



# Understanding patient experience of chronic cough in interstitial lung disease

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Patients with ILD describe physical symptoms and limitations, and social and emotional difficulties related to chronic cough. The nature and severity of chronic cough experienced by patients with ILD appears to be more heterogeneous than previously thought.

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## Abstract

**Rationale** Chronic cough is a common symptom in patients with interstitial lung disease (ILD), negatively contributing to health-related quality of life. Despite this, there is limited information and understanding on the experience of this group of patients with chronic cough. This study aimed to explore the symptom experiences for chronic cough in patients with ILD to identify its characteristics and impacts.

**Methods** A qualitative study using semi-structured telephone interviews was undertaken in 16 adults with a diagnosis of ILD of any type and severity. Patients were recruited from a quaternary referral centre in Melbourne, Australia. Interviews were transcribed verbatim and coded by two researchers using thematic analysis.

**Results** Patients (age range: 39–87 years, forced vital capacity: 53–107% predicted and diffusing capacity of the lung for carbon monoxide: 28–89% predicted) experienced a spectrum of cough severity and characteristics, including both dry and productive coughs. The impact of chronic cough included physical symptoms, social and emotional difficulties, and interference with work and vocational participation. Management strategies used to relieve cough included mucolytics, opiates, throat lozenges, warm drinks, pacing, breath control, relaxation exercises, movement, continuous positive airways pressure and supplemental oxygen. Patients expressed a need for further information and education regarding chronic cough, including its triggers and management.

**Conclusions** This study highlights the experience and significance of chronic cough in patients with ILD. The nature and severity of chronic cough in patients with ILD appears to be more heterogeneous than previously described, with physical, social and emotional impacts contributing to symptom burden.

## Introduction

Despite advances in disease-targeted therapy, people with interstitial lung disease (ILD) continue to experience a high symptom burden [1] with limited treatment options. Up to 80% of patients with idiopathic pulmonary fibrosis (IPF), the best studied ILD subtype, complain of chronic cough [2]. Cough, along with dyspnoea and depression, is a major contributor to health-related quality of life (HRQoL) among patients with IPF [3] and may independently result in anxiety and depression [4]. Unfortunately, there are few effective, evidence-based therapies for chronic cough in patients with ILD [5]. Reliable and validated measures for cough are essential in evaluating antitussive therapies in future clinical trials. Gaining an in-depth understanding of patients' experience of the cough symptom is an essential initial step in the development and validation of such measurement tools [6, 7]. This study aimed to explore the symptom experience of chronic cough in patients with ILD. This will uncover the unique and important



aspects of chronic cough for people with ILD, which will form the basis for the development of a new ILD-specific patient-reported outcome measure for cough. We further explored patients' perspective on current clinical care for cough management in ILD.

## Methods

A qualitative study using semi-structured telephone interviews was undertaken. The study protocol was approved by the Austin Health Research Ethics Committee (HREC/67030).

### Participants

We recruited patients from the ILD Outpatient Clinic at Austin Health, a quaternary referral centre. Eligible patients were adults ( $\geq 18$  years of age) with a multidisciplinary team diagnosis of ILD of any type and severity with chronic cough ( $\geq 8$  weeks duration [8]). Purposeful sampling was employed to ensure inclusion of patients at different disease stages and demographics. Patients with an acute exacerbation or respiratory tract infection within 4 weeks, or other respiratory conditions (COPD, asthma, eosinophilic bronchitis, bronchiectasis or lung cancer) were also excluded.

### Procedures

Individual semi-structured telephone interviews were conducted by a researcher with training in qualitative study conduct (J.M.V. Mann) using a topic guide conceived from the investigator team's clinical experience (with each having at least 5 years of ILD subspecialty experience) and literature review (table 1). Interviews were audio-recorded and transcribed verbatim. Data analysis was performed concurrently with the interviews to inform subsequent interviews and determine data saturation. Recruitment continued until no new themes emerged. Patient characteristics (age, ILD diagnosis, respiratory function tests, relevant comorbid conditions (including obstructive sleep apnoea, gastro-oesophageal reflux disease, heart failure and arrhythmia, rhinosinusitis [9]) and medication use) were collected.

