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Validation of the King's Sarcoidosis Questionnaire (KSQ) in a Dutch sarcoidosis population

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Abstract. *Background:* The King's Sarcoidosis Questionnaire (KSQ) is a brief questionnaire assessing health status using five modules (General Health Status, Lung, Medication, Skin, Eyes) in patients with sarcoidosis. The KSQ was only validated in one English sarcoidosis cohort. *Objective:* The aim of this study was to validate the KSQ in a Dutch sarcoidosis population. *Methods:* The KSQ was translated according to international guidelines and tested in interviews with patients. Consecutive outpatients completed multiple questionnaires twice, two weeks apart. Construct validity, internal consistency and repeatability were determined. *Results:* Of the 98 patients included 85 had lung, 22 skin and 24 eye disease. There was good construct validity of the KSQ General Health Status module against the World Health Organization Quality of Life-BREF questionnaire. The Medication module correlated weak to moderate with most questionnaires. The correlations with organ-specific questionnaires varied from strong for Eyes (r=0.75), Skin (r=-0.62) to moderate for Lung (r=-0.45 with MRC breathlessness scale). Internal consistency was good for all KSQ modules (Cronbach's α 0.72-0.93). Intraclass correlation coefficients (0.70-0.90) and Bland-Altman plots showed good repeatability of the KSQ. *Conclusion:* The Dutch KSQ is the first translation of the English KSQ, validated in a Dutch sarcoidosis population. *(Sarcoidosis Vasc Diffuse Lung Dis 2016; 33: 75-82)*

Key words: sarcoidosis, health status, questionnaire, quality of life

Introduction

Sarcoidosis is a heterogeneous multisystem disease with different clinical phenotypes. Sarcoidosis manifests most commonly in the lungs, but can affect skin, eyes, lymphatic nodes and other organs as well (1). Health status is impaired in the majority of patients with sarcoidosis due to symptoms such as dyspnea, persistent cough, peripheral pain, fatigue and cognitive dysfunction, leading to limitations in activities, social isolation and depression (1-3). Therapy for sarcoidosis often leads to side effects impacting health status (4, 5). In recent years patient related outcome measures (PROMs) have gained increasing importance in clinical trials and health status is now

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a standard outcome measure (6). Most studies evaluating health status used generic questionnaires such as the World Health Organization Quality of Life-BREF (WHOQOL-BREF) or the MOS 36-item Short Form Health Survey (SF-36), both non-disease specific questionnaires (7-12). Currently, no sarcoidosis specific instruments measuring health status in patients with sarcoidosis are available in Dutch. In 2012 the King's Sarcoidosis Questionnaire (KSQ) was developed (13). This self-administered measure for sarcoidosis covers different domains of health status; General Health Status (GHS), Lung (L), Medication (M), Skin (S) and Eyes (E). The aim of this study was to validate the KSQ in a Dutch sarcoidosis population.

Methods

Translation validation

The KSQ was translated from English to Dutch according to a multi-step forward-backward procedure, following international guidelines (14-16), and was reviewed by sarcoidosis experts and the developers (online supplement 1). The relevance and applicability of the translated KSQ was tested using ten structured patient interviews.

Psychometric validation

Subjects

In July 2014 consecutive sarcoidosis outpatients of the pulmonary department of the Erasmus Medical Center were asked to participate. During the same period sarcoidosis outpatients of the ild care team, Hospital Gelderse Vallei were approached by email. Patients were excluded from the study if they were unable to understand questionnaires due to intellectual impairment or language barrier, when comorbidities that severely impact health status existed (such as malignancies, collagen vascular diseases and cardiac failure other than due to sarcoidosis) or when they had unstable disease as considered by the treating physician. If patients completed less than 85% of a questionnaire they were withdrawn from the study. Formal consultation with the Medical Ethical Committee of the Erasmus Medical Center learnt that, under the Dutch act for medical research involving human subjects (Wet Medisch Onderzoek), approval of this study by the Medical Ethical Committee is not required.

