The Nordic Quality-of-Life Study in Patients with Psoriasis
A Preliminary Report

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The present study was introduced in *Forum for Nordic Dermato-Venereology* in 1998 (1) as a project initiated by NORDPSO (The Nordic Psoriasis Associations) and supported with a grant from Leo Pharmaceutical Products Ltd. The purpose of the study was to assess the relationship between psoriasis and quality of life (QOL) in Nordic patients with psoriasis, to ascertain if there are any differences in QOL among psoriasis patients in the different countries, and, if so, to try to determine the reasons for these differences. The study was also aimed at examining the impact of clinical severity, anatomical location, and complications such as psoriatic arthritis, as well as treatment of the disease, and the patients' own perception of stress. We have found it only natural now, when all the data from the study have been collected and a report has been submitted to NORDPSO, to give those Nordic dermatologists who assisted us with the study an update on the status of the project today.

Early on in the study, Nils Jørgen Mørk, and later Gunnar Swanbeck, asked to withdraw from the study group for personal reasons, and were replaced by Cato Mørk and Lars Molin. As planned (1), the two internationally recognized disease-specific questionnaires, the 15-item versions of the Psoriasis Disability Index (PDI) (2), and the Psoriasis Life Stress Inventory (PLSI) (3), were used. Prior to the main study, they were all translated into the various Nordic languages using a back translation method and were thereafter evaluated for reliability in a preliminary sample of 147 patients from all six countries. For practical reasons, the members from the Faeroe Islands agreed to use the Danish versions. To investigate the impact of psoriatic arthritis on QOL, we constructed an Arthritis QOL-index, which consisted of 11 items with the word 'psoriasis' substituted with 'psoriatic arthritis', together with items rating degree of pain and the degree to which assistance was required.

The respondents were also asked to rate their subjective experiences of psoriasis severity – the degree of erythema, scaling, plaque thickness and itch, and their general assessment of severity – on an 11-point scale. Respondents with both psoriasis and psoriatic arthritis were asked to indicate which parts of their bodies were afflicted. The remaining questions included family history, current and previous treatment, use of alternative treatments, educational status, employment, drinking and smoking habits, hospitalization, and other chronic diseases.

The questionnaire package was mailed to 2,000 randomly selected members of the psoriasis associations of Denmark, Finland, and Norway, to 4,000 in the Sweden association and to all members in Iceland and the Faeroe Islands. The response rates ranged from 40% (Iceland) to 67.8% from Denmark (Table I). To control for possible seasonal variation, an additional 800 questionnaires were mailed six months later, with a response rate of 42.6%, but no significant differences were found. As proposed, dermatologists from all the Nordic countries were invited to participate in the study by selecting up to five consecutive psoriasis patients, as was each university clinic, with 10 consecutive patients from their outpatient-clinics and 10 from their wards. The dermatologist visiting the main hospital in Thorshavn, where there is no university clinic, and the dermatologist in charge of patients from the Faeroe Islands, referred their patients to the balneotherapy care in Iceland. Besides being asked to distribute the questionnaire, all departments and dermatologists participating were requested to estimate the severity of the psoriasis by PASI-scoring (4). A total of 387 patients were recruited by the dermatologists and 385 from the departments. Only Danish departments fulfilled the national quota of 20 patients from each department. The entire sample included in the study totaled 6,497 subjects.

The results of the study will be published in peer-reviewed international journals. Two manuscripts have recently been submitted, one showing

Table I. Response rates from members of the different Psoriasis Associations.

	n	%
Denmark	1356	67.8
Finland	1125	56.3
Sweden	1828	45.7
Norway	903	45.2
Faeroe Islands	76	44.0
Iceland	451	40.0

the pattern of treatment of psoriasis in the Nordic countries, the other giving an overall picture of the quality of life among the patients. Two further manuscripts are under preparation, one concerning correlations to life-style and the other specifically dealing with QOL and psoriatic arthritis. Two reports have been accepted for presentation at the International Psoriasis Symposium in San Francisco in June 2001, and one at the 25th Hawaii Dermatology Seminar. One presentation has already been given at the annual dermatology meeting in Sweden (*Riksstämman*) and two have been accepted for the spring meeting of the Danish Dermatological Society. Hopefully, we will be able to present data at the coming Nordic Dermatology Congress in Gothenburg as well.

The overall results of the study show that when controlling for demographic factors, self-reported severity emerges as the most significant predictor of QOL among psoriatics, explaining between 24 and 29% of the variation, with the remaining factors accounting for only 5–7% of the variation (5). Norwegian psoriatics generally reported greater impairments of QOL than psoriatics from the remaining countries. The two most commonly used active agents, topical steroids (89%) and calcipotriol (73.1%) showed only small variations between the countries, while marked differences otherwise were to be found within all types of psoriasis therapy, including the patients' use of alternative therapy. The present use of alternative medicine ranged from 8.7% in the Faeroe Islands to 26.5% in Iceland. Marked differences were also found between countries in life-style factors such as alcohol consumption and cigarette smoking, in general in parallel to the use in the general population. The articles will deal with details as well as with the relation of these factors to QOL and specific psoriasis-related stress. The importance of psoriatic arthritis in this respect will also be dealt with.

The present study differs from most other studies on psoriasis and QOL, which have been hospital-based, by getting closer to the majority of psoriatics. It also reports on a large patient population from several (although closely related) countries, and describes differences in therapy and life-styles not earlier described in relation to QOL in psoriatics across boarders. The large sample increases statistical power. As mentioned above, the study will give an evaluation of the importance of psoriatic arthritis. We will therefore be able to fulfil the purpose of the study and answer most of the questions raised, the exception being difficulties in explaining the poorer QOL among Norwegians. The high Danish response rate among members is probably due to the fact that only the Danish Psoriasis Association followed an appeal from the study group to mail a reminder about the project to their members shortly prior to the mailing of questionnaires. Similarly, an appeal from the president of the Danish Dermatological Society, Torkil Menné, may have been the reason behind the 100% response rate from the departments in Denmark. The response rates from members are in accordance with what can be expected of longer questionnaires mailed out with and without previous notification (5), and should be considered satisfactory. Finally, we would like to conclude this preliminary report by showing patient responses to a question on satisfaction with the physician presently responsible for their treatment (Table II). A discussion on the high rate of alternative therapies used will follow later.

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Table II. Satisfaction with physician responsible for treatment in percent.

	Satisfied	Partly satisfied	Not satisfied
Faeroe Islands	31.3	61.3	7.5
Finland	29.7	64.6	5.7
Iceland	28.5	65.3	6.1
Norway	25.6	66.9	7.5
Denmark	24.1	67.9	8.0
Sweden	23.9	68.5	7.5