### Transcript analysis

Interview transcripts were analysed by two researchers (J.M.V. Mann and Y.H. Khor) independently using thematic analysis [10]. Transcripts were read line by line and fragmented into descriptive codes (open coding). Codes were then organised hierarchically to form themes and subthemes. The final themes were agreed through discussion (J.M.V. Mann and Y.H. Khor), with a third researcher (A.E. Holland) being available for arbitration.

## Results

A total of 16 patients were recruited (table 2), eight of whom were male and eight female. 11 patients had IPF, three had hypersensitivity pneumonitis and two had connective tissue disease-associated ILD. Patients' ages ranged from 39 to 87 years, with forced vital capacity of 53–107% predicted and diffusing capacity of the lung for carbon monoxide of 28–89% predicted. Four major themes and two minor themes were identified from the interviews (table 3).

### Major themes

#### Cough characteristics

There was a wide range of descriptions for cough characteristics, including frequency, duration and nature (table 4 and supplementary table S1). Most patients reported the onset of persistent cough preceding their diagnosis of ILD, with progression over time. For many, it was described as a productive cough with excess mucus and the need to clear sputum impacting morning routines and activities. Descriptors of cough severity included its uncontrollable nature, strong or hard cough, and frequent or continuous cough.

**TABLE 1** Interview topic guide questions

- 1) Tell me about your experience of cough?
- 2) How would you describe the cough?
- 3) What would a typical day with cough be like for you?
- 4) Tell me about anything that makes your cough worse?
- 5) Tell me about anything that makes your cough better?  
Prompts – Any treatments? Drugs, oxygen, alternative therapies? If yes: How do you find the treatment?
- 6) How does your cough make you feel?
- 7) Can you tell me about any information you received about managing your cough from your healthcare team?
- 8) Tell me about any information about managing your cough you've obtained from other sources?

TABLE 2 Characteristics of patients with ILD and chronic cough

Participant no.	Sex	Age years	Diagnosis	FVC % pred	$D_{LCO}$ % pred	Antifibrotic therapy	Immunosuppression	Relevant comorbidities	Cough severity VAS <sup>#</sup>
1	M	72	HP	63	42	No	Yes	-	52
2	M	71	IPF	64	44	P	No	-	49
3	M	73	IPF	53	31	N	No	OSA	90
4	F	87	IPF	107	48	P	No	-	-
5	M	79	IPF	75	35	No	No	OSA	79
6	F	76	HP	101	89	No	No	OSA	76
7	M	71	CTD-ILD	79	57	No	Yes	-	49
8	F	74	CTD-ILD	82	47	No	Yes	-	80
9	F	68	IPF	86	70	P	No	GORD	78
10	M	66	IPF	93	53	N	No	-	99
11	F	39	HP	60	40	N	Yes	-	40
12	M	65	IPF	54	54	N	No	-	72
13	M	68	IPF	60	28	P	No	GORD, allergic rhinitis	25
14	F	83	IPF	65	62	P	No	GORD	52
15	F	71	IPF	83	44	P	No	OSA	36
16	F	54	IPF	54	48	P	No	-	60

ILD: interstitial lung disease; FVC: forced vital capacity;  $D_{LCO}$ : diffusing capacity of the lung for carbon monoxide; VAS: Visual Analogue Scale; M: male; F: female; HP: hypersensitivity pneumonitis; IPF: idiopathic pulmonary fibrosis; P: pirfenidone; N: nintedanib; OSA: obstructive sleep apnoea; CTD-ILD: connective tissue disease-associated ILD; GORD: gastro-oesophageal reflux disease. #: cough severity VAS records patient's assessment of cough severity on a 100-mm linear scale from "no cough" (0 mm) to "worst cough ever" (100 mm).

