Exploring the Treatment Types and Challenges in Patients with Chronic Obstructive Pulmonary Disease: A Qualitative Study

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Received: November 2021; Accepted: December 2021; Published: January 1, 2022.
Citation: Baba M, Khan S, Hasnain F, Sakina R, Talat A, Irfan A. Exploring the Treatment Types and Challenges in Patients with Chronic Obstructive Pulmonary Disease: A Qualitative Study. World Family Medicine. 2022; 20(1): 23-29
DOI: 10.5742/MEWFM.2022.95202

Abstract

Introduction: World Health Organisation (WHO) indicates Chronic Obstructive Pulmonary Disease (COPD) to be emerging as the third leading cause of mortality by 2030. COPD not only affects the healthcare system of a country, but also the quality of life of patients and their families. Prevalence of COPD among Pakistani adults aged 40+ was found to be 2.1%; however, the research on patient's perspectives regarding the challenges faced in the diagnosis and management of COPD in Pakistan is still lacking. Therefore, the authors in this study aim to explore and document the barriers affecting the management of COPD by the patients and their families/care takers.

Methods: It is a qualitative study conducted within the boundaries of Islamabad capital territory and district Rawalpindi, Pakistan. The data was collected through in-depth and semi-structured interviews conducted with the respondents who included patients of COPD (n=8) as well as their treatment supporter(s) (n=7), recruited from the OPD wards of three hospitals (two public and one private hospital).

Conclusion: The study shows that COPD patients not only face challenges in their physical health, but also in socio-economic and psychological domains that are equally harmful. It highlights varying notions of the respondents as to how treatment-seeking of COPD posed challenges in their lifestyles, at both, household and individual levels. Patients with COPD need high levels of input from healthcare facilities; hence, health care professionals should be trained in case management of COPD.

Key words: Non-communicable diseases, chronic diseases, chronic obstructive pulmonary disease, patient's perspective

Introduction

Chronic obstructive pulmonary disease (COPD) is a respiratory condition that results in partially reversible airflow obstruction. Potential causes of COPD include exposure to smoke of cigarettes and various other environmental and occupational pollutants (1). Symptoms of COPD commonly include chronic cough, unusual production of sputum, and shortness of breath with exertion (2). Since it is non-transmissible and non-contagious, the mechanisms designed for its cure are more preventive in their approach. Therefore, it requires careful treatment and effective methods to reduce and fight the symptoms. Patients are further affected by this disease due to reduced functioning of lungs and compromised quality of life (QoL) (3-5). Currently, COPD is a potential global public health issue (6) causing a significant burden on the patients, societies, and the healthcare system on a wider level (7). As per the indications of the World Health Organisation (WHO), COPD is emerging to be the third leading cause of mortality by 2030 (8). The proportion of respiratory diseases leading to COPD is higher in developing countries than in the developed nations (9). One of the major reasons of higher prevalence of COPD in developing countries is the production of more industrial products without keeping in view health standards. Around 90% of the deaths caused by COPD are reported in low- and middle-income countries (LMICs) (10) since the majority of the patients of COPD in these countries remain undiagnosed or untreated. As per an epidemiological survey conducted in (11) countries of the Middle East and North Africa region (BREATHE), prevalence of COPD among the Pakistani adults more than the age of 40 was found to be 2.1% (11).

Increase in the prevalence of COPD not only affects the health care system of the country, but also deteriorates the quality of life of the patients, their care takers, as well as their families. In LMIC states like Pakistan, where there is a lack of trained staff and professional services, and limited facilities available to diagnose and cater to COPD at the primary health care level, the management of the disease can be extremely challenging. Through the mobilization and engagement of not only the health providers, but also the patients, care takers, families, and communities, it is possible to enable the patients to access the health services and manage their symptoms (12-14). Certain studies reveal that various barriers like patient empowerment (15, 16), poor health literacy (15, 17), social support (18, 19), comorbidities e.g., depression and anxiety (18, 19), inadequate training of health care providers in diagnosis and management of chronic disease (19, 20), and limited services for COPD at the primary health care setting (19, 20) often hinders patient's engagement in self-management.

The challenges in managing a chronic disease like COPD have been discussed in various studies in different settings; however, the research on patient's perspectives regarding the challenges faced in the diagnosis and management of COPD in Pakistan is still lacking. Therefore, the authors in this study aim to explore and document the barriers affecting the management of COPD by the patients and their families/care takers.

