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RESEARCH LETTER
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Living with chronic cough: experiences, burden and management in interstitial lung disease – a mixed methods study

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To the Editor:

Chronic cough (CC), defined as cough lasting for 8 weeks or more, is a prevalent and complex issue in interstitial lung disease (ILD) [1, 2]. Current research relies on quantitative diagnostic tests and patient-reported outcome measures (PROMs) to describe the impact of CC [3], while recent qualitative studies reveal its profound effect on quality of life [4]. These individual approaches, however, are insufficient to grasp the multifaceted nature of CC in ILD.

Combining qualitative and quantitative methodologies within validated frameworks allows for comprehensive understanding of CC in ILD. An integrated approach will facilitate developments of patient-centred treatment strategies, to address the complexities of CC and patient outcomes. Therefore, a mixed methods study is essential. To address this gap, we combined semi-structured interviews with validated PROMs to explore the characteristics, impact and management strategies of CC in people with ILD.

This is a secondary analysis of a study exploring the feasibility of a non-pharmacological cough therapy (Clinicaltrials.gov: NCT04767074). Participants were recruited from pulmonary rehabilitation programmes at West Park Healthcare Center and St. Joseph's Healthcare Hamilton between February 2021 and December 2023 (local ethics boards approved the study, ref. 20-005-WP and HiREB #13017). Participants with diagnosed ILD and cough lasting ⩾8 weeks were eligible. Exclusion criteria included: acute respiratory exacerbation, infection, or medication changes within the past month; use of angiotensin-converting enzyme inhibitors; existing medical conditions preventing exercise training; moderate or large amounts of sputum production (>2 tablespoons), as cough suppression therapy may be contraindicated in these cases [5]. The exclusion criteria and non-pharmacological cough therapy are detailed elsewhere [6].

Out of 29 interested individuals, 14 were ineligible, and four dropped out before the study began, leaving 11 participants included. After receiving consent, participants' sociodemographic and clinical characteristics were extracted from medical charts or self-reported. Participants completed the Cough Hypersensitivity Questionnaire (CHQ) [7] and the Leicester Cough Questionnaire (LCQ) [8]. Semi-structured interviews were conducted *via* Zoom by two researchers (A. Oliveira and A. Newman) not involved in the care of the participants. The interviews followed a guide with open-ended questions about participants' cough and management strategies, informed by previous literature and frameworks and the research team's expertise [9, 10].

Transcription analyses were completed by two researchers (S. Quach and A. Oliveira) using a hybrid thematic analysis combining inductive and deductive coding and theme development [9–11]. Thematic mapping was employed at each stage to track the development and evolution of themes and subthemes throughout the analysis. CHQ and LCQ scores were matched to the most appropriate subthemes to quantitatively characterise participants' experiences.

11 (four females, 37%) participants from West Park Healthcare Center (n=3, 27%) and St. Joseph's Healthcare Hamilton (n=8, 73%) enrolled, with a median (interquartile range) age of 67 (59–68) years.

Shareable abstract (@ERSpublications)
People living with interstitial lung disease and chronic cough have unique experiences in their cough characteristics, triggers, management strategies and overall impact on quality of life https://bit.ly/4e8vNZl

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Participants reported up to 5 years of CC following their diagnosis. Three (27%) never smoked, and the remainder (n=8, 73%) had a smoking history ranging from 2 to 27 years. Three participants (27%) used oxygen therapy (1.5–4 $L \cdot min^{-1}$) at rest and seven (64%) required oxygen therapy during exertion (2–15 $L \cdot min^{-1}$).

Three main themes were identified from the interviews (characteristics, consequences, coping and self-management) with a total of 17 subthemes. Participants' CHQ and LCQ scores were matched to distinguishing quotes from interviews (figure 1).

