

DISABILITY IN SYSTEMIC LUPUS ERYTHEMATOSUS

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ABSTRACT

Introduction. Systemic lupus erythematosus (SLE) is an autoimmune disease that affects various organs and systems. These patients develop disability in various stages of disease progression, which has a significant impact on individuals and society.

The objectives of the study were to assess work disability in patients with SLE.

Methods. We carried out a cross-sectional study including SLE patients (according to the Systemic Lupus International Collaborating Clinics – SLICC – classification criteria, 2012). The disability status was studied using American and Moldavian disability criteria. Validated questionnaires were applied: absenteeism and presenteeism at work, socio-economic status was calculated according to the Kuppuswamy scale and the quality of life using SF-8.

Results. The study included 132 SLE patients. 20 patients (15.1%) with early disease (<24 months) had disability and the frequency of disability increased over the course of the disease. The duration of the disease, the activity and the PGA correlated significantly with the disability. Predictors of early disability in SLE group were high disease activity, poor education, exhausting physical work and residents of the rural area.

Conclusions. Patients with SLE have disability in 81 (61.3%) cases. According to the criteria in list 14.02, it was found that 97 (73.4%) vs. 81 (61.3%) of the patients

RÉSUMÉ

L'incapacité de travail dans le lupus érythémateux disséminé

Introduction. Le lupus érythémateux disséminé (LED) est une maladie auto-immune qui affecte divers organes et systèmes et dont les patients développent un certain degré d'incapacité dans les différentes étapes de progression de la maladie, fait qui a un impact significatif sur les individus et la société.

Objectifs. Évaluation de l'incapacité de travail chez les patients atteints de LED.

Méthodes. Nous avons mené une étude observationnelle incluant des patients atteints de LED (selon les critères de classification SLICC, 2012). Le statut de l'incapacité a été étudié en utilisant des critères américains et moldaves. Des questionnaires validés ont été appliqués: l'absentéisme et la présence au travail, le statut socio-économique a été calculé selon l'échelle de Kuppuswamy et la qualité de vie à l'aide de SF-8.

Résultats. L'étude a inclut 132 patients atteints de lupus. Chez les patients avec LED, il y avait un haut niveau d'incapacité: 20 (15,1%) patients avec maladie précoce (<24 mois) avaient une incapacité, dont la fréquence augmentait au cours de l'évolution de la maladie. La durée de la maladie, son activité et l'évaluation globale par les patients ont corrélé significativement avec l'incapacité. Les prédicteurs de l'incapacité

included in the study complied with the American and Moldavian disability criteria.

Key words: systemic lupus erythematosus, disability, quality of life.

Abbreviations: SLE – systemic lupus erythematosus; VLA – deficiency of valuable life activities; PGA – Patient global assessment; PhGA – Physician global assessment.

INTRODUCTION

Systemic lupus erythematosus (SLE) is an autoimmune disease in which various organs and systems are affected. These patients develop disability in various stages of disease progression. Disability is a general term that covers deficiencies, restrictions of activity and attendance at social life. Current evidence indicates the definition of disability as a physical, mental, cognitive or developmental state that affects, interferes or limits a person's ability to engage in certain tasks or actions, or to engage in typical daily activities and interactions¹. The literature review highlights that disability is a problem for both physicians and patients, affecting the public health system. Due to the fact that lupus involves working-age people, mostly women, the impairment of work capacity is outlined by reducing work performance and hours, diminishing productivity or loss of work. The results of previous studies established that the loss of work during the first 5 years of the disease progression was estimated between 15-40%, and in the next 10 and 15 years between 36-51%, respectively². In older papers, Partdrage (1997) determined that after 3.4 years from the diagnosis of systemic lupus erythematosus, 40% of patients stopped working, 53% changed their duties and functions in their job and 49% reduced working hours; at the same time, 8% had left one or two jobs³. The disability model developed by Verbrugge in 1990⁴, subsequently modified and expanded by Nagi in 1991⁵, is one of the primary models used in research related to disability. The presented model comprises four components: pathology (biochemical and physiological abnormalities or lesions); deficiencies (significant dysfunction or abnormalities in specific body systems, with consequences on physical, mental or social functioning); functional limitations (limitations in generic, physical and psychic actions) and disability (difficulty in day-to-day activities). The potential predictors of disability were selected on the basis of the Verbrugge

