PHYSICAL INACTIVITY IN SARCOIDOSIS

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

Methods 15 pulmonary sarcoïdosis 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 Sarcoïdosis QOL Questionnaire (KSQ).

Results Compared to controls, patients had lower mean ± SD daily step count (5624 ± 1875 steps vs. 10429 ± 2942 steps, p < 0.01, figure 1) and time spent stepping (1.18 ± 0.35 hr.day⁻¹ vs. 1.97 ± 0.46 hr.day⁻¹; p < 0.01). There was also a trend to reduced bouts of activity in sarcoïdosis patients compared with controls, (sit-stand transitions: 49 ± 15 vs. 61 ± 20; p = 0.08).

Exercise capacity was significantly reduced in patients compared to controls (6MWT distance: 375 ± 59 m vs. 487 ± 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 controls (6MWT distance: 375 ± 59 m vs. 487 ± 92 m; 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 sarcoïdosis 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.

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

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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.
Conclusions I LD 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.

Poster sessions

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 unsurveyed. 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).

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...