

the first 6 months were  $11.0 \pm 7.5$  and  $11.0$  (6.0–13.5) days respectively for hospitalised patients and mean  $\pm$  S.D.  $1.2 \pm 4.2$  days for all patients. One patient was admitted to the Intensive Care Unit, for 5 days. Eighteen patients had IPF-related Accident and Emergency department visits, 3 had an IPF-related day-case and 67 outpatient clinic visits, with a mean of  $2.1 \pm 2.0$  outpatient clinic visits per patient in the first 6 months of the observation period.

**Conclusion** IPF is a terminal disease associated with significant morbidity and mortality. This is reflected in the high level of resource use and frequent accessing of health care services by this severely ill cohort of patients. Whether resource use has been positively impacted by the introduction of pirfenidone is unknown but merits prospective assessment.

## REFERENCE

Navaratnam V, Fogarty AW, McKeever T, Hubbard RB. The Increasing Secondary Care Burden of Idiopathic Pulmonary Fibrosis Hospital Admission Trends in England From 1998 to 2010. *CHEST* 2013; 143(4):1078–1084

## P197 PHYSICAL INACTIVITY IN SARCOIDOSIS

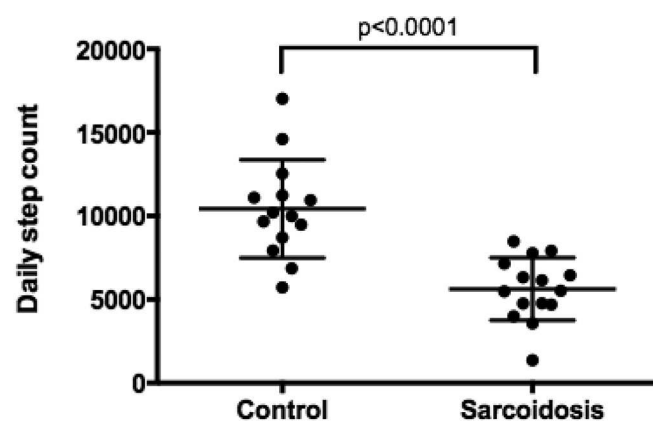
S Vasudevan, M Maddocks, S Chamberlain, A Spinou, C Wood, C Jolley, SS Birring; *King's College London, London, United Kingdom*

10.1136/thoraxjnl-2013-204457.349

**Introduction** Sarcoidosis is associated with dyspnoea, arthralgia, fatigue and poor health status. Little is known about physical activity in sarcoidosis. This study aimed to: 1) objectively measure physical activity in patients with pulmonary sarcoidosis; 2) investigate the relationship between physical activity and fatigue, exercise capacity, health status and lung function.

**Methods** 15 pulmonary sarcoidosis patients (mean age: 52.7 years; 4 males) and 14 healthy controls (mean age: 46.5 years; 4 males) were recruited. Physical activity was assessed objectively over one week, using a validated tri-axial accelerometer- ActivPal™, and subjectively with the International Physical Activity Questionnaire (IPAQ). All participants also underwent pulmonary function tests, 6MWT and completed the Fatigue Assessment Scale (FAS), MRC Dyspnoea Scale and the King's Sarcoidosis QOL Questionnaire (KSQ).

**Results** Compared to controls, patients had lower mean  $\pm$  SD daily step count ( $5624 \pm 1875$  steps vs.  $10429 \pm 2942$  steps,  $p < 0.01$ , figure 1) and time spent stepping ( $1.18 \pm 0.35$  hr.day<sup>-1</sup> vs.  $1.97 \pm 0.46$  hr.day<sup>-1</sup>;  $p < 0.01$ ). There was also a trend to reduced bouts of activity in sarcoidosis patients compared with



Abstract P197 Figure 1. Mean (SD) daily step count assessed with ActivPal.