Materials and Methods

The study employed qualitative data through in-depth and semi-structured interviews, and the data were analysed through thematic analysis.

The research was conducted in three hospitals within the boundaries of Islamabad capital territory and district Rawalpindi, Pakistan; two public and one private hospital. These hospitals were selected for the study as they are comprised of dedicated wards and outpatient care delivery (OPD) days designated for people with pulmonary disease(s). The access to these locales was obtained through medical practitioners in the relevant departments. The pulmonary wards and OPDs were observed for the recruitment of respondents for the study through purposive and snowball sampling. The criteria for selection of respondents were based on their diagnosis of COPD. Patients suffering from tuberculosis and Lung cancer were not interviewed. The interviews were based on the clinical investigations about the patient's disease. A total of 15 in-depth and semi structured interviews were conducted with the respondents that included patients of COPD (n=8) as well as their treatment supporter(s) (n=7).

The interviews were conducted in Punjabi, Urdu, and Potowari as per the linguistic background of the respondents. Each interview lasted for at least 30 minutes and was audio-recorded after obtaining verbal consent from the interviewee; however, the confidentiality of the respondent was maintained throughout the process. The findings were analyzed through thematic analysis. Interviews were transcribed verbatim and translated into English. The researcher developed newly emerged themes by drafting initial codes from the transcripts and categorizing them. Relevant verbatims were also incorporated in the themes following the analysis in order to contribute towards the credibility of the data.

Results

Barriers in treatment of COPD:
Various types of barriers were reported by the patients as well as their treatment supporters in seeking and complying with treatment for COPD. These barriers have been categorized as follows: 1) economic barriers; 2) social barriers and; 3) personal barriers.

Economic Barriers and Opportunity Cost
Any chronic illness increases the pressure over the family; it is not just related to transformation in the economic structure of the family but also on the social and domestic life of the people within the household. Many people fail to get proper treatment due to financial conditions and poor economic structure of the household. Treatment support was a common factor that was observed; people with severe cases of COPD were relying on their children for the treatment expenses since they were unable to work or were retired from their duties.

In many cases of lower middle class, people worked together to bear the burden of the disease if any member of the family suffered from COPD. In that case various people from the household acted as treatment supporters.

"Hum 4 bhai hen, abu kay ilaj ka kharcha hum mil kr pura krty hen, kisi ki karyany ki dukan hai aur koe naib qasid hai. Lekin hum mil k krty hen sb takay sbka hissa rahe iss men"

"We are four brothers; together we bear the expenditure of our father's treatment. One has a general store and another one is office boy. We try to do it together so that everyone can have a part in it" (R3)

People of the lower middle-class incomes prefer visiting government/public hospitals for their treatment needs. Some patients are entitled in public hospitals; in that case their treatment expense is reduced to a certain level.

"Hum gharib loag hen, pension aati hai lekin ilaj mehnga hai. Islye koshish hoti hai sarkari hospital men ayen. Wahan khrcha kam hotta hai."

"We are poor people; although I receive pension, the treatment is expensive. That's why we try to come to public/ government hospitals. It is less expensive here" (R6)

Elderly and retired people rely on their family members for treatment support. Treatment supporters get an extra burden financially and mentally. The treatment supporter's occupation determines the quality of treatment he chooses for the patient.

The type of disease and its severity directly affects the domestic economy of the family; it becomes an extra burden on the people of poor households. The choice of healthcare facility and the level of care received are determined by the socioeconomic status of the patients and their families. Before the process of diagnosis, clinical investigations cost a lot.

"Aik ABG test 1500 Rs ka hota hai aur sath e khoon k test wgera sb boht mehnga par jata hai"

"A single ABG test costs PKR 1500, combined with other blood tests becomes too expensive" (R3)

The patient in the public health facility belonged to middle and lower middle class. The patients from both private and public health facilities reported that they had paid an opportunity cost for the treatment of the disease. The domestic economy and overall system was entirely disturbed by a single family member with chronic illness. The patient needed clinical equipment (depending upon the severity of the illness), which is expensive and unaffordable for most of the treatment supporter respondents.

