LMJ LINK MEDICAL JOURNAL OF HEALTH AND COMMUNITY RESEARCH

Crossref DOI: https://doi.org/10.61919/rwa63j31

Original Article

Exploring The Lived Experiences of Patients with Chronic Obstructive Pulmonary Disease (COPD) In Managing Daily Life and Treatment Adherence

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ABSTRACT

Background: Chronic obstructive pulmonary disease (COPD) is a progressive respiratory condition that disrupts physical functioning, emotional well-being, social participation, and treatment adherence. Although COPD care is often evaluated through clinical outcomes, less is known about how patients experience daily disease management and integrate long-term treatment into routine life. Objective: To explore the lived experiences of adults with COPD, focusing on daily activity limitation, emotional burden, treatment adherence, coping strategies, healthcare communication, and contextual influences. Methods: A qualitative phenomenological study was conducted among 20 adults with clinically diagnosed COPD recruited through purposive sampling from outpatient and community healthcare settings. Data were collected using semi-structured, in-depth interviews and analyzed through inductive thematic analysis following Braun and Clarke's framework. Trustworthiness was supported through field notes, reflexive journaling, independent coding, audit trail documentation, and member checking. Results: Five themes emerged: physical disruption of daily life, emotional burden and uncertainty, treatment adherence challenges, coping and social support, and healthcare communication within environmental and cultural contexts. Breathlessness and fatigue restricted independence, while fear of exacerbation contributed to anxiety and social withdrawal. Adherence was shaped by medication cost, complex regimens, limited inhaler understanding, and clinician communication. Family support, activity pacing, breathing exercises, and clear explanations facilitated coping and treatment continuity. Conclusion: COPD care should address physical symptoms, psychological distress, treatment literacy, affordability, social support, and environmental barriers through holistic patient-centered strategies. Keywords: Chronic Obstructive Pulmonary Disease, Qualitative Research, Phenomenology, Patient Experience, Treatment Adherence, Thematic Analysis

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"Cite this Article" | **Received**: 21 July 2025; **Accepted**: 16 September 2025; **Published**: 31 December 2025.
Author Contributions: Concept: FU; Design: TR; Data Collection: NKM and SAA; Analysis: ZN; Drafting: HI. **Ethical Approval**: Jinnah Postgraduate Medical Centre, Karachi, Pakistan. **Informed Consent**: Written informed consent was obtained from all participants; **Conflict of Interest**: The authors declare no conflict of interest; **Funding**: No external funding; **Data Availability**: Available from the corresponding author on reasonable request; **Acknowledgments**: N/A.

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a progressive and disabling respiratory condition characterized by persistent airflow limitation, chronic inflammation, and recurrent exacerbations that substantially impair functional capacity and quality of life. It remains a leading contributor to global morbidity and mortality, with a disproportionately increasing burden in low- and middle-income countries due to continued exposure to tobacco smoke, biomass fuel, and environmental pollutants (1,2). While clinical management strategies have evolved to include pharmacological therapy, pulmonary rehabilitation, and self-management interventions, the lived experience of COPD extends beyond physiological impairment and encompasses profound disruptions in daily functioning, emotional stability, and social participation. Patients frequently report difficulty performing basic activities such as walking, climbing stairs, or self-care, reflecting the pervasive influence of breathlessness and fatigue on everyday life (3).

Despite advances in treatment, suboptimal adherence to prescribed regimens remains a persistent challenge in COPD management. Adherence is influenced by a complex interplay of factors including treatment complexity, health literacy, affordability, healthcare access, and patient–provider communication (4). Poor adherence has been associated with increased exacerbation rates, higher healthcare utilization, and diminished quality of life (5). However, most existing literature has emphasized clinical outcomes and pharmacological effectiveness, with relatively limited exploration of how patients perceive their illness, interpret symptoms, and incorporate treatment into their daily routines. This gap highlights the need for approaches that capture the subjective, contextual, and experiential dimensions of COPD management.

