

## How can SLE Impact patient's life

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### Abstract

This review examines the disease impact on life of 76 SLE patients by collecting data using special questionnaire. The impact of the disease on professional activities has confirmed that up to 63% of patients are registered disabled, of which 46% are granted full disability pension. SLE negatively affects patients' career – up to 39% of SLE patients stated that they had to change a job due to their disease. SLE has a strong impact on everyday life of patients. SLE symptoms are significant even during the period of quiescence – they predominantly include fatigue, reduced physical activity, and pain. Among the all activities of daily life the most influenced are staying in the sun and more stressful activities or sport. The fact that limitations in all monitored activities are present in more than 50% of patients is a serious issue. Treatment-related adverse events have negative impact on the quality of life in almost 70% of patients. The most frequent include gastrointestinal symptoms, visual disturbance, and osteoporosis.

SLE has a significant impact on the quality of life of patients and hinders them from leading everyday life at the level comparable to healthy population.

Key words: SLE; impact of the disease; job; and treatment related adverse event

### Introduction

Systemic Lupus Erythematosus (SLE) is an inflammatory autoimmune disease which is able to affect almost all organs of the body, and as a consequence, this can lead to diverse clinical signs. The disease itself and disease-related consequences as well as treatment-related adverse events have a significant negative impact on life expectancy and quality of patient's life [1,2].

Relatively little information is available about the disease epidemiology, the impact of the disease on patients' quality of life, career, disability, and their survival.

The aim of our survey was to identify the impact of the disease on life of SLE patients. The study was approved by the L. Pasteur University Hospital Ethical Committee in Kosice, Slovakia.

### Patients and Methods

Data were collected anonymously using a special questionnaire. The survey was a non-interventional survey and did not refer to any particular treatment. The survey was carried out at out-patient departments of rheumatology affiliated to the 1st and 3rd Department of Internal Medicine, University Hospital Kosice. No hypothesis was tested in the survey and the results were processed by conventional methods and descriptive statistic methods.

The group consisted of 76 patients (88% of women, 11% of men, in one case information on gender was not completed); the male to female ratio was 9:1. The average age of patients was 42.6 years (standard deviation [SD] 12.5), the youngest patient was 20 and the oldest patient was 79 years old. At the time of diagnosis, the average age was 29.3 years (SD 11.1, median 26 years). The average duration of the disease was 13.1 years.

### Results

The impact of the disease on professional activities has confirmed that up to 63% of patients are registered disabled, of which 46% are granted full disability pension, 52% are granted partial disability pension; 2% of patients did not provide this information. Among the patients with full disability pension, 27% are active (either working or studying); among the patients with partial disability pension, 64% are active. Most patients, who are not registered as disabled, work full-time (Figure 1).

SLE negatively affects patients' career – up to 39% of SLE patients stated that they had to change a job due to their disease, 24% of them had a job below their qualification level and 46% indicated lower income due to their disease. Only 12% of patients live on their own, 51% of patients live with a spouse and one third of patients live with their relatives or friends.

SLE has a strong impact on everyday life of patients. SLE symptoms are significant even during the period of quiescence – they predominantly include fatigue, reduced physical activity, pain, and cosmetic defects, occurring in over 90% of SLE cases (Figure 2).

The least represented signs include psychological symptoms such as depression and memory disorders, however, they affect up to 50% of patients. In spite of lower occurrence they are perceived by patients as significantly affecting their daily functioning, including nervousness, depression, psychological exhaustion, mood change, and mental imbalance.

