Functional, Disability-Related and Caregiver Productivity Burden in Pulmonary Fibrosis in Greece

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Introduction

- Pulmonary fibrosis (PF) is a chronic debilitating disease that limits daily activities and independence of patients, affecting their productivity and increasing their need for informal care. **[1,2]**
- The burden also extends to caregivers, who may experience physical and emotional strain. **[3]**
- Understanding these impacts, alongside patients' experiences of disability assessment and access to benefits, is essential to characterize the wider burden of PF and inform support services.

Objective

To describe the functional, disability-related and caregiver productivity burden among people with pulmonary fibrosis in Greece.

Methods

Study design:

- An online cross-sectional survey was conducted by the Hellenic Pulmonary Fibrosis Association "Lungs of Life" in Greece during May–June 2026.

Participants:

- Adults with self-reported PF who provided informed consent were eligible.

Data collection

Questionnaires were completed by patients or by caregivers on their behalf; a separate section captured caregivers' own experiences.

Patient measures included:

- paid employment,
- PF-related work changes,
- requests for early retirement,
- disability assessment
- perceived difficulty accessing disability benefits (0=very easy; 10=very difficult).
- Patient activity impairment assessed using the Work Productivity and Activity Impairment (WPAI) questionnaire, with a 7-day recall period.

Caregiver measures included caregiver productivity and activity impairment using the WPAI questionnaire, caregiving time and work impact.

Statistical analysis

- Categorical variables were summarized as n (%) and continuous variables as median (Q1–Q3), using available data for each measure.
- Work-productivity outcomes were assessed among respondents in paid employment.
- Exploratory comparisons used Wilcoxon rank-sum tests, and associations with caregiving time were assessed using Spearman's rank correlation.
- Tests were two-sided, with $\alpha=0.05$.

Results

Study population and patient functional burden

- The final sample included 165 patients. (Table 1)
- PF-related changes in work role or work environment were reported by 30/150 patients (20%), while 18/147 (12%) had requested early retirement because of PF.
- Median patient activity impairment was 70% (Q1–Q3: 40–90; n=155). **Activity impairment was higher among patients using oxygen devices than among non-users** [90% (70–100) versus 30% (10–50); p<0.001].

Disability-related burden

- Of 161 patients with available data, 80 (50%) had applied for or undergone disability assessment. (Fig.1)
- Among these patients, 61 (76%) reported approval, 3 (4%) rejection and 16 (20%) a pending decision.
- Among patients with an approved assessment, 19/61 (31%) reported "receiving no disability-related benefit".
- Median perceived difficulty accessing disability benefits was 7 (Q1–Q3: 3–9) on a 0–10 scale (n=113).

Caregiver productivity and activity burden

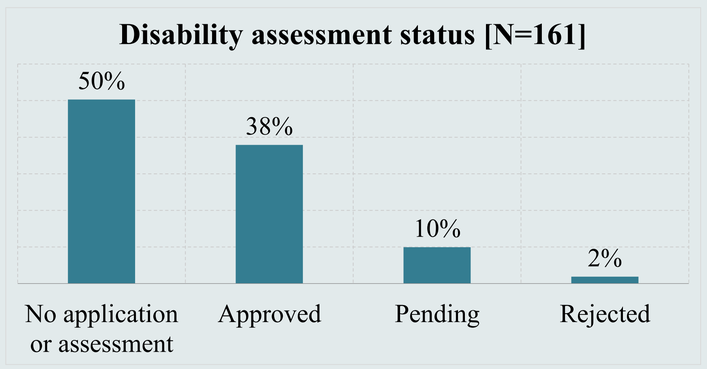
- Seventy-nine caregivers completed the caregiver section of the survey. Among those with available employment data, 29/78 (37%) were currently working for pay.
- Caregiving involved medication and appointment management (81%), emotional support (75%) and household tasks (73%) among 77 caregivers with available data; 24/77 caregivers (31%) reported providing 24-hour or continuous care.
- Caregiving affected work for 31/73 caregivers (43%), including reduced working hours (21%), changing jobs (1%) and stopping work (21%). (Fig. 2)
- Median caregiver overall work impairment was 57%, and activity impairment was 60% (Fig. 3).
- Caregiver activity impairment was positively associated with caregiving time (Spearman's rho=0.49; p<0.001) and was higher among caregivers of oxygen-device users than of non-users [70% (40–90) versus 30% (20–40); p<0.001].