### Triggers for cough

Potential triggers for cough were numerous, including aerosol exposure, smells and fragrances, lower respiratory tract infection, temperature and humidity changes, poor air quality, windy weather, certain foods, talking and laughing, and breathlessness.

P7: It depends on the weather. Whether it's windy or not.

P6: Or eating...I've noticed that at times I've got quite a cough where I've had to get up and leave the table...

P1: Speaking a lot because I guess I'm breathing much more, more frequently...Perhaps deeper.

P5: It begins with breathlessness and then develops into the coughing.

Physical activities that triggered cough included movement at the beginning of the day, household chores, showering and lifting heavy objects.

TABLE 3 Emergent themes from interviews with patients with interstitial lung disease and chronic cough

### Major themes

#### Cough characteristics

##### Triggers for cough

- triggers, comorbidities contributing to cough, throat symptoms

##### Cough impacts

- physical symptoms, fear or interruption of public engagement, self-consciousness, loss of hobby or responsibility, comfort with those close

##### Educational needs and management

- eager for more knowledge, personalised treatment, difficulties with sourcing online information, limited information about cough management from healthcare providers, multiple interventions with limited effects, opiate is effective for managing cough, pacing

### Minor themes

#### Cough interpretation

Impacts of the COVID-19 pandemic

TABLE 4 Cough characteristics

**Participant quotes**

P14: ...my cough has got worse as time has gone on...and it's getting to the stage where I can't control it.

P2: ...sometimes it's not too bad and other times it can be quite...you know...debilitating.

P3: I have a lot of mucus and sputum and every time I cough up, I cough up the sputum.

P2: ...continuous coughing...it's spasms of coughing where you cough and a bit of a break...cough...bit of a break...and sort of just goes on like that maybe 20 min an hour.

P1: Well, it will tend to make me croaky (clears throat)...So I'm constantly clearing my throat. It can make me just (pause) degenerate into a cough.

P9: I mowed my lawns on Tuesday and I coughed...the minute I started pushing the mower I coughed.

Patients recognised comorbidities contributing to cough and relevant comorbidities mentioned included obstructive sleep apnoea, cardiac arrhythmia, sinus congestion and allergic rhinosinusitis.

*Cough impacts*

Not surprisingly, impacts of the cough symptom on patients' daily living varied widely, which fell into two broad categories including physical symptoms and limitations, and social and emotional difficulties.

*Physical symptoms and limitations*

Patients associated their cough with several physical symptoms including wheeze, sneezing, weight loss, fatigue and dry retching. Fatigue was most commonly reported.

P11: You might cough until you vomit and that's a common thing.

P7: ...it wears you out sometimes if you cough a lot. It makes you tired.

Patients also reported that cough and breathlessness often occurred together.

P2: The breathless cough...it sort of builds up and builds up and builds up until you think you've gotta stop because otherwise you just can't breathe.

Pain or discomfort associated with cough was rarely mentioned. Most patients described in some detail how their body position affected cough. Supine position and bending over were frequent triggers for cough and sitting up was used to relieve the symptom. Despite a minority of patients describing nocturnal cough, it was reported to affect sleep in approximately half of the patients, who were also concerned about its impact on their partners' and close relatives' sleep quality.

P5: When I lay awake all night coughing...which doesn't do my wife much good...

*Social and emotional difficulties*

Chronic cough significantly restricted public engagement and social participation, with many patients feeling self-conscious and having the fear of uncontrollable coughing fit in public. Some patients reflected on the inability to participate in a hobby, carry out public speaking, or be exposed to cold weather with a preference for quiet, seated activities.

P9: to tell you the truth I probably didn't go out so much because of the fact I knew I was going to cough...different occasions I stopped going because I coughed too much... And I felt bad sitting at the table...even before COVID...