précoce dans le groupe LED étaient l'activité élevée de la maladie, le niveau bas de l'éducation, le travail physique épuisant et les habitants de la zone rurale.

Conclusions. Les patients atteints de lupus érythémateux disséminé ont eu un certain degré d'incapacité dans 81 cas (61,3%). Selon les critères de la liste 14.02, il a été constaté que 97 (73,4%) versus 81 (61,3%) des patients inclus à l'étude respectaient les critères d'incapacité américains et moldaves.

Mots-clefs: lupus érythémateux disséminé, incapacité de travail, qualité de vie.

and Jette model and included both functional limitations and health and illness measures representing the disability status of the disability model⁶. Changes in disability can occur both by worsening or by improving the condition of the patient. It should be noted that patients aged 18 to 64-years with systemic lupus erythematosus, in whom lupus was diagnosed recently, estimated the changes in the working hours⁷. Risk factors for job loss among employees at the time of diagnosis have been described. Productivity loss among weekday workers decreased by 35.4% (from 29.1 to 18.8) between the year at the diagnosis and 2004; weeks per year decreased by 23.7% and hours/year – by 32.2%. Longer illness and younger workers have had a low risk of losing their job, while women have had a substantially increased risk of losing their jobs. The level of education has been strongly and negatively correlated to the risk of losing the job. The conclusion of the study was, in this sample of SLE patients, that the diagnosis occurred when individuals had an average age of about 30 years. Given that half of those employees at the time of diagnosis have ceased to work for 15 years, such subjects lose nearly two decades of working life. Because much of the accumulation for the retirement savings takes place over the last two decades of careers, people with lupus will have to face retirement with a high risk of low retirement incomes². We reiterate that the study led by P. Katz, in 2008, identified the prevalence of disability in a wide range of important life activities among individuals with systemic lupus erythematosus and the predictors of impact on disability⁷; changes appeared over 1 year⁷. The research stated that the deficiency of valuable life activities (VLA) is frequent in people with SLE. Approximately half of patients were unable to perform ≥ 1 VLA due to lupus and approximately 35-40% were unable to perform ≥ 1 engaged or optional activity⁷.

Diminishing work capacity is common in rheumatological diseases, with a significant impact on individuals and society. Younger age at onset assumes

that people with SLE may be less likely to have completed their education, choosing a career, or having an important work experience. It has been demonstrated that a big number of people with autoimmune diseases, researched in other studies, have given up work and development due to illness. In later researches, including the results presented by Campbell in 2009, who conducted a complex survey, it was found that 21% of patients with lupus were absent at work for 15 days per year, compared with the control - 11 days⁸. As a conclusion, it is recommended to evaluate patients through self-administered questionnaires on productivity, presenteeism, absenteeism and disability. Thus, these questionnaires are suggested for assessing patient functionality, documenting the severity of the disease, which will help to measure the progression of lupus^{9,10}.

The economic burden of lupus and the loss of work capacity attributable to the disease, a component of indirect costs, have recently been subjected to studies. Clarke et al in 2015 studied 109 Canadian patients and found that the costs are higher with more severe illness and more frequent flares¹¹. The patients with the highest level of pain experienced the greatest decrease in work productivity. Similarly, it was found that the demographic factors associated with disability are age, duration of illness, duration of studies under 9 years and low socio-economic status¹¹. This study concluded that pain, fatigue, disease activity, organic damage, depression and comorbidities correlate with disability¹¹.

