

Patient confidence and quality of life in idiopathic pulmonary fibrosis and sarcoidosis

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Abstract

Background: Idiopathic pulmonary fibrosis (IPF) and sarcoidosis impact significantly on health-related quality of life (HRQOL). There are few studies on the impact of confidence on HRQOL in these conditions.

Objectives: 1. To investigate whether patient confidence is associated with HRQOL.

2. To assess if patient confidence is associated with inpatient admissions, access to community healthcare and, for IPF patients, mortality and disease severity.

Methods: Study participants self-completed seven questionnaires: Hospital Anxiety and Depression Scale, EuroQoL 5D (EQ5D), King's Brief Interstitial Lung Disease questionnaire (K-BILD), St George's Respiratory Questionnaire, MRC dyspnoea scale, Fatigue Assessment Scale and a non-validated questionnaire assessing patient confidence, symptom duration and access to community healthcare. Lung function and follow-up data were collected from hospital electronic databases. Spearman's rank correlation coefficients were calculated to assess for correlation between patient confidence, questionnaire variables and inpatient admissions. Chi-square tests were performed to assess for association between patient confidence, mortality and disease severity.

Results: 75 IPF patients and 69 sarcoidosis patients were recruited to the study. Patient confidence in IPF was significantly negatively correlated with depression and, fatigue, and significantly positively correlated with EQ5D scores. No associations were found between confidence and any of the variables assessed in sarcoidosis.

Conclusions: Lower levels of confidence in IPF patients are associated with higher levels of depression and fatigue and worse HRQOL. Efforts

should be made to improve patient confidence to assess the impact on HRQOL.

Introduction

Idiopathic pulmonary fibrosis (IPF) and sarcoidosis are chronic conditions that have a significant impact on patients' health-related quality of life (HRQOL). In both conditions, this is affected by factors such as fatigue, mood and sleep quality, which are not always directly linked to disease severity (1–3). Impaired health status has a negative impact on patients' ability to perform activities of daily living (ADLs) and work-related tasks, as well as their ability to have normal social interactions (2–5). Increased self-efficacy (which can be defined as the confidence people have in managing their health when living with a chronic disease) impacts positively on HRQOL in other conditions such as chronic obstructive pulmonary disease (COPD) (6,7), however there are few studies in this area in IPF and sarcoidosis.

“Confidence” itself is a non-specific term referring to strength of belief, however it is an important component of self-efficacy and, as has been shown in qualitative studies of pulmonary rehabilitation in COPD, increased confidence is a positive outcome of interventions that is valued by patients (8,9).

One study in IPF comparing the PRISM (Program to Reduce Idiopathic Pulmonary Fibrosis Symptoms and Improve Management) programme over a six week period with patients receiving their usual level of care (10) found that patients receiving the intervention (PRISM) reported worse generic quality of life health status (measured by the Medical Outcomes

Study 36-Item Short Form Questionnaire (SF-36)) and anxiety (measured by the Beck Anxiety Inventory) after the programme, although post-study qualitative interviews suggested that patients benefitted from the intervention. The IPF Care patient support programme for IPF patients receiving pirfenidone has been found to increase patients' confidence in knowing about the management of their disease and feeling in control of their condition (11). Patients in this study most frequently discussed topics that were not directly linked to pirfenidone, highlighting the importance of assessing the utility of such programmes for patients with IPF regardless of whether they are receiving

pharmacological treatment.

In sarcoidosis, although the disease has a negative impact on patients' quality of life, a lack of prospective longitudinal follow-up studies makes it challenging to draw conclusions about the cause of impaired health status and its consequences (12). Radiographic stage of pulmonary sarcoidosis, pulmonary function tests and levels of serum angiotensin converting enzyme (ACE) have been shown to be poorly associated with quality of life and levels of fatigue (2,13–15) despite their widespread clinical use as markers of disease severity.

Our study aimed to assess the relationship between patient confidence and quality of life, anxiety, depression, dyspnoea and fatigue in sarcoidosis and IPF patients. We chose to measure the King's Brief Interstitial Lung Disease (K-BILD) and St George's Respiratory Questionnaire (SGRQ), designed specifically for patients with lung disease, as well as the EuroQol 5D (EQ5D), a non-disease-specific measure of HRQOL, which we felt was a useful tool as sarcoidosis can affect multiple body systems. We also investigated whether patient confidence was related to access to healthcare in the community as well as outcome as measured by emergency hospital admissions. For the IPF cohort, we assessed the relationship of patient confidence with mortality and disease severity as measured by lung function.

