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a qualitative study

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Title: Needs assessment for introducing Pulmonary Rehabilitation for Chronic Obstructive Pulmonary Disease management in a rural Indian setting: a qualitative study.

Authors:

Diksha Singh¹, Harshpreet Kaur¹, Sudipto Roy², Sanjay Juvekar¹, Hilary Pinnock³, Dhiraj Agarwal¹

1. Vadu Rural Health Program, KEM Hospital Research Centre, Pune
2. Indian Council of Medical Research, New Delhi
3. NIHR Global Health Research Unit on Respiratory Health (RESPIRE), Usher Institute, The University of Edinburgh, Edinburgh

Corresponding Author:

Dr. Dhiraj Agarwal

Senior Scientist

Vadu Rural Health Program, KEM Hospital Research Centre, Pune

Email: dhiraj.agarwal@kemhrcvadu.org

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List of Abbreviations:

AYUSH: Alternative medicine encompassing Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy

CME: Continuing Medical Education

COPD: Chronic Obstructive Pulmonary Disease

CRD: Chronic Respiratory Disease

GP: General Practitioner

HCPs: Healthcare Professionals including those practicing modern and AYUSH medicine

KEMHRC, VRHP: King Edward Memorial Hospital Research Centre, Vadu Rural Health Program

LMIC: Lower-and-Middle Income Countries

MO: Medical Officers

NRHM: National Rural Health Mission

PHCs: Primary Health Centers

PR: Pulmonary Rehabilitation

Abstract

Background: Pulmonary Rehabilitation (PR) is an effective strategy to improve breathlessness, health status and exercise tolerance and to reduce readmissions and mortality. In India, there is no government health program for COPD management while in the private sector availability of PR is limited. Most PR centres are in urban areas, with few services accessible to rural populations. We aimed to assess the need for PR from the perspective of COPD patients and healthcare professionals (HCPs: registered medical practitioners and medical officers) in rural Maharashtra.

Methodology:

Between June and October 2020, we conducted semi-structured interviews with 14 COPD patients and nine HCPs to explore their perceptions of, and need for, PR in rural Maharashtra. Interviews were transcribed and analysed thematically.

Results:

We approached 14 COPD patients and nine HCPs practicing in rural areas. Five HCPs stated that they did not advise PR for COPD patients citing poor compliance to PR referral and follow up of the patients. COPD patients had symptoms and needs that could be helped by PR but commented how transportation would be a problem for them to visit a PR Center. In contrast, they could understand the benefits of PR and expressed their willingness to join such programs. A PR service was established that addressed these needs.

Conclusion:

COPD patients have unmet needs that could benefit from attending a PR program, but there are barriers at both healthcare and patient levels that we addressed in a new PR service for people with chronic respiratory disease in rural Maharashtra.

Key words: COPD, Health Care Providers, Need, Pulmonary Rehabilitation, Rural India, Qualitative Study

What is already known on this topic:

Prior research has shown that Pulmonary Rehabilitation (PR) is an effective strategy to improve the health outcomes of patients with COPD. However, in India, there is a lack of government-sponsored programs for COPD management and the availability of PR is limited especially in rural areas. Previous studies have highlighted the need for PR in India but have mostly been conducted in urban settings.

What this study adds:

This study adds to the existing body of knowledge by highlighting the need for PR programs in rural areas of India and identifying transportation as a significant barrier to accessing PR programs in rural areas. It also provides insights into the perspectives and needs of both COPD patients and healthcare professionals (HCPs) in rural Maharashtra regarding PR. The study highlights the unmet needs of COPD patients in rural areas, which is a new finding in the context of India. Additionally, this study resulted in the establishment of the first PR centre in rural Indian settings, providing access to PR programs for COPD patients in the area by providing solutions regarding the accessibility, transport, awareness and home based approach.

How this study might affect research, practice or policy:

Our study emphasises the importance of considering patient perspectives and needs when developing and implementing healthcare interventions. Our systematic approach to identifying the needs of the local community and establishing the first PR centre in rural Indian to respond to those needs could serve as a model for future efforts to increase access to PR programs in rural areas.