We were interested in analyzing not only the frequency, but also the criteria for disability in lupus, from multiple sources. In order to establish the degree of disability in the Republic of Moldova, there were developed and applied the functional and structural deficiencies of lupus: mild, moderate, acute, severe and absolute with description of the signs. We have analyzed the literature on lupus disability in Great Britain¹² and Romania¹³. The results of these publications assume that the criteria are based on the repetitive model that implies valuing the signs, while the modern model is based on cumulative parameters. The fact that the mixed working groups strive to adjust the disease criteria to international standards made us choose a model consisting of three sets of criteria such as: constitutional (by the presence of 2 out of 4 criteria), affected systems and organs (2 out of 7) and functional limitations for lupus disability (presence of one of three criteria) included in US List 14.02^{14,16}. In the same way, 5 criteria (2 constitutional, 2 organic and 1 functional) present are necessary to consider the patient with disability. In the explanation of criteria, it is specified that lupus may severely affect a single organ such as kidneys, for example;

in this case, the medical criteria are not met. If the patient is able to take care of himself, to clean the house, to shop for everyday necessities and to maintain social life, and there are no mental problems limiting professional activity, then the functional criteria of limitation are not met.

THE AIM OF OUR STUDY was to apply and assess the disability in patients with systemic lupus erythematosus (by two criteria sets).

MATERIAL AND METHODS

We examined a group of 132 patients with lupus, according to our approved research questionnaire, patients who met the Systemic Lupus International Collaborating Clinics (SLICC) classification criteria (2012) and met the criteria for inclusion in the study. We assessed and collected demographic data (sex, residency, medical insurance, marital status, years of study, family and work situation), SLEDAI-2k disease activity, damage index SLICC/ACR, fatigue - Fatigability Severity Scale, employee status and comorbidity - Charlson Comorbidity Index; social status: absenteeism and presenteeism at work, socio-economic status was calculated according to the Kuppuswamy scale and quality of life using SF-8. To be noted that absenteeism was assessed by the number of hours of work missing due to illness for the last 7 days. Presenteeism was defined as a reduction in productivity over the last 4 weeks, with ranges from 0 to 100%, where 100 is the ideal performance, high attendance over 80 percent. The professional situation was considered the state at the time of the diagnosis of lupus and categorized as the type of employment - full time, part-time, unemployed, in training, housewife, retired and disability.

The Ethic Committee of the State University of Medicine and Pharmacy „Nicolae Testemitanu“, Chisinau, approved the study on 8th of June 2017, session number 78. The study was conducted according to the ethical standards in the Helsinki Declaration of 1975, as revised in 2000⁵, as well as the national law.

RESULTS AND DISCUSSION

A number of 132 patients with systemic lupus erythematosus who met the inclusion criteria for the study were enrolled. Demographic parameters are included in Table 1.

The data in the table 1 reveal the predominance of female gender in the rural area, the mean age being 45 years, with ranges from 17 to 67 years. The duration of the disease range was from 1 month to 437 months (about 36 years), in average 10 years. Regarding the

Table 1. The general characteristics of patients with systemic lupus erythematosus.

<i>Variables</i>	<i>SLE patients, n=132</i>
Sex	
Female	129 (97.7%)
Male	3 (2.3%)
Age, years	45.11± 12.92 (17-67)
Disease duration, months	131.08±130.51 (iv 1 - 437)
Marital status	
Married	86 (65.2%)
Widower	11 (8.3%)
Divorced	16 (12.1%)
Bachelor	19 (14.4%)
Place of residence	
Rural	89 (67.4%)
Urban	43 (32.6%)
Studies, years	13.26± 3.09 (iv 9-21 years)
< 9 years	12 (9.1%)
9-14	63 (47.7%)
>15	57 (43.2%)
Employee status	
Full-time	39 (29.5%)
Part-time	30 (22.7%)
Unemployed	24 (18.2%)
In training	6 (4.5%)
Housewife	27 (20.6%)
Retired	6 (4.5%)

