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SUPPLEMENTARY MATERIAL

Beyond breathlessness: unveiling chronic cough in interstitial lung diseases. A pilot Portuguese cohort

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Supplementary Material A
Additional details on study methodology.

Data collection was carried out by completing two online surveys, one for people with ILD and one for healthcare professionals.

Healthcare professionals who, at the time of completing the survey, were professionally exercising the skills of a healthcare professional (for example, physician, nurse, physiotherapist, speech therapist, psychologist) with direct contact with patients with ILD, were included. Healthcare professionals who were not working in Portugal at the time of data collection were excluded. People with ILD were included if aged 18 years or over, fluent in Portuguese and had a diagnosis of an ILD by a pulmonologist. Individuals not currently living or being monitored in Portugal for their ILD, with a history of acute cardiac/respiratory conditions in the last month and presenting ILD-related medication changes in the last month were excluded from responding to the survey.

Participants were recruited through the dissemination of the survey by 65 scientific and patients' societies, public hospitals, private sector institutions with medical consultation for ILD and local health units (Table 1). These online surveys were distributed on a large scale, without any randomization procedure.

The surveys were built and disseminated through the LimeSurvey platform and they could be completed on any device with internet access. The surveys were open for completion for three months and six reminder emails were sent (once every two weeks) to the institutional emails of the institution's representatives.

Each participant's anonymity was ensured by not using URLs, storage of internet protocol addresses nor requesting participants to register their identities, contact or email. Cookies were used to avoid the survey being taken more than once from the same person (i.e., participants were not allowed to respond more than once from a single internet protocol address), thus avoiding participants' "multiple participation" in the LimeSurvey platform. In both surveys, there were direct questions (e.g., "Which of the following ILD have you been diagnosed with?" or "What is your current occupation (select the option that applies)?") to confirm the inclusion/exclusion criteria (e.g., that the participant was an individual with ILD or a healthcare professional who deals with this population). In addition, the first page of both surveys contained the informed consent, as well as some relevant information about the study.

Table 1: List of institutions contacted for the dissemination of the study

1. Senhora da Oliveira Hospital (Guimarães)¶	40. Santo Espírito Hospital (Terceira Island)¶
2. HC Trás-os-Montes e Alto Douro¶	41. HC Funchal ¶
3. HC Vila Nova de Gaia/Espinho ¶	42. Portuguese Association of Physiotherapists (APFISIO) – Cardiorespiratory Physiotherapy Interest Group¶
4. HC São João¶	43. Portuguese Society of Pulmonology¶
5. HC Baixo Vouga¶	44. Portuguese Society of Speech Therapy (SPTF)¶
6. ULS Guarda¶	45. Portuguese Association of General and Family Medicine (GRESP)¶
7. HC Universitário de Coimbra ¶	46. Portuguese Association of Nurses¶
8. HC Oeste ¶	47. Portuguese Association of Occupational Therapists (APTO)¶
9. Loures Hospital¶	48. Portuguese Association of Psychology¶
10. Fernando da Fonseca Hospital¶	49. Order of Physiotherapists¶
11. HC Lisboa Ocidental¶	50. Order of Physicians¶
12. HC Lisboa Central¶	51. Order of Nurses¶
13. HC Lisboa Norte¶	52. Order of Psychologists¶
14. HC Universitário do Algarve ¶	53. Portuguese Association of Cardiopneumologists (APTEC)¶
15. HC Médio Ave¶	54. Order of Pharmacists¶
16. HC Entre Douro e Vouga¶	55. Portuguese Society of Rheumatology¶
17. HC Póvoa Varzim/Vila do Conde ¶	56. Portuguese Association of People with COPD and Other Chronic Respiratory Diseases (RESPIRA)¶
18. HC do Tâmega e Sousa¶	57. Portuguese Lung Foundation¶
19. Santa Maria Maior Hospital¶	58. R.D Portugal – Union of Rare Disease Associations of Portugal¶
20. LUH Alto Minho¶	59. Association of Exceptionally Rare Syndromes of Portugal (SER - Sarcoidosis is represented by this association)¶
21. LUH Matosinhos ¶	60. Raríssimas¶
22. LUH Nordeste ¶	61. Portuguese League Against Rheumatic Diseases¶
23. Braga Hospital¶	62. National Association of Patients with Rheumatoid Arthritis (ANDAR)¶
24. HC Porto¶	63. Lupus Patients Association¶
25. HC Cova da Beira¶	64. Portuguese Association of Patients with Scleroderma¶
26. HC Leiria¶	65. Lung Transplant Patients Association¤
27. District Hospital Figueira da Foz¶	
28. LUH Castelo Branco¶	
29. HC Tondela-Viseu ¶	
30. HC Barreiro/Montijo ¶	
31. HC Médio Tejo¶	
32. HC Setúbal¶	
33. Cascais Hospital¶	
34. Vila Franca de Xira Hospital¶	
35. District Hospital Santarém¶	
36. Garcia de Orta Hospital¶	
37. LUH Baixo Alentejo ¶	
38. LUH Norte Alentejano¶	
39. Espírito Santo Hospital (Évora)¤	

