

# What are the attitudes and perceptions of patients with pulmonary fibrosis and their carers towards use of oxygen therapy?

## Included Studies:

Studies were included where it was reported that the perceptions of patients with IPF and their carers towards use of oxygen therapy either lived or anticipated.

- [1] Belkin A, Belkin A, Albright K, Swigris J. A qualitative study of informal caregivers' perspectives on the effects of idiopathic pulmonary fibrosis. [Erratum appears in BMJ Open Respir Res. 2014;1(1):e000007corr1; PMID: 25582666]. BMJ open respiratory research. 2014;1:e000007.
- [2] Duck A, Spencer LG, Bailey S, Leonard C, Ormes J, Caress AL. Perceptions, experiences and needs of patients with idiopathic pulmonary fibrosis. Journal of Advanced Nursing. 2015;71:1055-65.
- [3] Graney BA. Informal caregivers experience of supplemental oxygen in pulmonary fibrosis. Health and Quality of Life Outcomes. 2017;15:no.
- [4] Graney BA, Wamboldt FS, Baird S, Churney, Graney BA. Looking ahead and behind at supplemental oxygen: A qualitative study of patients with pulmonary fibrosis. Heart & Lung. 2017;46:387-93.
- [5] Jacobs SS. Patient perceptions of the adequacy of supplemental oxygen therapy: Results of the American thoracic society nursing assembly oxygen working group survey. Annals of the American Thoracic Society. 2018;15:24-32.
- [6] Khor YH, Goh NSL, McDonald CF, Holland AE, Khor YH, Khor YH. Oxygen Therapy for Interstitial Lung Disease. A Mismatch between Patient Expectations and Experiences. Annals of the American Thoracic Society. 2017;14:888-95.
- [7] Overgaard D, Kaldan G, Marsaa K, Nielsen TL, Shaker SB, Egerod I. The lived experience with idiopathic pulmonary fibrosis: a qualitative study. The European respiratory journal. 2016;47:1472-80.
- [8] Visca D, Mori L, Tsipouri V, Fleming S, Firouzi A, Bonini M, et al. Effect of ambulatory oxygen on quality of life for patients with fibrotic lung disease (AmbOx): a prospective, open-label mixed-method, crossover randomised controlled trial. Lancet Respiratory Medicine. 2018;6:759-70.

## Excluded Studies:

A number of studies have been excluded due to various reasons including the following: no information regarding patient or care giver perspectives or attitudes towards the use of oxygen therapy and overviews concerning palliative decision making for patients with advanced lung disease.

For a full list of studies excluded at full text reading stage please contact [PaCERSWCRC@cardiff.ac.uk](mailto:PaCERSWCRC@cardiff.ac.uk)

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## Additional materials available upon request:

- Critical appraisal / data extraction forms
- Search strategies
- List of excluded studies

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## Glossary:

IPF—Idiopathic Pulmonary Fibrosis  
MDT—Multidisciplinary Team  
PF—Pulmonary Fibrosis  
ICs—Informal Caregiver/s  
O2—Oxygen  
NJH—National Jewish Health  
US—United States  
PLO—Patient-loved one  
PR—Pulmonary resuscitation  
PR—Pulmonary Rehabilitation  
ILD—Interstitial Lung Disease  
COPD—Chronic Obstructive Pulmonary Disease  
LAM—lymphangioleiomyomatosis  
PAH—Pulmonary Arterial Hypertension  
AATD—Alpha-1 Antitrypsin Disease  
POCs—Portable O2 Concentrators  
mMRC—Modified Medical Research Council  
K-BILD—King's Brief Interstitial Lung Disease Questionnaire  
HRQOL—Health Related Quality of Life  
RCT—Randomised Controlled Trial  
UCSDSOBQ—University of California, San Diego Shortness of Breath Questionnaire  
SGRQ—St George's Respiratory Questionnaire  
HADS—Hospital Anxiety and Depression Scale