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Psychological Distress and Quality of Life in Fibrotic Interstitial Lung Diseases: A Real-World Observational Study

Sofrimento Psicológico e Qualidade de Vida nas Doenças Pulmonares Intersticiais Fibróticas: Um Estudo Observacional de Vida Real

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ABSTRACT

Fibrotic interstitial lung diseases are chronic, often progressive conditions that have a substantial impact on patients' quality of life. We conducted a prospective observational cross-sectional study including 44 outpatients with fibrotic interstitial lung diseases, assessing anxiety, depression, symptom burden, and quality of life using validated patient-reported outcome measures. Clinically significant anxiety and depression were present in 34.1% and 43.2% of patients, respectively. Psychological distress was associated with greater dyspnea severity and poorer self-perceived health status, although not with lung function parameters. These findings highlight the high prevalence and likely under-recognition of psychological distress in these patients, and support the routine integration of systematic mental health assessment into fibrotic interstitial lung diseases care pathways.
Keywords: Idiopathic Pulmonary Fibrosis; Psychological Distress; Quality of Life

RESUMO

As doenças pulmonares intersticiais fibróticas são entidades crónicas e frequentemente progressivas, com um impacto significativo na qualidade de vida. Realizámos um estudo observacional prospetivo, incluindo 44 doentes em regime de ambulatório, com o objetivo de avaliar a ansiedade, depressão, carga sintomática e qualidade de vida através de instrumentos validados. Verificou-se a presença de ansiedade e depressão clinicamente significativas em 34,1% e 43,2% dos doentes, respetivamente. O sofrimento psicológico associou-se a uma maior gravidade da dispneia e a pior perceção do estado de saúde, sem associação com parâmetros funcionais respiratórios. Estes resultados evidenciam a elevada prevalência e provável subdiagnóstico do sofrimento psicológico nesta população, reforçando a importância da sua avaliação sistemática na prática clínica.
Palavras-chave: Fibrose Pulmonar Idiopática; Qualidade de Vida; Sofrimento Psicológico

Fibrotic interstitial lung diseases (ILD) are chronic and often progressive conditions that pose challenges extending beyond respiratory impairment.[1] Prognostic uncertainty related to the unpredictable course of disease, physical limitations and loss of autonomy frequently leading to social isolation, sleep disturbance, and treatment burden may significantly affect patients' psychological well-being and quality of life (QoL).[2]

Even though previous studies have reported high prevalence rates of anxiety (21% - 60%) and depression (14% - 57%) among patients with fibrotic ILD,[3] these dimensions remain insufficiently addressed in routine clinical care. Patient-reported outcome measures (PROMs) may provide valuable insights into these less visible but clinically relevant aspects of disease burden and contribute to a more holistic approach to ILD care.

The aim of this study was to assess psychological distress and quality of life in patients with fibrotic ILD and to explore clinical, functional and sociodemographic factors associated with anxiety and depression.

We conducted a multicenter prospective observational study including adult outpatients with fibrotic ILD followed at two hospitals. Diagnosis was established through multidisciplinary discussion in accordance with the International American Thoracic Society/European Respiratory Society (ATS/ERS) recommendations.[4]

Eligible patients had a diagnosis of fibrotic ILD confirmed by high-resolution computed tomography and/or lung biopsy, were aged ≥ 18 years, and provided written informed consent. Patients with previously diagnosed psychiatric disorders, active malignancy, severe cardiac, renal or hepatic disease, or cognitive impairment were excluded. These criteria were assessed through review of electronic medical records and, when necessary, confirmed by patient self-report.

Psychological distress and QoL were assessed using validated PROMs: the Hospital Anxiety and Depression Scale (HADS), the EQ-5D-5L (including EQ-VAS), and the Patient Global Impression of Severity (PGIS) for dyspnea and cough.

The primary objective was to assess the prevalence of anxiety and depression and their impact on quality of life. Secondary objectives included the identification of clinical, functional and sociodemographic factors associated with emotional burden.

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Clinically significant anxiety and/or depression were defined as HADS subscale scores ≥ 8, in accordance with established cut-offs.[5] Demographic, clinical, and functional data were collected from medical records.

Forty-four patients were included, predominantly male (81.8%), with a mean age of 67.4 years. Idiopathic pulmonary fibrosis was the most frequent diagnosis (45.5%). The EQ-5D-5L dimensions revealed moderate to severe limitations in mobility in 38.6% of patients, in usual activities in 34%, and in pain/discomfort in 22.7%.

The HADS questionnaire showed that clinically significant anxiety was identified in 34.1% of patients and depression in 43.2% (Fig. 1A). Table 1 illustrates baseline characteristics according to the presence of anxiety or depression.