Introduction

Patients with all severities of COPD, have reduced physical activity, increased hospital admissions and mortality even when optimal medical care is provided (1). Pulmonary rehabilitation (PR) is a cost-effective intervention involving supervised exercises and self-management education for individuals with COPD (2) with robust evidence that it provides meaningful improvement in shortness of breath, exercise tolerance and quality of life as well as reducing mortality (3) (2). PR also reduces the healthcare burden of COPD, by preventing unnecessary hospital admissions and reducing the length of hospital stays (4) and is recommended as a core management strategy for all symptomatic patients (GOLD) (5), there is some evidence of benefits of PR in low-and middle-income countries (LMICs) (6) in which respiratory illness may be poorly differentiated and there are significant differences in the resources, awareness, culture, profile of the disease and healthcare configuration that affect uptake by clinicians and patients especially in the rural communities.

The Indian rural healthcare system is a mix of public and private facilities run by Modern medicine (evidence-based modern medicine) and AYUSH (alternative medicine encompassing Ayurveda, Yoga and Naturopathy, Unani, Siddha, and Homeopathy) practitioners. (7) Despite the prevalence of risk factors in India, (27.2% smoking, 70% of the homes use biomass fuel especially in rural areas), (8)(9) there is no government health program for COPD management. Private sector PR programmes rarely include all recommended components and referral to them is infrequent (8). Most PR centres are in urban areas where diagnostic and specialist facilities are based (8)(9) in a model of care that focuses on acute management rather than proactive care of a chronically disabling non-communicable disease (NCD). There is little understanding about the feasibility of provision in rural areas where PR may be even more important because it helps reduce exacerbations. Likely barriers to provision include a shortage of trained medical practitioners and their limited knowledge about PR, lack of community awareness and reluctance of individuals with COPD to seek help for their slowly progressive disabilities (9) (10)(11) and underdeveloped physical and social infrastructure (12).

Individuals living in rural areas are more exposed to biomass risk factors, such as use of wood for cooking or heating than urban counterparts, thus increasing their COPD risk but reducing the healthcare that could improve the impact of their symptoms. There is thus a need to

- explore local health-related perceptions about the need for PR and
- to gather views on the design of acceptable, feasible and effective PR programs (13)

The ultimate aim is to inform the development of a PR service, that is widely available with clear pathways from referral to completion of PR (14) in order to improve the morbidity of patients suffering from COPD in a rural Indian setting in Pune District.

Materials and Methods

Ethical consideration and consent to participate

This qualitative study was conducted between June and October 2020, with ethics approval from the KEM Hospital Research Centre ethics committee (Reference number: KEMHRC/RVM/EC/1834-A); and permissions from health officers at the district and block level, and from the private GPs' association. The study was sponsored by the University of Edinburgh (ACCORD: Reference number: AC18111). Written informed consent was obtained from each participant, confirmed verbally prior to the interviews. The study was implemented following National Ethical Guidelines for Biomedical and Health Research involving Human Participants issued by the Indian Council of Medical Research in 2017 and the recent National Guidelines for Ethics Committees Reviewing Biomedical & Health Research During COVID-19 Pandemic issued in 2020.

Study area

The study was conducted in 22 villages of the rural Pune District covered by Vadu Rural Health Program (VRHP), which hosts the Health and Demographic Surveillance System (HDSS) of KEMHRC Pune. The geographical region under study, rural western Maharashtra, holds similarities to numerous other rural areas in India and potentially other South Asian LMICs. These similarities include socio economic factors, cultural practices, healthcare infrastructure, and disease patterns. Therefore, the findings of this study are likely to have relevance and applicability beyond the specific area of investigation

Study population

The COPD patients invited to participate in this study were identified during the BOLD COPD prevalence study conducted in Vadu HDSS area in 2008-2010 (15). They were identified according to the GOLD guideline criteria for COPD (5) based on their responses to the validated study questionnaires, spirometry, and pulmonologist assessment. We invited HCPs who were providing public and/or private primary healthcare services in the rural settings to participate, excluding professionals who did not treat COPD patients.

