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CANOPY: CARE NEEDS OF PATIENTS WITH IDIOPATHIC PULMONARY FIBROSIS AND THEIR CARERS

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10.1136/bmjspcare-2014-000838.30

Introduction Idiopathic pulmonary fibrosis (IPF) is a chronic, fibrotic interstitial lung disease of unknown origin and median survival of three years. National Institute for Clinical Excellence guidelines promote patient and carer centred approaches, emphasising multidisciplinary, supportive and palliative care interventions. However there is limited evidence of patient and carer experiences to guide care pathways.

Aim(s) and method(s) Multi-centre mixed methods study identifying palliative and supportive care needs of patients and carers to inform future clinical management pathways. Interpretative Phenomenological Analysis used with 8 sets of semi-structured interviews with patients (27) and paired carers (21) in 4 groups (n=48). Patients also completed validated questionnaires for symptoms and QoL.

Results Patients and carers experienced uncertainty in five domains across all IPF stages.

- ▶ Communication and Information
- ▶ Understanding symptoms and interventions
- ▶ IPF course
- ▶ IPF and everyday life
- ▶ Adapting roles and coping strategies

Patients and carers perceived disparity between clinic assessments and their lived experience of IPF. Potential intervention triggers were complex diagnosis, health deterioration, oxygen use, carer information needs, and interpreting symptoms, particularly cough and breathlessness.

Conclusion(s) Key turning points for patients and carers are structured around:

- ▶ Assessment, including diagnosis.
- ▶ Active role of carers, specifically information and symptom management.
- ▶ Access triggers, around changes in health status and management, such as oxygen use.

The development of a keyworker service delivery model, responding to need as appropriate along an ongoing trajectory of decline, offers palliative care intervention in conditions where there is a terminal prognosis but an uncertain disease course.