P1: it's kind of important work (volunteer firefighting), so I think if I can't do it properly I'll (stop) ...that's probably a major impact on my life is not being able to do that.

Patients described feeling withdrawn or embarrassed by cough, with some reporting that they would try to cover their cough up as a sneeze.

P7: I think it's more embarrassing than anything else. That draws my attention to it because it's annoying and embarrassing at times.

They also adapted their lifestyle to fit in with their cough.

P4: I sit very still, under a blanket, doing crosswords and wordfinders. Most of the day...that is my entertainment.

Most older patients with more severe ILD had to rearrange their daily activities to accommodate cough. The morning routine involved clearing sputum and breathing techniques to settle cough after showering and dressing, which could take up to an hour. For patients in full-time work, the impact of cough was less, with stoicism and a sense of "getting on with things" predominating.

P17: ...I always seemed to deal with it and it never really became a feature of anything I did.

Some interference with personal relationships was commonly reported, but overall most felt comfortable around close family and friends. Negative emotions associated with cough included annoyance, frustration and a feeling of aggravation.

P14: It's hard to control...it's a bit stressful...we are [I am] trying so hard to control it...

#### *Educational needs and management*

##### *Educational needs*

An eagerness for more knowledge on the triggers for cough, as well as how to control cough, were expressed by the majority of patients.

P2: if we could find out what was actually causing the cough...I mean the trigger for it.

P10: I probably should be asking for some pointers on controlling the cough better. I should probably talk to (specialist ILD nurse) about that.

Patients were generally aware of the individualised experience of the cough symptom with a need for a personalised treatment approach.

P2: ...I don't think one size fits all to be honest.

Few patients had accessed information on managing cough from online or other sources including their general practitioner and specialist. Difficulties accessing online information included avoidance of forums due to their depressing and negative content and the lack of ILD-specific information on cough.

P11: It's hard to relate because a lot of it is COPD. And that makes me angry.

P13: I've looked on groups, forums and all that sort of stuff. I haven't found anything either to suppress a cough, get rid of cough.

P7: I don't really recall getting much stuff on cough specifically (from the treating physician). More treatments for the inflammation which I guess cough is the result of that.

##### *Management*

Self-management strategies varied and included mucolytics, throat lozenges, warm drinks, pacing, breath control, relaxation exercises, movement, continuous positive airways pressure and supplemental oxygen.

P11: I just try and slow myself down and just breathe and take a breath. I think breathing exercises in a sense is really important.

P15: I'm learning to pace myself. Just do things a bit slower. So that I don't stress myself out.

Some reported that participation in a pulmonary rehabilitation programme had improved their cough in addition to breathlessness.

P15: ...the whole exercise program, along with the breathing that they showed us to do to open up your chest and airways. That must help with my coughing. It must open things up somehow.

Many had tried over-the-counter cough suppressants or inhaler therapies but found these unhelpful. Opiates were found to be effective and were frequently trialled.

P9: ...the codeine mixture and it was probably the first time in about 6 months that I hadn't coughed.

P7: I was having a cough mixture called Rikodeine...That is really good and if we are going out for a special occasion I will have a dose of cough mixture...you have to have a prescription but I find it works well.

Despite the benefits of opiates, patients reported that they did not like to use it or rationed its use to important occupational or social situations.

P11: I only reserve that stuff (Codeine Linctus) for work so that I don't get looked at strangely.

P9: I don't want to be dependent on it (Codeine Linctus).

Overall patients described trials of multiple treatments with limited effects.

P13: My recollection is that everything works the first time you try it but then the disease overcomes the medication. Because it gets used to it.

Many were left with passive management strategies.

P1: How do I treat it? Most probably just by waiting until it stops.

### *Minor themes*

#### *Cough interpretation*

Cough was described as a reminder of their own disease; however it was generally accepted as a symptom of ILD.

P2: it's just something we've gotta live with.

