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Test-retest repeatability for fatigue assessment scale, short-form 6-dimension and King's sarcoidosis questionnaire in people with sarcoidosis associated fatigue

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Abstract. *Background and aim:* Patient related outcomes are important in sarcoidosis, but the medium-term repeatability of the key patient reported outcome measure is not known. We aimed to test the repeatability of the Fatigue Assessment Scale (FAS), Short Form 6-Dimension (SF-6D), and King's Sarcoidosis Questionnaire (KSQ) in free living people with sarcoidosis associated fatigue. *Methods:* Twelve people with sarcoidosis associated fatigue completed the FAS, short form 36 questionnaire (SF-36) and the KSQ at baseline and 12 weeks. The SF-6D utility was calculated from the SF-36. The difference between baseline and 12 week assessments was measured. *Results:* The interclass correlation (95% confidence interval) showed good agreement between the baseline and 3 months measurements: FAS 0.91 (0.74, 0.71), SF-36 0.98 (0.94, 1), KSQ 0.98 (0.93, 0.99), SF-6D utility 0.98 (0.93, 0.99). The baseline (standard deviation) FAS was 27.83 (5.86) and at 12 weeks was 27.25 (7.55) representing a 0.58 difference (95% CI for difference (-1.89, 3.06)), SF-6D utility was 0.69 (0.16) at baseline and 0.68 (0.17) after 3 months representing at 0.00 (-0.03, 0.03) difference and corresponding values for KSQ were 59.12 (18.68) and 56.91 (27.26) with a difference of -1.87 (5.49,1.76). *Conclusions:* There was good repeatability of FAS, SF-36, SF-6D and KSQ in free living people with sarcoidosis associated fatigue. Fatigue, general and disease specific health related quality of life showed no significant change over 12 weeks. Studies identifying changes in these outcomes can confidently report a true change and not measurement error or regression to the mean.

Key words: Sarcoidosis, Fatigue Assessment Scale, Short Form 6-Dimension

Introduction

Sarcoidosis is a chronic multisystem disorder of unknown aetiology characterised by the presence of non-caseating granulomata (1). As sarcoidosis is rarely fatal but frequently results in ongoing symptoms, assessing health related quality of life (HRQOL) is an important objective (2). HRQOL can be measured using the short-form 36 questionnaire (SF-36) and utility can be calculated from the EuroQol 5-Dimension 5-level (EQ-5D-5L) (3) or the short-form 6 dimension (SF-6D) which is derived from the SF-36 (4). Indeed the latter may be preferable to the EQ-5D-5L because it includes a vitality domain. Although the SF-36 has been used to evaluate outcomes in sarcoidosis in clinical trials (5, 6) the test-retest reliability has not been reported. Disease specific HRQOL can be undertaken using the King's Sarcoidosis Questionnaire (7) and although the short term (2-week) repeatability is known – the longer term repeatability at 3 months has not been reported.

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Being a multi-system disorder, sarcoidosis can cause a wide variety of constitutional and non-specific symptoms. The most frequent of which is fatigue which is present in up to 80% of patients (8) and is associated with reduced quality of life (9, 10). Fatigue is commonly measured in sarcoidosis using the fatigue assessment scale (FAS). This tool contains ten questions, with a score of 22 or more indicating the presence of significant fatigue (11) and a 4-point change representing a minimal clinically important difference (MCID) (12). Content validity, construct validity and internal consistency are all established. However, the test-retest reliability at 3 months in sarcoidosis remains unknown.

In addition, there was a noticeable reduction in fatigue, as measured by the FAS, in the placebo arm of an intensive controlled trial (13). This finding cannot be fully explained but it is possible that the improvement was due to positive benefits obtained from participating in a clinical trial and increases in interaction with the study team. Measuring the change in FAS after 12 weeks in those not undergoing intensive investigations and assessment, will determine the true change in fatigue due to the condition itself without the unintended counselling obtained from participating within a trial.

We therefore aimed to assess the test-retest reliability of the FAS, SF-6D and KSQ in free-living people with sarcoidosis associated fatigue and to examine the change in these questionnaires after 6 and 12 weeks.

