

Quality of Life, Coping and Depression in Systemic Lupus Erythematosus

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ABSTRACT: Physical, mental and social well-being are important outcomes in patients with chronic rheumatic diseases, including systemic lupus erythematosus (SLE). The MOS SF-36 and the WHO QoL Bref are appropriate for assessing quality of life (QoL) in patients with SLE. The QoL of patients with SLE is impaired compared with that of controls. Fibromyalgia adversely affects the QoL of SLE patients. Women with SLE had significantly lower scores on subscales of the sense of coherence (SoC) compared with matched controls. This reduced SoC in SLE women represents impaired adaptive coping and is independently associated with reduced QoL in women with SLE. Depression and anxiety are common among SLE patients, and the frequency is similar to that in patients with rheumatoid arthritis. A reciprocal longitudinal relationship between depression and illness intrusiveness was found in patients with SLE. Disease activity and damage are not associated with depression. The subjective experience, not the illness per se, causes depression.

IMAJ 2016; 18: 144–145

KEY WORDS: systemic lupus erythematosus (SLE), quality of life (QoL), sense of coherence (SoC)

Systemic lupus erythematosus (SLE) is a chronic illness with a wide spectrum of disability and morbidity. The chronic illness state of patients with SLE leads to impaired psychological coping, development of depressive symptoms and anxiety, and impaired quality of life (QoL). Those features may occur in all age groups of patients with SLE.

During the last three decades several studies were performed at the Soroka University Medical Center lupus clinic to study the association between QoL, coping mechanisms, depression and measures of SLE activity and damage. The data of those studies are summarized in this review.

QUALITY OF LIFE AND SLE

Systemic lupus erythematosus is a chronic autoimmune disease that is characterized by a high prevalence of neuropsychiatric manifestations, unpredictable course, and variable

patterns of organ involvement. Quality of life is defined as the general well-being of individuals and societies, based on the individual's culture and life values with respect to that individual's objectives, expectation and standards.

Health-related QoL is the impact of disease and its treatment on the individual's ability to function based on physical, mental and social well-being. Variables that may affect the QoL of SLE patients include: disease activity, damage, fibromyalgia (FM), co-morbidity, medical therapy, education, illness intrusiveness (extent to which chronic illness interferes with routines, activities and interests), self-criticism, illness-related interpersonal relationships, and physician-patient relationship.

In a previous study [1] we compared the QoL of 75 SLE female patients with that of healthy women and women with primary FM using the QoL scale. The data of the study indicated that patients with SLE were dissatisfied with their health-related QoL. Compared with the healthy women, patients with SLE had lower scores for the health, work, active recreation and independence items. Fibromyalgia has a major effect on QoL of patients with SLE [2]. Patients with SLE and FM had significantly lower scores for the health-related items compared to patients with SLE without FM. The QoL scores were not associated with the SLE disease activity scores (SLEDAI).

In a subsequent study [3], the QoL of patients with SLE was assessed by the Medical Outcome Study (MOS) short form SF-36 and by the World Health Organization (WHO) QoL Bref scale. The MOS SF-36 has eight health scales, each of which measures a health concept: physical functioning, role functioning-physical, role functioning-emotional, social functioning, bodily pain, mental health, vitality, and general health perceptions. In addition, the scores of the eight subscales were computed into two summary scores: physical component summary (PCS) and mental component summary (MCS).

The World Health Organization QoL-Bref scale is composed of 26 items that encompass 5 health scales: general, environmental, social, physical, and psychological. The mean scores for the eight individual health scales and for the physical and mental health summary scores of the MOS SF-36 scales and the mean scores of the five individual health subscales of the WHO QoL-Bref for women with SLE were

significantly lower compared to controls. No linear correlation was identified between the SLEDAI and SLE damage scores (SDI) and the scores of the five subscales of the WHO QoL-Bref scale. An inverse correlation was detected between SLEDAI and the physical functioning scale of the SF-36. The SDI score was inversely correlated with the scores for physical functioning, role functioning-physical, social functioning, general health perception and PCS.

SENSE OF COHERENCE AND SLE

The sense of coherence (SoC) construct refers to a global orientation to one's inner and outer environment, which significantly determines the link between stressors, coping with disease, and health. This construct is driven by the adaptive coping of human beings with continuous stressors and by generalized resistance resources. The salutogenic theory maintains that people are able to cope with stressful situations insofar as they can make sense of the world around them. It claims that the SoC is a construct that predicts success in coping with stressors along the continuum from 'disease' to 'ease', and makes conflict resolution possible. The SoC comprises three concepts: comprehensibility, manageability, and meaningfulness.

The association between SoC and QoL scores (SF-36, WHO QoL-24) and measures of disease activity and damage were studied in a group of 60 women [3]. Women with SLE had a significantly lower overall SoC score and lower scores for the comprehensibility and meaningfulness subscales. No significant correlation was seen between SoC scores and measures of disease activity or end-organ damage. The results of the study [3] indicate that education, age, SDI and SoC are independently associated with QoL in women with SLE. The SoC scores were directly associated with the QoL scores. Multivariate analyses models found that age, SoC and SDI significantly affected PCS scores of QoL, and SoC was the only independent variable for the MCS score of MOS SF-36. Education and SoC were significantly associated with the general WHO QOL-Bref.

DEPRESSION IN SLE

Depressive episodes occur in 9%–35% of chronically ill patients. Up to 32% of patients with congestive heart failure develop depression, and patients with diabetes mellitus had a twofold increased risk of depression. The occurrence of depression among patients with chronic diseases is associated with increased morbidity and mortality.

We compared the prevalence of anxiety and depression in 56 SLE patients and 58 women with rheumatoid arthritis (RA) (unpublished data). The Montgomery Asberg depression rating scale and the Hamilton anxiety scale were used. We found that the prevalence of current depression, past depression and generalized anxiety were not statistically different between

SLE and RA patients. Current depression was reported in 17.8% of SLE patients compared to 24.1% among RA patients. The frequencies of past depression and generalized anxiety were 35.7% vs. 36.2% and 35.7% vs. 39.2% in the SLE and RA patients, respectively. Regression models revealed that depression, anxiety and dysthymia were not associated with SLEDAI, SDI, steroid therapy, and/or non-steroidal anti-inflammatory therapy.

In a subsequent qualitative study [4], patients with SLE were interviewed according to the Giorgi method, which sums up the participant's illness experience. The main finding was that participants constructed their illness as an 'object' that explains various aspects of their experience. This means that patients with SLE assign the illness the role of a principal character (protagonist) and SLE is personified, implying the existence of 'traits' ascribed to the illness.

In a longitudinal study [5], various predictors of depression were assessed in patients with SLE. Those variables included illness intrusiveness, self-criticism (described themselves as perfectionists, driven by high and demanding internal standards), illness-related interpersonal relationships, and physician-patient relationship. Illness intrusiveness, self-criticism and symptom concealment were predictors of depression in SLE. Disease activity and damage were not part of this relationship. The subjective experience, not the illness per se, was found to cause depression.

CONCLUSIONS

SLE is a chronic disease that is significantly associated with poor QoL, impaired SoC and a high rate of depression. Treating fibromyalgia, improving coping mechanisms, and identifying anxiety and depression should be an integral part of the therapeutic management of patients with SLE.

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