Overall self-perceived health status was impaired, with a mean EQ-VAS score of 56.9 ± 20.8. Patients with anxiety and depression showed a trend towards lower EQ-VAS scores, although differences did not reach statistical significance (p = 0.51). However, patients with clinically significant depression reported significantly lower EQ-VAS values compared with those without depressive symptoms (p = 0.05).

Patients with concomitant anxiety and depression reported significantly greater dyspnea severity on the PGIS scale (p = 0.03) (Fig. 1B), longer duration of fibrotic ILD (p = 0.04), and longer exposure to antifibrotic therapy (p = 0.03).

No significant differences were observed between groups regarding demographic characteristics, lung function, ILD subtype, oxygen therapy, immunosuppressive treatment, pulmonary rehabilitation, or history of exacerbations, findings that should be interpreted considering the limited sample size.

In this real-world cohort, psychological distress was highly prevalent and associated with greater symptom burden and poorer perceived health status, reinforcing the multidimensional impact of fibrotic ILD.

These findings are consistent with previous studies reporting high rates of anxiety and depression in ILD,[2,3] highlighting that these conditions remain under-recognized and potentially under-treated in clinical practice. Importantly, the absence of association with lung function parameters underscores the limitations of relying solely on physiological measures to assess disease burden, highlighting the dissociation between physiological impairment and patient-perceived disease burden.

Similar findings have been described in other chronic respiratory diseases, such as chronic obstructive pulmonary disease, where PROMs provide complementary information beyond spirometry and contribute to a more patient-centered approach to care.[6]

The association between psychological distress, longer disease duration and greater exposure to antifibrotic therapy likely reflects cumulative disease burden rather than a direct treatment effect. These relationships may also reflect the psychological impact of living with a chronic and progressive disease, although causality cannot be established.

Our findings support the need to systematically integrate mental health assessment into ILD care pathways and reinforce the importance of multidisciplinary approaches aimed at improving overall patient well-being.

This study has several limitations, including the small sample size, potential selection bias related to outpatient recruitment, and its observational prospective cross-sectional design, which precludes causal inference.

Future research should focus on longitudinal assessment of psychological distress, the role of antifibrotic therapy, and the impact of targeted multidisciplinary interventions.

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AUTHOR CONTRIBUTIONS

MJM: Study conception and design, data collection, development and implementation of questionnaires, writing of the manuscript.

MS: Implementation of questionnaires, critical review of the manuscript.

ALF, NM: Data interpretation, critical review of the manuscript.

IN: Study conception and design, data collection and interpretation, critical review of the manuscript.

All authors approved the final version to be published.

PROTECTION OF HUMANS AND ANIMALS

The authors declare that the procedures were followed according to the regulations established by the Clinical Research and Ethics Committee and to the Helsinki Declaration of the World Medical Association updated in October 2024.

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DATA CONFIDENTIALITY

The authors declare having followed the protocols in use at their working center regarding patients' data publication.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

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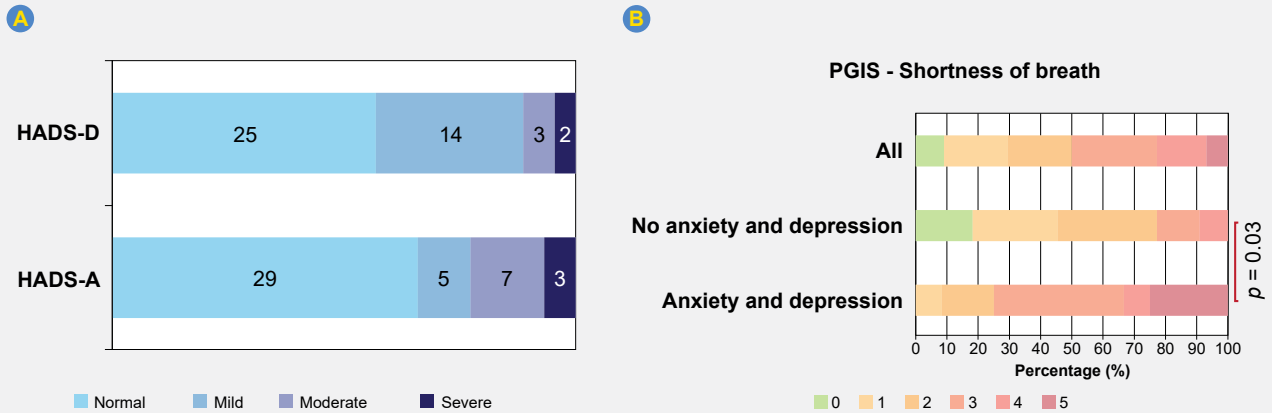