Methods

Study design and setting

This was an observational study with the administration of questionnaires to patients with sarcoidosis at baseline and after 6 and 12 weeks. Participants either completed the questionnaires whilst attending a hospital outpatient clinic or at home and returned the questionnaires via a pre-paid postal envelope. Demographic and clinical information was obtained from the patient's medical records. The study was conducted in accordance with Good Clinical Practice and all participants gave written informed consent. Ethical approval was sought from the London - Hampstead Research Ethics Committee (19/LO/0211) and the study was registered on the ClinicalTrials.gov database (NCT04508361). Patients with sarcoidosis were also involved with the design of this study.

The study was undertaken at a specialist centre for interstitial lung disease at the Norfolk and Norwich University Hospital NHS Foundation Trust. The study commenced in April 2019 and data collection was completed by January 2020. The follow-up questionnaire measurements were completed by the participants at home.

Participants

The study population consisted of patients with sarcoidosis who were under the care of the Norfolk and Norwich University Hospital respiratory medicine department. Patients who met the entry criteria (Table 1) were approached to participate. All participants had a FAS score of greater than 21 points and were able to complete the questionnaires.

Recruitment

Participants with sarcoidosis were identified from a database of individuals expressing an interest to undertake research and from a review of medical records. In order to ensure that patients unable to travel to Norfolk and Norwich University Hospital could participate in the study, consent was taken remotely i.e. not in person. Potential participants received a copy of the patient information sheet at least 24 hours prior to a pre-arranged conversation via phone or via the internet to discuss the study organised by Norwich Research Team. When both the participant and researcher were happy that the participant understood the study implications, the participant signed and returned the consent form in a pre-paid envelope. The consent form was then counter signed by the researcher and a copy was returned to the patient by post.

Table 1. Entry criteria.

Inclusion Criteria	Exclusion Criteria
Aged 18 or over	Significant cardio-respiratory disease
Histological[a] or clinic-radiological diagnosis of sarcoidosis[b]	Chronic inflammatory conditions, other than sarcoidosis
	Any major organ disease

[a]Histology identified non-caseating granulomas consistent with sarcoidosis. [b]The diagnosis was established in a multidisciplinary team.

Study assessments

The baseline assessments took place when potential participants attend a clinic appointment or when they were in contact with the clinical or research team for another reason e.g. at the interstitial lung disease patients support group. After written informed consent had been obtained, participants completed the questionnaires and returned them in person or via a pre-paid addressed envelope. Both the 6 week and 12 week assessments were administered by post, with participants returning them in a pre-paid addressed envelope. Participants received a telephone call if they did not return the questionnaires to remind them to do so.

Demographic information including age, gender, date of diagnosis, comorbid conditions, medication, lung function and radiological staging, was obtained from the medical notes.

The following questionnaires were administered at baseline, 6 and 12 weeks:

1. Fatigue Assessment Scale (FAS) – A measure of fatigue symptoms validated in sarcoidosis populations, ranging from 10 to 50 with higher values representing greater fatigue (11). There are specified cut-off values for clinically significant fatigue (score >21) and severe fatigue (score >35).
2. Short Form 36 (SF-36) – A 36-question score measuring quality of life across multiple domains; ranging between 0 (maximum disability) and 100 (no disability) (14). The SF-36 score can be converted to utility scores using values within the questionnaire.
3. King's Sarcoidosis Questionnaire (KSQ) – A disease-specific measure of health-related quality of life; ranging between 0 and 100 with higher values representing better health (7). It has been validated in UK sarcoidosis populations.
4. Global Rating of Concept Scale (GRCS) - A ranking between 6 options to rate overall quality of life from no problem to very severe problem.

Concomitant medications

There were no restrictions on current medications for patients participating in this study.

Analysis

Scores for the SF-36 were calculated using the scoring instructions (15) and health utility values were derived from the SF-6D using existing calculated values from UK populations (4). Repeatability was assessed using the interclass correlation coefficient with a two-way mixed model assessing for absolute agreement between baseline and 12 weeks were calculated using a paired T-test. Correlations (Spearman's r value) were performed between the FAS, SF-6D utility and the KSQ (General Health Status and Lung domains) at 12 weeks. The analysis was undertaken using SPSS (IBM. SPSS statistics. Version 28.0.1.1. Armonk. NY: released 2021).