Legend: HC-Hospital Center; LUH- Local Unit Health.

Supplementary Material B
Sociodemographic and clinical characteristics of individuals with interstitial lung disease and healthcare professionals participating in the study.

Table 1. Variables analyzed from the survey addressed to people with interstitial lung disease.

Sociodemographic characteristics	
ILD type (n=52)	
Connective Tissue Diseases - ILD	13 (25.0%)
Sarcoidosis	11(21.2%)
Don't know the name of the ILD	11 (21.2%)
Idiopathic Pulmonary Fibrosis	9 (17.3%)
Others ILD	8 (15.4%)
Age (n=51)	64.3 (±13.5)
Gender (n=52)	
Feminine	30 (57.7%)
Masculine	22 (42.3%)
Marital status (n=52)	
Married	37 (71.2%)
Single	6 (11.5%)
Divorced	4 (7.7%)
Non-marital partnership	4 (7.7%)
Widowed	1 (1.9%)
Residence district (n=51)	
Aveiro	27 (52.9%)
Coimbra	6 (11.8%)
Porto	5 (9.8%)
Viseu	3 (5.9%)
Lisbon	2 (3.9%)
Leiria	2(3.9%)
Guarda	2(3.9%)
Braga	1 (2.0%)
Castelo branco	1(2.0%)
Portalegre	1(2.0%)
Setúbal	1(2.0%)
Academic qualifications (n=52)	
Less than 4 years of schooling	4 (7.7%)
4 years of schooling	19 (36.5%)
6 years of schooling	5 (9.6%)
9 years of schooling	1 (1.9%)
12th grade (High school)	9 (17.3%)
University education	14 (26.9%)
Employment status (n=52)	
Employee	12 (23.1%)
Unemployed	2 (3.8%)
Sick leave	2 (3.8%)
Retired	36 (69.2%)
Profession/economic sector (n=51)	
Primary sector	4 (7.8%)
Secondary sector	20 (39.2%)
Tertiary sector	27 (52,9%)
Risk Factors and health-related characteristics	
BMI (n=49), Kg/m^2	26.8 (±4.36)
Hospitalizations in the last year (n=49)	
No hospitalization	37 (75.5%)
1 hospitalization	11 (22.4%)