Participant recruitment

COPD patients were identified by Field Research Assistants from the list of COPD patients from the COPD prevalence survey cohort who had agreed to be approached for future research. People over the age of 18 years with COPD were selected for participation using purposive sampling to provide a range of age, gender, smoking history, and educational status. 15 HCPs practising in the study area were approached telephonically and as per their availability, nine consented to participate.

Interview topic guides

We developed two semi-structured interview schedules, one for COPD patients and another for HCPs. The interviews explored the need for PR from the two different viewpoints; the COPD patient's perspectives and perceptions about the need for PR and assessed the HCP's knowledge, perception, and actual practice regarding PR in the rural Pune District. Both schedules were informed by the ERS PR guidelines (16). Table 1 lists the over- arching domains included in the interviews; the full topic guides are in Supplementary File 1 and 2. After initial questions exploring viewpoints about COPD and role of PR, the participants were given a short explanation about PR and its proven benefits (3). The interview was then resumed, and the participants were asked to reflect on what they had heard and consider whether they saw a need (or not) for PR and the feasibility for provision in a rural setting.

Table 1: Domains included in the semi- structured interview schedule.

Domains (COPD Patients)	Domains (Healthcare Providers)
Experience of clinical signs and symptoms	Experience of managing COPD
Perceived risk factors and reasons for their respiratory condition	Risk factors that they recognized
Current management of their COPD (medicines used; other strategies)	Current management strategies that they prescribed
At this point in the interviews the researcher described PR and the potential benefits	
Awareness of PR as a treatment for COPD/lung diseases	Awareness of PR, and their experience of advising PR
Perception of the need (or not) for a PR service	Perception of the need (or not) for a PR service

Feasibility of attending PR Sessions	Feasibility of patients attending PR (including Post PR Follow-up) in their rural setup
-	Views on the practicalities of delivering a PR service: Components, Duration, Eligibility (in terms of disease severity), Benefits, Risks, Challenges

Data Collection

Interviews were conducted by DS, a counselling psychologist and HK, a public health researcher, and were arranged face-to-face at the patient's home or the HCP's clinic, or telephonically to suit the participant's convenience.

Data Quality and Monitoring

The semi-structured interview schedules, and interview transcripts were monitored and checked for quality, completeness, and accuracy by DS, the senior experienced research team member.

Data handling and analysis

All interviews were digitally recorded and transcribed verbatim in the spoken language (Marathi). Transcripts were translated by the research team from Marathi to English for analysis, retaining the Marathi version so that the nuances of the discussion could be checked in the original language. We used thematic data analysis to analyse the data (17) allowing patterns and themes to emerge from the data as well as important variations in responses. Initially, the transcripts were coded, and the codes were then used to build themes and domains aligned with the expected outcomes of acceptability, feasibility, barriers, and facilitators for implementing PR. The analysis of the concept of need used Bradshaw's Classification of needs as a framework. This framework distinguishes four different types of needs: felt need, expressed need, normative and comparative need (18). See table 2 for a description of these types of need.

Table 2: Summary of Bradshaw's classification of need

Need	Description
Felt need	Felt need may be limited by the perceptions of the person with COPD and by their lack of knowledge of PR services and may be influenced how they perceive their

	respiratory symptoms compared to their friends or other members of their family. Whether, and how, they describe the impact of their symptoms may depend on who asked the question: they may give a different answer to the researcher than to their GP, a chest specialist, a friend or a family member.
Expressed need	Expressed need is demand or felt need turned into action, and help is sought. However, to express need it is necessary to have heard of a service, consider the service to be acceptable, accessible, and priced appropriately.
Normative need	Normative needs are defined by experts (professionals, doctors, policymakers). Often a desirable standard is laid down and compared with the standard that exists. They are not absolute and different experts set different standards. Assessment of normative needs can also be used to judge the validity of an expressed need.
Comparative need	Comparative need has to do with equity: if some people are in receipt of a service and others, in similar circumstances, are not, then the latter are in need. Relative availability will influence comparative need as the benchmark is to achieve equal access

Results

Participants

We interviewed 14 COPD patients and nine HCPs from public and private hospitals. See Tables 3 and 4 for summaries of their demographic characteristics. One HCP with a qualification of MD Pediatrics was included in the interviews because, in the study area where there was a shortage of practitioners, he provided care to patients of all age.