matrimonial status of 132 patients, we found out that at the time of the research 19 were single, 86 patients were married, 11 widows and 16 divorced, living alone. It should be noted that the duration of the studies varied from 9 to 22 years, 12 patients (9.1%) had 9 years of study, 63 (47.7%) – college, 57 (43.2%) – university studies, including 4 individuals (3.0%), who had master studies. We assessed the employee status in the SLE group and found that 39 (29.5%) of 132 patients were full-time employed, 30 (22.7%) – part time, 24 (218.2%) – unemployed, and half of them were not looking for work, 7 (5.3%) – in training, 27 (20.6%) – housewives and 5 (3.7%) were already retired and did not work at the time of the research.

We assessed the patients in terms of both clinical manifestations and the results at assessment

through validated medico-social and clinical tools used in rheumatology.

Thus, we found that the activity of the disease determined by SLEDAI-2k and SLAM activity indexes was 6.8 and 7.7 points; this might be interpreted as moderate / high activity.

Fatigue was estimated according to the Severity Fatigue Scale (0-100 mm) using VAS Scale. 83 (62.8%) patients had the index below 50, the mean value was 46.2 points. The assessment of the overall patients' status was 51 points, noting that 1/3 of the patients exaggerated their general condition, meanwhile the others did not appreciate the real general state, explaining their fatigue through various daily or environmental situations. The assessment of the global condition of the lupus patient was

Table 2. Clinical features of patients with systemic lupus erythematosus

<i>Variables studied</i>	<i>SLE patients, n=132</i>	<i>Ranges</i>
Disease activity		
SLEDAI-2K, points	6.8 ± 4.07	0-20
SLAM, points	7.7 ± 3.49	1-15
Fatigue	46.26 ± 11.66	20-68
PGA	50.95 ± 17.91	10-74
PhGA (0-3)	1.860±0.59	0-3
GWB	65.38± 7.94	45-75
SF-8 mental compound	41.50± 11.04	20.98-60.4
SF-8 physical compound	39.74± 9.44	19.98-54.4

Table 3. Disability criteria for SLE according to list 14.02

Parameters	SLE pts, n	SLE pts,%
Constitutional criteria		
1. Fever (in the absence of other causes)	48	36.4
2. Severe fatigue (according to Fatigue Severity Scale - FSS> 50)	108	81.8
3. Asthenia, continuously pain or body discomfort	72	54.5
4. Weight loss intended / unintended	18	13.6
Criteria: in the presence of 2 out of 4 constitutional criteria		
Affected systems / organs		
1. Renal (diminished renal function - GFR, lupus nephritis or glomerulonephritis)	42	31.8
2. Respiratory (chest pain, pneumonitis or pulmonary embolism)	12	9.1
3. Cardiovascular (pericarditis, myocarditis, endocarditis or vasculitis)	12	9.1
4. Neurological (headache, convulsions)	78	59.1
5. Hematologic (anemia, leukopenia, lymphopenia or thrombocytopenia)	102	77.3
6. Involvement of the nervous system (anxiety, cognitive impairment, or organic brain damage)	60	45.4
7. Arthritis	66	50.0
Involvement of two or more organs/body systems. At least one organ or system should be affected from moderate to severe		
Functional Limitations for Disability in Lupus. SLE must repeat one of the functional problems		
1. Limitation of activities of daily living.	42	31.8
2. Limitation in maintaining social functioning.	77	58.3
3. Limitation in completing tasks in a timely manner due to deficiencies in concentration, persistence, or pace.	18	13.6
To consider disability in a patient when met 5 criteria (2 constitutional, 2 organic and 1 functional)		

performed by doctor applying the scale (Physician Global Assessment 0 to 3), which established a higher average value (1.86 points). We continued the research by assessing adherence to the medication, which assumed the Morrisky Index - 2.84 p, qualified as moderate / high compliance. We analyzed such indices as the well-being and quality of life, that showed an average of 65 points, rated as „moderate stress“, with ranges from 45 to 75, which implies that patients had severe suffering with a score from 45 to 60 points, but also 73 points showing their well-being. The quality of life assessed by SF-8 indicated a decrease in both physical and mental compounds, more pronounced in the physical one, constituting 39.7.