Study procedure

All patients were asked to complete up to seven questionnaires (depending on organ involvement) in addition to the KSQ: WHOQOL-BREF (7), Fatigue Assessment Scale (FAS) (17), Small Fiber Neuropathy Screening List (SFNSL) (18), Medical Research Council dyspnea scale (MRC dyspnea scale) (19), Dermatology Life Quality Index (DLQI) (20), National Eye Institute Visual Function Questionnaire (NEI-VFQ25) (21) and Euroqol-5D-5 level (EQ-5D-5L) (22). Online supplement 2 shows the organ specific questionnaires and corresponding KSQ modules. Patients also completed two general health status measurements: Punum Ladders (23) and Global Rating of Change-Quality of Life (GRC-QoL) (24). Patients were asked to self-complete the questionnaires at home, two weeks apart.

Results of routinely measured pulmonary function outcomes were gathered from the medical records. The diagnosis of sarcoidosis was established when there was compatible clinical behaviour and pathological or BAL confirmation, according to international guidelines (25). Patients were asked about their organ involvement during a short face to face interview or interview by telephone.

Statistical analysis

Data are presented as mean values (± standard deviation). KSQ scores were calculated on a logit scale as this scale is more linear and has the potential to perform better at the extreme ends of health related QoL (26). The validity of the KSQ remains unchanged from the original format (27). Construct validity between the general and organ specific domains of KSQ and the corresponding questionnaires were determined using Pearson's correlation coefficients. A correlation coefficient of < 0.30 is considered weak, 0.30-0.50 moderate and > 0.50 strong (16). Cronbach's α coefficient was used to determine the internal consistency of the reliability of the KSQ. A minimum of 0.70 is considered a good internal consistency. Bland-Altman plots and intraclass cor-

relation coefficients were used to evaluate the repeatability at baseline and at two weeks, in patients with stable disease. To assess stable disease we used Punum ladders (23). Patients with ≥ 4 differences in Punum score were excluded in the repeatability analyses. The limits of agreement were calculated as mean ± 1.96 X SD of within-subject differences. Values of $p < 0.05$ were considered statistically significant. All data were analyzed with SPSS version 21.

Results

Translation validation

A Dutch version of the KSQ, achieved after forward and backward translation, was approved by the KSQ developers. Following this approval, ten patient interviews with the Dutch version of the KSQ took place (step T3 online supplement 1). Discussion of these interview results with the KSQ developers did not necessitate any further adaptations of the translation and resulted in the final Dutch KSQ-version (online supplement 3).

Psychometric validation

One hundred and four consecutive outpatients in the Erasmus Medical Center were evaluated for participation, 89 were interested and 54 participated in this study. At the same time 117 patients of the ild care team, Hospital Gelderse Vallei were approached by email, 60 patients responded and 44 were recruited. Reasons for exclusion were: clinical instability (15), comorbidity that severely impacted quality of life (14), no PA/BAL confirmation (9), not able to read or write Dutch (5) or other reasons (8) (not willing to participate, not reachable by telephone or by email, participating in another study). Thus in total 98 patients were included. Eighty-eight (90%) of them completed week zero and 83 (85%) week two (figure 1).

