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Title: Perceptions, experiences and information needs of patients with idiopathic pulmonary fibrosis (IPF): A qualitative study

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Body: Background: Idiopathic Pulmonary Fibrosis (IPF) is a rapidly progressive lung disease, with median survival of 2-4 years from diagnosis with symptoms that impact on quality of life. There has been little work to date which explores the experiences of these patients, or their family carers, in-depth. Aim: To understand the experiences, perceptions and information needs of patients with IPF. Methods: Qualitative study, involving in-depth, audio-recorded, semi-structured interviews, supported by a topic guide (developed from review of the literature and input from patients and clinicians). Seventeen patients with moderate to advanced IPF referred to a tertiary respiratory centre in north-west England, and six of their family carers, were interviewed. Data were analysed using Framework Analysis (Ritchie and Spencer 1994). Results: Patients' diagnostic pathway was often complex and several had initially been misdiagnosed. All patients and carers had unmet information needs throughout the disease trajectory, regarding disease causation, prognosis, treatments and side effects. Patients and carers reported a loss of the life they had, with IPF impacting markedly on independence, spontaneity and roles within relationships. Patients reported struggling to live with increasing breathlessness, cough, lethargy and fatigue. Learning to live with increasing disability and dependency on oxygen, whilst facing an uncertain future, was a struggle for all. Conclusions: Patients with IPF have many unmet information and support needs. There is an urgent need for improved recognition of these needs, as well as increased availability and accessibility of services.