Methods

Patients under the care of the respiratory department at the Norfolk and Norwich University Hospital with a diagnosis of IPF and sarcoidosis were identified from an electronic database of interstitial lung disease (ILD) patients, by their primary consultant physician within clinic, or from patient support days run by the respiratory research group for patients with sarcoidosis or IPF. Participants were eligible for inclusion if they were over the age of 18, had a diagnosis of IPF or sarcoidosis, were able to give informed consent to take part in the study, and did not have any major co-morbidities apart from their diagnosed lung disease.

IPF patients were included if they met the diagnostic criteria for IPF as per the American Thoracic Society's 2011 guidelines (16). Patients in the sarcoidosis group required histological evidence of granuloma formation consistent with sarcoidosis plus radiological evidence of pulmonary involvement (17).

Patients were recruited to the study between February 2013 and March 2014. This study was conducted in accordance with Good Clinical Practice, all applicable subject privacy requirements, and the guiding principles of the declaration of Helsinki. The study received ethics committee approval, reference 12/EM/0413. Consent was gained for the use of patients' pulmonary function tests to determine disease severity.

Data regarding lung function measured at baseline and 6 and 12 months preceding recruitment to the study was collected in order to classify the IPF patients as having previous stable or declining lung function. Subsequent data regarding mortality and inpatient admissions was collected up to September 2015 using the Sunquest ICE (Integrated Clinical Environment) system at the Norfolk and Norwich University Hospital.

All study subjects were asked to complete a number of questionnaires; these were all self-completed either at home or in the outpatient clinic waiting room (unsupervised by a health professional). Questionnaires were completed in the following order:

1. Hospital Anxiety and Depression Scale (HADS) (18)
2. EuroQoL 5D (EQ5D) (19,20)

3. King's Brief Interstitial Lung Disease questionnaire (K-BILD) (21)

4. MRC dyspnoea scale (MRCd) (22)

5. Fatigue Assessment Scale (FAS) (23)

6. St George's Respiratory Questionnaire (SGRQ) (24,25)

7. Non-validated questionnaire

For the questionnaires above, higher scores in the EQ5D and K-BILD questionnaires a less impaired HRQOL, whereas higher scores in the SGRQ indicate a more impaired HRQOL. Higher scores in the HADS, MRCd and FAS questionnaires indicate a higher degree of anxiety, depression, dyspnoea or fatigue respectively.

Were: "How confident are you about when to call a doctor?", with the response options on a 5 point scale (1 representing "not at all" and 5 representing "very confident") and "Have you discussed with a doctor what you can do to keep yourself as well as possible?", with response options "yes" or "no". Use of community healthcare resources was assessed by asking them to report the number of times they had sought help from a doctor, nurse or other health professional in the community over the year preceding recruitment to the study for pulmonary fibrosis or for other reasons. The questionnaire also asked participants to report the duration of any cough or breathlessness in order to assess whether patient confidence was related to duration of symptoms.

Statistical Analysis

Spearman's rank correlation coefficient was used to assess for any correlation between the following parameters: level of confidence about when to call a doctor, age, duration of cough and breathlessness, number of times a doctor, nurse or other health professional had been consulted over the 12 months preceding recruitment to the study, number of emergency inpatient admissions and questionnaire scores (HADS-Anxiety (HADS-A), HADS- Depression (HADS-D), MRCd score, total K-BILD score, EQ5D score, total SGRQ scores, and FAS score). A two-tailed t-test was performed to assess whether the mean level of confidence about when to call a doctor differed according to gender.

Two-tailed t-tests were performed to assess whether questionnaire scores (as above) differed in patients who had discussed with a doctor how they could optimise their wellbeing compared to those who had not. The chi-square test was used to assess for any association between level of confidence in when to call a doctor and discussion of optimisation of wellbeing with a doctor.

For the IPF cohort chi-square tests were performed to assess for any difference in level of confidence about when to call a doctor according to mortality status, disease severity as measured by lung function at recruitment and previous stable versus declining lung function.

All statistical analysis was performed using IBM SPSS version 22.