2 hospitalizations	1 (2.0%)
mMRC (n=49), points	2 (2-3)
Use of O_2 at rest (n=49)	4 (8.2%)
Use of NIV (n=49)	7 (14.3%)
Smoking habits (n=49)	
Smoker	1 (2.1%)
Ex-smoker	23 (46.9%)
Non-smokers	25 (51.0%)
Smoking burden(n=23), packs per year	12.0 (5.0-43.0)
Chronic cough evaluation	
Opinion related to "Cough is an important symptom and should be evaluated by a healthcare professional." (n=48)	
I totally disagree	0 (0.0%)
I disagree	1 (2.1%)
I neither disagree nor agree	4 (8.3%)
I agree	29 (60.4%)
I totally agree	14 (29.2%)
Have chronic cough in ILD (n=48)	21 (43.8%)
Have chronic cough in ILD per subcategories of ILD	
Connective Tissue Diseases - ILD (n=12)	7 (58.3%)
Don't know the name of the ILD (n=10)	5 (50.0%)
Idiopathic Pulmonary Fibrosis (n=9)	4 (44.4%)
Other ILD (n=8)	4 (50.0%)
Sarcoidosis (n=9)	1 (11.1%)
Duration of chronic cough (n=21), years	2.0 (0.5-6.0)
Spoke with healthcare professionals (n=21)	
Yes	19 (90.5%)
No	2 (9.5%)
Type of chronic cough (n=21)	
Dry cough	9 (42.9%)
Cough with phlegm	8 (38.1%)
Other type of cough	4 (19.0%)
Factors that aggravate chronic cough (n=21)	
Smoke	12 (57.1%)
Smells/perfume/fragrances	10 (47.6%)
To speak	10 (47.6%)
Cold/dry air	10 (47.6%)
Perform exercise	9 (42.9%)
Throat irritation	8 (38.1%)
To laugh	7 (33.3%)
Another factor	7 (33.3%)
Eat	6 (28.6%)
Symptoms associated with chronic cough (n= 21)	
Sputum	16 (76.2%)
"Kittens" on the chest	13 (61.9%)
Hoarseness	12 (57.1%)
Shortness of breath	11 (52.4%)
Fatigue	11 (52.4%)
Chest pain	10 (47.6%)
Throat irritation/itching	9 (42.9%)
Sleep disorders	5 (23.8%)
Vomiting	5 (23.8%)
Urinary incontinence	4 (19.0%)
Anxiety	3 (14.3%)
Other	2 (9.5%)
Syncope	1 (4.8%)
No symptoms are associated with the cough	1 (4.8%)

Impacts of chronic cough (n=20)	
The cough decreases my quality of life	11 (55.0%)
The cough limits my ability to perform ADL	10 (50.0%)
The cough has economic impacts on my life	6 (30.0%)
The cough limits my social activities (e.g., parties, get-togethers…)	6 (30.0%)
The cough decreases my ability to work	5 (25.0%)
The cough limits my family/relational activities	5 (25.0%)
The cough has no impact on my life	3 (15.0%)
Impacts of chronic cough on ADL (n=20)	
Socialization/conviviality activities	14 (70.0%)
Housework	9 (45.0%)
Wear; to have a bath; eat; do personal hygiene	7 (35.0%)
Getting up/laying out of bed; getting up/laying down from a chair; walk indoors or outdoors	6 (30.0%)
Outdoor recreational activities	6 (30.0%)
Going shopping; manage finances; use means of transport	4 (20.0%)
Work activity	3 (15.0%)
Cough has no impact on ADL	3 (15.0%)
Recreational activities	2 (10.0%)
Other Impact on ADL	1 (5.0%)
Chronic cough management	
Performs treatment for chronic cough (n=21)	17 (81.0%)
Performs treatment for chronic cough indicated by a healthcare professional (n=17)	12 (70.6%)
Treatments for chronic cough (n=12)	
Pharmacological treatment	11 (91.7%)
Strategies to reduce/control the presence of cough	5 (41.7%)
Breathing exercises	2 (16.7%)
Physiotherapy	2 (16.7%)
Speech therapy	1 (8.3%)
Performs treatment for chronic cough not indicated by a health professional (i.e. eat candies, eat honey; drink lemon tea; natural syrup) (n=17)	8 (47.1%)

Legend: ILD-Interstitial Lung Diseases; BMI- body mass index; mMRC- modified Medical Research Council dyspnea scale; O_2-oxigen; NIV- Non-invasive ventilation; ADL- activities of daily living. Mean and standard deviation were used for continuous numerical variables that followed a normal distribution, median and interquartile range (IQR) were used for non-normally distributed variables. Categorical variables were presented as absolute and relative frequencies.