During the interviews, participants reported their CC to have sudden, random and multiple triggers, including emotions, time of day, season, talking, morning phlegm and oxygen therapy. Hypersensitivity to various triggers was reflected in participants' moderately high CHQ scores (15 (15–18) out of 23). When triggered, cough frequency, fit and duration varied, occurring 2–7 times consecutively and lasting from seconds to minutes or hours. Coughs were sometimes strong and intense, more prominent at certain times of the day and activity dependent, leading to participants' perception of always coughing.

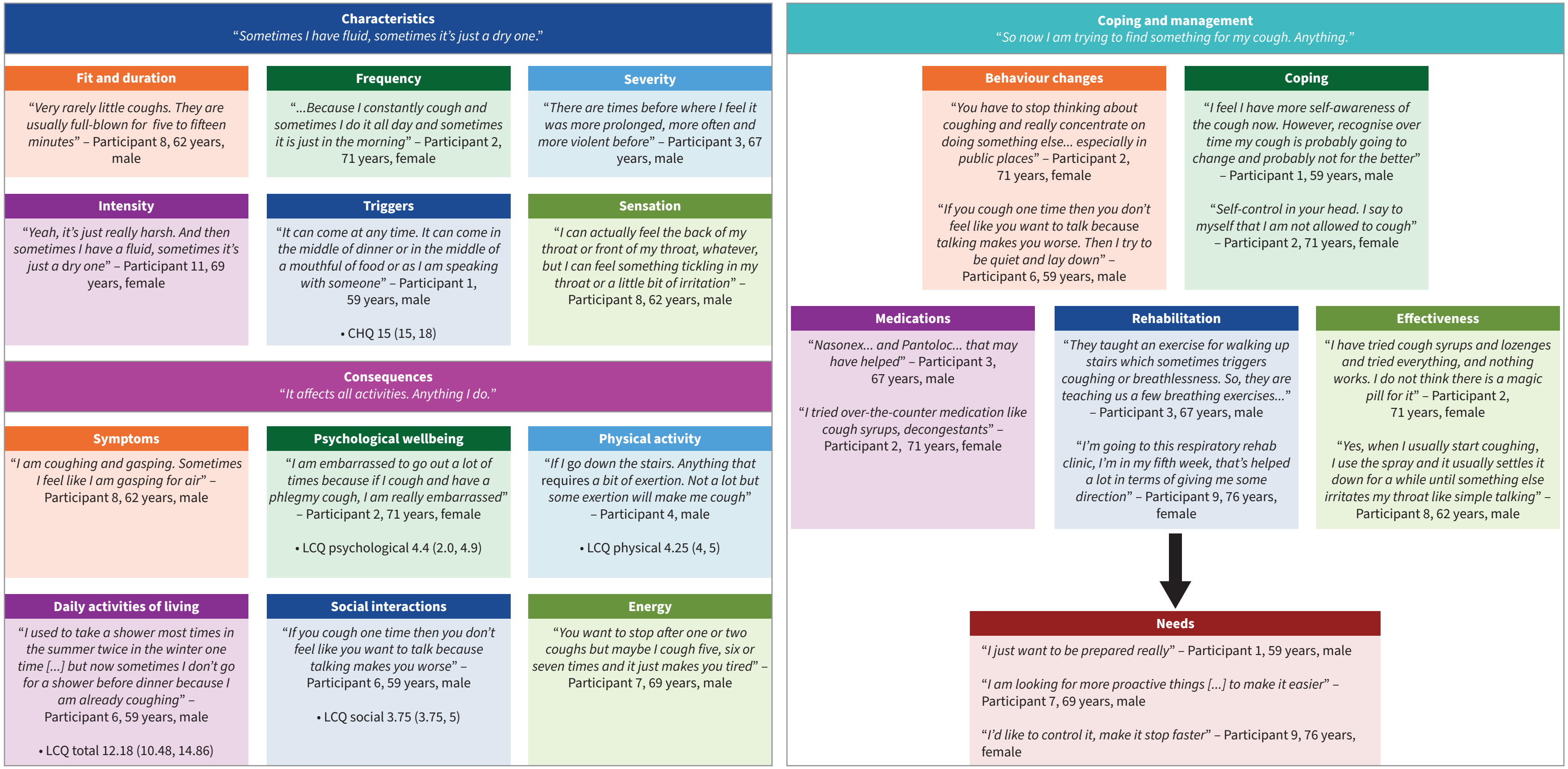
CC consequences varied over time and by day. Participant-reported symptoms from interviews included tachycardia, dyspnoea, voice changes, throat soreness, chest tightness, chest pain and variable sputum production. 10 participants noted their coughs exacerbated dyspnoea and fatigue, impacting their physical capacity (LCQ physical 4.25 (4–5) out of 7). Their CC also caused embarrassment, self-consciousness and anxiety, affecting their psychological well-being (LCQ psychological 4.43 (2.89–4.86) out of 7) and preventing them from engaging in social events (LCQ social 3.75 (3.75–5) out of 7). Overall, participants felt their quality of life was significantly impacted by their cough as reflected in the LCQ total score (12.18 (10.43–14.86) out of 21).