"Aik oxygen concentrator ki qeemat 1.5-2 lac Rs hoti hai, hr bnda nahe lai skta. Cylinder iss sy zada mehngy partay hain. Men kbhe kbhe cylinder wali oxygen istemal krta hn wrna yeh mera 3sra concentrator hai"

"One Oxygen concentrator costs around 1.5-2 lac rupees, everyone cannot afford it. Cylinders cost even more than that. Sometimes I take oxygen from cylinders, but this is my third concentrator" (R1)

Social Challenges

The patients reported about the changes in their social patterns and interactions due to the disease, where in severe cases of COPD, the patients were forced to stay at home. Most of the respondents were retired individuals, but their daily activities like offering prayers in the mosque, meeting friends/relatives, and attending social gatherings were compromised.

"Main masjid jata tha namaz parhta tha, sbsy milta tha magr ab chalta bhe hun tou saans phulta hai"

"I used to go and pray in the mosque and meet everyone, but now even if I walk, my breath shortens" (R6)

Carrying the equipment along, which in most cases is an oxygen cylinder, is a hard task for the patient as well as the family; an extra hand was needed to carry the equipment.

"Pehly bahar jata tha, logon sy milta tha ab yeh oxygen ki machine hai islye na kahen jaaskty hen na himmat hoti hai"

"I used to go outside and meet people, but now I am on concentrator, so neither can I go outside nor do I have the strength to go anymore" (R1)

Since all the respondents of the study were male and they play an active role in domestic decision-making process, the disease caused them to become dependent upon other individuals of the family. The patients reported that being bed-ridden had drastically compromised their decision-making power as the head of the family.

Treatment supporters were of the view that overstressing the patient by discussing family matters with them affected their health more. Hence, they kept their matters to themselves and decided to make decisions without disturbing the patients.

Being the elder male member of the family, children usually required final approvals for their decisions. But in the case of their fathers' chronic illness, families took their decision themselves without bothering the patient, including matters relating to marriage.

"Bachay cheezen daikh laity hen phr mujh sy approve krva laitay hen"

"My children look after the matters themselves, and then get them approved from me" (R1)

Personal Challenges

For any chronic illness, the main issue for the patient observed was the acceptance of being a patient. This happened after the appearance of the symptoms and consequent diagnosis of the disease. The patients found it difficult to comply with the treatment. Hence, to adhere

with the treatment, children and other family members counselled and convinced them to ensure follow-ups and maintain a proper lifestyle as recommended by the physician.

It is usually hard to accept and live with a progressive disease, having rare chances of complete recovery. Will power and counselling are highly required in such cases, as the disease intensity and symptom severity can lead to harmful consequences.

"7 saalon sy iss bemari sy lar raha hn, ab aadat hogae hai lekin takleef to rehti hai"

"I am fighting this disease for 7 years; I have developed its habit but still there is pain" (R1)

Parallel treatment

The respondents reported that they never completely relied on allopathic or modern medicinal treatment; an additional/supplemental treatment was sought by the respondents in almost all types of illnesses. The parallel treatments i.e., religion/spiritual or indigenous ones were usually derived from their cultural trends and transferred from generation to generation.

Dum/Duroods[1], Role of Religion and Spirituality

Most of the respondents reported that they were dependent upon their religious affiliations for their treatment.

"Bhai Allah pr Imaan hai lekin hum dam wgera krvaty hen, Allah kay kalam men asar tou hota hai"

"Brother, we have faith in Allah, but we go for Religious prayers, because they are words of God and they have an impact" (R3)

"Hamare peer hen Kashmir men unky pass jatay hen dua krvany, kuch behtri bhe hue hai inhen. Lekin illaj to zruri hai woh sath sath chal raha hai"

"Our spiritual mentor (peer) is in Kashmir, we go to him for prayers. He is getting better, but other treatment is equally important and we are getting it" (R5: Treatment Supporter)

Homeopathic Treatment

Homeopathic is one of the most common types of treatments used as a parallel treatment in Pakistan. The impact of homeopathic treatments was comparatively slower than the allopathic treatment, however the chances of recovery were guaranteed.