Many of those experiencing cough compared their symptoms to those they knew with other respiratory conditions. A few associated their cough with lung damage and declining physiological function.

P1: I wonder whether also...how much is to do with damage to my lungs.

P12: But sometimes the...it feels the lung capacity is reduced, I'm tending to cough...my blood oxygen level is probably lower than it normally would be because I do shallow breathing.

One participant described the fear of cough as an end-of-life symptom.

P1: I don't fear death but I do fear how I might die.

#### *Impacts of the COVID-19 pandemic*

The impacts of the COVID-19 pandemic on the cough symptom were mixed (table 5). Some found that using a protective face mask during the COVID-19 pandemic triggered cough. Overall, patients felt the stigma of coughing during the pandemic, which was associated with anxiety and self-consciousness. For others, the social isolation imposed by the COVID-19 pandemic reduced triggers for cough.

TABLE 5 Impacts of the COVID-19 pandemic

**Participant quotes**

P9: ...when I put a mask on the minute I walk into a shop, I start to cough which makes the whole store jump to the side...thinking it's COVID. And I think I keep explaining to others I've got a lung problem...it's not COVID.

P14: ...it's a matter of people...what notice...with the COVID-19...I've got my mask on but people think "oh god".

P2: ...stay in my own home...I'm not out wandering around...or walking or talking in groups of people.

**Discussion**

Our qualitative study on the experience of chronic cough in patients with ILD identified four major themes related to cough characteristics: triggers for cough, cough impacts, and educational needs and management, with two minor themes on cough interpretation and impacts of the COVID-19 pandemic.

In contrast to the common perception that cough due to ILD is non-productive [2, 11], the description of cough in our patients was variable. A surprising number of patients described productive cough, with sputum clearance occupying time and energy and impacting negatively on their HRQoL. As people with other co-existing respiratory diseases were excluded from this study, this may represent interindividual variation or the impact of other comorbidities on sputum production. In fact, many patients were aware of the contribution of relevant comorbid conditions to their cough. While most patients experienced cough predominantly during the day, some reported nocturnal symptoms, and these voiced concern about the impact on their loved ones' sleep quality. Triggers for cough were diverse, and appeared to be relatively innocuous. Together with the commonly reported associated throat symptoms, these suggest an element of cough hypersensitivity [8] in these patients.

There are few reports in the literature assessing the impact and lived experience of chronic cough in people with ILD. The American Food and Drug Administration's Patient-focused Drug Development Initiative released a series of reports titled "The Voice of the Patient" in 2015 [12]. In facilitated discussion, participants described the inability to control coughing, often leading to episodes of shortness of breath, hypoxia or exhaustion. Triggers identified included physical activity, weather-related issues and speaking, all of which we have identified. Our in-depth one-on-one interviews and sampling of other ILD subtypes revealed additional aspects and impacts of cough including sputum production, triggers (lower respiratory tract infections, certain foods, stress and lifting heavy objects), physical symptoms (wheeze, sneezing, weight loss, dry retching) and impacts on work and vocational participation, social relationships and associated negative emotions.

The evidence supporting the management of chronic cough in ILD is limited [5]. Current guidelines recommend assessment for disease progression and complications of immunosuppressive therapy [5], with evaluation and management for other contributing factors according to general chronic cough guidelines [8]. The use of opiates for symptom control in the palliative care setting where other treatments have failed is recommended [5]. Among our patients, there was a strong theme of self-management, with many having tried several strategies and treatments for cough that were generally ineffective. This reflects the experience of many patients with chronic or refractory cough in general [13–15]. It was perceived that treatments were impractical or caused unwanted side effects. Although patients frequently described opiate-based linctus as effective, its use was limited by restrictions on driving, sedation and the small amount supplied on prescription resulting in rationing for emergencies or planned activities.