The patients had a mean age of 62 years, were evenly split between genders, and with a range of educational status. Only four had a history of smoking. All but one of the physicians were male and had between three- and 25-years professional experience and consulted with a mean of 32 COPD patients a month.

Table 3: Demographic characteristics of COPD Patients

Characteristic	COPD Patients (n=14)
Gender (Male: Female)	7:7
Age in years	
<i>Mean in years (SD)</i>	62.0 (10.0)
<i>Range</i>	49 to 80
Smoking History	

<i>Smoker</i>	0
<i>Ex-smoker</i>	4
<i>Non- smoker</i>	10
Educational status	
<i>Uneducated</i>	4
<i>Primary Education</i>	3
<i>Secondary Education</i>	5
<i>Graduate/ Postgraduate</i>	2

Table 4: Demographic characteristics of HCPs with their experience and qualification and the number of COPD cases.

Characteristic	Healthcare Professionals (n=9)
Gender (Male: Female)	8:1
Experience of clinical practice in years	
<i>Mean, SD</i>	10.7 ± 8.9
<i>Min</i>	3
<i>Max</i>	25
COPD cases	
<i>In last 1 month (Mean, SD)</i>	32.4 ± 18.9
Qualification	
<i>MD Internal Medicine</i>	4
<i>MD Pediatrics</i>	1
<i>MBBS</i>	2
<i>AYUSH Practitioners</i>	2

Over-arching findings

Using Bradshaw’s framework, our study highlighted two main areas of discrepancies, i.e., the gap between people’s felt needs and those they express at an assessment. In parallel with this, there was a gap between healthcare professionals’ perception of normative and comparative needs and the reluctance of patients to accept these.

Felt and expressed needs of individuals with COPD

When we asked the patients what it was like to live with COPD, they told us that they suffered from cough and sputum production, and shortness of breath while bending down and working. They sometimes experienced wheezing or 'whistling' in their chest. When asked about the causes, the patients believed that their COPD symptoms were mainly due to seasonal changes, 'tadka', lifelong usage of chewing tobacco, chulha smoke, damp/ rainy weather, smoking and occupational hazards.

Boredom and inability to participate in activities because of their breathlessness was a commonly 'felt' need, though typically they had adapted to the imposed limitations rather than expressing their need and actively seeking help. In general, they were not willing to seek help from any professionals, rather they preferred to accept care from family members.

"I get bored simply sitting at home. I usually think to myself that if I feel so breathless then I shouldn't go anywhere and stress myself." (P3, 50-59 years old, Ex-smoker and mason worker)

"Feeling breathlessness and experiencing shortness of breath have started causing pain and problems with my hands and legs and I face difficulties because of that. I am unable to do anything, I just sit in one place." (P5, 50-59 years old, Female; Non-smoker, Farmer)

A key barrier which inhibited the expression of these felt needs was the limited understanding of COPD and the overall lack of awareness amongst the population. After they were provided with information about the potential benefit of PR services, the participants showed significant willingness to participate in the PR program

"Yes, I do need it. If doing this will make me feel better then I will definitely want to do it" (P3, 50-59 years old, Male; Ex-smoker, Mason Worker)

"Whenever you ask me to come I will definitely come. I will stay for as much time as you ask me to." (P8, 60-69 years old, Female; Non-smoker, Homemaker)

"I will do the pulmonary rehabilitation; if my lungs start functioning better I will be able to do some work!" (P9, 70-79 years old, Male; Non-smoker, Retired)

Alternative treatment strategies were not always acceptable as there was a stigma attached to using inhalers. There was also a misbelief that they were already active enough as work done in the fields was a type of exercise.

