# Health Related Quality of Life Regarding to Gender in Sarcoidosis

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#### ABSTRACT

Evaluation of the health-related quality of life (HRQoL) in patients with respiratory diseases has been increasingly included into regular clinical studies, and HRQL in sarcoidosis has been evaluated since not a long ago. The aim of the study was to evaluate HRQoL in patients with sarcoidosis regarding gender differences, pre and after therapy. We investigated 202 pathohistologically verified sarcoidosis patients (154 female and 48 male) without comorbidities. HRQL was assessed by the disease-specific Sarcoidosis Health Questionnaire (SHQ), which contains 29 items, and cover three domains: everyday functioning, physical activities and emotional state. Total score, as well as the scores for each SHQ domains were calculated. HRQoL was estimated pre and after three months of therapy. At the study start, the lowest score value for the whole group was reported in SHQ emotional state domain (4.24), and the highest in domain of physical functioning (4.7). After three months, the lowest values were reported in domain of everyday activities, while the highest scores were found in emotional domain; all SHQ scores increased, but reached the statistical significance only in the everyday functioning and the physical activities domains. Analyzing mean SHQ scores in male and female sarcoidosis pts before therapy we found high statistically lower emotional and total score in female pts, as well as lower physical score. After the three months therapy we found high statistical difference in physical domain (i.e.women had lower physical score than men). Female sarcoidosis pts showed lower emotional, physical and total score before therapy. After the three--month therapy we found that women had lower physical score than men. SHQ showed good measurement properties both in the cross-sectional and longitudinal assessment of sarcoidosis patients.

**Key words:** sarcoidosis, health-related quality of life, sarcoidosis health questionnaire, gender

### Introduction

Sarcoidosis is a chronic disease which largely interferes with physical, emotional and social aspects of patients' life, both in working environment and everyday activities<sup>1</sup>. It is a condition developing in younger adults (20–40 years). In this age period, it is certainly difficult to face with multi-organ disease of unknown etiology and unpredictable progress<sup>2,3</sup>. Chronic condition in so young age might result in working and social problems, especially if a person looked healthy<sup>4</sup>. Patients perceive the condition of their affected health and, by insight into their quality of life, they often may suggest the present condition of their disease as well as the success of treatment.

The studies dealing with sarcoidosis, have, until recently, estimated the disease exclusively by focusing on

pulmonary manifestations viewed on X-ray films, and values of the lung functions and gas exchange<sup>5–7</sup>. However, these clinical variables are not correlated strongly with long-term outcome of disease<sup>8,9</sup>, do not consider psychological discomforts of patients<sup>10</sup> and other organ system difficulties that may have effect on satisfaction of patients with their life style. More important is that these studies have found poor correlation with the way patients see their quality of life<sup>11,12</sup>.

Evaluation of the health-related quality of life (HRQoL) in patients with respiratory diseases has been increasingly included into regular clinical studies. Yet, the reference literature reports a small number of evaluations of the HRQoL in sarcoidosis. So far, available literature has

failed to demonstrate data that analyze follow-up of changes in the HRQoL after therapeutical regimes.

#### **Materials and Methods**

The aim of the study was to evaluate HRQoL in patients with sarcoidosis regarding gender differences, pre and after therapy. The study included 202 pts (154 female and 48 male), median age 46 (range 18–75) years, examined and treated at the Institute for Pulmonary Diseases and TB, Clinical Center of Serbia, Belgrade.

Criterion for patients' entering the study was pathohistologically verified sarcoidosis of the lungs or any other organ. A Case Control Etiologic Study of Sarcoidosis (ACCESS) criteria of the American Association of Cardiopulmonary and Hematological Studies were used for diagnosis of sarcoidosis in other organs<sup>13</sup>. According to Paris classification criteria, and on the basis of posterior-anterior radiography of the chest, the form of pulmonary sarcoidosis was divided into 5 stages: 0, I, II, III and IV<sup>21</sup>.

In order to assess HRQoL in sarcoidosis patients we used Sarcoidosis Health Questionnaire (SHQ) which is the first disease specific questionnaire for HRQoL analysis in sarcoidosis. It consists of 29 questions which cover three fields: everyday functioning, physical activities and emotional state. The response scales range 1 (all of the time) to 7 (none of the time). Reliability and validity of this questionnaire appear to be very good<sup>14</sup>. The questionnaire was filled by patients themselves pre and after three months therapy.