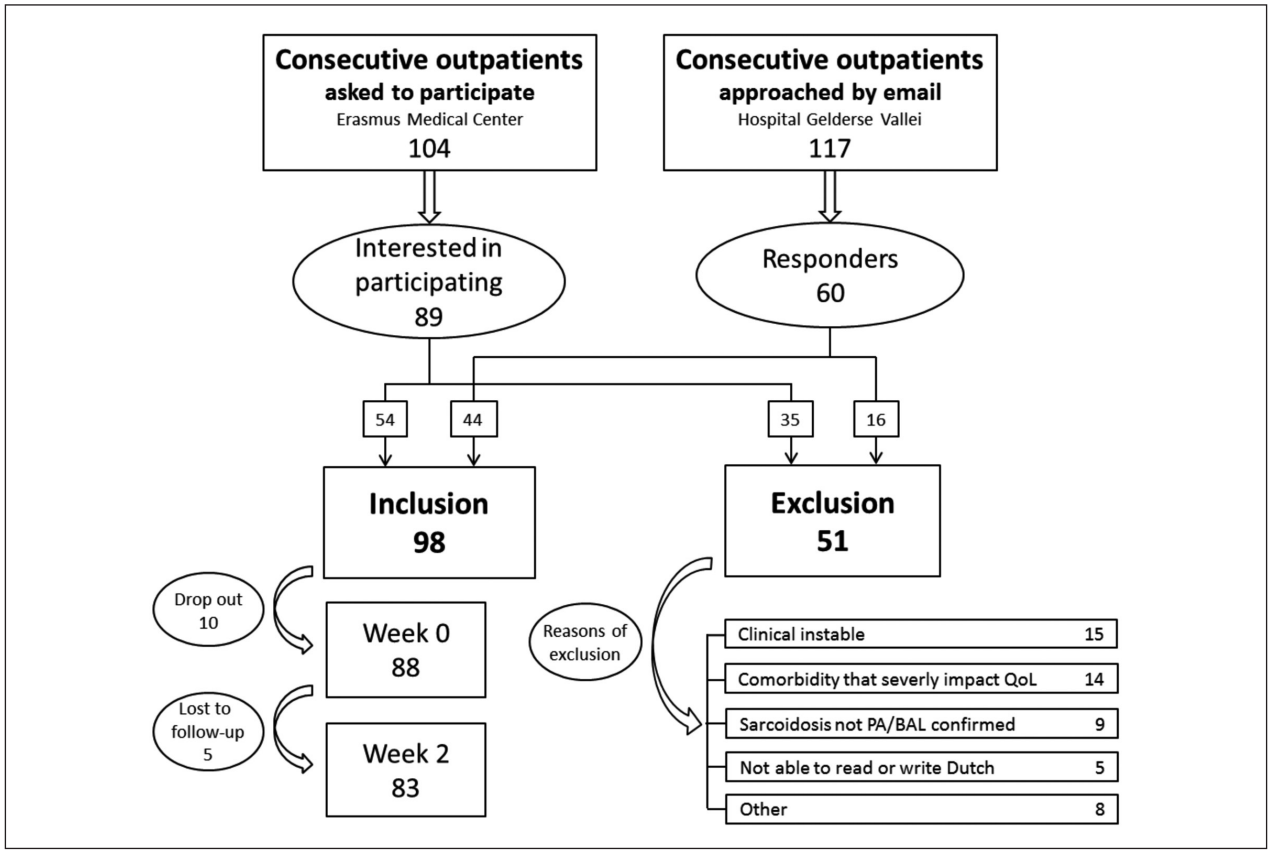

Fig. 1. Study design

Demographics

Table 1 shows the demographics of the patients included. Patients with two or more organs involved showed a significantly worse health status than patients with single-organ disease: mean (SEM) KSQ GHS score 53(1.6) versus 68(3.7); mean difference 15; 95% Confidence Interval (CI) 7-23; p = 0.001. No significant difference was found between the KSQ GHS score for females compared with males: mean (SEM) 54(2.5) versus 60(2.3); mean difference 5; 95% CI 1-12, p = 0.115. Patients with more complaints of fatigue (FAS score ≥ 22) have a significantly worse health status (mean (SEM) KSQ GHS 52(1.5)), than those with lower FAS scores (mean (SEM) 76(3.2); mean difference KSQ GHS -24; 95% CI -30 to -17, p = 0.000).

Construct validity

The correlations between the KSQ GHS domain and all generic questionnaires (WHOQOL-BREF and EQ-5D-5L) were strong (r= 0.50-0.84). KSQ organ modules combined with the GHS module all showed a moderate to strong correlation with the WHOQOL-BREF and EQ-5D-5L (r= 0.44-0.85). The Medication module showed a weak to moderate correlation with the generic questionnaires (r= 0.26-0.47) (Table 2).

All KSQ modules correlated moderately to strongly with the FAS. The relationship between the KSQ organ-specific modules and their corresponding organ-specific questionnaires was also moderate to strong. The Lung module was weakly correlated with the FVC% predicted (r= 0.24) (Table 2).