Figure 1 – Psychological distress and symptom burden in patients with pulmonary fibrosis. (A) Distribution of depression (HADS-D) and anxiety (HADS-A) severity levels among the study population, categorized as normal (0 - 7), mild (8 - 10), moderate (11 - 14), and severe (15 - 21). Clinically significant depression and anxiety (HADS ≥ 8) were present in 43.2% and 34.1% of patients, respectively. (B) PGIS for dyspnea, graded from 0 (no dyspnea) to 5 (very severe dyspnea), according to psychological distress status. Patients with concomitant anxiety and depression reported significantly greater dyspnea severity compared with those without psychological symptoms (p = 0.03).
HADS: Hospital Anxiety and Depression Scale; PGIS: patient global impression of severity.

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Table 1 – Baseline characteristics according to the presence of anxiety or depression (section 1 of 2)

Characteristic	Non-anxiety n = 29	Anxiety n = 15	*p*-value	Non-depression n = 25	Depression n = 19	*p*-value
Age (years), mean ± SD	73.0 ± 7.9	67.1 ± 14.0	0.08	71.5 ± 9.8	70.3 ± 11.9	0.71
Male sex, n (%)	25 (86.2)	11 (73.3)	0.29	22 (88)	14 (73.7)	0.26
BMI (kg/m^2), mean ± SD	25.7 ± 4.2	26.9 ± 3.0	0.33	26.4 ± 3.8	25.8 ± 3.8	0.59
Smoking status, n (%)						
Current smoker	0	2 (13.3)		0	2 (10.5)	
Previous smoker	19 (65.5)	9 (60)	0.13	18 (72)	10 (52.6)	0.17
Non-smoker	10 (34.5)	4 (26.7)		7 (28)	7 (36.8)	
Smoking burden (packs-years), mean ± SD	19.5 ± 19.6	25.2 ± 21.3	0.38	21.3 ± 20.8	21.5 ± 19.7	0.97
Lung Function (% pred), mean ± SD						
FVC	79.8 ± 16.9	75.8 ± 17.9	0.47	78.8 ± 16.5	78.0 ± 18.4	0.88
DLCO	52.1 ± 13.0	51.5 ± 15.1	0.89	52.9 ± 13.7	50.7 ± 13.8	0.60
6MWD	74.0 ± 21.5	70.3 ± 23.3	0.63	76.3 ± 21.1	67.3 ± 22.8	0.22
Educational level, n (%)						
Primary education	19 (65.5)	8 (53.3)		17 (68)	10 (52.6)	
Secondary education	2 (6.9)	3 (20)	0.42	1 (4)	4 (21.2)	0.20
University degree	8 (27.6)	4 (26.7)		7 (28)	5 (26.3)	
Underlying ILD diagnosis, n (%)						
FPI	15 (51.7)	5 (33.3)		12 (48)	8 (42.1)	
HP	9 (31)	4 (26.7)		9 (36)	4 (21.1)	
NSIP	1 (3.4)	2 (13.3)		1 (4)	2 (10.5)	
CTD-ILD	1 (3.4)	1 (6.7)	0.62	0	2 (10.5)	0.50
CPFE	1 (3.4)	1 (6.7)		1 (4)	1 (5.3)	
FPF	1 (3.4)	1 (6.7)		1 (4)	1 (5.3)	
Unclassifiable PF	1 (3.4)	0		1 (4)	0	
Sarcoidosis	0	1 (6.7)		0	1 (5.3)	
Duration since ILD diagnosis (month), median (IQR)	40 (60)	47 (53)	0.31	43 (59)	47 (53)	0.26
Definite or probable UIP Pattern, n (%)	20 (68.9)	7 (46.7)	0.40	16 (64)	11 (57.9)	0.61
Antifibrotic therapy, n (%)	25 (86.2)	10 (66.7)	0.13	21 (84)	14 (73.7)	0.40
Time on antifibrotic therapy (months), median (IQR)	21 (42.0)	34 (73.0)	0.22	13.5 (33)	37 (60)	0.22
Immunosuppressive therapy, n (%)	14 (48.3)	7 (46.7)	0.92	12 (48)	9 (47.4)	0.96
Time on immunosuppressive therapy (months), median (IQR)	33 (60)	46 (58)	0.28	38 (82)	39 (70)	0.32
LTO (no.), median (IQR)	2 (6.9)	2 (13.3)	0.48	1 (4)	3 (15.8)	0.18
AOT (no.), median (IQR)	6 (20.7)	3 (20)	0.96	4 (16)	5 (36.3)	0.40
Respiratory rehabilitation (< 1 year), n (%)	7 (24.1)	5 (33.3)	0.52	8 (32)	4 (21.1)	0.72
Hospitalization due to exacerbation (<1 year), n (%)	4 (13.8)	1 (6.7)	0.48	3 (12)	2 (10.5)	0.89
CV Comorbidities (no.), median (IQR)	3 (2)	2 (3)	0.08	3 (2.0)	2 (3)	0.08