Results

A total of 52 patients were screened for inclusion into the study and 24 participants provided written informed consent. Twenty-two participants met the entry criteria and provided baseline data. They had a mean (standard deviation) FAS of 28.36 (6.4), KSQ General Health State of 55.19 (20.43), SF-36 total score of 55.28 (28.11) and SF-6D utility score of 0.65 (0.15). Fifteen participants completed the 6 week data and twelve participants completed the 12 week data (Table 2).

The interclass correlation showed good agreement between the baseline and 12 weeks measurements: FAS 0.91 (0.71, 0.98), SF-36 0.98 (0.94, 1), KSQ General Health Status 0.98 (0.93, 0.99), KSQ Lung 0.93 (0.77, 0.98), SF-6D utility 0.98 (0.93, 0.99). The FAS, SF-36 domains, SF-6D utility, GRCS and KSQ remained static over time with no significant change from baseline to 6 weeks (supplementary material S1) or 12 weeks (Table 3). The FAS was closely correlated with the SF-6D utility and the total KSQ score but not the lung domain of the KSQ (Table 4).

Discussion

We have found no evidence that fatigue, as measured by FAS, disease related quality of life, as measured by KSQ, and generic health related quality of life, as assessed by the SF 6D utility score changes significantly over 12 weeks. The 95% confidence interval for the mean change in FAS did not include the minimum important difference (12), thus we

Table 2. Participant characteristics.

	Baseline	Baseline and 6 weeks	Baseline and 12 weeks
Number (female)	22 (8)	15 (4)	12 (4)
Age, years, mean (SD)	59.7 (11.2)	61.2 (12.7)	60.2 (12.9)
Never smokers	11	10	10
BMI Kg/m2, mean (SD)	32.0 (10.1)	33.3 (11.4)	34.4 (12.6)
Disease duration, years, mean (SD)	8.2 (12.3)	8.9 (12.0)	9.0 (13.5)
Extra-pulmonary disease	5	3	1
Arthralgia	1	1	0
Erythema nodosum	3	2	1
Uveitis	1	0	0
Anti-inflammatory treatment	9	5	2
Prednisolone	8	5	2
Prednisolone plus Azathioprine	1	0	0
FEV1 absolute. (L)	2.8 (0.9)	3.0 (0.9)	2.8 (0.9)
FEV1 % predicted	94.5 (17.8)	97.3 (14.4)	94.3 (14.1)
FVC absolute (L)	3.7 (0.9)	4.0 (1.0)	3.8 (1.0)
FVC % predicted	102.0 (15.2)	104.9 (10.7)	104.0 (10.0)
TLCO absolute (mmol/min/kPa)	7.6 (2.4)	8.3 (2.5)	8.2 (2.7)

[a]There were no current smokers; SD: standard deviation, BMI: body mass index, Kg: kilograms, m: metres, FEV1: forced expiratory volume in 1 second, FVC: forced expiratory volume, DLCO: diffusing capacity of the lung for carbon monoxide. L: Litres, mmol/min/KPa: millimoles per minute per kilopascal, %: percent

Table 3. Study outcomes at baseline and 12 weeks.

	Baseline Mean (SD)	12 weeks Mean (SD)	Difference Mean (SD)	95% CI	p
FAS	27.83 (5.86)	27.25 (7.55)	0.58 (3.90)	-1.89, 3.06	0.61
SF-36					
Physical functioning	59.17 (36.05)	61.25 (34.39)	-2.08 (15.14)	-11.71, 7.54	0.64
Physical role limitation	50.00 (48.85)	50.00 (46.47)	0.00 (15.08)	-9.58, 9.58	1.00
Emotional role limitation	75.00[a] (45.23)	75.00[a] (45.23)			
Energy/ fatigue	42.08 (29.81)	35.42 (31.66)	6.67 (16.42)	-3.77, 17.10	0.19
Emotional well being	70.00 (20.64)	72.67 (18.90)	-2.67 (9.85)	-8.92, 3.59	0.37
Social functioning	65.63 (39.57)	61.46 (37.10)	4.17 (14.43)	-5.00, 13.34	0.34
Pain	56.88 (32.88)	58.13 (36.10)	-1.25 (11.10)	-8.31, 5.81	0.70
General health	45.83 (26.18)	45.00 (27.22)	0.83 (9.00)	-4.89, 6.55	0.75
Total	57.08 (29.78)	56.78 (28.64)	0.30 (7.78)	-4.64, 5.24	0.90
GRCS	1.92 (1.31)	1.92 (1.68)	0.00 (1.04)	-0.66, 0.66	1.00
KSQ					
GHS	59.12 (18.68)	60.98 (20.95)	-1.87 (5.71)	-5.49, 1.76	0.28
Lung	61.91 (27.34)	56.91 (27.26)	5.00 (13.50)	-3.58, 13.58	0.23
Medication	84.27 (30.95)	88.09 (31.53)	-3.82 (8.05)	-9.58, 1.94	0.17
SF-6D	0.69 (0.16)	0.68 (0.17)	0.00 (0.05)	-0.03, 0.03	0.76

