, practicing self-management at home. Patients first time admitted/visiting with COPD symptoms, medically unstable patients and pregnant women with COPD were excluded. Non probability convenient sampling technique was used to recruit participants from indoor and outpatient department (OPD) of the study hospital. A sample size of 377 was calculated through Rao-soft online calculator, keeping the margin of error 5%, level of significance 95 % and response distribution 50%.

**Instrument and Data Collection**

Instrument used for data collection was interviewer-administered questionnaire developed by Bayliss et al. [23] and modified by the research team after reviweing relevent literature and interviews with key stakeholders (physicians, nurses, community health worker and patients). The modified questionnaire's validity was assessed using the Content Validity Index (CVI) to ensure its relevance and clarity. For, CVI, the questionnaire was shared with five experts selected based on their experience in the field of research, expertise related to the topic and tool development. Scale CVI calculated was 0.96 and 0.80 for relevance and clarity respectively. For reliability, a pilot test of modified questionnaire was conducted on 10% of the sample size. 38 participants included in pilot sample, were not included in the total sample size of the study. The cronbach alpha for internal consistency reliability calculated was 0.77. The questionnaire consisted of two sections. Section I included sociodemographic information of the participants with questions about their age, gender, education status, marital status, living arrangements, employment status, monthly income, nature of work and smoking status. Section II encompassed questions concerning barriers faced by COPD patients while self-managing at home. These barriers included knowledge/information related barriers, physical, psychosocial barriers, barriers related to physical activity and medication adherence, and barriers related to healthcare service and providers. The questionnaire was administered by the researcher (GS) to avoid missing or incompleted information. Written permission from hospital administration was obtained for data collection. Moreover, a formal authorization in the form of written informed consent was taken from each participant after comprehensive explanation of the study purpose, procedures involved, and opportunity for clarification/ questions. For the purpose of anonymity, names of the participants were not included in the questionnaire. As well as, all participants had the liberty to withdraw from the study or giving any part of the data even after signing the consent form. The safety of the data was assured by keeping the hard data in locked cabinet and soft data in password protected laptop.

**Data Management and Analysis**

Statistical Package for Social Sciences (SPSS) version 23 was used for data entry, management and analysis. Descriptive statistics were used to summarise all the study variables. For continuous data (age, income etc), Mean and Standard deviation (SD) were calculated. For categorical data (gender, education level, marital status, employment status, nature of work, smoking status etc.) frequencies (n) and percentages (%) were used. COPD self-management barriers as perceived by the participants, were summarized with n(%) for no, yes and don’t know data.

**Results**

Out of the total sample of 377, 371 participated in the study with a response rate of 98% (371/377). Age of the participants ranged from 41-73 years, with a mean of 53.3 (SD ± 9.65) years. Majority of the participants were male (82%: 305/371), married (96.76%: 359/371) and living in rural areas (90.6%: 336/371). Above one third of the participants (37%) were illiterate. About a quarter (23%) were un-employed. With regards to the work nature, majority (65.5%) were laborers. Majority (79%) of the participants reported being current or previous smokers. Sociodemographic characteristics of the participants are outlined in Table 1.

**Table 1: Sociodemographic characteristics of the participants (n=371)**

| Variable | n | % |
|---|---|---|
| **Gender** | | |
| Male | 305 | 82.21 |
| Female | 66 | 17.79 |
| **Education** | | |
| No formal education | 138 | 37.20 |
| Primary education | 143 | 38.54 |
| Secondary education | 79 | 21.29 |
| Intermediate and above | 11 | 2.97 |
| **Employment Status** | | |
| Un-employed | 88 | 23.72 |
| Employed | 283 | 76.28 |
| **Nature of work** | | |
| Laborer | 243 | 65.50 |
| Office worker | 19 | 5.12 |
| Businessman | 79 | 21.29 |
| Other | 30 | 8.09 |
| **Marital Status** | | |
| Un-married | 14 | 3.77 |
| Married | 357 | 96.23 |
| **Area of Living** | | |
| Rural | 339 | 91.37 |
| Urban | 32 | 8.63 |
| **Smoking Status** | | |
| Never smoked | 79 | 21.29 |
| Previously Smoked | 101 | 27.23 |
| Current Smoker | 191 | 51.48 |
| | **Mean** | **SD** |
| **Age** | 53.3 | 9.65 |
| **Household Monthly Income in rupees (PKR)** | 21218 | 7100 |

