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Perceptions and beliefs in sarcoidosis

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Abstract. *Background:* Sarcoidosis is a chronic multisystem disease with a high prevalence of depression although this is often not recognised. It is not known how patients perceive their disease or the medications required for treatment. We hypothesised that perceptions of illness and beliefs about medications may relate to psychological distress in this condition. *Methods:* 81(42 female) patients with sarcoidosis completed the following: Hospital Anxiety and Depression Scale, Illness Perception Questionnaire, Beliefs about Medications Questionnaire. Demographic and clinical data were collected and the physician's perception of symptom severity and relationship to sarcoidosis recorded. *Results:* The prevalence of depression (23%) and anxiety (33%) was high and related to self reported symptoms of sarcoidosis. Those on current treatment reported different illness perceptions than those not, and illness perceptions related to anxiety and depression scores. The majority of the sample felt that sarcoid medications were unnecessary but few patients reported concerns about potential adverse consequences of taking them. Beliefs about medications were related to illness perceptions but not associated with anxiety or depression scores or with clinical perception of disease state. There were significant gender differences in perceptions of illness and beliefs about medications. *Conclusions:* These data confirm earlier reports that anxiety and depression are common in patients with sarcoidosis and in turn perceptions of illness impact on emotional wellness in this disorder. Use of the Illness Perceptions Questionnaire in clinical practice may help to identify those patients who would benefit from interventions to change their perceptions of illness. *(Sarcoidosis Vasc Diffuse Lung Dis 2010; 27: 36-42)*

Key words: sarcoidosis, medication, depression, anxiety, beliefs

Introduction

Sarcoidosis is a chronic multi-system disease with a myriad of different clinical presentations (1). Not all patients require treatment, but most remain under specialist outpatient follow-up for years, undergoing multiple investigations in order to determine the status of their disease. The cause of sarcoidosis is unknown and although the course can be self-limiting many patients diagnosed with sarcoidosis face an uncertain future with chronic disease.

Research to date suggests that the burden of chronic illness includes emotional and social factors as well as physical. Patients are required to adjust and cope with changes in their state of health which may be challenging if the illness is unpredictable, unexpected and has multiple effects (2). Few studies have investigated the psychological impact of sarcoidosis, but the disease is associated with a negative impact on quality of life and high prevalence of depression (3-5).

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The Illness Perceptions paradigm has demonstrated that the way patients cognitively represent their illness can influence their overall experience of the illness. This paradigm is based on the self-regulatory model (6) which proposes that patients create cognitive models of their illness, which aid them to understand and cope with their illness. Such cognitive models act as standards against which patients match and evaluate information about experienced symptoms (7), thus guiding illness behaviour and emotional experience. These models are constantly modified and updated as patients integrate feedback from the illness itself but also information from health care providers, media and social systems (6). In addition to holding their own cognitive models of their illness, patients have their own ideas about the necessity of taking their prescribed medications and the long term effects of medication regimens. Beliefs that taking medication will result in side effects may be a source of worry and apprehension which may lead to the treatment being feared more than the illness. Patients may eventually decline treatment if they perceive that it might diminish quality of life (8).

We hypothesised that perceptions of illness and beliefs about medications may relate to, and in turn be of use in predicting which sarcoidosis patients experience psychological distress. The aim of this study was to investigate the relationships between psychological distress, illness perceptions and beliefs about medications in patients with sarcoidosis.

METHODS

Subjects

Patients with sarcoidosis attending the Interstitial Lung Disease clinic between January 2003 and May 2005 were invited to participate. Patients were excluded from the study if they were not fluent English speakers. The study was approved by the Ministry of Health Northern Regional Ethics Committee.

Patients were given a self-administered questionnaire which included demographics, the Hospital Anxiety and Depression scale, the Illness Perceptions Questionnaire, and the Beliefs about Medications Questionnaire. A respiratory physician also completed a medical information form and clinician rating form. 87 patients consented to participate but only 81 questionnaires were returned and this formed the basis for analysis.

Psychological Questionnaires

The Hospital Anxiety and Depression Scale (HADS) (9) is a one-dimensional measure of anxiety and depression designed for use in non-psychiatric hospital clinics. The scale includes 7 anxiety and 7 depression items presented alternately. A 4 point response format is used with answers scoring 0 - 3 with a high score indicating a depression or anxiety case. This scale has demonstrated reliability and validity, including studies of sarcoidosis patients (10).