Results

144 subjects were recruited to the study: 75 patients with a diagnosis of IPF and 69 with a diagnosis of sarcoidosis. Of the IPF cohort, lung function was obtained for 63 patients at recruitment. Multiple lung function measurements enabling measurement of decline in lung function was obtained for 54 of the IPF patients; of these 21 (28%) had declining lung function. The patient characteristics are summarised in table 1.

The questionnaire completion rate was 89% (incomplete questionnaires were not included in statistical analysis). For the IPF cohort, significant negative correlation was found between level of confidence in when to call a doctor and level of depression, fatigue and number of emergency inpatient admissions due to lung disease. Significant positive correlation was found between level of confidence in when to call a doctor and HRQOL as measured by the EQ5D (Table 2).

No significant correlation was found between level of confidence in when to call a doctor and gender, age, duration of cough or breathlessness, MRCd score, HADS-A score, K-BILD score, total SGRQ score, or the number of time patients sought help from a doctor, nurse or other health professional in the community. For the sarcoidosis cohort, no correlation was found between level of confidence in when to call a doctor and any of the parameters tested (Table 3).

When investigating whether subjects had discussed with a doctor how they could optimise their wellbeing, no difference was found in any of the parameters tested for the IPF cohort (Table 4). For the sarcoidosis cohort, participants who had had discussed optimisation of wellbeing with their doctor ~~this~~ had a significantly higher level of depression, dyspnoea and fatigue and a significantly lower level of quality of life as measured by the scores in all of the questionnaires used (Table 5). The mean level of confidence in when to call a doctor for help

did not differ between subjects who had discussed with a doctor how they could optimise their wellbeing and those who had not (IPF cohort: mean confidence level 3.8 versus 3.7 for those who had discussed versus those who had not discussed optimising wellbeing with their doctor, $p=0.958$; sarcoidosis cohort mean confidence level 4.1 versus 3.6 for those who had discussed versus those who had not discussed optimising wellbeing with their doctor, $p=0.053$).

Analysis of the IPF cohort revealed no significant difference in the level of confidence in when to call a doctor according to mortality status, more versus less advanced disease or previous stable versus declining lung function.

Discussion

Patient confidence versus HRQOL

A lower level of confidence in when to call a doctor was associated with significantly higher scores of depression and, fatigue, and a more impaired quality of life as assessed by the EQ5D in IPF patients. Whilst patients with a higher level of confidence had fewer emergency admissions due to lung disease, there was no association of confidence with disease severity. This emphasizes the importance of obtaining patients' subjective accounts of the effect of their condition on their lives, in addition to monitoring disease progression objectively, as objective measures of disease progression may not accurately reflect the full impact IPF has on patients' lives.

For the sarcoidosis cohort, there was no association between any of the parameters tested and level of confidence in when to call a doctor.

The reasons for the difference between the IPF and sarcoidosis cohorts are unclear, however the demographics of the cohorts were different, with the IPF cohort being older, having a higher proportion of males and a higher burden of respiratory disease as assessed by the SGRQ score, which may in part explain the difference in results.

Discussion of optimisation of wellbeing

Discussion of optimisation of wellbeing was associated with higher levels of depression, dyspnoea and fatigue and a more impaired HRQOL in the sarcoidosis cohort, however no association was seen with any of the variables in the IPF cohort. As the questionnaires were only completed at a single point in time, it is unclear what impact the discussion of optimising wellbeing had on the various questionnaire scores (i.e. whether for example, high levels of depression prompted the discussion, persisted despite the discussion or arose in spite of it).

Nevertheless, it would be of value to implement interventions to try and improve the mood, breathlessness, energy levels and quality of life of these patients. Given that discussion of optimisation of wellbeing with a doctor was not associated with higher confidence levels, it seems that discussions with doctors alone is inadequate to achieve these aims.

As can be seen from Table 1, a higher proportion of IPF patients had discussed optimizing wellbeing with their doctor compared to the sarcoidosis cohort, however mean confidence levels were comparable between the two cohorts. The mean age of the IPF cohort was greater than that of the sarcoidosis cohort, which may account for the greater rate of discussion of optimising wellbeing with their doctor, as this older group of patients may have had more health concerns to address. The fact that such a high proportion of IPF patients

discussed optimising wellbeing with their doctor may have made it more difficult to detect any differences in the questionnaire values between those who did or did not discuss the topic, which may explain why the results were not statistically significant.