Qualitative research is particularly suited to addressing this gap, as it enables in-depth exploration of patients' perceptions, beliefs, and coping strategies within their social and cultural contexts. In chronic conditions such as COPD, where psychological distress, social isolation, and environmental constraints intersect with physical symptoms, understanding lived experience is critical for designing patient-centered interventions (6,7). Phenomenological inquiry, in particular, allows for a nuanced understanding of how individuals make sense of their illness and navigate the challenges associated with long-term disease management (8,9). Through this approach, it is possible to uncover patterns related to adherence behavior, emotional responses, healthcare interactions, and contextual influences that are not captured through quantitative measures alone.

Using a PICo framework, the population of interest comprises adults living with COPD receiving ongoing treatment; the phenomenon of interest is their lived experience of managing daily life and adhering to prescribed therapies; and the context includes outpatient and community healthcare environments where patients interact with healthcare providers and social support systems. The study is guided by the research question: "How do patients with COPD experience and manage their daily lives and adhere to prescribed treatment regimens within their social, cultural, and healthcare contexts?" The objectives are to explore patients' perceptions of symptom burden, identify barriers and facilitators to treatment adherence, examine coping strategies, and understand the influence of healthcare communication, social support, and environmental factors on disease management.

The significance of this study lies in its potential to generate contextually grounded, patient-centered insights that can inform clinical practice and healthcare policy. By moving beyond a purely biomedical perspective and incorporating the voices of patients, this research aims to contribute to the development of holistic care strategies that address both clinical and experiential dimensions of COPD. Such strategies may include tailored education, improved clinician–patient communication, psychosocial support, and context-sensitive interventions that enhance adherence and quality of life. In doing so, the study responds to the growing recognition that effective chronic disease management requires alignment between clinical recommendations and patients' lived realities.

MATERIALS AND METHODS

This study was conducted as an interpretative qualitative inquiry using a phenomenological approach to explore the lived experiences of patients with chronic obstructive pulmonary disease (COPD) in managing daily life and adhering to prescribed treatment. The design was selected to enable an in-depth understanding of how individuals perceive, interpret, and respond to their illness within their social and healthcare contexts. The study was grounded in an interpretivist paradigm, recognizing that participants' experiences of COPD are shaped by subjective meanings, personal histories, and environmental influences (9).

Participants were recruited through purposive sampling from outpatient respiratory clinics and community healthcare settings to ensure inclusion of individuals with direct and sustained experience of COPD management. Eligible participants were adults aged 18 years or older with a confirmed diagnosis of COPD and at least six months of treatment experience, allowing them to reflect meaningfully on adherence and daily disease management. Individuals with severe cognitive impairment, acute exacerbation requiring hospitalization at the time of recruitment, or coexisting terminal illness were excluded to minimize confounding influences on experiential reporting. Recruitment was facilitated through healthcare providers who identified eligible individuals and introduced the study, after which participants were approached by the research team. Participation was voluntary, and no financial incentives were provided.

Written informed consent was obtained from all participants prior to data collection. Participants were informed about the purpose of the study, confidentiality measures, voluntary participation, and their right to withdraw at any stage without affecting their care. Interviews were conducted in private settings either within healthcare facilities or participants' homes, depending on participant preference, to ensure comfort and confidentiality. Audio recording was conducted with permission, and anonymity was maintained by assigning unique identifiers and removing all personal identifiers during transcription and reporting.

Data were collected through semi-structured, in-depth interviews guided by an interview schedule developed from existing literature and expert consultation. The guide covered domains including symptom experience, daily activity limitations, treatment use and adherence, understanding of medications, healthcare interactions, emotional responses, and coping strategies. Interviews were conducted in a language comfortable to participants, lasted approximately 40–60 minutes, and were facilitated by trained researchers experienced in qualitative interviewing. Field notes were recorded immediately after each interview to capture contextual observations, non-verbal cues, and preliminary reflections, enhancing depth of interpretation (11).

Interviews were transcribed verbatim, and where necessary, translated into English while preserving the original meaning. Transcripts were checked for accuracy against audio recordings, and all data were de-identified prior to analysis. Data were analyzed using Braun and Clarke's six-phase thematic analysis framework, involving familiarization with data, generation of initial codes, development of candidate themes, review and refinement of themes, definition and naming of themes, and synthesis of findings (12). An inductive approach was adopted, allowing themes to emerge from the data rather than being pre-determined. Coding was performed independently by two researchers to enhance analytical rigor, and discrepancies were resolved through discussion and consensus. An audit trail documenting coding decisions, theme development, and analytic reflections was maintained to ensure transparency and reproducibility.