"I don't take any medications. I work on the farm so that in itself is a lot of exercise and physical activity." (P6, 50-59 years old, Female; Non-smoker, Homemaker)

Healthcare providers perception of normative and comparative needs and the care they provide

The professionals that were interviewed also reflected on the significant unmet 'normative' needs of people suffering from COPD. but were also aware of the inequities that meant these were not always met.

Most of the patients they saw were in the mild to moderate category of COPD (according to the GOLD classification[05]) with common symptoms of cough, breathlessness, shortness of breath and wheezing. The most common risk factors that they identified were exposure to air pollutants, weather change, smoking and exposure to dust though an Internal Medicine practitioner added that low birth weight, congenital disorders, genetic factors, and poverty were additional risk factors for COPD.

"I think pollution and older people who have a smoking history, some have allergies like allergic asthma, occupational dust (people who work in a flour mill or a person who works in an industry where there is dust production) and seasonal change like winters" (HCP, S3)

When asked about the treatments they prescribed to these patients, most cited oral medications, inhalers, and nebulization. In the absence of a PR service, a few professionals described how they recommended some of the main components of PR (e.g., exercising and diet modification):

"Most providers do not conduct pulmonary rehabilitation in the rural area. We recommend exercise, yoga, pranayam, education, inspiratory exercises, psychiatric opinion for anxiety and depression, and a high protein diet for nutrition." (HCP, S6)

One practitioner mentioned how he tailored the advice based on the patient's condition to avoid any risks due to PR.

"No exercises are recommended. For unstable patients I suggest psycho social support, smoking cessation, exercise training, chest physiotherapy." (HCP, S1)

When the professionals were asked about their arrangements for following up COPD patients, they described that although this 'should be conducted every 1-2 months' it often did not happen.

"If the patients come back to us post treatment, we definitely reassess them. Not all patients come back, they only come back when they suffer and their symptoms are aggravated" (HCP, S5)

A key theme was the lack of understanding (on the part of patients, public and professionals) of the benefits of PR, and the stigma attached to a diagnosis of COPD. Some of the professionals felt that educating patients about the benefits (reduced exacerbations, giving health and other economic benefits) would enhance acceptability.

"Until and unless the patient realizes the benefits of PR he will not come to the centre for the various exercises and breathing exercises. If proper counselling is given, then they will definitely come. They will also follow up the given exercises at home as they usually listen to whatever we advise." (HCP, S1)

"People think that once they are diagnosed with Asthma or COPD it is like they are tagged and they need to hide it. That fear and dilemma should be taken care of and they should be educated." (HCP, S9)

A practitioner with 25 years of experience stressed the need for general awareness of PR and emphasized the role of skilled professionals in leading this:

"Conduct educational programs, mass community or society level training programs should be conducted. Doctors, nurses, teachers will play a huge role in this, basic level government servants like Sarpanch, Gramsevak Anganwadi, ASHA's, consultants will have a major role, etc." (HCP, MBBS, S8)

"If training is provided to general practitioners or consultants in the rural areas then it will definitely be beneficial and feasible for sure. (HCP, S4)

PR services from HCP and patient perspectives

When the professionals were asked about their management of COPD, they stated that they had no experience in advising PR to any of their patients.

"Doctors should be trained first and then side by side the Nurses or other healthcare workers should be trained. There is a program through National Rural Health Mission (NRHM) where there is someone called Mr Wagh who is a counsellor who counsels people with Diabetes, hypertension, etc to quit smoking or quit tobacco products every week at the hospital. So, such people along with doctors and nurses should be trained." (HCP, S1)

"I just feel that if physicians like me are trained properly then we can start advising these people that way." (HCP, S2)

Most of them felt that services such as PR should ideally be recommended only by chest physicians. This opinion was held by most of the HCPs that participated.