The revised *Illness Perceptions Questionnaire* (IPQ-R) (11) was used to measure illness perceptions. Eight subscales were used measuring the strength and nature of beliefs. The timeline acute/chronic subscale assesses beliefs in duration of illness (e.g. “My sarcoidosis will last a long time”) and the timeline cyclical scale assesses the degree to which the illness is considered cyclical or unstable in nature (e.g. “My symptoms of sarcoidosis come and go in cycles). The consequences subscale measures beliefs about the seriousness of the illness, in terms of social, emotional and physical factors (e.g. “My sarcoidosis strongly affects how others see me”). The personal control subscale assesses beliefs about one’s ability to control symptoms (e.g. The course of my sarcoidosis depends on me”) whereas the treatment control subscale assesses beliefs that treatment is an effective way of controlling illness (“My treatment will be effective in curing my sarcoidosis). Illness coherence measures the degree to which a structured understanding or model of illness has been developed (“My sarcoidosis is a mystery to me”) and the emotional representations subscale assesses the belief of the impact the illness has on emotion (e.g. ‘My sarcoidosis makes me angry”). Items are rated on a 5 point Likert scale from strongly agree to strongly disagree and a high score indicates a stronger belief e.g. a stronger belief that the illness will have serious consequences (physical, emotional, social). The identity subscale presents a list of 15 symptoms (e.g. pain, cough, nausea, upset stomach) that patients first rate whether they have experienced this symptom since being diagnosed with sarcoidosis and then rates whether they feel this symptom is related to sarcoidosis. Subscale scores are derived by adding together the number of symptoms related to sarcoidosis. The reliability and validity of the IPQ-R has been demonstrated across multiple illness populations.

Beliefs about medications questionnaire (BMQ) (12) is an 18 item questionnaire assessing beliefs about specific medications and beliefs about medications in general. There are 4 subscales including specific necessity (it is necessary), assessing beliefs about the necessity and efficacy of medicines prescribed for sarcoidosis (e.g. "Without sarcoidosis medicines I would be quite ill"), specific concern, assessing beliefs about concern about the harmful effects of medicines prescribed for sarcoidosis (e.g. "Having to take sarcoidosis medicines worries me"), general overuse, assessing beliefs about the overuse of medicines in general (e.g. "Doctors use too many medications") and general harm, assessing beliefs about harm associated with medications in general (e.g. medicines do more harm than good"). Items are rated on a 5 point Likert scale and a higher score indicates a stronger belief.

Clinical data and clinician ratings

Clinical data included the date of diagnosis, tissues affected by sarcoidosis, lung function and treatment history. Clinicians rated current symptoms as being related to active sarcoidosis and perception of disease state as worsening, stable or improving.

Statistical analysis

Where data was parametric data is expressed as mean (SD) and non parametric median (range). The students T test and one-way ANOVA were used to compare data between groups and Pearson's correlation coefficient to examine associations between variables. Missing data were excluded from analysis. SPSS software (version 13) was used for all analyses. A p-value of <0.05 was considered to be significant.

RESULTS

The majority of subjects were female, European, and never smokers. The demographic and clinical characteristics of the sample are presented in Table 1.

Table 1. Demographics and clinical characteristics of the 81 patients

Gender, n (%)	
Male	39 (48)
Female	42 (52)
Age (years), mean ± SD	49 ± 13
Ethnicity, n (%)	
European	58 (75)
Maori/Pacific Island	5 (7)
Indian/Asian	8 (10)
Other (not specified)	6 (8)
Smoking status, n (%)	
Never smoked	44 (55)
Quit 12+ months ago	31 (39)
Current smoker	5 (6)
Months since diagnosis (months), median (IQR)	64 (71)
FEV1 % predicted, mean ± SD (range)	82 ± 21 (24-120)
FVC % predicted, mean ± SD (range)	85 ± 21 (46-123)
Organs involved, n (%)	
Lung parenchyma	56 (69)
Hilar/mediastinal nodes	67 (82)
Nervous system	4 (4)
Eyes	10 (12)
Skin	7 (9)
Liver	4 (4)
Hypercalcemia	10 (12)
Treatment History, n (%)	
Ever received treatment	49 (60)
Receiving current treatment	31 (38)
Inhaled Corticosteroids*	8 (10)
Oral Corticosteroids*	16 (20)
Methotrexate/Azathioprine *	13 (16)
Current symptoms, n (%)	
Patient reporting current symptoms	55 (68)
Physician reporting patient has current symptoms	50 (62)
Clinician perception of disease state, n (%)	
Worsening	8 (10)
Stable	48 (59)
Improving	25 (31)

* Numbers refer to current treatment

Psychological distress

The scores from the HADS were separated into subscale scores. Zigmond and Snaith (9) suggest a cutoff score of ≥ 8 for both scales to include all possible cases. Of the 77 patients with complete HADS data, 25 (32%) patients scored above the cutoff range on the anxiety subscale and 18 (23%) on the depression subscale. Those whose sarcoidosis was rated as

Table 2. Disease state group means

Disease state	Mean	SD	p
Worsening	6.25	4.62	0.025
Stable	3.38	3.46	
Improving	5.80	3.99	

worsening had a significantly higher depression mean than those whose sarcoidosis was rated as stable and improving (Table 2). Scores of anxiety and depression were not related to length of time since diagnosis or being on current treatment. No patients at the time of study were on prescribed antidepressant medication.