"Sleep apnea hai mujhe, meny isky lyay homeopathic treatment krvaya tha. Shuru men farq para lekin jab tabeat zada kharab hona shuru hue tou meny hospital men doctor ko dikhaya unhon ny mujhe phir sy Allopathic py daal dia ab bhe kbhe kbhe zrurt paray tou men who dawai lai leta hn, side effect tau nahe hai mujhe iska"

"I have sleep apnoea, for that I also sought homeopathic treatment. I was recovering in the start but when the symptoms got severe, I went to the doctor in the hospital. He again gave me the Allopathic medicines. I still take Homeopathic medicines sometimes. I don't feel any side effects from them" (R2)

Indigenous Medicine/Home-based Remedies

Indigenous methods have a wide range of availability across every culture. The use of this form of treatment is effective, cheap, and accessible. All of the patients were using some type of home-based remedies for the treatment of COPD in this study. Using honey and black pepper together was one of the most commonly used remedies for cough and cold, helping in clearing the throat infection and controlling cough.

"Bachpan men jb damay ki wajah sy boht khaansi hoti thee, tou Ammi Shehad aur Kaali mirch daite thee. Uss sy kuch din aram ajata thaa. Abhe bhe men who istemal krta hn aur tabeat behtr rehti hai"

"During my childhood, I used to have severe cough due to Asthma. My mother used to give me Honey and Black Pepper. It was very recovering and I still use that" (R2)

The Cassia is also known as the Golden Shower tree. Tea was made from the sticks of the tree, which was reported to be helpful for patients with pulmonary disorders and fever. It is a commonly planted and an easily accessible tree.

"Kisi ny btaya tha k iss bemari men Amaltas ka kehva peena chaye uss sy seeny ko araam aata hai aur saans behtr rehti hai, meny istemal kia aur mujhe farq para. Islye ab men roz peeta hn"

"Someone told me to have Cassia's tea for chest relief. I used it and it helped, now I use it daily" (R6)

Seafood was also considered a good diet for people with respiratory diseases e.g., those having COPD. This included soup made from the fish's head.

"Machli kay Sir ki Yakhni bana ki pee jati haii uss sy boht behtri aati hai"

"Fish Head soup is used; it helps in recovery" (R1)

The home-based remedies are widely accepted and majorly used alongside the main treatment course, continuing from generation to generation and rooted within the cultures.

Role of Hakeem

Hakeems, or traditional healers, play an integral part in recovery mechanisms of diseases. Patients from rural as well as urban areas rely on these hakeems, and the remedies and traditional medicines given by them.

"Abbu ki pehly agr saans khrab hoti thee tou jaa k sharbat

Footnotes

(1) Religious/spiritual chants usually used in healing

"Abbu ki pehly agr saans khrab hoti thee tou jaa k sharbat lai aatay they hakeem sy. Wooh sharbat hakeem jari bootion sy banata tha. Uss sy aram bhe ajata aur saans behtr hojati thee"

"If our father had difficulty in breathing, we used to get medicinal syrup from the Hakeem. That syrup was made from herbs. It was a reliever of difficulty in breathing" (R3: Treatment Supporter)

Patients reported that the hakeems had been their first preference in treatment seeking; in case of severity, hospital-based treatment was considered.

"Doctor k pass tou ab aaye hen, pehly tou Hakeem sahib ilaj krty thy"

"We have come to the doctor now; earlier we used to get treated by the Hakeem" (R6)

People are dependent on these traditional healers in various capacities. They are considered an integral part of the recently designed interventions as they are regarded as communal assets.

Discussion

Asthma and COPD are emerging areas in the public health discourse. Pulmonary diseases are mostly progressive; hence, any intervention designed to tackle them are based on the idea of lifestyle change and management, and adaptation with the disease.

This study explores challenges faced by the patients and their family in managing the disease, and the types of treatment opted by the patients along with the modern medicinal course. The study was designed to capture views of patients and their families, and the modification in their economic and social life after the diagnosis. This allowed exploration of different barriers/challenges that are faced by the patients.

The findings of this study clearly show that the patients faced economic, social, and personal challenges during- and post-treatment phases. The study highlights varying notions of the respondents as to how treatment-seeking of COPD posed challenges in their lifestyles, at both household and individual levels.