At the time of inclusion of 132 patients with lupus, we found disability in 81 patients (61.36%). In the following, we examined disability in 2 groups of patients with lupus - early and late. It has been found that in early lupus patients, who were diagnosed from 1 to 24 months after the onset, 20 of 35 (57.1%) had disability. In the same time, we analyzed the frequency of disability in patients with the duration of more than 2 years, known as late lupus, so 61 (62.8%) of 97 patients benefited from a different degree of disability ($p < 0.05$).

We continued the research by assessing the time of establishment of disability in the course of the disease. Based on literature, we divided the patients into batches according to the time of attribution of disability. It was found that for the disease duration till 24 months, disability was found in 20 (15.1%) patients, with 25-60 months - 41 (31.1%), 61-120 months -12 (9.1%), after 121 months with lupus - 8 (6.1%) and 51 (38.6%) patients did not have disability. It is obvious that the frequency of disability increases during the disease up to 5 years, constituting 46.2%, followed by 9% and 6% after 5 and 10 years of illness, respectively.

In the following, we applied the American criteria for assessing disability in patients with systemic lupus erythematosus, included in list 14.02. It was found that the most common criteria were fatigue - 81.8% cases, followed by 77.3% hematological abnormalities, as well as headache derived from damage of the brain (59.1%) and limitation in ability to maintain social activity due to functional limitations - 58.3% of cases.

In the following, we selected patients with disabilities regardless of the degree of handicap and compared them with the criteria from American list 14.02. Thus, of the 81 patients with disability

according to the criteria from Republic of Moldova, 6 (7.4%) patients did not meet the American criteria at the time of our research.

We also applied disability criteria in patients with systemic lupus erythematosus without degree of disability. It was found that of 51 patients with lupus, with no degree of disability according to local criteria, 23 (45.1%) meet the American Disability Criteria.

We were interested in analyzing the factors that led to the establishment of disability by such demographic indices as age, duration of illness and clinical indices – disease activity, PGA, PhGA and fatigue using Pearson correlation coefficient. We have found that the duration of the disease, the activity and the PGA correlated significantly with the disability ($r=0,62$, $r=0,56$ and $r=0,67$, respectively; $p<0,05$), the strongest correlation was established with fatigue ($r=0,72$, $p<0,05$), while the age had poor inverse correlation ($r=[-0,31$, $p<0,05$). From the medical and social indices, we analyzed the correlation of disability with the adherence to treatment, the quality of life, the educational level and the global well-being index – GWB and we concluded that medico-social indices have had poor correlation with disability, with no statistical significance.

Disability in work has been self-reported as working age years in which they did not work due to lupus in order to identify clinical, demographic and medico-social risk factors for early disability in systemic lupus erythematosus. It was proved that after 5 years of diagnosis 60 (45.4%) patients left work. Predictors of early disability were high activity disease, study duration under 9 years, exhausting physical work and residents in villages.

CONCLUSIONS

Patients with systemic lupus erythematosus have disability in 81 (61.3%) cases. According to the criteria in list 14.02, it was found that 97 (73.4%) vs. 81 (61.3%) of the patients included in the study complied with the American and Moldavian disability criteria.

Compliance with Ethics Requirements:

„The authors declare no conflict of interest regarding this article“

„The authors declare that all the procedures and experiments of this study respect the ethical standards in the Helsinki Declaration of 1975, as revised in 2008(5), as

well as the national law. Informed consent was obtained from all the patients included in the study“

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