Perceptions of illness

Correlations between illness perceptions subscales are shown in Table 3. The longer the duration sarcoidosis was perceived to have, the more serious the consequences were perceived to be, and weaker the belief in personal and treatment control of sarcoidosis. The more serious the consequences of sarcoidosis were perceived to be, the more sarcoidosis was associated with an unstable course, emotional impact and symptoms more likely to be identified with sarcoid. Belief in treatment control was strongly associated with a belief in personal control.

Table 4 demonstrates that there were significant gender differences in the perception of illness. Females perceived a longer illness course (timeline), a less stable course (more cyclical timeline) and made more emotional representations (ie there was more emotional impact) about sarcoidosis than males. Patients receiving current treatment perceived sarcoidosis to have a longer course, and more serious consequences than those who were not on current treatment. Those who had ever received treatment perceived sarcoidosis to have more serious consequences than those who had never received treatment. Patients whose illness was considered to be worsening by their clinician perceived there to be a longer disease course than those whose sarcoidosis was considered to be improving.

Patients who had a smoking history had a significantly higher illness coherence mean than patients who had never smoked i.e. they perceived a greater understanding of their disease. Those who were anxious had a greater sense of illness coherence than those who weren't anxious. Patients who were depressed perceived there to be more serious consequences of sarcoidosis than those who weren't depressed.

Lung function parameters correlated with illness perceptions. FEV1 correlated with shorter perceived illness duration, whilst FVC correlated with greater illness coherence. Both parameters correlated with perception of less serious consequences.

Patients who had disease confined to the lungs or hilar/mediastinal nodes did not report significant differences in their perceptions of sarcoidosis from patients with extra pulmonary manifestations.

Beliefs about medications

Few patients endorsed the belief that their current or future health depended on sarcoid medication. Only 28% of the sample reported that their medications kept their health from deteriorating. Most patients were not worried about the long-term effects of sarcoid medications including dependency. Few patients believed that doctors overused medications in general or that medications are harmful.

Table 3. Correlations between illness perceptions

	Timeline acute/chronic	Consequences control	Personal control	Treatment cyclical	Timeline representations	Emotional	Identity
Timeline acute/chronic	1						
Consequences	0.287*	1					
Personal control	-0.247*		1				
Treatment control	-0.332**		0.409**	1			
Timeline cyclical		0.331**			1		
Emotional representations		0.586**			0.368**	1	
Illness coherence						0.278*	
Identity		0.595**				0.573**	1

Data expressed as Pearson's r. *p<0.05, **p<0.01

Table 4. Illness perceptions and gender, treatment, disease state and smoking

Illness perception	Grouping variable	Mean	SD	P
Timeline	Male	2.99	0.82	0.047
	Female	3.36	0.78	
Timeline cyclical	Male	2.40	0.84	0.005
	Female	2.99	0.08	
Emotional representation	Male	2.25	0.84	0.007
	Female	2.77	0.88	
Timeline	On current treatment	3.51	0.72	0.012
	Not on current treatment	3.04	0.75	
Consequences	On current treatment	3.09	0.74	<0.001
	Not on current treatment	2.24	0.76	
Consequences	Ever had treatment	2.87	0.75	0.001
	Never had treatment	2.21	0.80	
Timeline	Worsening illness state	3.56	0.84	0.023
	Improving illness state	2.83	0.61	
Illness Coherence	Smoking history	3.41	0.86	0.014
	Never smoker	2.90	0.87	
Illness coherence	Anxiety	3.47	0.78	0.011
	No anxiety	2.92	0.90	
Consequences	Depression	3.38	0.71	<0.001
	No depression	2.41	0.79	

Beliefs about medications subscales were related to each other (table 5). The stronger the beliefs that prescribed medications were necessary for sarcoidosis, the stronger the concern about drug side effects, and the stronger the beliefs about the overuse and harm that medications in general can cause. This was irrespective of whether the patient reported current symptoms.