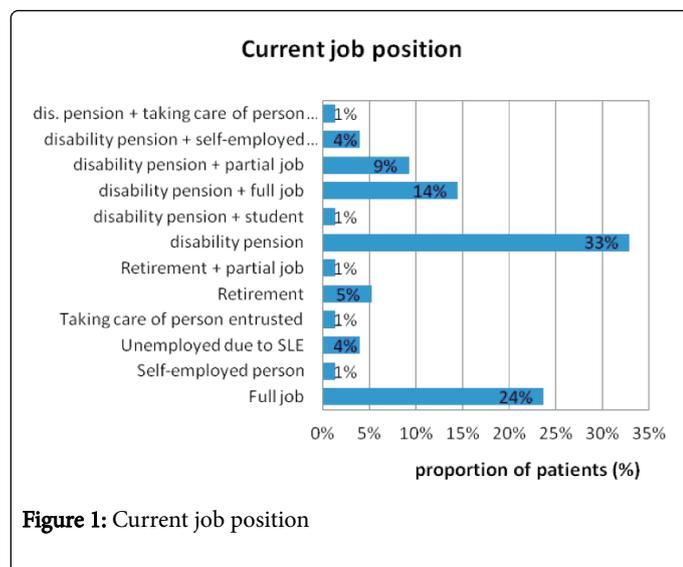


Figure 1: Current job position

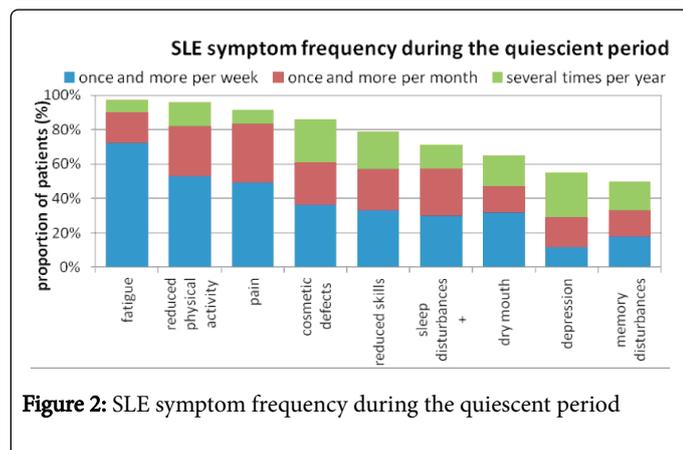


Figure 2: SLE symptom frequency during the quiescent period

The most frequent signs of the disease were at the same time evaluated by patients as the most intensive. During the quiescent period, fatigue occurs in almost 72% of patients and pain occurs in half of patients (49%). Regardless pain frequency, the intensity is either significant (42%) or mild (50%); only 8% of patients do not feel pain during the quiescent period.

At the time of data collection, 16% of all patients experienced deterioration, 66% were found to have stabilized SLE symptoms, and only 18% did not present with any disease symptoms. Most of the patients consider the overall impact of SLE on the quality of life as either restrictive (57%) or very restrictive (21%). The most influenced areas include career (68%) and social activities (63%), and almost one third of patients indicate problems within their family and partnership, 30% of patients indicate limitation in "having a child or having more children".

The most influenced activities of daily living included staying in the sun (during the summer season) and more stressful activities or sport, including a significant proportion of patients who cannot carry out these activities at all (Figure 3).

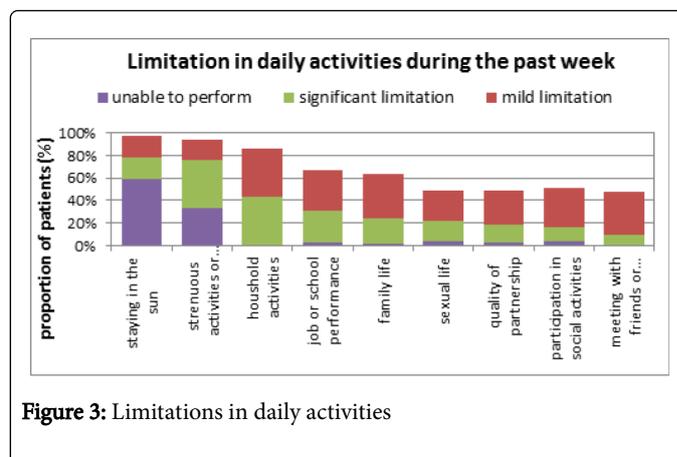


Figure 3: Limitations in daily activities

The fact that limitations in all monitored activities are present in more than 50% of patients is a serious issue.

Treatment-related adverse events have negative impact on the quality of life in almost 70% of patients, with most of them experiencing several adverse events at a time.

## Discussion

The survey shows that lupus negatively affects aspects of patient's life. More than half of the patients regard the overall impact of SLE as restrictive or very restrictive. Over half of patients are registered disabled. Our results are similar with the LUMINA study. Analysis of 273 patients with early SLE employed at enrolment, 19% were unable to work because of disability after a 5-year follow-up [3]. Yelin, et al. reported a steadily increasing proportion of SLE patients who stopped working with increasing period of follow-up, from 15% at 5 years to 63% at 20 years duration [4]. The disease gives rise to a wide range of clinical manifestations including the quiescent period that most often involve fatigue, reduced physical activity, and mild or severe pain. The symptoms as fatigue, pain, and musculoskeletal distress were most frequently reported also in another studies [5]. Patients suffer from multiple symptoms concurrently and even the least frequent symptoms such as depression or memory disturbance occur in more than 50% of patients in the period of quiescence. Relationship between glucocorticoid dose and depression was observed also in study of Choi and co-authors [6].

The disease affects many aspects of patient's life [7]. Of life situations, patients perceive disturbance in the area of job performance, career building, and social activities. The disease affects the area of human relationships, partnership and family life. Problems within family and partnership were recorded in approximately one third of patients.

The most influenced ordinary activities included staying in the sun and more strenuous activities or sport, including a significant proportion of patients who cannot carry out these activities at all. Limitations in all monitored activities are present in more than half of patients. Finally, we can conclude that SLE has a significant impact on the quality of life of patients and hinders them from leading everyday life at the level comparable to healthy population.

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