Reliability

All domains of the KSQ had good internal consistency, Cronbach α; 0.90 (GHS), 0.91 (Lung), 0.72 (Medication), 0.84 (Skin), and 0.93 (Eyes). With regard to the repeatability (test-retest) 83 patients (lung n= 80, skin n= 20 and eyes n= 22) completed the KSQ twice. The following intraclass correlations were found: GHS 0.85, Lung 0.74, Medication 0.70, Skin 0.77, Eyes 0.90, suggesting a good reliability. Twelve patients in the GHS and 13 patients in the Lung module groups were

Table 1. Patient demographics

		Organ involvement		
	All patients	Lung	Skin	Eyes
Number	88	85	22	24
Age, years, mean (SD)	52 (11)	51 (11)	52 (11)	52 (13)
Women, n (%)	36 (41)	35 (41)	10 (46)	11 (46)
Ethnicity, n (%)				
Caucasian	70 (80)	67 (79)	17 (77)	16 (67)
Afro-American	2 (2)	2 (2)	-	-
Surinamese-Hindi	13 (15)	13 (15)	4 (18)	5 (21)
Morrocan	2 (2)	2 (2)	1 (5)	2 (8)
Unknown	1 (1)	1 (1)	-	1 (4)
Smoking status, n (%)				
Current	3 (3)	3 (4)	-	1 (4)
Ex	15 (17)	15 (18)	5 (23)	8 (33)
Never	64 (73)	61 (72)	15 (68)	12 (50)
Unknown	6 (7)	6 (7)	2 (9)	3 (13)
Time since diagnosis, years, mean (SD)	8.0 (8.8)	8.1 (8.9)	7.4 (10.5)	8.4 (11.2)
Organs involved, n (%)				
Lungs	85 (97)			
Skin	22 (25)			
Eyes	24 (27)			
Small nerve fibers	26 (30)			
FVC % predicted, mean (SD), [n]	92 (20) [84]	91 (20) [81]		
FEV1/FVC ratio % predicted, mean, [n]	76 (13) [74]	76 (13) [72]		
TLCOc % predicted, mean (SD) , [n]	81 (21) [73]	81 (21) [70]		
TLC % predicted, mean (SD) , [n]	86 (18) [57]	86 (18) [56]		

FVC, forced vital capacity; FEV1, forced expiratory volume in 1 s; TLCO, diffusing capacity of the lung for carbon monoxide, corrected for hemoglobin level; TLC, total lung capacity as % predicted.

Table 2. The relationship between KSQ and disease-specific outcome measures

	Generic QoL						Fatigue	Lung		Skin	Eye	SFN
	WHOQOL-BREF				EQ-5D-5L		FAS	FVC	MRC	DLQI	NEIVFQ-25	SFNSL
	DOM1	DOM2	DOM3	DOM4	Index Value	VAS	Total	%Pred	Breathlessness	Total	Total	Total
KSQ modules												
General Health Status	0.84	0.70	0.61	0.50	0.69	0.67	-0.81	-	-0.29	-0.43*	0.52	-0.60
Lung	0.55	0.52	0.47	0.44	0.55	0.39	-0.63	0.24*	-0.45	-	-	-0.56
Skin	0.37**	0.46*	0.35**	0.44*	0.48*	0.32**	-0.50*	-	-	-0.62	-	-0.37**
Eyes	0.36**	0.32**	0.51*	0.45*	0.49*	0.28**	-0.56	-	-	-	0.75	-0.59
Medication	0.47	0.31	0.28*	0.36	0.30	0.26*	-0.39	-	-0.19**	-0.45**	0.66	-0.33
Overall Health Status												
Lung + GHS	0.79	0.68	0.60	0.52	0.68	0.59	-0.79	0.15**	-0.40	-	-	-0.64
Skin + GHS	0.85	0.83	0.70	0.64	0.61	0.44*	-0.76	-	-	-0.51*	-	-0.63
Eyes + GHS	0.72	0.56	0.62	0.58	0.81	0.68	-0.74	-	-	-	0.75	-0.69
Lung + Skin + GHS	0.77	0.76	0.65	0.65	0.58	0.35**	-0.72	0.18**	-0.13**	-0.60	-	-0.64

