Perceptions, Expectations, and Adherence in Interstitial Lung Disease: Insights from a Multicentre Mixed-Methods Study

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BACKGROUND AND AIMS

Interstitial lung diseases (ILD) are a heterogeneous group of chronic disorders leading to progressive lung damage and disability. While their physiological impact is well documented, the effects on quality of life, fatigue, and daily functioning remain less clear. Understanding how patients perceive their illness and treatments may offer new insights into adherence and self-management.[1]

This study examined whether illness perceptions and expectations influence adherence to antifibrotic therapy, oxygen therapy, and non-invasive ventilation. It also explored emotional responses, perceived barriers, and perceived benefits associated with illness and treatment in individualswith ILD.[2]

MATERIALS AND METHODS

This multicentre, prospective, mixed-methods study was conducted by IRCCS Fondazione Don Carlo Gnocchi, Milan, in collaboration with the Ospedale Maggiore Policlinico of Milan, Italy. Respiratory function, comorbidities, and treatment adherence were assessed at baseline (T0), 6 months (T1), and 12 months (T2). Psychological measures included the Brief Illness Perception Questionnaire (B-IPQ), Beliefs about Medication Questionnaire (BMQ), Medication Adherence Rating Scale-5I (MARS-5I), and Illness Cognition Questionnaire (ICQ). In parallel, semi-structured interviews were analysed using Interpretative Phenomenological Analysis to capture patients' lived experiences and meanings attached to illness and treatment.

RESULTS

A total of 125 adults with ILD were enrolled (median age: 73 years; 72% male). The present report focuses on preliminary data from 48 participants who completed at least one follow-up assessment. Full adherence was observed in 61.5% of patients for antifibrotic therapy and 68.0% for oxygen therapy. A significant negative correlation emerged between diffusing capacity for carbon monoxide and antifibrotic adherence (r=−0.571; p<0.001). No significant linear associations were detected between illness perceptions, medication beliefs, and adherence scores. However, exploratory analyses suggested a non-linear trend: patients with moderate illness perception scores showed the highest adherence across time, whereas those with very low or very high perceived illness threat tended to adhere less. From a cognitive perspective, ICQ scores remained relatively stable, but higher 'Acceptance' and 'Perceived Benefits' scores were observed in participants with sustained adherence.

The qualitative strand identified four major themes describing patients' lived experiences: 1) illness perception and uncertainty; 2) illness and treatment knowledge; 3) relationship with therapy and healthcare professionals; and 4) expectations of the future. Together, these findings suggest that adherence is not merely a behavioural outcome, but a dynamic process shaped by how patients understand and emotionally integrate their illness.[3,4]

CONCLUSION

Adherence in ILD appears to be influenced by both medical and psychological factors, with illness perception profiles and perceived benefits being particularly relevant. Extreme perceptions, either minimising or catastrophising illness, may undermine long-term engagement with therapy. Strengthening education, emotional support, and individualised communication could help realign patients' beliefs and expectations, thereby promoting adherence and improving quality of life.[1] Future studies with the full sample will clarify whether specific cognitive–emotional patterns predict adherence trajectories, and may inform tailored psychosocial interventions in ILD care.

References

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