COPD is an important cause of mortality worldwide, with smoking being one of the leading risk factors (21). Use of low quality or cheap cigarettes and tobacco intake is common especially among rural residents. According to the American Lung Association, risk of death caused by COPD is 13 times higher in smokers as compared to non-smokers (22, 23). In the early stages, COPD is often milder in severity unlike most of the diseases. However, the disease worsens and becomes unmanageable if diagnosed at later stages, mostly among patients of older ages (24).

Patients with COPD exhibit serious symptoms, and their life is compromised due to restricted activities, social isolation, and financial burden. Families and caretakers of COPD patients are required to provide physical and emotional support (25).

Patients with COPD need high levels of input from healthcare facilities; however, unfortunately they are often overlooked in providing specialized nursing, critical and sensitive care, and/or social and community support. The current research makes a clear case for the implementation of improved services and support for patients with COPD. The patients were reported to face challenges while paying for their daily medicines as well as the healthcare equipment, which is expensive and not affordable for everyone. Other patients reported the impact of reduced physical functioning on their social lives and interaction skills. According to research, physical barriers including reduced body functioning among patients with COPD require intense emotional and psychological support. Moreover, economic barriers are difficult to overcome (26).

The present study shows that a majority of the patients who sought treatment for COPD were diagnosed with Stage 2. Similar studies show similar trends in the sense that patients who reach healthcare facilities have symptoms with severe intensity. This leads to more complex treatment (27). COPD patients and their families rarely reported to have any complete understanding of the condition and its prevention. It is for this reason public health interventions also focus on awareness raising regarding the disease and adoption of preventive measures.

Many studies reported the attribution of symptoms to aging or smoking (28); this trend is also consistent with the findings of the current study. Patients of older age with initial symptoms emerging at the age of 40-45 years were relatively more ill as compared to younger patients. This may be due to the reason that many patients did not perceive their respiratory symptoms to be related to a serious condition like COPD, as many lacked sufficient information and awareness regarding the disease. Symptoms such as breathlessness were not taken seriously, and the ability of the patients to adapt to their symptoms further increased the risk.

Several clinical trials have investigated the effect of herbal medicines on lung function and potential impacts of their anti-inflammatory properties on systemic circulation (29). Similarly, the present study reveals various perspectives of the patients regarding the use of home-based remedies or indigenous herbal medicines. Cassia tree sticks were reportedly used as an effective treatment that proved to be efficacious, providing immediate relief for chest pain and breathlessness.

Results from a controlled observational study indicated that homeopathic drugs have a preventive effect on the onset of respiratory disease episodes; however, the conclusion would be firmly reached after a randomized study (30). In contrast, the current study reported that

although homeopathic medicines provided complementary results to the allopathic treatment, nonetheless they were ineffective in their entirety and the patients had to reach out for hospital-based remedies for quick recovery and relief. Moreover, patients using herbal treatment were recovering at a slower rate.

A study also reported that patients had to physically adapt themselves to the disease and limit their activities as COPD progressed (28). Similarly, this study revealed complaints from the patients regarding the severity of the symptoms. Reportedly, symptoms of COPD were progressive and unrecoverable; the patients reported to feel relieved for a while only, and the pain would re-emerge within the span of the next few hours or days.

Conclusion

Apparently, healthy individuals are likely to develop underlying COPD if they are smokers. Patients with COPD should be screened before time so that the progressiveness of the disease can be controlled; thus, active screening through Spirometry and Peak Expiratory Flow Rate (PEFR) plays an important role in early detection of this disease. Smoking and exposure to certain dangerous environmental pollutants, including cigarette smoke, smoke from fuel, wooden stoves, and pesticides is responsible for development and progression of COPD.

Patients not only face challenges in their health, but also in socioeconomic and psychological domains that are equally harmful. A disease, be it of any kind, demands care and management; however, this is quite more significant in the case of diseases that may cause organ dysfunction.

Health care professionals should be trained for case management of chronic diseases, specifically COPD, in order to clearly communicate the diagnosis of COPD and its care practices to the patients in an appropriate manner. Smokers should be reassured that they will additionally receive care that is related to smoking cessation.

Parallel treatments help in reducing the symptoms for a limited time only. Hence, the allopathic treatment (based on the use of inhaled bronchodilators and corticosteroids) should be emphasized and reinforced for people with COPD, which is currently the best approach for its management, and has proved effective for improving lung function and quality of life, as well as reducing symptoms and disease exacerbations.

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