



**Karolinska
Institutet**

Department of Neurobiology, Care Sciences and Society

Hand function, activity limitation and health-related quality of life in patients with polymyositis and dermatomyositis

AKADEMISK AVHANDLING

som för avläggande av medicine doktorexamen vid Karolinska Institutet offentligen försvaras i Rolf Luft auditorium (L1:00)

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av

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ABSTRACT

Background: Polymyositis (PM) and dermatomyositis (DM) are rare idiopathic inflammatory myopathies. Common clinical features are proximal muscle weakness and reduced muscle endurance, which can lead to activity limitation and reduced health-related quality of life (HRQoL). The current body of knowledge about hand function, activity limitation, and HRQoL in patients with PM and DM is limited.

Aim: The overall aim of this thesis was to describe and explore hand function, activity limitation, work ability, and HRQoL in patients with PM and DM.

Methods: Four papers with cross-sectional, over-time, or intervention pilot study designs have been applied in this thesis. Descriptive, comparable, over time, and correlational statistics have been used. In all, 143 patients with PM and DM participated in the studies.

Results: The results in this thesis showed that both women and men with PM and DM have reduced grip force and HRQoL compared to gender- and age-matched values from the literature. The reduced grip force and HRQoL were measured at the time of diagnosis in both women and men. Women had a reduced grip force at years 1-4 and at 6 years after diagnosis, while the men were affected up to 2 years after diagnosis. The HRQoL was rated lower than the normative values up to 6 years after diagnosis in women and 2 years following diagnosis in men. The grip force had a moderate to high correlation to the HRQoL dimensions of Role Physical, General Health, Vitality, and Mental Health.

A hand exercise intervention seemed to be feasible to perform with good adherence but generated few individual improvements in hand function and activity performance why the protocol needs to be adjusted. Patients with reduced hand grip strength also demonstrated activity limitation (according to the Disability of the Arm, Shoulder, and Hand questionnaire) and reduced dexterity.

In patients with PM and DM, 44% worked full-time (40 h/week), 31% worked part-time, and 25% were on full-time sick leave. More than 50% of patients with PM and DM self-rated their work ability as “poor” or “less good”. Physically strenuous work components were present “quite often” to “very often” in up to 79% of the patients and were more prevalent in patients on sick leave ≥ 2 years. For those working, interfering factors in the work environment concerned task and time demands. Supporting factors were the meaning of their work, interactions with co-workers, and others.

A low self-rated work ability was correlated moderate-high with a low percentage of full-time employment, the presence of work-related risk factors, and constraints in the work environment.

Conclusion: Patients with PM and DM have reduced hand grip strength, lower ratings on HRQoL, and poor to less good self-rated work ability and the low grip strength may influence HRQoL whereas the proximal weakness seems to affect the ability to work. Measures of hand function and work ability should be included in care of patients with PM and DM to guide interventions that could minimize impairment and as measures in the evaluation of treatment.

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