controls, (sit-stand transitions:  $49 \pm 15$  vs.  $61 \pm 20$ ;  $p = 0.08$ ). Exercise capacity was significantly reduced in patients compared to controls (6MWT distance:  $375 \pm 59$  m vs.  $487 \pm 92$  m;  $p < 0.01$ ). There was a significant association between daily step counts, and 6MWT distance, of patients ( $r = 0.63$ ,  $p = 0.01$ ). Physical activity (overall) reported subjectively was not significantly different between groups (Overall IPAQ median score: 2153 vs. 3230 MET.min.week-1;  $p = 0.32$ ). However, 87% of patients reported doing no vigorous physical activity compared to 50% in controls (vigorous activity IPAQ;  $p < 0.01$ ). There were no significant correlations between daily step count and fatigue, dyspnoea, health status, lung function and self reported physical activity (IPAQ).

**Conclusion** Physical activity is significantly reduced in sarcoidosis compared to healthy subjects. Objective measures of physical activity assess a unique dimension of health in the patient's own environment that is not captured by existing clinical tools and should be further investigated.

## P198 ESTABLISHING THE PALLIATIVE AND SUPPORTIVE CARE NEEDS OF PATIENTS WITH IDIOPATHIC PULMONARY FIBROSIS AND NON SPECIFIC INTERSTITIAL PNEUMONIA

<sup>1</sup>J Wall, <sup>2</sup>V Crosby, <sup>2</sup>A Hussain, <sup>2</sup>A Wilcock, <sup>1</sup>G Saini, <sup>1</sup>R Braybrooke, <sup>1</sup>G Jenkins; <sup>1</sup>Nottingham Respiratory Research Unit, University of Nottingham, Nottingham, England; <sup>2</sup>Nottingham University Teaching Hospitals NHS Trust, Nottingham, England

10.1136/thoraxjnl-2013-204457.350

**Background** Idiopathic Pulmonary Fibrosis (IPF) and Non Specific Interstitial Pneumonia (NSIP) are Idiopathic Interstitial Lung Diseases (ILD) without a known cure. IPF is progressive and fatal. Management of Idiopathic ILD must address patients' palliative and supportive care needs. The Sheffield Profile for Assessment and Referral to Care (SPARC©) questionnaire is a health needs assessment tool covering common biological, psychological and social needs. Local use of SPARC led to service refinements for thoracic cancer patients.

We now explore SPARC in patients with Idiopathic ILD to identify patients' perceptions of disease burden.

**Methods** Patients within 18 months of an Idiopathic ILD diagnosis, identified through specialist clinics, were invited to complete a SPARC questionnaire as part of an ongoing multicentre clinical study. Patients were excluded if concerns existed regarding ability to consent.

SPARC questionnaires included 45 questions: four (concerning personal, communication and information issues) required "yes/no" responses. 41 questions related to symptoms and issues which were rated by patients as to the degree of distress they'd caused in the preceding month. Ratings were 0 "not at all", 1 "a little bit", 2 "quite a bit" and 3 "very much".

Responses were analysed using descriptive statistics. To highlight the most troubling issues, the percentage of patients reporting either "very much" or "quite a bit" of distress was identified for each question.

**Results** 97 patients with Idiopathic ILD (77 male) with median age 69 (range 47- 86) were included. 79 (81%) had IPF, 18 (19%) NSIP. 38 (39%) had severe lung function defects (TLCO <40%).

Table 1 shows the 20 most common issues reported to cause "quite a lot" or "very much" distress.

**Conclusions and implications** Symptoms causing highest levels of distress in the Idiopathic ILD group reflect the commonly observed 'fibrotic triad' of dyspnoea, fatigue and cough.

## Poster sessions

**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

S Tsim, G Chalmers; *Glasgow Royal Infirmary, Glasgow, United Kingdom*

10.1136/thoraxjnl-2013-204457.351

**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

<sup>1</sup>AM Russell, <sup>2</sup>C Vancheri, <sup>3</sup>M Maronati, <sup>3</sup>C Giot; <sup>1</sup>National Heart & Lung Institute, Royal Brompton, London, UK; <sup>2</sup>University of Catania, Catania, Italy; <sup>3</sup>InterMune IAG, Muttens, Switzerland

10.1136/thoraxjnl-2013-204457.352

**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