

Methods 207 patients with sarcoidosis (89% lung, 26% skin, 22% eye, 29% other organ involvement) attending outpatient clinics at King's College and Royal Brompton Hospitals completed the KSQ. KSQ domain scores range from 0 to 100, a higher score representing a better HRQOL. Demographic data, immunosuppressant medication, organ involvement, lung function, Scadding CXR stage, physicians global assessment (PGA) of severity of skin disease and visual acuity (VA) were recorded.

Results Patients had a mean (SEM) age 48 (11) years, 54% were female and 30% were Afro-Caribbean. Patients had a mean (SEM) FEV₁ 80 (23)% predicted, FVC 94 (19)% predicted and TLCO % predicted 66 (17). HRQOL was impaired in all domains, mean (SEM) scores: general HRQOL 51 (2), lung 61 (2), medication/side-effects 49 (3), skin 54 (4), and eye 50 (4). Patients with 2 or more organ involvement compared to single organ involvement had worse general HRQOL (44 (3) vs 58 (3); $p < 0.01$) and worse medication/side-effects scores (44 (3) vs 58 (3); $p = 0.04$). Female patients compared to males had worse general HRQOL (45 (3) vs 57 (3); $p < 0.01$) and medication/side-effects scores (41 (3) vs 58 (4); $p < 0.01$). There were no associations between HRQOL and age ($r = -0.02$ to 0.13) or ethnicity ($p = 0.42$). There was a weak but significant relationship between lung HRQOL and FEV₁ ($r = 0.38$, $p < 0.01$), FVC ($r = 0.38$, $p < 0.01$) and TLCO % predicted ($r = 0.22$, $p < 0.01$). Patients with Scadding CXR stage 3–4 disease compared to stage 0–2 disease had significantly worse lung HRQOL (51 (4) vs 63 (3); $p = 0.02$). Skin health was associated with physician's global assessment (PGA) of severity of skin disease ($r = 0.51$, $p < 0.01$). Eye health was associated with VA ($r = -0.56$, $p < 0.01$). Patients taking immunosuppressant medication for sarcoidosis compared to those not taking immunosuppressants had significantly worse general HRQOL (45 (2) vs 66 (4); $p < 0.01$) and lung HRQOL scores (58 (3) vs 70 (4); $p = 0.01$).

Conclusions HRQOL is impaired in sarcoidosis. Gender, immunosuppressant medication, multi-system organ involvement and severity of lung function impact on HRQOL. This study provides further clinical validation of the KSQ.

P87 THE NEEDS AND EXPERIENCES OF PROGRESSIVE IDIOPATHIC FIBROTIC INTERSTITIAL LUNG DISEASE PATIENTS, INFORMAL CAREGIVERS AND HEALTH PROFESSIONALS: A QUALITATIVE STUDY

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While there have been some studies looking at the needs of patients with idiopathic pulmonary fibrosis, to date no qualitative research has been conducted in the UK. This novel study aimed to assess the needs and experiences of people living with end stage progressive idiopathic fibrotic interstitial lung disease (PIF-ILD) and their informal caregivers. We also interviewed health professionals to examine views of current services, communication between health professionals and end of life planning. 18 qualitative semi-structured in-depth interviews were conducted with patients, their informal caregivers, and health professionals across two specialists ILD centres in London and in the community. Many participants reported that their main symptoms were shortness of breath and cough which impacted on every part of both theirs and the informal

caregivers' lives. Psychologically, patients were frustrated and angry at the way in which their illness severely limited their ability to engage in activities of daily living and compromised their independence. Further, both patients and informal caregivers also reported that the disease seriously affected family relationships especially spousal relationships where strain was pronounced. Patients and their informal caregivers reported a good understanding of the progressive nature of their illness but held unrealistic expectations about prognosis. Health professionals expressed that there was a poor understanding of the palliative care needs of these patients, reluctance to recognise the terminal phase and poor end of life planning. All participants expressed that communication was often poor between health professionals and there was a lack of clarity about where primary responsibility for the care of the patient lay. This Phase I study has provided valuable insight into the overwhelming experiences of patients with PIF-ILD and their informal caregivers. It is clear that the disease affects the patients physically and also impacts greatly psychosocially. The palliative care needs of these patients are not being met and better co-ordination of care with improved communication is needed.

P88 THALIDOMIDE AS TREATMENT FOR IPF ASSOCIATED COUGH

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Introduction and Objective Idiopathic pulmonary fibrosis (IPF) is a chronic, irreversible fibrotic disease with more than 5000 incident cases annually in UK. IPF related cough is present in 80% cases and is often refractory to current treatments. Cough has a significant impact on quality of life, causing sleep disturbance, difficulties at work and stress incontinence. A previously published prospective open label phase II trial of thalidomide for treatment of pulmonary fibrosis suggested that IPF associated cough responded well to thalidomide. We have been using thalidomide as an "off-license" indication for selected IPF patients. The objective of this study was to review our experience of using Thalidomide as treatment for cough in IPF.

Methods Nine patients were referred to Nottingham Academic Interstitial Lung Disease clinic between 2009 and 2011 for assessment of their cough. A modified version of Leicester Cough Questionnaire was used, in conjunction with subjective symptoms, to clinically assess their cough. A trial of PPI (omeprazole 40 mg) and Prednisolone (10 mg) for 6 weeks was given to all subjects. Two were excluded as did not have significant cough, one patient declined thalidomide after initial screening.

Results Six patients were treated with thalidomide. Four had IPF, one had Hypersensitivity Pneumonitis and one had fibrotic Cryptogenic Organising Pneumonia. 72% were males with mean age 69 years (range 51–88 years). The median pre-thalidomide cough score was 74.5 (IQR 13.25) and post treatment cough score was 51.5 (IQR 49.25). This was statistically significant ($p = 0.046$). Three stopped thalidomide subsequent to rash. Two patients are currently stable with 50 mg once daily, and 1 with 50 mg alternate daily of thalidomide.

Conclusion Our observation of a carefully selected cohort of patients suggests that thalidomide has potential for treatment of IPF associated cough. It works quickly (within days) as reflected both subjectively and objectively via questionnaire, even when prednisolone has failed. However, it does have a significant side-effect profile. Identification of thalidomide's mechanism of action may aid the development of novel, effective anti-tussive therapy for this debilitating aspect of IPF. We will assess this in randomised open label trial comparing thalidomide vs prednisolone for treatment of IPF associated cough.