# **Statistical Analysis**

SHQ scores were calculated by original calculator made in Microsoft Excel, which was obtained directly from the author of questionnaire (Dr Christopher Cox, University of South Carolina, USA). Statistical analysis was performed using SPSS version. 12 for Windows (SPSS Inc., Richmond, USA). The following methods were used: descriptive statistics, Student's test for independent samples, Student's test for paired samples, oneway ANOVA and Pearson's correlation coefficient. Levels of statistical significance were determined at p<0.05 (\*) and p<0.01 (\*\*).

# Results

The demographic characteristics of sarcoidosis patients are listed in Table 1. Radiographic stage of sarcoidosis is presented in Table 2. In studied group of 202

TABLE 1
DEMOGRAPHICS

	Males	Females	Smokers	Non-smokers	Ex-smokers
N	48	154	19	167	16
%	23.2	76.8	9.6	82.6	7.8

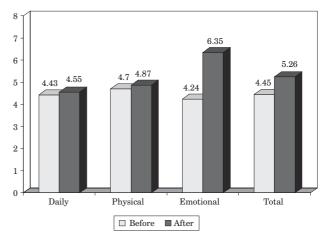


Fig. 1. Mean values of SHQ scores before and after treatment.

sarcoidosis patients, the largest number of patients was in stage I group: 21 male (43.7%) and 64 (41.5%) female. Substantially lesser patients were found in stage II: 17 male (35.4%) and 56 (36.3%) female, while the small number was reported in stages III, IV and 0. There was no statistical difference between male and female patients according to the radiographic stage of the disease.

Mean SHQ scores before the applied therapy in the whole group are demonstrated in Figure 1. It was noted that the lowest value was reported in domain of emotional score (4.24 $\pm$ 0.7), and the highest in domain of physical score (4.7 $\pm$ 1.0). The score results three months after therapy are presented in the same Figure. This time, the lowest values were reported in domain of every-day activities (4.55 $\pm$ 0.9) while the highest scores were found in emotional domain (6.36 $\pm$ 2.65).

Analyzing mean SHQ scores in male and female sarcoidosis patients before therapy we found statistically significant lower emotional and total score in female sarcoidosis patients  $(5.01\pm0.9 \text{ vs. } 4.60\pm1.0 \text{ and } 4.47\pm0.7 \text{ vs. } 4.17\pm0.7, \text{ respectively; p} < 0.05 \text{ in both cases})$ , as well

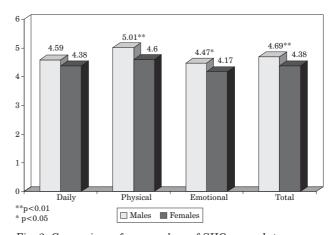


Fig. 2. Comparison of mean values of SHQ scores between gender before treatment.

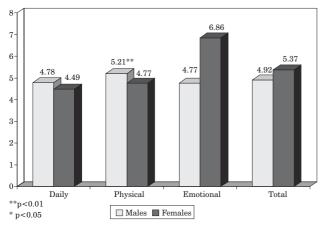


Fig. 3. Comparison of mean values of SHQ scores between gender after treatment.

as lower physical score  $(4.69\pm0.6~vs.~4.38\pm0.7;~p<0.01)$ . After the three months therapy we found highly significant difference in mean values of physical domain: i.e. women had lower physical score than men  $(5.20\pm1.0~vs.~4.77\pm1.1;~p<0.01)$  (Figure 2). Differences in emotional domain and daily activities are not statistically significant.

#### Discussion

It is well known that gender can influence the quality of life. This is especially important in sarcoidosis where the majority of patients are female.

Our results show lower emotional, physical and total SHQ scores in female than in male sarcoidosis patients before applying therapy regimes. This might lead to a conclusion that male sarcoidosis patients showed significant lower emotional dysfunction as well as they might be better adopted to physical limitations that were present at the moment of establishing the diagnose (fatigue, ankle pain, etc.). Similar results were found in the investigation of De Vries et al. <sup>15</sup> as well as Michielsen et al. <sup>16</sup> who showed bigger percentage of women with fatigue. These investigations were performed on Dutch and Croatian sarcoidosis patients. Those results do not agree with Wirnsberger's investigation <sup>17</sup> which showed no gen-

der differences considering fatigue. The results of Wirnsberger et al. suggest that men complain on fatigue at the same level as women, but only when their disease is multisymptom. In that case, fatigue is the major indicator of disease severity.