BMI: body mass index; FVC: forced vital capacity; DLCO: diffusing capacity of the lungs for carbon monoxide; 6MWD: 6-minute walk distance; ILD: interstitial lung disease; FPI: idiopathic pulmonary fibrosis; HP: hypersensitivity pneumonitis; NSIP: nonspecific interstitial pneumonia; CTD-ILD: connective tissue disease–associated interstitial lung disease; CPFE: combined pulmonary fibrosis and emphysema; FPF: familial pulmonary fibrosis; UIP: usual interstitial pneumonia. LTO: long-term oxygen; AOT: ambulation oxygen therapy; CV: cardiovascular

(Table 1 continues next page)

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Table 1 – Baseline characteristics according to the presence of anxiety or depression (section 2 of 2)

Characteristic	Both anxiety and depression n = 12		Neither anxiety nor depression n = 22		*p*-value
Age (years), mean ± SD	67.5 ± 13.9		72.3 ± 9.0		0.22
Male sex, n (%)	8	(66.7)	19	(86.4)	0.11
BMI (kg/m^2), mean ± SD	26.7 ± 3.3		26.2 ± 4.0		0.54
Smoking status, n (%)					
Current smoker	2	(16.7)	0		
Previous smoker	6	(50)	15	(68.2)	0.13
Non-smoker	4	(33.3)	7	(31.8)	
Smoking burden (packs-years), mean ± SD	23.5 ± 20.1		19.8 ± 20.3		0.68
Lung Function (% pred), mean ± SD					
FVC	74.5 ± 18.9		78.5 ± 16.9		0.54
DLCO	50.9 ± 15.4		52.7 ± 13.6		0.72
6MWD	67.7 ± 25.9		75.9 ± 22.2		0.38
Educational level, n (%)					
Primary education	5	(41.7)	14	(63.6)	
Secondary education	3	(25)	1	(4.5)	0.18
University degree	4	(33.3)	7	(31.8)	
Underlying ILD diagnosis, n (%)					
FPI	4	(33.3)	11	(50.0)	
HP	3	(25)	8	(36.4)	
NSIP	1	(8.3)	0		
CTD-ILD	1	(8.3)	0		0.41
CPFE	1	(8.3)	1	(4.5)	
FPF	1	(8.3)	1	(4.5)	
Unclassifiable PF	1	(8.3)	1	(4.5)	
Sarcoidosis	0		1	(4.5)	
Duration since ILD diagnosis (month), median (IQR)	46.5	(60)	36	(61)	**0.04**
Definite or probable UIP Pattern, n (%)	6	(50)	15	(68.1)	0.77
Antifibrotic therapy, n (%)	8	(66.7)	19	(86.4)	0.18
Time on antifibrotic therapy (months), median (IQR)	47	(75)	13.5	(36)	**0.03**
Immunosuppressive therapy, n (%)	6	(50)	11	(50)	1.00
Time on immunosuppressive therapy (months), median (IQR)	39.5	(55)	32.5	(66)	0.46
LTO (no.), median (IQR)	2	(16.7)	1	(4.5)	0.23
AOT (no.), median (IQR)	3	(25)	4	(18.2)	0.65
Respiratory rehabilitation (< 1 year), n (%)	3	(25)	6	(27.3)	0.88
Hospitalization due to exacerbation (<1 year), n (%)	1	(8.3)	3	(13.6)	0.69
CV Comorbidities (no.), median (IQR)	1.5	(3)	3	(2)	0.07

BMI: body mass index; FVC: forced vital capacity; DLCO: diffusing capacity of the lungs for carbon monoxide; 6MWD: 6-minute walk distance; ILD: interstitial lung disease; FPI: idiopathic pulmonary fibrosis; HP: hypersensitivity pneumonitis; NSIP: nonspecific interstitial pneumonia; CTD-ILD: connective tissue disease–associated interstitial lung disease; CPFE: combined pulmonary fibrosis and emphysema; FPF: familial pulmonary fibrosis; UIP: usual interstitial pneumonia. LTO: long-term oxygen; AOT: ambulation oxygen therapy; CV: cardiovascular

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