SD: standard deviation, CI: confidence interval, FAS: Fatigue assessment scale, SF-36: Short form 36 questionnaire, GRCS: Global rating of concept scale, KSQ: King's Sarcoidosis Questionnaire, GHS: General Health Status, L: lung, E: eyes, S: skin, M: medication, SF-6D: short form 6-dimension utility. [a]values identical so T-test could not be performed.

can be confident that any potential differences are too small to be of clinical importance. We have also shown that fatigue is related to health related quality of life but not to lung symptoms in people with sarcoidosis.

The strength of this study is that it was undertaken in free-living people with sarcoidosis and did not have direct involvement or intervention from a research team. The questionnaires were completed at home and mailed to the research site. Participants received one follow-up reminder phone call if they did not complete the questionnaires but did not receive any further contact in addition to this. We are confident that our findings reflect that the degree of fatigue people with sarcoidosis experience over 3 months without influence by the medical profession or researchers represents the natural variation of the disease.

The present study is however, limited by the small sample size and the large withdrawal rate. It is possible that a clinically significant difference would

Table 4. Spearman's Correlation coefficients for comparison between the outcome questionnaires.

	SF-36	KSQ GHS	KSQ Lung	SF-6D
FAS	-0.88	-0.87	-0.65	-0.88
SF-36		0.94	0.72	0.95
KSQ GHS			0.64	0.92
KSQ Lung				0.70

SF-6D: short form 6 dimension utility, FAS: Fatigue assessment scale, KSQ: King's Sarcoidosis Questionnaire, GHS: General Health Status. All values have p<0.001.

have been identified between the various assessment tools had a larger sample size been recruited, however, given the small absolute difference in value, this is unlikely. We believe that people with a greater change in fatigue or quality of life would be more engaged in reporting their findings to the research team and that the large withdrawal rate does not influence the overall conclusion of the study. In other words, the lack of difference is not due to a disproportionate number of people with improvement or deterioration withdrawing from the study; there was no difference between the baseline FAS values of those providing data at 6 weeks (28.1) (supplementary material, Table S1) and 12 weeks (27.3) (Table 3).

There are several differences between the findings of this study and our previous feasibility study exploring the study design of a trial to evaluate methylphenidate in sarcoidosis (13). Firstly, in contrast to the large change in FAS in the placebo group in the feasibility study, we showed no difference in FAS in this study after 12 weeks. Possible explanations for this include the placebo effect, where beneficial effects are experienced from receiving an inert intervention (16), or the 'Hawthorne effect', which is a phenomenon where participants in an experimental study change their behaviour or performance as they are aware that they are being observed (17). The latter explanation credits the frequent study visits in the feasibility study as likely having resulted in a larger change in FAS. Other studies have reported significant improvements in placebo groups due to intensive monitoring (18); indeed, in a trial with low and high intensity follow-up placebo arms, the outcomes were better in the latter group (19).

In the study of fatigue specifically, cancer patients enrolled in open label placebo trials and assigned to the placebo group have demonstrated improvements in fatigue, compared to patients who were not given placebo medication but still enrolled in the trial with treatment as usual or waitlist control (20, 21). This substantiates the explanation placebo, or its biological mechanism is linked to fatigue.