Chang et al investigated depression in sarcoidosis patients and found that female patients expressed more depression symptoms than male<sup>18</sup>. But, the authors show critical attitude about that data, especially considering epidemiologic study of Frerich et al., who found greater percentage of female with depression in the whole population of Los Angeles<sup>19</sup>.

After the three months of therapy, female patients expressed lower physical scores than male. The explanation might be found in the fact that sarcoidosis is more often in women and in their case the disease is often expressed with chronic and severe forms of disease. So, it is logical explanation that physical limitations in female patienst showed slower and more difficult recovery than in male sarcoidosis patients.

The largest study on 1026 sarcoidosis patients was performed by De Vries et al.<sup>20</sup> and was conducted with the aim to examine gender differences in quality of life of sarcoidosis patients. The authors found that women experienced more symptoms than men. Female patients had worse physical and psychological aspects of HRQoL.

To the best of our knowledge, our study is the first one that analyzes HRQoL of such large number of sarcoidosis patients, and follows up the HRQoL pre and after therapy. However, it has certain limitations. First, we used only one instrument for measuring HRQoL. Secondly, for SHQ minimal statistical difference was not established yet. And finally, three months of therapy might not be enough to identify real differences in HRQoL in sarcoidosis patients.

In conclusion we can say that analysis of quality of life may enhance the communication between the clinicians and patients. We consider SHQ useful instrument for evaluating of HRQoL in sarcoidosis patients.

Our study is contribution in helping to understand which are the causes of differences in HRQoL in female and male, whether they are consequence of the different hormonal/genetic status, or life style. We agree with De Vries et al.<sup>20</sup> that future studies in this field are needed.

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## KVALITETA ŽIVOTA OBZIROM NA SPOL KOD SARKOIDOZE

# SAŽETAK

Evaluacija sa zdravljem povezane kvalitete života (engl. health-related quality of life (HRQoL)) kod pacijenata sa respiratornim bolestima se sve više uključuje u uobičajene kliničke studije pa je tako HRQL kod sarkoidoze tek nedavno evaluiran. Cilj studije je evaluirati HRQoL kod pacijenata obzirom na spolne razlike, prije te nakon terapije. Istražili smo 202 pacijenta (154 ženska i 48 muška) sa patohistološki potvrđenom sarkoidozom bez komorbiditeta. HRQL je određen prema bolešću određenim upitnikom za sarkoidozu (engl. Sarcoidosis Health Questionnaire (SHQ)) koji se sastoji od 29 stavaka a koji pokrivaju tri domene: svakodnevno funkcioniranje, tjelesne aktivnosti i emocionalno stanje. Izračunati su ukupni bodovi, kao i bodovi za pojedinačnu domenu. Procjenjen je HRQoL koji sadrži 29 jedinica te pokriva tri domene: svakodnevno funkcioniranje, fizička aktivnost i emocionalno stanje. Izračunat je ukupan rezultat, uključujući i rezultate za svaku SHQ domenu. HRQoL je određen prije i poslije tromjesečne terapije. Na početku istraživanja, najniža vrijednost za cijelu grupu izračunata je u SHQ u domeni emocionalnog stanja (4,24), a najviša u domeni fizičkog funkcioniranja (4,7). Nakon tri mjeseca, najniže vrijednosti izračunate su u domeni svakodnevnih aktivnosti, a najviše u emocionalnoj domeni; svi SHQ rezultati su narasli, ali statističku značajnost su postigli tek u domenama svakodnevnih aktivnosti i fizičkih aktivnosti. Analizirajući glavne SHQ rezultate sarkoidoze kod muškaraca i žena prije terapije pronađen je visok statistički niži emocionalni i ukupni rezultat u ženskim bodovima, jednako kao i rezultatima tjelesnih aktivnosti. Nakon tromjesečne terapije pokazuje se visoka statistička različitost u domeni tjelesnih aktivnosti (npr. žene su imale niži fizički rezultat od muškaraca). Sarkoidoza kod žena prije terapije pokazuje niže emocionalne, tjelesne i ukupne rezultate. Nakon tromjesečne terapije žene imaju niži rezultat tjelesnih aktivnosti od muškaraca. SHQ pokazuje dobre karakteristike mjerenja i u poprečnim kao i u longitudinalnim pristupima istraživanja pacijenata oboljelih od sarkoidoze.