Our study findings highlight the importance of implementing interventions to improve confidence in patients with ILD, in order to try and improve their quality of life. These interventions may take the form of patient self-help groups, counselling, education and support. Wuyts et al. (29) have suggested that models for patient-centred care used for palliative patients may be useful in IPF to help address patient expectations when there is a poor prognosis. They suggest the utility of the “three pillars of care” model (30), encompassing disease-centred management, symptom-centred management and education and self-management.

A qualitative survey of IPF patients from five European countries (31) has highlighted the need to provide emotional support for patients from the time of their diagnosis, in view of patients reporting feelings of apprehension, confusion and devastation when being diagnosed with IPF. IPF patients have themselves expressed a need for greater healthcare support and education in the form of patient-based advocacy groups, familial support and counselling programmes (32). Patients managed at a tertiary care centre who had been given the opportunity to interact with other patients with IPF felt this was beneficial in terms of gaining psychological support and practical disease management tips, in contrast to those who were mainly managed in the community and felt less well-informed about their disease and treatment options (32).

Previous studies investigating the effect of interventions to improve education and support for IPF patients have reported positive results based on patient satisfaction surveys (11) and post-study qualitative interviews (10). Our study is the first to suggest an association

between low levels of confidence and a low level of quality of life by performing quantitative analysis using a validated measures of HRQOL. Studies of interventions aiming to promote patient empowerment in COPD have shown benefits in terms of increased cost-effectiveness of care and fewer visits by primary care physicians in the intervention group compared to the control group (33), as well as patients perceiving their condition and its treatment as less intrusive (34). Whilst there are no pre-existing studies assessing the effect of improving patient confidence in sarcoidosis and conflicting evidence in IPF, our finding of an association between low levels of confidence and a low level of quality of life suggests that it would be worth assessing whether, like in COPD patients, promoting patient confidence will have a beneficial effect on sarcoidosis or IPF patients.

Patient confidence versus discussion of wellbeing with a doctor and access to medical services

Previous discussion of how to improve wellbeing with a doctor did not seem to impact on confidence in when to call a doctor, suggesting that there were probably areas that were not addressed adequately during these discussions to improve subjects' confidence and understanding of their condition. Efforts therefore need to be made to try and adequately address patients' concerns during such discussions to promote their self-efficacy. Given that patients in the IPF Care study reported feeling more comfortable discussing their health with a nurse over the telephone than in a clinic environment (11), providing support using a variety of methods in addition to patient consultations with doctors may help to maximise patient confidence.

No significant association was found between the level of confidence in when to call a doctor and the number of times medical help was actually sought in the community. Whilst it is reassuring that a lack of confidence in seeking medical help does not translate to less utilisation of resources in the community, it is important to consider the effect of low confidence on patients' quality of life given the

findings of our study. It is unclear whether IPF patients' lack of confidence was a result of the greater level of depression, fatigue or worse quality of life, or whether it caused or exacerbated these. Helping patients to feel more confident by educating them about their condition and encouraging them to be involved with decisions regarding their care may help to improve their quality of life and have a positive impact on their level of fatigue and depression.

Study limitations

Our study had several limitations. There was recruitment bias in that the patients approached to take part in the study were those attending regular clinic appointments or support days, or had volunteered to be part of a research database. This led to an acceptance rate of 100% to take part in the study. However we obtained a large enough sample size that we feel the cohort encompasses individuals who have been affected by their conditions to varying extents and in different ways.

We did not use a validated tool to assess patient confidence, such as the Self-Efficacy for Managing Chronic Disease 6-Item Scale (35).

Furthermore, our assessment of patients' confidence was made by assessing their confidence in when to call a doctor for help about their health in general as opposed to specifically for IPF or sarcoidosis-related problems. However regardless of the fact that we did not use a validated tool or assess confidence related to patients' specific condition, we found statistically significant associations between confidence, fatigue, depression and quality of life.

Conclusion

IPF patients with higher levels of fatigue and depression, and a more impaired quality of life have a significantly lower level of confidence in

when to call a doctor, however this association was not seen in the sarcoidosis cohort. In sarcoidosis, discussion of optimising wellbeing is associated with greater levels of depression, dyspnoea, fatigue and a more impaired quality of life. Discussing improving wellbeing with a doctor however, did not impact on confidence in either cohort.

For the IPF patients, severity of lung disease and the previous degree of change of lung function were not associated with confidence, highlighting the importance of obtaining patients' subjective accounts of the effect of their condition on their lives.