Data shown are Pearson's correlation coefficients for organ-specific comparisons. All p<0.01 except *p<0.05 and >0.01 and **p>0.05 (not significant). WHOQOL-BREF, World Health Organization Quality of Life-Brief questionnaire; DOM1 = physical, DOM2 = psychological, DOM3 = social relationships, DOM4 = environment; EQ-5D-5L, Euroqol-5D-5 level; FAS, Fatigue Assessment Scale, FVC, forced vital capacity; MRC, Medical Research Council dyspnea scale; DLQI, Dermatology Life Quality Index; NEIVFQ-25, National Eye Institute Visual Function Questionnaire-25; SFN, small fiber neuropathy, SFNSL, Small Fiber Neuropathy Screening List.

excluded from the analysis for repeatability, because they did not show stability in their Punum scores. The Bland-Altman plots in figure 2 and 3 show the repeatability of the KSQ GHS and Lung module, respectively. Both plots have a few outliers (outside the 95% of limits of agreement). We found a mean difference between the first and second measurement of 2.20 in the KSQ GHS module and 2.45 in the Lung module.

Discussion

The Dutch KSQ is the first health status questionnaire for sarcoidosis in the Netherlands. It is also the first non-English validation of the questionnaire. The KSQ is simple to administer, adaptable to individual organ involvement and shown to be a valid and reliable health status measurement in Dutch patients with sarcoidosis.

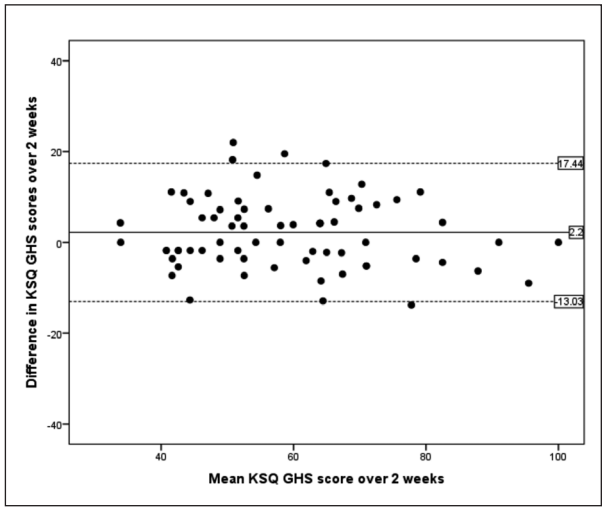

Fig. 2. Bland Altman plot of repeatability of King's Sarcoidosis Questionnaire General Health Status module. Solid line represents mean difference and dashed lines represent 95% limits of agreement

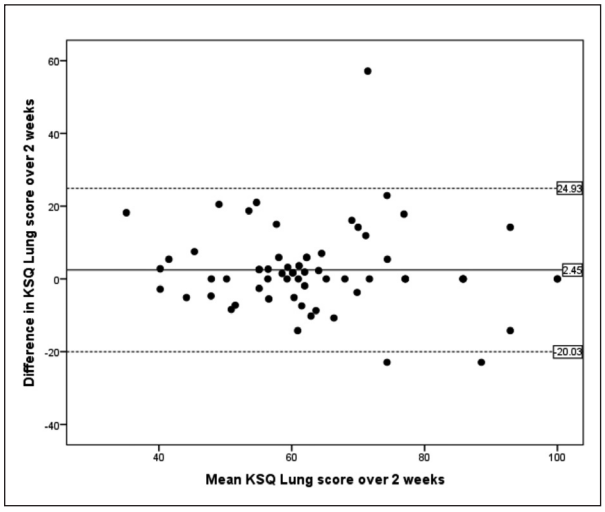

Fig. 3. Bland Altman plot of repeatability of King's Sarcoidosis Questionnaire Lung module. Solid line represents mean difference and dashed lines represent 95% limits of agreement