A prolonged period of observation is not guaranteed to reduce the Hawthorne effect and methods such as creating a separate control group which is unrelated to the trial (such as this sample in comparison to the previous study or triangulation, where data is collected from different perspectives, are required (22). The feasibility study may also have exhibited a placebo effect which is evident in subjective continuous outcomes (23). Secondly, we had a 30% withdrawal rate to completion compared to no withdrawals in the feasibility study. The closer observation in the feasibility study may have resulted in better engagement in the study and reduced the withdrawal rate.

Other studies have evaluated the repeatability of FAS and other sarcoidosis questionnaires used in this study. In the study by de Kleijn *et al* (12) to determine the minimal important difference for the FAS, the FAS was repeated after 12 months. Although the difference between the two measurements is not reported, there were similar numbers of people with improved and worsened fatigue (12) suggesting little change in the overall mean score which is in keeping with the findings of our study. The two week repeatability of KSQ is good with interclass correlation coefficients for modules of 0.90–0.96 (7). In a recent study of low dose dexamethasone, the change in SF-36 General Health Score was 6 units compared to 1.5 units in our study, with both values representing a non-significant change.

FAS has been compared to the SF-36 in patients with sarcoidosis with pearson correlation coefficients of -0.63 for the physical component score and -0.51 for the mental component score (24). Our findings for the relationship between FAS and SF-6D utility are in keeping with these studies.

In conclusion, this study has shown that fatigue and HRQOL remain stable over a period of 12 weeks in free-living people with sarcoidosis. It therefore assumes that changes in patient related outcome measurements in the placebo or control groups of clinical trials are due to their involvement in the trial rather than spontaneous improvement of their condition. These findings are important for designing future clinical trials in studies with subjective outcome measures such as fatigue. Future studies should also focus on the inclusion of sufficient participants to achieve larger sample sizes.

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Conflict of Interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

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AppendixOriginal article

Supplementary Table S1. Study outcomes at baseline and 6 weeks.

	Baseline Mean (SD)	6 weeks Mean (SD)	Difference Mean (SD)	95% CI	p
FAS	28.21 (5.62)	28.21 (5.62)	0.29 (1.77)	-0.74, 1.31	0.56
SF-36					
Physical functioning	51.00 (36.07)	51.00 (36.07)	7.00 (14.98)	-1.29, 15.29	0.09
Physical role limitation	30.00 (40.31)	30.00 (40.31)	8.33 (22.49)	-4.12, 20.79	0.17
Emotional role limitation	62.22 (45.19)	62.22 (45.19)	8.89 (26.63)	-5.86, 23.63	0.22
Energy/fatigue	34.00 (29.89)	34.00 (29.89)	4.33 (14.98)	-3.96, 12.63	0.28
Emotional well being	67.47 (23.99)	67.47 (23.99)	1.33 (18.56)	-8.94, 11.61	0.78
Social functioning	55.83 (36.86)	55.83 (36.86)	5.83 (15.57)	-2.79, 14.46	0.17
Pain	61.67 (32.16)	61.67 (32.16)	-10.67 (24.56)	-24.27, 2.93	0.11
General health	38.33 (30.51)	38.33 (30.51)	2.00 (11.31)	-4.26, 8.26	0.50
Total	48.82 (29.40)	48.82 (29.40)	4.26 (9.68)	-1.10, 9.63	0.11
GRCS	2.20 (1.52)	2.20 (1.52)	-0.13 (0.83)	-0.60, 0.33	0.55
KSQ					
GHS	55.27 (19.48)	55.27 (19.48)	0.79 (8.29)	-3.80, 5.39	0.72
Lung	58.80 (25.19)	58.80 (25.19)	5.37 (13.29)	-1.98, 12.73	0.14
Medication	84.34 (29.83)	84.34 (29.83)	-2.09 (10.47)	-8.14, 3.95	0.47
SF-6D	0.66 (0.17)	0.66 (0.17)	0.01 (0.08)	-0.03, 0.06	0.56

SD: standard deviation, CI: confidence interval, FAS: Fatigue assessment scale, SF-36: Short form 36 questionnaire, GRCS: Global rating of concept scale, KSQ: King's Sarcoidosis Questionnaire, GHS: General Health Status, L: lung, E: eyes, S: skin, M: medication, SF-6D: short form 6 dimension utility.