Participants used pharmacological and non-pharmacological methods to manage CC. Pharmacological treatments included over-the-counter and prescribed medications for their underlying diseases, such as antifibrotics, proton pump inhibitors, antitussives and antibiotics. Non-pharmacological techniques included behaviour changes, rehabilitation, coping approaches and lifestyle modifications. Pulmonary rehabilitation helped participants optimise their lifestyle routines by educating them on airway clearance, breathing and energy conservation techniques to help control their cough. Participants were aware of their coughing patterns, with many recognising signs and sensations before they started coughing, allowing them to suppress or induce coughs to address the underlying trigger. The effectiveness of these techniques varied, with participants often trying multiple strategies simultaneously, without professional help. Participants reported their healthcare providers usually described their coughs as uncurable and part of the disease. However, they expressed the need for more information to guide and support them in developing self-management skills.

By matching qualitative and quantitative data, our study highlights unique characteristics of CC in people with ILD not previously reported. Our participants identified oxygen therapy as a cough trigger, contributing to the existing body of knowledge [4]. The drying effect of long-term oxygen therapy, frequently used in individuals with advanced ILD, can cause irritation, inflammation and desiccation of mucous membranes, triggering a cough reflex [12]. This trigger is not considered in commonly used questionnaires like the CHQ.

Reported treatment ineffectiveness may stem from participants' use of self-management techniques without professional guidance. Their cough management needs are often unrecognised by clinicians, prompting them to seek their own information and strategies [13, 14]. However, cough management techniques require professional guidance to ensure appropriateness and proper implementation as techniques should be patient-tailored. The variability in cough characteristics further complicates management, highlighting the need for personalised self-management resources and support [15].

CC significantly burdens people with ILD [2], and our participants reported poorer quality of life compared to those with refractory CC (persisting cough despite targeted treatments) [9, 10], reflected in their lower LCQ scores [9, 16]. This may be due to their CC's unpredictability, variable triggers and ineffective management. We reported quantitative measures (CHQ, LCQ) with matched subthemes to describe our participants' unique experiences objectively. However, these cough-related PROMs were insufficient at providing comprehensive impressions of triggers and management experiences of individuals' ILD and CC. Therefore, validated cough-related PROMs for quality of life, symptoms, psychological well-being, functional status, knowledge and coping mechanisms in people with ILD are needed.



Characteristics
"Sometimes I have fluid, sometimes it's just a dry one."

Fit and duration
"Very rarely little coughs. They are usually full-blown for five to fifteen minutes" – Participant 8, 62 years, male

Frequency
"…Because I constantly cough and sometimes I do it all day and sometimes it is just in the morning" – Participant 2, 71 years, female

Severity
"There are times before where I feel it was more prolonged, more often and more violent before" – Participant 3, 67 years, male

Intensity
"Yeah, it's just really harsh. And then sometimes I have a fluid, sometimes it's just a dry one" – Participant 11, 69 years, female

Triggers
"It can come at any time. It can come in the middle of dinner or in the middle of a mouthful of food or as I am speaking with someone" – Participant 1, 59 years, male

- CHQ 15 (15, 18)

Sensation
"I can actually feel the back of my throat or front of my throat, whatever, but I can feel something tickling in my throat or a little bit of irritation" – Participant 8, 62 years, male

Consequences
"It affects all activities. Anything I do."

