

chronic, debilitating fatigue, decreasing quality of life, increasing risk of work disability with associated cumbersome health-care costs.

Several research papers show that the only thing clinically proven to have an effect on Lupus fatigue is moderate exercise. If you tell this to a Lupus patient experiencing fatigue, however, you will find it very difficult to motivate them to exercise. The challenge is to make them realise that exercise does not necessarily mean running a marathon or going to the gym – a little movement goes a long way.

Objectives To get lupus patients to exercise and thereby experience less fatigue/better manage their disease.

Methods Develop an exercise program, that is approved by physiotherapists and leading lupologists, easy to do and inspires Lupus patients to keep active even when they feel exhausted.

Results In collaboration with physical therapists Lupus Europe has developed an exercise program from our own experiences and had it approved by leading European lupologists. The program has five levels; from lying in bed up until being able to run and jump. All exercises can be done at home without training tools. In order to make it accessible we have made five videos, showing how to do each exercise and five connected pamphlets. The materials will be made available to all Lupus patients on the Lupus Europe web site and YouTube channel free of charge.

Conclusion We have already seen good results within the Lupus community, where people are finding the program easy to use and a help to keeping them active. Our hope is, that doctors/nurses/HCPs will find it a useful tool to help fight fatigue and recommend it to their patients.

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HEALTH-RELATED QUALITY OF LIFE ASSESSED BY LUPUSQOL QUESTIONNAIRE AND SF-36 IN RUSSIAN PATIENTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS

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The LupusQoL is a disease-specific health-related quality of life (HRQoL) measure for patients with lupus. We conducted this study to compare the efficiency of LupusQoL with the 36-item Short-Form Health Survey (SF-36), a generic quality of life (QoL) scale, in Russian patients with lupus. Both questionnaires were conducted at a single visit to the clinic. Disease activity was evaluated by the SLEDAI-2K, and chronic damage by the Systemic Lupus International Collaborating Clinics Damage Index score (SDI). Associations between the LupusQoL and SF-36 domains were examined, while also examining age, disease duration, and disease activity for each questionnaire. Descriptive statistics, Spearman's correlation coefficients, and Students t test were performed to analyze the data.

A total of 328 patients with lupus (F/M 298:30, mean age 34,4±11.5 years, mean disease duration 106,3±91,9.0 months) were included, and 65,3% of these were active and

56,5% of these had SDI≥1. The mean SLEDAI 2K score was 9,6±8,0.

QOL as assessed by SF-36 and LupusQoL was low in this group of patients with SLE. The mean scores for each of the domains of the LupusQoL and SF-36 are shown in table 1. The mean scores are <60 in 8 domains of the SF-36 but not in social functioning (62,03±27,19) and physical function (62,35±28,53).

The MCS and PCS scores were both <50. Despite the fact that the mean score in LupusQoL was always higher than in SF-36 for each of the comparable domains, 3 standardized p values were not statistically significant (mean score in 328 patient visits: physical health/physical function, 66,20±23,18/62,35±28,53, p = 0.96; emotional health/mental health, 64,65±24,75/50,51±8,40, p=0.94; and fatigue/vitality 62.70±24.73/53.04±22.59, p=0.83), 1 standardized p values was statistically significant pain/bodily pain 70.03±24.68/47.00±8.86, p=0.02. The correlation of the comparable domains of LupusQoL and SF-36 was studied. There was a strong correlation between comparable domains in LupusQoL and SF-36 in 328 patient visits (physical health and physical functioning, r=0.77; emotional health and role emotional, r=0.38; pain and bodily pain, r=-0,33; and fatigue and vitality, r=-0.70; all p values <0.0001).

For the 4 non-comparable domains of the LupusQoL, there was a correlation between 3 domain of LupusQoL and 1 of the component scores of SF-36: body image and SF-36 MCS, r=0.20; planning and SF-36 MCS, r=0.13, r=0.73; and burden to others and SF-36 MCS, r=0.19; body image and SF-36 PCS, r=0,38; planning and SF-36 PCS, r=0,66; and burden to others and SF-36 PCS, r=0,38.

Abstract P111 Table 1 Descriptive statistics and correlation coefficient for SF-36 and LupusQoL

LupusQoL domains	Mean (SD)	SF-36 domains	Mean (SD)	r	P
Comparable					
Physical health	66,20±23,18	PF	62,35±28,53	0,77	0,96
Emotional health	64,65±24,75	MH	50,51±8,40	0,38	0,94
Pain	70,03±24,68	BP	47,0±8,86	-0,33	0,02
Fatigue	62,7±24,73	VT	53,04±22,59	-0,70	0,83
Noncomparable					
Planning	63,90±28,46	SF	62,03±27,19		
Intimate relationships	72,92±30,93	GH	49,14±20,51		
Burden to others	50,68±27,79	RE	49,84±43,86		
Body image	65,18±27,60	RP	40,46±41,35		
		PCS	45,15±7,65		
		MCS	48,46±5,41		

The Lupus QoL scales such as: pain, planning, intimate relationships, burden to others and bodily image correlated with disease activity (by SLEDAI 2K).

Conclusions The LupusQoL-Russian is sensitive to change in SLE patients with active SLE. LupusQoL and SF-36 were equivalent in assessing the HRQoL in Russian SLE patients. Both LupusQoL and SF-36 are easily completed by patients and correlate very well with each other.

The HRQoL by LupusQoL-Russian strongly correlated with disease activity.