Table 2. Variables analyzed from the survey addressed to healthcare professionals.

Sociodemographic characteristics	
Age (n=68)	38.0 (33.0-47.0)
Gender (n=69)	
Feminine	47 (68.1%)
Masculine	22 (31.9%)
Number of years working with ILD (n=68)	5.5 (4.0-13.8)
Professional activity (n=69)	
Pulmonologist	38 (55.1%)
Physiotherapist	12 (17.4%)
Rheumatologist	9 (13.1%)
Other healthcare professional	4 (5.8%)
Family or General doctor	3 (4.3%)
Nurse	3 (4.3%)
Academic qualifications (n=69)	
Master's degree	36 (52.2%)
Graduation	26 (37.7%)
Doctorate	5 (7.2%)
Bachelor's degree	1 (1.4%)

Postgraduate	1 (1.4%)
Number of years as healthcare professional (n=69)	13.0 (7.5-23.0)
Number of years working with ILD (n=68)	5.5 (4.0-13.8)
Workplace with people with ILD (n=69)	
Hospital	56 (81.2%)
Primary care	4 (5.8%)
Research	4 (5.8%)
Pulmonary Rehabilitation	3 (4.3%)
Private Practice	2 (2.9%)
Work district (n=69)	
Lisbon	16 (23.2%)
Coimbra	15 (21.7%)
Porto	13 (18.8%)
Aveiro	11 (15.9%)
Castelo Branco	3 (4.3%)
Leiria	2 (2.9%)
Setúbal	2 (2.9%)
Vila Real	2 (2.9%)
Viana do Castelo	1 (1.4%)
Bragança	1 (1.4%)
Viseu	1 (1.4%)
Guarda	1 (1.4%)
Azores	1 (1.4%)
% of ILD monitored per week (n=63)	
Hypersensitivity pneumonitis	20.0 (5.0-30.0)
Sarcoidosis	17.0 (5.0-25.0)
Idiopathic Pulmonary Fibrosis	15.0 (5.0-20.0)
Connective Tissue Diseases - ILD	15.0 (9.0-30.0)
Idiopathic interstitial pneumonia	5.0 (0.0-10.0)
Occupational exposure- ILD	4.0 (0.0-10.0)
Other ILD	2 (0.0-9.0)
Chronic cough characteristics	
% Chronic cough in people with ILD (n=50)	52.1 (±25.7)
% Chronic cough per ILD subtypes (n=50)	
Idiopathic Pulmonary Fibrosis	48 (84.0%)
Hypersensitivity pneumonitis	40 (80.0%)
Connective Tissue Diseases - ILD	35 (70.0%)
Sarcoidosis	28 (56.0%)
Occupational exposure- ILD	26 (52.0%)
Idiopathic interstitial pneumonia	23 (46.0%)
Other ILD	3 (6.0%)
Ranked 1st for the most prevalence of chronic cough (n=33)	
Idiopathic Pulmonary Fibrosis	22 (66.7%)
Connective Tissue Diseases - ILD	4 (12.1%)
Occupational exposure- ILD	3 (9.1%)
Sarcoidosis	2 (6.1%)
Hypersensitivity pneumonitis	1 (3.0%)
Idiopathic interstitial pneumonia	1 (3.0%)
Other ILD	0 (0.0%)
Knowledge duration of chronic cough in ILD (n=51)	
I don't know this information	36 (70.6%)
I know the duration of the chronic cough	15 (29.4%)
Number of years of chronic cough (n=15)	2.0 (2.0-3.0)
Type of chronic cough chronic cough (n=50)	
% Dry cough	80.0 (68.0-86.3)
% Cough with phlegm	20.0 (10.0-30.3)
Factors that aggravate chronic cough (n=49)	
Smoke	40 (81.6%)