Reflexivity was integral to the research process. Researchers acknowledged their clinical backgrounds and prior exposure to COPD patients, which could influence interpretation. To mitigate bias, reflexive journaling was maintained throughout data collection and analysis, and regular team discussions were conducted to critically examine emerging interpretations. Efforts were made to remain grounded in participants' narratives and avoid imposing preconceived assumptions about adherence behavior or disease experience.

Trustworthiness was ensured through established qualitative criteria. Credibility was enhanced through prolonged engagement, use of verbatim quotations, and member checking of selected transcripts and interpretations. Dependability was supported through a detailed audit trail of methodological and analytical decisions. Confirmability was strengthened through reflexivity and independent coding, while transferability was facilitated by providing rich descriptions of participant characteristics and study context. Data saturation was achieved when successive interviews did not yield new themes or insights, indicating sufficient depth and breadth of data (10).

Ethical approval was obtained from the relevant Institutional Review Board prior to study initiation (Approval No. COPD-2025-017). All procedures adhered to established ethical principles for human participant research, including confidentiality, voluntary participation, and secure data handling (13). Data were stored in password-protected systems accessible only to the research team, ensuring integrity and confidentiality throughout the study.

RESULTS

The study included 20 adults with clinically diagnosed COPD, comprising 11 males and 9 females aged 42–74 years, with disease duration ranging from 1–12 years. Participants were receiving ongoing COPD care through inhalers, oral medications, lifestyle modification advice, and pulmonary rehabilitation-related guidance. Thematic analysis of semi-structured interview data generated five major themes: physical disruption of daily life, emotional burden and uncertainty, treatment adherence challenges, coping and social support, and healthcare communication within environmental and cultural contexts. These themes were interconnected, showing that participants' adherence behaviors were shaped not only by symptoms but also by affordability, understanding of treatment, family support, and clinician communication.

Table 1. Participant Characteristics

Characteristic	Description
Total participants	20
Age range	42–74 years
Gender	11 male, 9 female
Disease duration	1–12 years
Treatment exposure	Inhalers, oral medications, lifestyle modification advice, pulmonary rehabilitation-related guidance
Data collection method	Semi-structured in-depth interviews
Analytical approach	Inductive thematic analysis

Table 2. Theme Matrix Showing Major Themes, Subthemes, and Participant Evidence

Major Theme	Subthemes	Representative Quote	Interpretation
Physical disruption of daily life	Breathlessness, fatigue, activity limitation, dependence on others	"Sometimes just walking to the washroom feels like climbing a mountain. I have to stop and catch my breath every few steps" (Participant 3).	COPD was experienced as a direct restriction on ordinary daily activities and independence.
Emotional burden and uncertainty	Anxiety, fear of exacerbation, depressive feelings, uncertainty	"I never know when it will get worse. That fear is always there, even when I feel okay" (Participant 11).	Participants lived with persistent fear linked to unpredictable symptom worsening.
Treatment adherence challenges	Medication cost, complex regimens, poor inhaler understanding, perceived limited benefit	"The inhalers are expensive, and sometimes I skip doses to make them last longer" (Participant 8).	Non-adherence was shaped by financial and educational barriers rather than unwillingness alone.
Coping and social support	Activity pacing, breathing exercises, family reminders, practical help	"My son reminds me to take my medicines and helps me when I feel weak. Without him, it would be much harder" (Participant 15).	Family involvement and adaptive routines helped participants manage symptoms and treatment.
Healthcare communication and context	Inadequate explanation, trust in providers, environmental triggers, cultural beliefs	"The doctor just tells me to use the inhaler, but no one really explains how or why. I had to figure it out myself" (Participant 6).	Clear clinician communication was central to treatment understanding and confidence.

The first theme, physical disruption of daily life, reflected the central role of breathlessness and fatigue in shaping participants' everyday routines. Participants described COPD as a condition that reduced their ability to perform basic activities independently. Walking short distances, climbing stairs, household work, and self-care were repeatedly described as exhausting. The quote from Participant 3 illustrates how even a routine task such as walking to the washroom could become physically overwhelming. This theme shows that COPD was not experienced only as a respiratory diagnosis but as a continuous limitation on autonomy, mobility, and participation in family and social life.