"Chest physicians only recommend this, we don't" (HCP, S3)

The lack of local facilities was highlighted as a problem by HCPs and patients. HCPs observed that referring symptomatic patients to a PR centre was 'not possible' as there were no such facilities available in the rural areas and patients were often reluctant to travel. Patients endorsed this, commenting that their doctor's advice did not include the mention of PR.

In the acute situation, most practitioners would refer patients to the district hospital in the city of Pune (about two hours travel from their hospital or clinic) or other tertiary level hospitals due to the unavailability of necessary equipment and expertise in the rural areas.

"The patient is not willing to go even after referring; the patient goes to a nearby hospital and gets saline or injections for immediate relief." (HCP, S1).

An MBBS practitioner with over 24 years of experience expanded on the issues related to the lack of transport facilities, dependency on family members for travelling and unavailability of PR in the rural areas.

"The concept of Pulmonary Rehabilitation is very nice, but such a service isn't available in our area. If we recommend them to even go to the city area for such a service, hardly 1-2% of them would give it a thought. If these services are available in the same premises as their hospital or someplace close by, then they might accept such a service". (HCP, S5)

Home-base PR was considered as an acceptable option by both HCPs and patients as that could overcome the challenge of transportation, and ease the commitment required for attending 16 sessions. Avoiding Centre-based PR was a particular concern in the pandemic for reasons of infection. Control.

"Home-based would be feasible for patients" (HCP, S1)

"I prefer home based exercises." (P2, 50-59 years old, Male; Ex-smoker, Retired)

"I am willing to undergo PR. If it is possible to do it at home, I will do it (P4, 50-59 years old, Male; Occasional smoker, Service)

For patients, however, the practical challenge was not only poor transportation, but living with symptoms that limited their mobility, and the day and duration of the PR service.

“I can come every day but coming and going will be a huge issue. My only tension is that I experience shortness of breath.” (P9, 70-79 years old, Male; Non-smoker, Retired)

“I will come only if transportation is provided” (P14, 50-59 years old, Female; Non-smoker, Homemaker)

HCPs observed that an additional factor was the socio-economic backgrounds of most of the population in the rural areas being low or very low and hence that would make the affordability of a Centre-based setup difficult. Need to design a service that was cost effective was suggested.

“Design the program’s module keeping in mind regarding their economic condition” (HCP, S1)

“Cost factor is very important” (HCP, S3)

Responding to the needs: the new PR service

Table 5: Summarises how we sought to meet the needs of both patients and professionals in our new PR service at the Vadu Rural Health Program which was opened on 16th December, 2020.

What we learnt from the needs assessment	How the new PR service meets those needs
There is a gap between the needs that people with COPD ‘feel’ and described in our study and the needs that they express during assessments.	<ul style="list-style-type: none"> • Providing the patients with comprehensive psychoeducation and information about COPD, its symptoms and the potential benefits of PR services. • Patients are encouraged to actively seek help and express their needs by raising awareness and knowledge. • The new PR service uses COPD Assessment Test (CAT), St George’s Respiratory Questionnaire (SGRQ), Patient Healthcare Questionnaire (PHQ-9) and Generalised Anxiety Scale (GAD-7) to assess the symptom and the impact on the patient’s quality of life and well-being.