Patients with ILD and their caregivers have previously identified cough as a priority symptom [16] and have made it clear that they want to be educated about cough, even in the absence of evidence-based therapies [17]. In our study, patients commonly reported that management of cough was rarely discussed during the physician consultation. It is unclear whether the reluctance by physicians to discuss the symptom of cough is due to competing priorities and time pressure in the clinical consultation or a reflection of a lack of confidence and education in the assessment and management of cough due to the paucity of evidence in this area. There is a clear need for the development of effective antitussive medications and supportive therapies in ILD.

In order to assess the effectiveness of treatments for chronic cough in ILD in clinical trials, validated cough outcome measures, such as objective cough monitoring and cough quality of life questionnaires, should be used. Recommended patient-reported outcome measures for cough in current guidelines [5]

include the Leicester Cough Questionnaire (LCQ) [18] and the Cough Quality of Life Questionnaire (CQLQ) [19]. However, these measures were developed in patients with non-ILD chronic cough, and their development was not informed by qualitative data obtained from patients with ILD at inception. While they cover some of the characteristics and impacts that have emerged in this study, they do not capture all ILD-specific aspects of chronic cough, particularly related to disease progression and treatments. For instance, an item in the LCQ asks whether “cough may indicate a severe illness” and in the CQLQ “I am concerned that I have cancer because of my cough”, which focuses on the evaluation in patients without a clear diagnosis that can be attributed for their cough and are of less relevance for patients with ILD. Items asking patients whether they associate cough with concerns of ILD progression or exacerbation and their experience of breathlessness related to cough may be more relevant. Similarly, the King’s Brief Interstitial Lung Disease Questionnaire [20], a HRQoL questionnaire that is commonly used in clinical trials, only provides a brief assessment of chest symptoms such as tightness and wheeze and does not adequately cover the aspects of cough highlighted by patients in this study.

Themes related to cough characteristics and impacts on quality of life identified from this study will be useful in the future development of an ILD-specific cough questionnaire. A recently published conceptual framework for the development of cough symptom severity in patients with refractory or unexplained chronic cough identified two broad domains: urge to cough sensations (frequency and intensity) and cough symptom (triggers, control, frequency, fit/bout duration, intensity, quality, associated features) [21]. Differences in the associated features described by patients with ILD compared to those with refractory or unexplained cough include significant breathlessness and fatigue predominating, while pain and dizziness were not a feature of our interviews. In this study patients also clearly described the impacts on social and emotional function, as well as their connotation of increased cough severity with worsening of disease and lung function. Additional themes on educational needs and self-management as well as impacts of the COVID-19 pandemic in our interviews highlight patient needs and support future research to advance management of chronic cough in ILD.

The strengths of this study are the in-depth exploration of different aspects of chronic cough with ILD encompassing its nature, impacts and management in ILD. While qualitative interviewing has been undertaken previously in patients with ILD to assess their HRQoL, none has directly focused on the cough symptom. Limitations include recruitment from a single centre and sampling of three subtypes of ILD. Purposeful sampling may introduce observer bias. However, it was necessary to ensure good representation with inclusion of patients with common ILD subtypes and disease severities from different demographic backgrounds. All patients were English-speaking, reducing the generalisability to patients with ILD from non-English-speaking backgrounds. We conducted telephone interviews due to the restrictions of the COVID-19 pandemic. While this increased the geographical variation, it may have limited the non-verbal information we could gather. The perspectives of carers and family members were not formally captured in this study, although carers were present in some interviews providing little direct information.

### Conclusion

The nature and severity of chronic cough experienced by patients with ILD appear to be more heterogeneous than previously thought. Patients experience a significant burden related to chronic cough, with impacts on work and vocational participation, social relationships and emotions. Overall, patients find limited effects on cough with prescribed treatments, and restrict their use due to side effects. Self-management strategies employed for cough included mucolytics, throat lozenges, warm drinks, pacing, breath control, relaxation exercises, movement, continuous positive airways pressure and supplemental oxygen. This study advances our understanding on the important aspects of cough and its nature, impacts and management in ILD.

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