Table 6 demonstrates that there were significant gender differences in beliefs about medications in general. Males perceived medications in general to be more harmful than females did, and males also believed more strongly that medications are overused.

Table 6. Beliefs about medication scale according to gender

Belief about medication	Gender	Mean	SD	p
General Harm	Male	4.04	0.49	0.017
	Female	3.78	0.40	
Overuse	Male	3.99	0.46	0.011
	Female	3.65	0.57	

Beliefs about medications were related to illness perceptions. Patients who believed that sarcoidosis treatment was necessary tended to perceive less disease consequences, a more stable course and less emotional impact. Beliefs about medications were

Table 5. Correlations between beliefs about medications questionnaire subscales and illness perceptions

	Necessity	Concern	Overuse	Harm
Necessity	1			
Concern	.554*	1		
Overuse	.416**	.312*	1	
Harm	.321**		.545**	
Consequences	-.250*			
Timeline cyclical	-.379**			-.392**
Emotional representations	-.308*			

Data expressed as Pearson's r. *p<0.05, **p<0.01

not associated with anxiety or depression scores, or with clinical perception of disease state.

Discussion

These data confirm previously published observations that patients with sarcoidosis experience depression but the finding of a high rate of anxiety is novel. Anxiety and depression were clearly linked to perceptions about the disease but not to beliefs about medications although the latter did relate to perceptions of illness. Depression in sarcoidosis has been linked with disease related symptoms (5, 13), although our cohort cannot be directly compared due to differences in demographics and the instruments used to determine the prevalence of depression. Chang *et al.* reported that the prevalence of depression was much lower with fewer organ systems involved or if the patient was asymptomatic (5). The lower prevalence of depression in our cohort may reflect the fact that the majority of our sample had only two organ systems involved and with nearly a third reporting no symptoms.

These data inform us that our patients may have significant psychological distress relating to perception of their disease, irrespective of the clinical reality, and that distress is probably underestimated by their clinician. A weakness of this study is that whilst the clinician was asked about their perception of the patient's physical symptoms, he/she was not asked about perception of their psychological symptoms.

Beliefs about medications were related to perceptions of illness. This is important to consider as it demonstrates that emotional distress is related to the amount of discrepancy between beliefs patients hold about their illness and treatment, and the actual illness and treatment experience. Patients who perceived their disease in a more positive light also perceived sarcoidosis medication to be more necessary, although there were no differences in the rates of prescribed medication between these patients and those who viewed their sarcoidosis more negatively. Because we did not measure such we have no way of knowing whether these perceptions influenced adherence with prescribed medication.

Beliefs about medications were not found to be related to anxiety and depression and this could reflect the fact that our sample had relatively preserved lung function and less requirement for treatment. The lack of association between beliefs about medications and anxiety and depression, or other illness perceptions components, may have been different if a greater proportion of our sample was on current treatment.

The study did have a number of other limitations: those patients who could not answer the questions in English were excluded so biasing the cohort in favour of predominantly Caucasian respondents. In Auckland, approximately 62% of the population is Caucasian (2001 Census data) with Maori and Pacific people having the same prevalence of sarcoidosis (14). Maori and Pacific people may have very different beliefs about sarcoidosis and its treatment but the small numbers in this study did not allow for sub-group analyses. The mean lung function parameters indicate a population with less severe pulmonary disease and the prevalence of extra-pulmonary disease, so often associated with symptoms, was lower than in other reported studies (15), reflecting the heterogeneity of disease in different populations. It may be that our data would have been strengthened had we restricted recruitment on the basis of disease severity.

Care of the sarcoidosis patient in the outpatient setting centres around the physical symptoms, the extent of radiologic abnormality and physiologic impairment. Our data and that of others suggest that emotional and social issues need also to be taken into account, particularly if one is considering treatment. Use of a quality of life measure such as that developed and validated by Cox *et al.* (4) might address the patient's perception of illness. Although not yet fully tested and found to be applicable to other populations of sarcoidosis patients, such an instrument may facilitate management of the patient's perceived symptoms which include psychiatric and emotional health concerns. Use of the Illness Perceptions Questionnaire in clinical practice may help to identify those patients who could benefit from interventions to change their perceptions to align them more closely with the actual illness and treatment experience. This could also assist patients to use more adaptive coping strategies which would help to prevent anxiety and depression. Studies have demonstrated that interventions designed to address illness perceptions can improve both emotional and physical experience of illness (16-18).

In summary these data demonstrate that anxiety and depression are common in patients with sarcoidosis and in turn, perceptions of illness impact on emotional wellbeing in this disorder.

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