<p>Patients tended to adapt to their limitations, normalising their symptoms as 'old age' and seeking support and care from family members.</p>	<ul style="list-style-type: none"> • Understanding the importance of involving family members of the patients in COPD management. • Family members are counselled and encouraged to accompany the patients to the PR Centre, where they receive family therapy and learn about COPD and its impact along with the importance of PR services and any home based exercise training for them to assist the patients at home. • Including family support and education as part of the psychosocial support component ensures that patients receive comprehensive care and understanding.
<p>The lack of awareness in the population acted as a barrier to patients expressing their needs.</p>	<ul style="list-style-type: none"> • The lack of awareness was addressed by implementing community education and awareness programs. These initiatives aim to educate the population about COPD, its symptoms, and the benefits of PR services. • These programs help patients overcome the barrier of limited knowledge encouraging them to express their needs and seek appropriate support.
<p>Stigma associated with having a COPD diagnosis is a barrier exacerbated by the lack of patient education about COPD and PR, and the misconceptions of the community.</p>	<ul style="list-style-type: none"> • The new PR service actively works to reduce the stigma associated with COPD by conducting community awareness campaigns and educational initiatives. • It aims to improve understanding and acceptance of PR services by providing accurate information and highlighting the benefits of PR for COPD management. • By addressing stigma and enhancing awareness, the service promotes the uptake and acceptability of PR among patients and the community.
<p>There is a gap between the HCPs' perception of the needs that they observed and the reluctance of patients to accept that they needed and could benefit from help and guidance.</p>	<ul style="list-style-type: none"> • The new PR service focuses on bridging this gap by providing HCPs with comprehensive training on effective communication and patient-centred care. • HCPs are equipped with the knowledge and skills to address patients' concerns, understand their needs, and engage them in shared decision-making.

	<ul style="list-style-type: none"> • A supportive and empathetic environment is maintained which promotes better acceptance of HCPs' guidance and recommendations.
The follow-up assessments were often not attended as scheduled.	<ul style="list-style-type: none"> • The new PR service emphasises the importance of regular follow-up assessments in order to monitor patients' progress and adjust their treatment plans accordingly. • It implements a systematic scheduling reminder system to ensure that the follow-up assessments are conducted as scheduled. • By improving adherence to follow up appointments, the service aims to enhance the continuity and effectiveness of the care provided to the patients
Patients and some professionals were unaware of the benefits of PR and highlighted the cost and travel barriers.	<ul style="list-style-type: none"> • The PR service is adapted to the socio-economic background of the rural population ensuring that it is accessible and affordable for local patients. • Professional training, and public awareness campaigns promote the benefits of the local PR service and address the barriers to increase uptake. • The location of the PR centre is at the secondary level hospital which is situated on the main road and is easily accessible for the patients in the study area.

Discussion:

Summary of results

The study found that there was a clear need for PR services in the region as many of our participants described patients suffering from disabling symptoms and social isolation due to COPD and other respiratory illnesses who could benefit from the PR services.

Most of the practitioners had no experience in advising PR to their patients, believing it to be a service that was not available locally and was usually recommended by chest physicians and physiotherapists rather than the Medical Officers or GPs, though some recommended exercises in the absence of accessible services to which they could refer. Most of the population from the rural area belonged to very low socioeconomic backgrounds and were unable to afford even the basic treatments needed

for their COPD. Transport was the biggest challenge as the people suffering from COPD were typically older and dependent on a family member for transport. Home-based PR was considered as a feasible option by both HCPs and patients to overcome practical mobility challenges, particularly during the pandemic as it addressed infection control issues.

The findings of the study suggest a disconnect between the felt needs of COPD patients, the normative and comparative needs perceived by the HCPs and the barriers that are preventing the effective provision of PR services. There was general agreement that there was a need to raise awareness of PR amongst patients, the community, and professionals to enhance referral to, and uptake of a PR service. Follow up of COPD patients was also difficult because they do not give importance to their condition once they feel better after an exacerbation.

Overall, this study provides an insight into the gaps and discrepancies in management of COPD from the perspectives of patients with COPD and healthcare professions and highlighted the importance of developing a PR service that is adapted to the socio-economic background of the rural population ensuring that it is accessible and affordable for local patients

Discussion in relation to published literature

Socio-cultural barriers play a significant role in defining needs. Research conducted previously suggests that shame, blame, and guilt fall within “stigma-related experiences” of individuals suffering from chronic respiratory diseases (19). Delay in seeking medical help, increase in symptom severity, poor adherence and diagnosis concealment can be the result of such experiences (20)(21). Using an inhaler is seen as a sign of weakness or addiction affecting compliance. Lack of support from the family has been described as reducing follow-up (22). Most participants expressed a lack of support from their families but were also reluctant to ask for help (23). In common with work from the UK, “normalising” and “silencing” their limitations because of “old age” about which “nothing can be done”(11) was a common finding amongst the rural Indian population. Since the study was being conducted during the COVID-19 Pandemic, a preference for home-based PR as a strategy was suggested by the HCPs to overcome concerns about visiting the centre due to the fear of infection. Home-based PR is as effective as centre-PR (24), and could potentially help overcome the barriers of travelling, time, distance, and accessibility of the PR services especially in LMICs (6).