PROMs are becoming more important in clinical trials and daily care (6). Health status is nowadays a standard outcome measure. Most sarcoidosis studies use non-disease specific questionnaires such as the WHOQOL-BREF and the SF-36 (10-12). The KSQ is a self-administered sarcoidosis specific instrument. The KSQ questionnaire was originally developed in the UK and was not available in languages other than English. The availability of the KSQ in other languages could facilitate international collaboration aiming at measuring, comparing and improving health status in patients with sarcoidosis, which is often severely affected. During translation in Dutch and the patient interviews no major cultural difference was noted and the questionnaire was considered comprehensible and relevant by Dutch patients.

The patient demographics of the current Dutch study population were in line with the original study, though there were slightly more Caucasians in our study and lung function was less severely affected (13). Quality of life was worse in females similar to Patel et al. but in contrast did not reach statistical significance (13, 28).

The following domains of health status are covered in the KSQ: General Health Status, Lung, Medication, Skin and Eyes. Construct validity of the organ-specific questionnaires with their corresponding modules is similar to the development paper (13). The KSQ Lung module showed a weaker correlation with the MRC. In the original article from Patel et al. the MRC dyspnea scale as well as the St. George Respiratory Questionnaire (SGRQ) was used. They found a Pearson's correlation of -0.58 for the MRC dyspnea scale and -0.85 for the SGRQ. It therefore seems that the MRC dyspnea scale is a less reliable tool to assess construct validity in this population. We did not include the SGRQ, because of the high number of questionnaires patients had to complete for validation and we feared this would lead to 'questionnaire fatigue'. Moreover, the SGRQ is a disease-specific questionnaire developed for chronic obstructive pulmonary disease, with 50 items and no questions about skin or eye involvement.

We found a difference in study population between Patel et al. and ours; our population had less patients with a severe impairment of the lungs, which is shown in the difference in TLCOc% predicted (63 vs. 81 in our group) (13). This could also explain the weaker correlation found between the Lung module and FVC% predicted (r= 0.24). To date, this lack of correlation between health status questionnaires and lung function has often been reported in other pulmonary diseases as well (29). This underlines the idea that health status questionnaires measure different aspects of disease severity and therefore are very important additional outcome measures. When combined with the KSQ GHS module all organ-specific KSQ modules showed a better correlation with the generic questionnaires. This supports the use of organ-specific modules in combination with the GHS module.

Fatigue is a major problem in patients with sarcoidosis with an important impact on health status (30). This was reflected by a strong correlation between the FAS and GHS. This confirms that the KSQ also captures influence on health status caused by fatigue (13). Our results are in line with other studies showing the major effect of fatigue on the wellbeing of patients (30).

Small fiber neuropathy related symptoms, which are disabling and difficult to control, can also significantly reduce health status (31). We chose to include the SFNSL questionnaire to evaluate if the KSQ also captures this problem as this had not been evaluated before. Strong correlations with the SFNSL were found by combining the KSQ GHS and the organ-specific KSQ modules. This suggests that the KSQ captures the small fiber neuropathy related influences on health status.

In line with Patel et al. findings, weak to moderate correlations were found between the optional Medication module and almost all questionnaires (13). Therapy for sarcoidosis, as for instance corticosteroids, often causes burdensome side effects. It is tempting to speculate that these side effects may have affected health status more than the symptoms of sarcoidosis. In both Patel et al. and the present study the Medication module does not contribute much. Longitudinal studies are needed with changes in medication to see if the KSQ captures influences of medication on health status.

According to the study of Patel and colleagues, we found that the KSQ has a good internal consistency (13). Reliability was also assessed with Bland-Altman plots showing good repeatability (test-retest) in measurements.

At the time of this study, the Sarcoidosis Health Status Questionnaire (SHQ) was the only alterna-

tive sarcoidosis health status questionnaire (32). In our view this 29-item instrument, developed in 2001, has some important limitations. It contains only few organ-specific questions, has not been validated for eye and skin disease and can, therefore, not be tailored to individual clinical phenotypes. Furthermore, the SHQ is mostly longer than the KSQ, because most patients do not have to fill in all the organ-specific KSQ modules.