Further studies are required to assess the relationship between patient confidence, disease severity and progression and HRQOL in IPF and sarcoidosis patients longitudinally, as well as to assess whether promoting patient confidence has a positive impact on their quality of life, mood and energy levels.

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Tables

Table 1: Patient demographics and lung function

Parameter	I	S
Number of people(n)	7	6
Age (years) (mean, (S.D.))	7	5
Male (n, %)	5	3
Baseline FVC % predicted (mean (S.D.))	8	9
Baseline TLCO-SB % predicted (mean (S.D.))	5	7
Follow-up in months (mean (S.D.))	2	2
More advanced-disease (n, %)	1	N
Mortality (n, %)	2	2
Total SGRQ score (mean, (S.D.))	4	3
Confidence level in when to call doctor	3	3
Discussed optimising wellbeing with	4	3

Table illustrating demographics, lung function and mean values for selected questionnaires.

Key: n = number of subjects, S.D. = standard deviation, N/A = not applicable (disease severity and decline in lung function only assessed for IPF patients)

Table 2: Spearman’s rank correlation coefficient analysis results comparing level of confidence in when to call a doctor with scores of HRQOL, duration of symptoms, emergency inpatient admissions and access to community healthcare for IPF cohort

Parameter	r	p
Age (years)	-	0
HADS-A	-	0
HADS-D	-	0
MRCd	-	0
FAS	-	0
K-BILD	0	0
EQ5D	0	0
SGRQ	-	0
Duration of cough (months)	-	0
Duration of breathlessness (months)	-	0
Total emergency inpatient admissions	-	0
Emergency inpatient admissions (lung	-	0
Times consulted doctor (community)	0	0
Times consulted nurse (community)	-	0
Times consulted other health professional	-	0

Table illustrating Spearman’s rank correlation coefficient analysis results comparing level of confidence in when to call a doctor with various parameters for the IPF cohort. Level of confidence in when to call a doctor is significantly positively correlated with the EQ5D scores, and significantly negatively correlated with HADS-DA and FAS scores and emergency inpatient admissions due to lung disease.

Table 3: Spearman’s rank correlation coefficient analysis results comparing level of confidence in when to call a doctor with scores of HRQOL, duration of symptoms, emergency inpatient admissions and access to community healthcare for sarcoidosis cohort

Parameter	r	p
Age (years)	0	0
HADS-A	-	0
HADS-D	-	0
MRCd	0	0
FAS	-	0
K-BILD	0	0
EQ5D	-	0
SGRQ	0	0
Duration of cough (months)	-	0
Duration of breathlessness (months)	-	0
Total emergency inpatient admissions	0	0
Emergency inpatient admissions (lung	0	0
Times consulted doctor (community)	0	0
Times consulted nurse (community)	0	0
Times consulted other health professional	0	0

Table illustrating Spearman’s rank correlation coefficient analysis results comparing level of confidence in when to call a doctor with various parameters for the sarcoidosis cohort. No correlation was found between any of the variables.

Table 4: Two-tailed t-test analysis results comparing patients who had discussed optimising their wellbeing with a doctor with those who had not (IPF cohort).

	D	N	
HADS-A	5	5	0
HADS-D	5	4	0
MRCd	2	2	0
AS	2	2	0
K-BILD	6	7	0
EQ5D	6	6	0
SGRQ	4	4	0

Table illustrating two-tailed t-test analysis results comparing patients who had discussed optimising their wellbeing with a doctor with those who had not (IPF cohort). There was no difference in any of the parameters according to whether patients had discussed optimising wellbeing with their doctor.

Key: S.D. = standard deviation, CI = confidence interval

Table 5: Two-tailed t-test analysis results comparing patients who had discussed optimising their wellbeing with a doctor with those who had not (sarcoidosis cohort)

	D	N	
HADS-A	7	5	0
HADS-D	6	4	0
MRCd	2	2	0
FAS	2	2	0
K-BILD	7	8	0
EQ5D	6	7	0
SGRQ	4	2	0

Table illustrating two-tailed t-test analysis results comparing patients who had discussed optimising their wellbeing with a doctor with those who had not (sarcoidosis cohort).

Patients who had discussed optimising their wellbeing with their doctor had significantly higher scores on the HADS-D, MRCd, FAS and SGRQ and significantly lower scores on the K- BILD and EQ5D.

Key: S.D. = standard deviation, CI = confidence interval