Physical burden
"Sometimes just walking to the washroom feels like climbing a mountain. I have to stop and catch my breath every few steps" — Participant 3.

The second theme, emotional burden and uncertainty, captured the psychological consequences of living with an unpredictable chronic illness. Participants described fear, anxiety, and depressive feelings, particularly in relation to sudden breathlessness and possible exacerbations. Participant 11's statement reflects how uncertainty persisted even during stable periods. This emotional burden appeared closely linked to physical symptoms, as participants who feared breathlessness often reduced activity, avoided social situations, or became more dependent on family members.

Emotional uncertainty
"I never know when it will get worse. That fear is always there, even when I feel okay" — Participant 11.

The third theme, treatment adherence challenges, showed that adherence was influenced by practical, financial, and knowledge-related barriers. Participants reported difficulty maintaining regular treatment because of medication cost, complex regimens, inadequate understanding of inhaler technique, and uncertainty about why medicines were needed when symptoms improved. Participant 8's account of skipping inhaler doses to make them last longer demonstrates that non-adherence was often a coping response to financial constraint rather than a simple refusal to follow medical advice.

Cost-related non-adherence
"The inhalers are expensive, and sometimes I skip doses to make them last longer" — Participant 8.

The fourth theme, coping and social support, highlighted how participants adapted to COPD through activity pacing, breathing exercises, avoidance of triggers, and reliance on family members. Family support was especially important for medication reminders, emotional reassurance, and assistance with daily tasks. Participant 15's quote demonstrates how caregiver involvement could strengthen both practical disease management and emotional resilience. However, some participants also described maladaptive coping patterns, including social withdrawal and avoidance of exertion due to fear of symptom worsening.

Family support
"My son reminds me to take my medicines and helps me when I feel weak. Without him, it would be much harder" — Participant 15.

Poor healthcare communication
"The doctor just tells me to use the inhaler, but no one really explains how or why. I had to figure it out myself" — Participant 6.

The fifth theme, healthcare communication and context, reflected participants' mixed experiences with health services. Some participants reported trust in providers and better adherence when instructions were clear, while others felt inadequately informed about inhaler technique and treatment purpose.

Participant 6's statement illustrates a common communication gap in which treatment was prescribed but not sufficiently explained. Environmental and cultural factors also shaped disease management, as participants described symptom aggravation from indoor pollutants, dust, smoke, and household exposures, while cultural beliefs and stigma influenced help-seeking and social participation.

Table 3. Qualitative Variability in Patient Experiences

Domain	More Supportive Experience	More Restrictive Experience	Qualitative Meaning
Daily functioning	Activity pacing, family assistance, breathing strategies	Dependence, fatigue, avoidance of exertion	Functional limitation varied according to coping resources and symptom control.
Emotional adjustment	Acceptance, reassurance, family support	Anxiety, fear, social withdrawal	Emotional distress was intensified when participants felt unsupported or uncertain.
Treatment adherence	Clear instructions, reminders, follow-up care	Cost barriers, poor inhaler understanding, skipped doses	Adherence was shaped by affordability, education, and healthcare communication.
Healthcare interaction	Trust, empathy, explanation of treatment	Rushed consultation, limited counseling	Communication quality influenced confidence in treatment use.
Environmental context	Trigger avoidance where feasible	Continued exposure to smoke, dust, biomass fuel, pollutants	Environmental barriers restricted patients' ability to control symptoms.

Overall, the qualitative findings indicate that COPD management was experienced as a negotiated process in which participants continuously balanced symptoms, treatment demands, financial limitations, family dependence, and environmental exposure. The strongest interpretive pattern across interviews was that adherence improved when participants understood their treatment, received practical family support, trusted healthcare providers, and had feasible strategies to manage breathlessness. Conversely, poor explanation, medication cost, emotional distress, and unavoidable environmental triggers weakened treatment continuity and reduced confidence in self-management.

