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.

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
disease experience. Pirfenidone was well tolerated and offered hope to the majority of patients (83%). However 44% of patients reported anxieties re continuing access.

Conclusions Post diagnosis, many patients demonstrate resourcefulness in accessing information and have realistic expectations of how to improve care. There is a need to improve the information given in the consultation to improve subsequent understanding and to increase provision of psychological support particularly when prescribing O2 therapy. The availability of pirfenidone was perceived by patients to offer hope and reassurance. Strategies to reduce the delay in diagnosis and standardise access to information and therapies are needed.

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RITUXIMAB AS RESCUE THERAPY IN INTERSTITIAL LUNG DISEASE REFRACTORY TO CONVENTIONAL IMMUNOSUPPRESSION

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Background Rituximab, a B cell-depleting monoclonal antibody, may offer an effective rescue therapy in a subgroup of patients with severe interstitial lung disease (ILD), progressing despite conventional immunosuppression.

Methods Retrospective assessment of 50 patients with severe, progressive ILD treated with rituximab between 2010 and 2012. This included 33 with connective tissue disease-associated ILD (CTD-ILD), 6 with fibrotic hypersensitivity pneumonitis, 3 with likely drug-induced ILD, 2 with desquamative interstitial pneumonitis (DIP) and the rest with miscellaneous ILD patterns, excluding idiopathic pulmonary fibrosis. At the time of rituximab treatment, mean FVC was 49.1% (- + 17.6) and DLco 25.5% (- + 9.9). Four patients were mechanically ventilated. Prior to rituximab, all patients except one had received immunosuppressive treatment, including IV cyclophosphamide in 44 patients. Change in pulmonary function tests, as compared to pre-rituximab levels, was assessed at six to twelve months post-treatment and analysed by Wilcoxon signed rank test. Categorical trends (improvement, stability, deterioration) before and after treatment were defined using either ≥10% change in forced vital capacity (FVC) or ≥15% change in diffusing capacity for carbon monoxide (DLco) as threshold values.

Results In the six to twelve months following rituximab treatment, a median improvement in FVC of 5.7% (p < 0.01) and stability of DLco (p < 0.01) was observed. This was in contrast to a median decline in FVC and DLco of 14.6% and 18.8% respectively, in the six to twelve months prior to rituximab therapy (p < 0.01). Patients with CTD-ILD were most represented in this cohort and were more likely to improve or stabilise following rituximab (28/33), than those with non CTD-related ILD (8/17) (p = 0.008, Fisher exact test). However, of the four patients requiring invasive ventilation, improvement to extubation was observed in three patients with non CTD-ILD (one DIP, one acute interstitial pneumonia, one unclassifiable ILD). Two patients developed serious infections (pneumonia) requiring hospitalisation following rituximab, and ten patients died, all from progression of underlying ILD, a median of 5.1 months after treatment.

Conclusions Rituximab may offer a safe and effective therapeutic intervention in a subgroup of patients with severe, progressive ILD unresponsive to conventional immunosuppression. Future prospective, controlled trials are warranted to validate these findings.