Recently, Judson et al. validated a new patient reported outcome measure, the Sarcoidosis Assessment Tool (SAT) (31, 33). The SAT was constructed in a similar way as the KSQ and also consists of organ-specific modules. With 51 questions it is considerably longer than the KSQ. The SAT was validated in an interventional study giving the advantage that the MCID has been calculated (5). However, to our knowledge repeatability has not yet fully been assessed making it difficult to conclude if a difference in scores indicates a low repeatability or a true change in health status. It would be valuable to compare the different sarcoidosis questionnaires prospectively.

In sarcoidosis any organ can be involved and it remains unclear if the KSQ will also capture the impact of more rare forms of sarcoidosis on health status. Another limitation of our study is the lack of follow-up after two weeks. Responsiveness of the questionnaire can thereby not be assessed. Further research, through longitudinal studies in larger patient cohorts, is warranted to determine the responsiveness, the influence of rarer disease forms and the value of the Medication module.

In conclusion, the Dutch KSQ is the first translation of the English KSQ, validated in a Dutch sarcoidosis population.

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References

1. Valeyre D, Prasse A, Nunes H, Uzunhan Y, Brillet PY, Muller-Quernheim J. Sarcoidosis. Lancet 2014 Mar 29; 383(9923): 1155-67.
2. Victorson DE, Cella D, Grund H, Judson MA. A conceptual model of health-related quality of life in sarcoidosis. Qual Life Res 2014 Feb; 23(1): 89-101.
3. Drent M, Wirnsberger RM, Breteler MH, Kock LM, de Vries J, Wouters EF. Quality of life and depressive symptoms in patients suffering from sarcoidosis. Sarcoidosis Vasc Diffuse Lung Dis 1998 Mar; 15(1): 59-66.
4. Vorselaars AD, Cremers JP, Grutters JC, Drent M. Cytotoxic agents in sarcoidosis: which one should we choose? Curr Opin Pulm Med 2014 Sep; 20(5): 479-87.
5. Judson MA, Baughman RP, Costabel U, et al. Safety and efficacy of ustekinumab or golimumab in patients with chronic sarcoidosis. Eur Respir J. 2014 Nov; 44(5): 1296-307.
6. Belkin A, Swigris JJ. Health-related quality of life in idiopathic pulmonary fibrosis: where are we now? Curr Opin Pulm Med 2013 Sep; 19(5): 474-9.
7. Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group. Psychol Med 1998 May; 28(3): 551-8.
8. Alilovic M, Peros-Golubicic T, Radosevic-Vidacek B, et al. WHOQOL-bREF questionnaire as a measure of quality of life in sarcoidosis. Coll Antropol 2013 Sep; 37(3): 701-6.
9. Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care 1992 Jun; 30(6): 473-83.
10. Bourbonnais JM, Malaisamy S, Dalal BD, Samarakoon PC, Parikh SR, Samavati L. Distance saturation product predicts health-related quality of life among sarcoidosis patients. Health Qual Life Outcomes 2012; 10: 67.
11. Elfferich MD, De Vries J, Drent M. Type D or 'distressed' personality in sarcoidosis and idiopathic pulmonary fibrosis. Sarcoidosis Vasc Diffuse Lung Dis 2011 Jul; 28(1): 65-71.
12. Heij L, Niesters M, Swartjes M, et al. Safety and efficacy of ARA 290 in sarcoidosis patients with symptoms of small fiber neuropathy: a randomized, double-blind pilot study. Mol Med 2012; 18: 1430-6.
13. Patel AS, Siegert RJ, Creamer D, et al. The development and validation of the King's Sarcoidosis Questionnaire for the assessment of health status. Thorax 2013 Jan; 68(1): 57-65.
14. Acquadro C, Conway K, Hareendran A, Aaronson N, European Regulatory I, Quality of Life Assessment G. Literature review of methods to translate health-related quality of life questionnaires for use in multinational clinical trials. Value Health 2008 May-Jun; 11(3): 509-21.
15. U.S. Department of Health and Human services Food and Drug Administration. Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims. December 2009.
16. Cohen J. Statistical power analysis for the behavioral sciences. Hillsdale, NJ: Lawrence Erlbaum Associates; 1988.
17. Michielsen HJ, De Vries J, Van Heck GL, Van de Vijver FJ, Sijtsma K. Examination of the Dimensionality of Fatigue: The Construction of the Fatigue Assessment Scale (FAS). Eur J Psychol Assess. 2004; 20(1): 39-48.
18. Hoitsma E, De Vries J, Drent M. The small fiber neuropathy screening list: Construction and cross-validation in sarcoidosis. Respir Med 2011 Jan; 105(1): 95-100.
19. Michielsen HJ, Drent M, Peros-Golubicic T, De Vries J. Fatigue is associated with quality of life in sarcoidosis patients. Chest 2006 Oct; 130(4): 989-94.
20. Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)--a simple practical measure for routine clinical use. Clin Exp Dermatol 1994 May; 19(3): 210-6.
21. Mangione CM, Lee PP, Gutierrez PR, et al. Development of the 25-item National Eye Institute Visual Function Questionnaire. Arch Ophthalmol 2001 Jul; 119(7): 1050-8.
22. Herdman M, Gudex C, Lloyd A, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Qual Life Res 2011 Dec; 20(10): 1727-36.
23. Fletcher KE, French CT, Irwin RS, Corapi KM, Norman GR. A