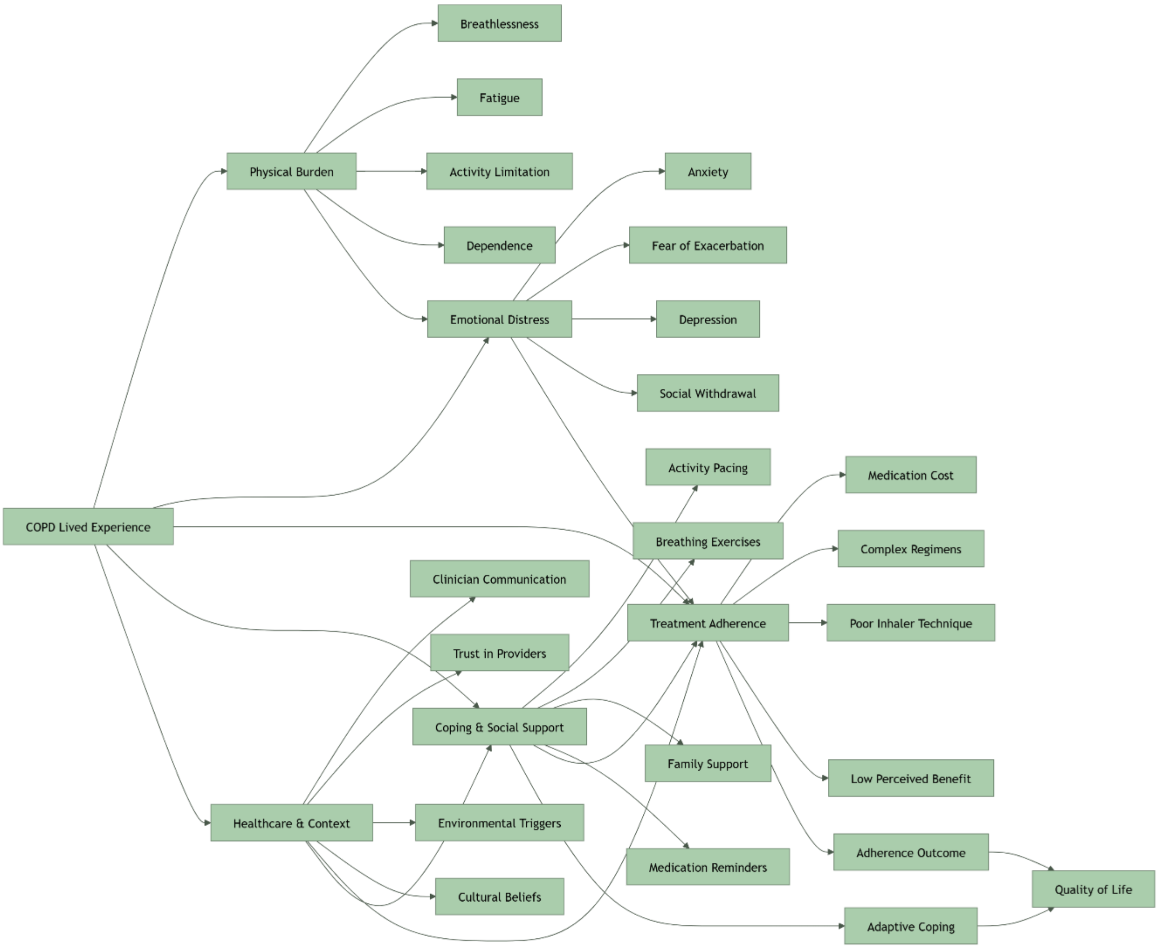

Figure 1 Thematic Flowchart

DISCUSSION

This qualitative phenomenological study explored how adults with COPD experience daily life and treatment adherence within outpatient and community healthcare contexts. The findings show that COPD was experienced not only as a respiratory disorder but as a sustained disruption of physical independence, emotional stability, social participation, and treatment routines. Breathlessness and fatigue were central to participants' accounts, limiting ordinary activities such as walking, climbing stairs, household tasks, and self-care. These findings are consistent with previous qualitative and clinical evidence showing that dyspnea is one of the most disabling symptoms of COPD and often becomes the organizing feature around which patients restructure daily life (3,20).

