

Abstract P198 Table 1. Percentage of patients reporting issue as causing 'quite a lot' or 'very much' distress

Issue	%	95% CI	Issue	%	95% CI
1 Shortness of breath	64	(54 – 74)	10= The effect of your condition on your sexual life	21	(12 – 30)
2 Cough	51	(40 – 61)	12= Changes in your ability to carry out your usual household tasks	20	(12 – 29)
3 Feeling tired	49	(39 – 59)	12= Feeling everything is an effort	20	(11 – 29)
4 Dry mouth	34	(24 – 44)	14= Changes in your ability to carry out your usual daily activities, e.g. bathing	18	(10 – 26)
5 Feeling weak	33	(23 – 43)	14= Losing your independence	18	(10 – 26)
6 Feeling sleepy during the day	32	(22 – 42)	16 Pain	17	(9 – 25)
7 Worrying about the effect of your illness on other people	27	(18 – 37)	17= Feeling as if you are in a low mood	15	(7 – 22)
8 Problems sleeping at night	24	(15 – 33)	17= Sore mouth	15	(7 – 23)
9 Feeling that your symptoms are not controlled	22	(13 – 30)	17= Bladder problems (urinary incontinence)	15	(7 – 23)
10 Feeling anxious	21	(12 – 29)	20 Feeling restless and agitated	14	(6 – 21)

Surprisingly concerns with dry mouth, sleep and effect on sexual life were also in the 'top 10' of distressing issues: further investigation into these is suggested.

Utilisation of SPARC can highlight troublesome issues experienced by patients with Idiopathic Interstitial Lung Diseases. Addressing these concerns, which may have been otherwise unrecognised, can guide best supportive care.

P199 DISCREPANCY BETWEEN SYMPTOM SEVERITY AND SELF-REPORTED PALLIATIVE CARE NEEDS IN INTERSTITIAL LUNG DISEASE PATIENTS

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Introduction Patients with interstitial lung disease (ILD) have a high symptom burden but their palliative care needs are not well reported. We hypothesised that there was an unmet need for social and palliative care input in ILD patients.

Methods 131 consecutive ILD clinic patients (September 2013–January 2013) completed a questionnaire unsupervised. 6 ILD patients on home oxygen completed the same questionnaire during a home visit. The questionnaire consisted of the 15 questions included in the King's Brief Interstitial Lung Disease (K-BILD) health status questionnaire, concerning experiences in the preceding two weeks, and an additional 9 questions aimed at assessing patients' perceptions of their needs and concerns.

Results Despite reporting significant physical symptoms in the questionnaire, including breathlessness in 69%, chest tightness in 52% and wheeze (60%), only 10% felt that their physical needs were not being met.

Emotional and psychological symptom reporting was high, including worry about the seriousness of their lung condition (54%), feeling "down" in 52% and anxiety in 43%. Only 32% felt in control of their lung condition, with 43% expecting to get worse and 39% thinking about the end of their life. 49% of patients worried about how their spouse or carer was coping with their condition. However, only 7% and 9% felt they needed more emotional or spiritual support respectively.

The majority of patients avoided doing things that made them breathless (64%) and felt that their lung condition interfered with their activities of daily living (60%) or limited them carrying things (43%) but only 13% felt they needed more practical help.

Most patients wanted to be involved in care decisions should they become unwell (81%, n = 110).

Conclusions ILD patients report significant physical and psychological symptoms, but there is a marked discrepancy between reported symptoms and the perceived need for additional support, including practical, emotional and spiritual support. The reason for this is unclear. It may relate to perceived lack of benefit of such services or to poor understanding of the questionnaire itself. Most patients wanted to be involved in care decisions if they become unwell, highlighting the importance of anticipatory care planning.

P200 A QUALITATIVE EUROPEAN SURVEY OF PATIENTS PERCEPTIONS OF CURRENT MANAGEMENT OF IDIOPATHIC PULMONARY FIBROSIS

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Objectives Idiopathic pulmonary fibrosis (IPF) is a chronic, progressive, fibrotic lung associated with significant mortality. There has been a marked increased interest in IPF and new emerging therapies have been shown to improve either the survival or quality of life for some people with IPF. This study aimed to explore patient's perceptions of current therapy & management of IPF, specifically pirfenidone as the first approved treatment.

Methods Patients diagnosed with IPF according to current criteria and prescribed pirfenidone by one of 3 European specialist ILD centres were enrolled in a qualitative survey. One-to-one in-depth interviews were conducted between September and October 2012.

Results 45 Participants (71% male; mean age 68.5 years). Mean time from diagnosis to interview 3.5 years. Post diagnosis, 68% of patients felt their knowledge about IPF severity, treatments and prognosis increased markedly, predominantly through the use of the internet. 32% of patients relied exclusively on information gained from the consultation and demonstrated a lack of understanding of the disease and its process. For all patients the transition to oxygen therapy signalled a significant change impacting upon the view of their future. O₂ therapy was associated with social exposure of disease, often with feelings of "shame" (35%). This impacted quality of life: "restricting activity"; "making simple tasks difficult...even talking" and was associated with impaired emotional well-being (Figure 1). There was an overwhelming lack of psychological support (79%) as patients struggled to comprehend the disease process. Patients spontaneously identified specific approaches that could improve their