Table 1. Patient characteristics

Characteristic	Total (N=165)
Age, years, median (Q1–Q3)	74 (68–80)
Male, n (%)	114 (69.1%)
Diagnosis, n (%)	
Idiopathic pulmonary fibrosis	107 (65%)
Other pulmonary fibrosis	58 (35%)
Time since diagnosis, years, median (Q1–Q3)	6 (3–9)
Questionnaire completed by, n (%)	
Patient	106 (64%)
Caregiver on behalf of the patient	59 (36%)
Currently working for pay, n/N (%)	13/163 (8%)
Use of any oxygen device, n/N (%)	99/160 (62%)

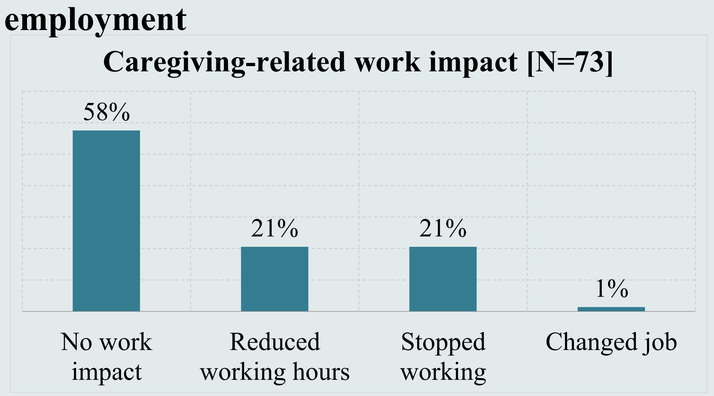
Age and time since diagnosis were available for 161 patients. Percentages were calculated using available responses. Other PF included autoimmune-related ILD (n=21), unknown type (n=18), progressive PF (n=4), unclassifiable ILD (n=4), fibrotic sarcoidosis (n=3), and other/free-text diagnoses (n=8). Diagnoses were self-reported.

Figure 1. Disability assessment status among patients with pulmonary fibrosis



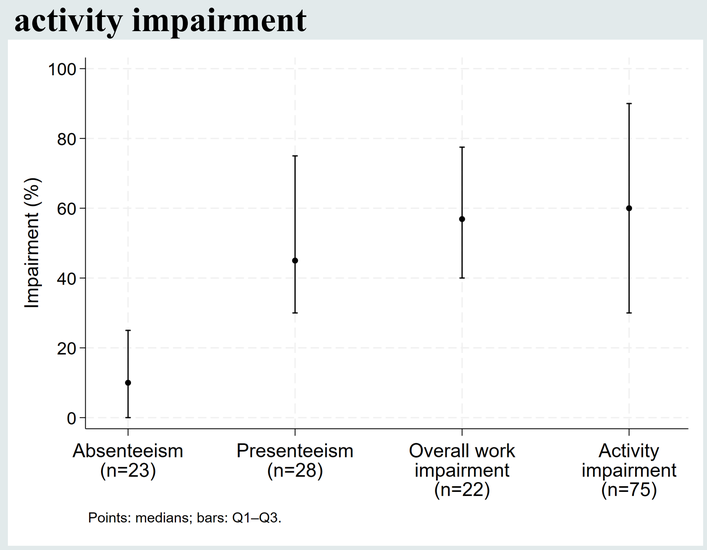
Percentages are based on 161 patients with available data.

Figure 2. Impact of caregiving on employment



Percentages are based on 73 caregivers with available work-impact data, including those who had stopped working.

Figure 3. Caregiver work productivity and activity impairment



Work impairment measures were assessed among caregivers in paid employment with available data; activity impairment was assessed among all caregivers with available data. All measures refer to the preceding 7 days.

Limitations

- The cross-sectional design precludes causal inference.
- Voluntary participation in an online survey may limit representativeness, while self-reported and caregiver-proxy responses may introduce reporting bias.
- Missing responses and small employed-caregiver subsamples limit the precision of productivity estimates.
- Oxygen-use comparisons were unadjusted and may reflect differences in disease severity and other patient characteristics.

Conclusions

- Patients and caregivers in this Greek survey reported substantial burden associated with PF, including limitations in daily activities, difficulties accessing disability benefits and caregiver productivity losses.
- Activity impairment was greater among patients using oxygen devices and their caregivers.
- These findings highlight the need for support addressing both patient functioning and caregiver needs. These findings could be included in future in disease-burden and health-policy assessments.

References

[1] T. F. Riegler et al., BMJ Open Respir. Res., vol. 12, no. 1, article e003303, Nov. 2025; [2] S. Shetty et al., Lung, vol. 204, no. 1, article 32, May 2026; [3] C. S. Graham et al., BMC Pulm. Med., vol. 25, article 221, May 2025.

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