The emotional burden described by participants further demonstrates the multidimensional nature of COPD. Anxiety, fear of exacerbation, depressive feelings, and uncertainty were closely linked to the unpredictability of breathlessness. Participants did not describe distress as separate from physical symptoms; rather, fear of sudden worsening shaped their mobility, social confidence, and willingness to engage in routine activity. This supports earlier evidence that psychological comorbidity is common in COPD and may influence symptom perception, self-management behavior, and quality of life (6,21). Clinically, these findings suggest that routine COPD care should include psychological screening and supportive counseling, particularly for patients who report fear-driven activity avoidance or social withdrawal.

Treatment adherence emerged as a negotiated process shaped by affordability, health literacy, treatment complexity, inhaler understanding, and healthcare communication. Participants' narratives indicated that missed or reduced medication use was often linked to cost, unclear instructions, or uncertainty about treatment benefit rather than simple refusal to comply. This interpretation aligns with evidence that COPD adherence is influenced by patient-, therapy-, and health-system-related factors (4,5,7,22). The findings reinforce the need for repeated inhaler technique assessment, simplified medication counseling, affordability-sensitive prescribing, and follow-up communication that confirms patients' understanding rather than assuming it.

Coping and social support acted as important facilitators of disease management. Participants described activity pacing, breathing exercises, avoidance of triggers, and family reminders as practical strategies that helped them manage symptoms and maintain treatment routines. Family support was particularly important for medication reminders, assistance with daily tasks, and emotional reassurance. However, dependence on others also carried potential emotional consequences, including reduced autonomy and embarrassment. These findings are consistent with qualitative evidence showing that COPD affects both patients and family caregivers and that supportive relationships can improve coping while also creating new relational burdens (19).

Healthcare communication was a recurring influence across themes. Participants who understood why and how to use inhalers appeared more confident in treatment, while those who received limited explanation described confusion and self-directed trial-and-error. This finding supports the need for patient-centered communication, shared decision-making, and repeated education in COPD care (18,23). In this study, clinician communication was not merely an informational issue; it shaped trust, perceived treatment value, and willingness to sustain long-term therapy.

Environmental and cultural context also influenced COPD management. Participants described smoke, dust, biomass exposure, and household irritants as symptom triggers, but economic limitations often restricted their ability to reduce exposure. Cultural beliefs and stigma also affected openness, help-seeking, and social participation. These findings are especially relevant in low- and middle-income settings, where COPD may be shaped by household air pollution, occupational exposure, limited respiratory services, and social constraints (24,25,33,34). Interventions should therefore be realistic, culturally sensitive, and adapted to patients' living conditions rather than limited to medication advice.

The study's trustworthiness was strengthened through purposive sampling, semi-structured interviews, field notes, verbatim transcription, independent coding, reflexive journaling, audit trail documentation, and member checking. Nevertheless, several limitations should be considered. The sample of 20 participants was appropriate for qualitative inquiry but limits broad transferability. Participants were recruited from healthcare-linked outpatient and community settings, which may have excluded patients with weaker service access or more severe illness. Social desirability may have influenced how participants described treatment use or interactions with healthcare providers. Translation and interpretation may also have affected subtle meanings in participant narratives. Finally, because interviews were conducted at a single point in time, the study could not capture how experiences and adherence behaviors evolve across disease progression.

The findings have several practical implications. COPD care should move beyond prescription-focused management and include structured inhaler education, affordability-sensitive treatment planning, psychological assessment, caregiver-inclusive counseling, environmental risk reduction, and culturally responsive communication. Future research should explore longitudinal patient experiences, include caregiver and healthcare-provider perspectives, and evaluate context-sensitive interventions that combine education, family support, clinician communication, and environmental counseling. Such work may help develop COPD care models that are clinically effective and responsive to patients' lived realities.

CONCLUSION

This qualitative study shows that patients experienced COPD as a complex and continuous disruption of daily life, shaped by breathlessness, fatigue, emotional uncertainty, treatment burden, family support, healthcare communication, and environmental constraints. Adherence was influenced by medication cost, inhaler understanding, treatment complexity, perceived benefit, and clarity of clinician guidance rather than by patient motivation alone. Participants' accounts suggest that holistic COPD care should integrate symptom control, psychological support, repeated inhaler education, caregiver involvement, affordability-sensitive prescribing, and realistic environmental counseling. These findings support patient-centered approaches that align clinical recommendations with the practical, emotional, and social realities of living with COPD.

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