Table 2 vividly presents participants' responses categorized into 'No', 'Yes', and 'Don't Know' regarding their perceived barriers towards self-management at home. The foremost obstacle, as identified by a substantial majority, pertained to knowledge about the disease and its self-management (61% and 76% respectively). In terms of physical barriers, over half of the respondents (51%) attributed age as a hindrance to COPD self-management at home. Additionally, a majority (76%) noted physical symptoms such as breathlessness, fatigue, pain, and sleep disturbances as significant barriers. A predominant (58%) cited work-related factors impacting breathing and overall health. Weather-related effects were also noteworthy, with 49% acknowledging them as barriers to self-management at home. Psychosocial barriers were also prevalent, with a majority (72%) reporting lack of confidence as a significant obstacle. The accessibility and affordability of inhalers/medications and other necessary facilities were paramount concerns for the majority (79%). Family and friends' support, though noted by a few participants (10%), was acknowledged as a contributing barrier. A substantial proportion (68%) identified absence of community support services as a primary hurdle. Furthermore, the lack of training in exercise, breathing techniques, and relaxation methods was identified by a mostly (78%) as a major obstacle to physical activity. Notably, knowledge gaps regarding the proper use of inhalers/medications and access to crucial treatments like inhalers/home-based oxygen therapy were cited by a majority (57% and 56% respectively) as substantial barriers to medication adherence. Lastly, participants raised concerns about access to hospital/healthcare services and providers (67%), the ability to communicate needs or issues with healthcare providers (75%),

understanding of their needs/problems by healthcare providers (51%), and the inability to reach healthcare providers in emergency situations (68%) as prevalent barriers.

**Table 2: Perceived Barriers towards COPD self-management at home (n=371)**

| Type of barrier | No<br>f (%) | Yes<br>f (%) | Don't Know<br>f (%) |
|---|---|---|---|
| **Knowledge/ Information barriers** | | | |
| Knowledge related to disease | 127(34) | 225(61) | 19(5) |
| Knowledge related to self-management at home | 79(21) | 283(76) | 9(3) |
| **Physical barriers** | | | |
| Advanced age | 56(15) | 191(51) | 124(34) |
| Physical symptoms (shortness of breath, fatigue, pain, lack of sleep) hindering physical functioning. | 88(24) | 283(76) | 0(0) |
| Work related effects on breathing and overall health | 106(29) | 216(58) | 49(13) |
| Weather related effects on breathing and overall health | 110(30) | 183(49) | 78(21) |
| **Psychosocial barriers** | | | |
| Feeling of deterioration | 126(34) | 136(37) | 109(29) |
| Lack of confidence | 22(6) | 266(72) | 83(22) |
| Affordability of cost of inhaler/medications and other facilities | 77(21) | 294(79) | 0(0) |
| Lack of support from family and friends | 273(73) | 36(10) | 62(17) |
| Lack of community support services | 39(11) | 254(68) | 78(21) |
| **Barriers towards physical activity** | | | |
| Fear of breathlessness | 126(34) | 129(35) | 116(31) |
| Lack of training in exercise, breathing and relaxation techniques | 9(3) | 291(78) | 71(19) |
| Lack of motivation to continue physical activity | 119(32) | 129(35) | 123(33) |
| **Barriers towards medication adherence** | | | |
| Access to inhaler/medications and home-based oxygen therapy | 93(25) | 209(56) | 69(19) |
| Knowledge about proper use of inhaler/medications | 80(22) | 213(57) | 78(21) |
| Trouble remembering to take medications | 141(38) | 144(39) | 86(23) |
| **Barriers towards healthcare services/healthcare professionals** | | | |
| Access to hospital/healthcare services | 111(30) | 248(67) | 12(3) |
| Feasibility in setting appointment/ scheduling with healthcare provider | 178(48) | 157(42) | 36(10) |
| Opportunity to ask questions/ discuss needs/problems with healthcare provider | 31(8) | 279(75) | 61(17) |
| Understanding of needs/problem by healthcare provider | 138(37) | 188(51) | 45(12) |
| Delays in receiving consultation, care and service provision from healthcare provider/hospital | 168(45) | 132(36) | 71(19) |
| Access to/Contact with healthcare provider in emergency situation | 65(18) | 253(68) | 53(14) |

## Discussion

The findings of this study shed light on the significant barriers perceived by COPD patients in their efforts towards self-management at home. Notably, there is a dearth of research on this subject in Pakistan, with no prior studies addressing barriers towards COPD self-management. Despite its pivotal role disease management, previous studies have generally overlooked the aspect of self-management, making this research the pioneering effort in Pakistan to gain insight into the barriers

faced by COPD from their own perspectives. With a high response rate of 98%, it is evident that the participants were engaged and invested in sharing their perceptions, providing a robust foundation for the insights gained.

