



**Karolinska
Institutet**

**Department of Neurobiology, Care Sciences and Society
Division of Nursing**

**Fatigue –
perceived, described and assessed
by persons with
systemic lupus erythematosus**

AKADEMISK AVHANDLING

som för avläggande av medicine doktorsexamen vid
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Abstract

Fatigue is an individual and subjective sensation interfering with daily living for patients with several chronic conditions. Systemic lupus erythematosus (SLE) is characterized by inflammation in different organs combined with immunological abnormalities. The complexity of the disease SLE has several consequences for daily living, and fatigue is among one of the most burdensome symptoms of SLE. The impact of fatigue in a person's life is difficult for others to understand. Therefore, to better understand the enigma of fatigue, how fatigue can be measured and patient's descriptions of how fatigue is experienced are necessary.

Aim: The overall aim of this cohort-based project, was to explore patients experiences of symptoms related to SLE with a main focus on fatigue, how it is described and measured.

Subjects: 327 patients from the SLE-cohort at Karolinska University Hospital, Solna, and 311 age- and gender- matched control persons contributed to the data. Both qualitative and quantitative data have been used, with interview material from focus group discussions (study I), free-written answers (study II) and self-assessments measures/questionnaires (study II+III+IV).

Results: In study I, women (n=33) in seven focus group discussions (FGD) described their experience of SLE-related fatigue; how they perceived the feeling of fatigue, impact on life and strategies developed to manage fatigue in daily living. Transcripts from the FGD were analyzed using content analysis. The results were presented as four themes where the "Nature of fatigue" involved the sensation, occurrence and character of fatigue, "Aspects affected by fatigue" described emotions that arose with fatigue as well as aspects of work, family life, social contacts, and leisure activities that were affected by SLE related fatigue; "Striving towards power and control" described a balance of strategies used to manage daily life and were categorized into mental struggle, structure, restrict, and provide; "Factors influencing the perception of fatigue" described understanding from surrounding persons and the pain as strongly influencing the experience and perception of fatigue. The result from the open questions in study II (n=324), showed that fatigue and pain were reported as most troublesome symptoms of SLE, followed by musculoskeletal symptoms. In study III (n=51) in groups of 6-9 patients patients filled in seven questionnaires about fatigue; Numeric rating scale (NRS), Chalder fatigue scale, Vitality from SF-36, Fatigue Severity Scale, Multi-dimensional Assessment of Fatigue, Multidimensional Fatigue Inventory and Functional Assessment of Chronic Illness Therapy – Fatigue. This followed by a dialogue procedure resulting in 260 contrasting assessment. The minimally clinically important difference for the seven measures of fatigue was calculated using the comparative assessment as anchor. All measures of fatigue used in the study seemed to capture differences as experienced by the group of patients themselves, least favorable was however the one question (NRS) this were strengthen by patients free written comments. In study IV (n=305 patients and 311 controls) three clusters of fatigue were identified. The High fatigue cluster (n = 221) had most symptoms of anxiety/depression, lowest health related quality of life and were dominated by the patients (80%). Participants in the Low fatigue cluster (n = 240, controls 78%) reported more physical exercise and less smoking than the other clusters.

Conclusion: Patients description of SLE related fatigue (study I) provide important knowledge that can be used in educational discussions with patients as well as health care workers. The recommended measures of fatigue, evaluated in this thesis, can detect clinically important differences as perceived by the patients (study III). Not all patients with SLE experienced distress from current illness, 10 % reported that they did not perceive any SLE related symptom (study II) and 17% had low levels of fatigue and healthy behavior (physical exercise, non-smoker)(study IV). With special focus on fatigue, this thesis contributes to the understanding of patients' experience of SLE. Knowledge of the experience of symptoms from the patients' perspective is pivotal in order to support the patient, facilitate assessment and choice of treatment as well as generate a base for appropriate intervention programs.