Symptoms
"I am coughing and gasping. Sometimes I feel like I am gasping for air" – Participant 8, 62 years, male

Psychological wellbeing
"I am embarrassed to go out a lot of times because if I cough and have a phlegmy cough, I am really embarrassed" – Participant 2, 71 years, female

- LCQ psychological 4.4 (2.0, 4.9)

Physical activity
"If I go down the stairs. Anything that requires a bit of exertion. Not a lot but some exertion will make me cough" – Participant 4, male

- LCQ physical 4.25 (4, 5)

Daily activities of living
"I used to take a shower most times in the summer twice in the winter one time […] but now sometimes I don't go for a shower before dinner because I am already coughing" – Participant 6, 59 years, male

- LCQ total 12.18 (10.48, 14.86)

Social interactions
"If you cough one time then you don't feel like you want to talk because talking makes you worse" – Participant 6, 59 years, male

- LCQ social 3.75 (3.75, 5)

Energy
"You want to stop after one or two coughs but maybe I cough five, six or seven times and it just makes you tired" – Participant 7, 69 years, male

Coping and management
"So now I am trying to find something for my cough. Anything."

Behaviour changes
"You have to stop thinking about coughing and really concentrate on doing something else… especially in public places" – Participant 2, 71 years, female

"If you cough one time then you don't feel like you want to talk because talking makes you worse. Then I try to be quiet and lay down" – Participant 6, 59 years, male

Coping
"I feel I have more self-awareness of the cough now. However, recognise over time my cough is probably going to change and probably not for the better" – Participant 1, 59 years, male

"Self-control in your head. I say to myself that I am not allowed to cough" – Participant 2, 71 years, female

Medications
"Nasonex… and Pantoloc… that may have helped" – Participant 3, 67 years, male

"I tried over-the-counter medication like cough syrups, decongestants" – Participant 2, 71 years, female

Rehabilitation
"They taught an exercise for walking up stairs which sometimes triggers coughing or breathlessness. So, they are teaching us a few breathing exercises…" – Participant 3, 67 years, male

"I'm going to this respiratory rehab clinic, I'm in my fifth week, that's helped a lot in terms of giving me some direction" – Participant 9, 76 years, female

Effectiveness
"I have tried cough syrups and lozenges and tried everything, and nothing works. I do not think there is a magic pill for it" – Participant 2, 71 years, female

"Yes, when I usually start coughing, I use the spray and it usually settles it down for a while until something else irritates my throat like simple talking" – Participant 8, 62 years, male

Needs
"I just want to be prepared really" – Participant 1, 59 years, male

"I am looking for more proactive things […] to make it easier" – Participant 7, 69 years, male

"I'd like to control it, make it stop faster" – Participant 9, 76 years, female

FIGURE 1 Three main themes and 17 subthemes were identified to describe participants' chronic cough. For each subtheme, a participant quote is provided to illustrate their experience. Where appropriate, the Leicester Cough Questionnaire (LCQ) and Cough Hypersensitivity Questionnaire (CHQ) subdomain and total scores were paired with subthemes.

Limitations to our study include a small sample size and participants recruited exclusively from pulmonary rehabilitation programmes, which may introduce bias, as those enrolled in pulmonary rehabilitation may be inherently interested in managing their CC. However, we sampled participants from two regions to reflect diverse ILD subpopulations.

In conclusion, the unpredictability of CC in ILD impacts social interactions, limiting participants' time with others, contributing to poor quality of life. Participants often felt frustrated and embarrassed by their cough, needing better management strategies as current ones are ineffective. Future work must address patients' needs for better support from clinicians, exploring additional management strategies and evaluating their effectiveness.

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