The demographic profile, largely comprising males, married and residing in rural areas, represents a distinct subgroup, potentially shaping the type and extent of barriers faced, particularly in the context of COPD self-management. Moreover, a noteworthy proportion of participants reported being illiterate, which may impact their comprehension of self-management strategies and the ability to access relevant information. The prevalence of smokers (79%) among the participants aligns with established literature linking smoking with COPD development[24-25] thus, underscoring the importance of targeted smoking cessation interventions within COPD management programs.

The identified barriers encompass a wide spectrum, ranging from knowledge gaps to psychosocial and health services related factors. Notably, knowledge deficits were particularly pronounced, with a majority of participants reporting inadequate understanding of the disease and its self-management amongst the major barriers. This finding is consistent with the previous researches highlighting the same issue about COPD patients grappling with inadequate knowledge and comprehension about their condition, posing challenges for effective self-management[26-27]. Thus, highlighting the critical need for targeted educational interventions empowering patients with comprehensive knowledge and skills necessary for COPD self-management.

Physical barriers, including age-related limitations and symptoms burden, were also prominent concerns. These findings are consistent with a previous study that noted high symptom burden is associated with poor self-management scores.[28] Similarly, another study also found the negative impact of fatigue on daily life of COPD patients.[29] Such challenges may necessitate tailored interventions, including symptom management strategies, to enhance overall well-being and self-management capabilities in this population.

Work-related barriers emerged as significant barriers, particularly for laborers who may face unique challenges in managing their condition while fulfilling occupational responsibilities. Weather-related barriers further compounded the difficulties faced by participants, emphasizing the importance of adaptable self-management strategies that account for environmental factors. The finding supports those of existing study in which participants have similarly expressed, the impact of environmental triggers including weather & transportation as invasive to their ability to self- manage symptoms.[30]

Psychosocial barriers, such as lack of confidence, illuminate the emotional and psychological dimensions of COPD self-management. Community and family support were identified as influential factors, with a notable proportion of participants recognizing their importance. A prior systematic review also highlighted psychosocial factors, emphasizing the imperative of prioritizing patients' psychosocial well-being and social support strategies in conjunction with medication and exacerbation control for effective self-management.[31]

Access and affordability of medications, inhalers, and home-based oxygen facilities emerged as critical concerns in this study, indicating potential financial barriers that may hinder optimal self-management at home. These findings align with prior studies that recognize financial strain as a significant factor contributing to inaccessibility, noncompliance with medications and poorer outcomes among COPD patients of lower socioeconomic status. [32,33,34] This emphasizes the need for accessible and affordable healthcare resources tailored to the specific needs of COPD patients.

The study's limitations include a relatively small sample size restricted to a single setting, cautioning against generalization of the findings to a larger population from other locations. The use of convenient sample selection might have introduced the response bias. However, to counter the biases in data collection, the questionnaire was administered by the researcher (GS), enhancing the study's robustness by avoiding incomplete or missing information. Moreover, the questionnaire was modified based on the literature review and stakeholder feedback on specific contextual factors, with ensured validity and reliability. Lastly, 98% response rate adds strength to the study which despite limitations, uncovered various barriers faced by COPD patients in self-management at home, offering insights for developing strategies to support this population.

## Conclusion

This study comprehensively highlighted the multi-faceted barriers faced by COPD patients in their pursuit of self-management at home, emphasizing the necessity for comprehensive, patient-centered interventions that address knowledge gaps, psychosocioeconomic challenges, and hospital/healthcare considerations. By tailoring interventions to the specific needs and circumstances of COPD patients, healthcare providers can play a pivotal role in enhancing their capacity for successful self-management.

## List of abbreviations

**COPD:** Chronic Obstructive Pulmonary Disease
**CVI:** Content Validity Index
**ERC:** Ethical review Committee
**LMIC:** Low- Middle Income Country
**SPSS:** Statistical Package for Social Sciences
**WHO:** World Health Organization

## Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Funding

None

## Author Contributions

**GS:** Study conception and design, literature retrieval, data collection, data analysis & interpretation, drafting of the manuscript.
**PA:** Study conception and design, data analysis & interpretation, critical revision of the manuscript.
**KA:** Study conception and design, data analysis & interpretation, critical revision of the manuscript.

## Acknowledgments

None

## Availability of data and materials:

Data and materials are available from the first author upon request.

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