Providing professional training and education to the local practitioners is also important to encourage the local practitioners to advise components of PR along with developing an efficient referral system

to facilitate access to a PR service. Affordability was a need pointed out by most caregivers as they suggested the cost of such a service will play a major significant role in determining the feasibility of the service.

Strengths and limitations of the study:

The individuals with COPD recruited in the study were from the cohort recruited from the previously conducted BOLD study in the 22 villages of Vadu Rural Health Program (VRHP) so included people who had been detected by the survey as well as some who had received a clinical diagnosis. This study is the first to explore the perceptions of both COPD patients and HCPs in a rural Indian setting on local provision of a PR service. The interviews were carried out by two researchers, DS and HK with different backgrounds helping to address reflexivity as regular communication meant that preconceived perspectives could be challenged. The use of Bradshaw's framework provided a structured and systematic approach to understanding the gaps between the different needs and further strengthened the credibility and rigor of the findings from the study. Discussion with the multidisciplinary team enabled a balanced interpretation.

As this study was conducted in a single block of Maharashtra, the findings may not apply to other blocks within the state or more widely in India. Our study focused on rural settings as we wanted to inform the development of a local PR service, so our findings may not reflect the need in other demographic and social contexts. It is rare to find specialists in rural areas, and most of the HCPs included in the study were general practitioners and Medical Officers; none of the interviewed practitioners were chest specialists. Due to the COVID-19 pandemic, most of the interviews with the professionals were conducted virtually. The interviews with the patients were conducted in person due to limited availability of telephonic communication in this group of patients.

Conclusion:

This qualitative study amongst patients with COPD and the local GPs and MOs of the area highlighted the need for PR centres in the rural settings and considered the challenges of stigma related to respiratory diseases, lack of awareness of the benefits of PR, and a tendency to treat exacerbations rather than address long term strategies. There are barriers at both healthcare and patient levels that we addressed in developing a new PR local service for people with chronic respiratory disease in rural Maharashtra

The RESPIRE collaboration:

The University of Edinburgh, Edinburgh, UK; The Allergy & Asthma Institute, Islamabad, Pakistan; Maternal Neonatal and Child Health Research Network, Islamabad, Pakistan; University of Malaya, Malaysia; KEM Hospital Research Centre, Pune, India; Aga Khan University, Karachi, Pakistan; Christian Medical College, Vellore, India.

Patient and Public Involvement:

We involved patients and members of the public throughout our research study to ensure its relevance and benefit to the community. Our PPI group provided valuable input and feedback, enhancing the quality of our research. We strongly advocate for the inclusion of PPI in all research studies.

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Availability of data and materials:

Data analysed during the current study are not publicly available as data collection for qualitative aspect of the study is still ongoing. Corresponding author will upload data on Edinburgh DATASHARE data sharing repository (<https://datashare.ed.ac.uk/>) after completion of data collection for the current study. However, data used for current publication will be available from the corresponding author on reasonable request.

Competing Interests:

The authors declare that they have no competing interests

Contributorship statement:

Sanjay Juvekar and Hilary Pinnock led the development of the study. Diksha Singh wrote the first draft of the manuscript which was critically reviewed and refined by Dhiraj Agarwal, Harshpreet Kaur, Sanjay Juvekar, Hilary Pinnock and Sudipto Roy. Diksha Singh, Harshpreet Kaur and Dhiraj Agarwal performed the qualitative and quantitative analysis. RESPIRE UMC members provided advice and contributed to discussions. All authors approved the final version.

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