prospective global measure, the Punum Ladder, provides more valid assessments of quality of life than a retrospective transition measure. J Clin Epidemiol 2010 Oct; 63(10): 1123-31.
24. Kamper SJ, Maher CG, Mackay G. Global rating of change scales: a review of strengths and weaknesses and considerations for design. J Man Manip Ther 2009; 17(3): 163-70.
25. Statement on sarcoidosis. Joint Statement of the American Thoracic Society (ATS), the European Respiratory Society (ERS) and the World Association of Sarcoidosis and Other Granulomatous Disorders (WASOG) adopted by the ATS Board of Directors and by the ERS Executive Committee, February 1999. Am J Respir Crit Care Med 1999 Aug; 160(2): 736-55.
26. Patel AS, Siegert RJ, Bajwah S, et al. Rasch analysis and impact factor methods both yield valid and comparable measures of health status in interstitial lung disease. J Clin Epidemiol. 2015 Apr 10.
27. Sinha A, Bajwah S, Gosker HR, et al. A comparison of two scoring methods for the King's Sarcoidosis Questionnaire. Abstract accepted for the ERS 2015.
28. De Vries J, Van Heck GL, Drent M. Gender differences in sarcoidosis: symptoms, quality of life, and medical consumption. Women Health 1999; 30(2): 99-114.
29. Obaseki DO, Erhabor GE, Awopeju OF, Obaseki JE, Adewole OO. Determinants of health related quality of life in a sample of patients with chronic obstructive pulmonary disease in Nigeria using the St. George's respiratory questionnaire. Afr Health Sci 2013 Sep; 13(3): 694-702.
30. Drent M, Lower EE, De Vries J. Sarcoidosis-associated fatigue. Eur Respir J 2012 Jul; 40(1): 255-63.
31. Judson MA, Costabel U, Drent M, et al. The WASOG Sarcoidosis Organ Assessment Instrument: An update of a previous clinical tool. Sarcoidosis Vasc Diffuse Lung Dis 2014; 31(1): 19-27.
32. Cox CE, Donohue JF, Brown CD, Kataria YP, Judson MA. The Sarcoidosis Health Questionnaire: a new measure of health-related quality of life. Am J Respir Crit Care Med 2003 Aug 1; 168(3): 323-9.
33. Judson MA, Mack M, Beaumont JL, Watt R, Barnathan ES, Victorson DE. Validation and important differences for the Sarcoidosis Assessment Tool. A new patient-reported outcome measure. Am J Respir Crit Care Med 2015 Apr 1; 191(7):786-95.