Exercise	39 (79.6%)
Cold/dry air	37 (75.5%)
Throat irritation	31 (63.3%)
Smells/perfume/fragrances	25 (51.0%)
Speaking	22 (44.9%)
Laughing	17 (34.7%)
Eating	13 (26.5%)
No factor	7 (14.3%)
Other	4 (8.2%)
Symptoms associated with chronic cough (n=49)	
Fatigue	36 (73.5%)
Shortness of breath	35 (71.4%)
Throat irritation/itching	24 (49.0%)
Anxiety	24 (49.0%)
Sleep disorders	23 (46.9%)
Chest pain	22 (44.9%)
Sputum	21 (42.9%)
"Kittens" on the chest	20 (40.8%)
Hoarseness	18 (36.7%)
Urinary incontinence	18 (36.7%)
Depression	15 (30.6%)
Vomiting	12 (24.5%)
Syncope	7 (14.3%)
No symptoms are associated with the cough	4 (8.2%)
Impacts of chronic cough on ILD (n=48)	
Decreased quality of life	47 (97.9%)
Impact/decrease in terms of social activities	37 (77.1%)
Decreased/limited ability to perform ADL	33 (68.8%)
Decreased capacity for work activities	26 (54.2%)
Decrease in family/relational activities	23 (47.9%)
Economic impacts	9 (18.8%)
No impact on person's life	1 (2.1%)
Impacts of chronic cough on ADL (n=48)	
Outdoor recreational activities	24 (50.0%)
Socialization/conviviality activities	24 (50.0%)
Functional Mobility	22 (45.8%)
Self-care	19 (39.6%)
Work activity	19 (39.6%)
Instrumental ADL	18 (37.5%)
Chores/household management	14 (29.2%)
Recreational activities	6 (12.5%)
Chronic cough evaluation	
Evaluates cough in people with ILD (n=46)	43 (93.5%)
Chronic cough assessments (n=46)	
Medical history/clinical antecedents	42 (91.3%)
Pulmonary function assessment	25 (54.3%)
Physical exam	21 (45.7%)
Scales/questionnaires	15 (32.6%)
Complementary diagnostic tests	15 (32.6%)
Blood tests	3 (6.5%)
Cough characteristics assessed (n= 46)	
Type of cough (i.e. dry, productive)	44 (95.7%)
Duration of cough	39 (84.8%)
Impact of cough on daily life	37 (80.4%)
Aggravating factors (triggers)	36 (78.3%)
Cough frequency	35 (76.1%)
Cough intensity	27 (58.7%)
Factors that relieve coughing	27 (58.7%)

Cough severity	24 (52.2%)
Risk factors for cough	13 (28.3%)
Chronic cough management	
Regularly treats/helps manage chronic cough (n=44)	38 (86.4%)
Interventions for dry chronic cough (n=44)	
Education	32 (72.7%)
Pharmacological Therapy	27 (61.4%)
Breathing exercises	19 (43.2%)
Referral to another health professional	16 (36.4%)
Bronchial hygiene techniques	12 (27.3%)
Cough suppression techniques	10 (22.7%)
Behavioral Strategies	8 (18.2%)
Other	1 (2.3%)
Interventions for productive chronic cough (n=44)	
Bronchial hygiene techniques	35 (79.5%)
Pharmacological Therapy	27 (61.4%)
Education	27 (61.4%)
breathing exercises	15 (34.1%)
Behavioral Strategies	11 (25.0%)
Referral to another health professional	13 (29.5%)
Cough suppression techniques	2 (4.5%)
Other	1 (2.3%)
% of ILD patients with refractory chronic cough (n=44)	15.0 (5.0-47.5)

Legend: ILD-Interstitial Lung Diseases; ADL- activities of daily living. Mean and standard deviation were used for continuous numerical variables that followed a normal distribution, median and interquartile range (IQR) were used for non-normally distributed variables. Categorical variables were presented as absolute and relative frequencies.