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CLINICAL REPORT

Quality of Life and Prevalence of Arthritis Reported by 5,795 Members of the Nordic Psoriasis Associations

Data from the Nordic Quality of Life Study

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Quality of life measures are widely used in dermatology as well as in rheumatology, but there are no large studies taking arthritis into consideration when studying quality of life in psoriasis. The aim of this study was to investigate psoriasis-related quality of life in a large sample of members of the psoriasis associations from the Nordic countries including an arthritis-related evaluation. The prevalence of reported arthritis within the groups was also estimated. An Arthritis Disability Index suitable for parallel use together with Finlay's Psoriasis Disability Index was constructed. A total of 5,795 members and 702 patients seen by Nordic dermatologists rated the severity of their disease and completed the Psoriasis Disability Index formula and a Psoriasis Life Stress Inventory, and if arthritis had been diagnosed, the Arthritis Disability Index formula. Approximately 30% of all psoriatic patients, irrespective of group, received a diagnosis of arthritis either by their dermatologist or a rheumatologist. Members previously hospitalized for their disease had a higher frequency of arthritis (41%) than those without a history of hospitalization (23%). The highest prevalence of arthritis was found in Norway (33.8%). Members with arthritis exhibited greater impairment of psoriasis-related quality of life, longer disease duration, and greater self-reported disease severity for psoriasis. Important predictors for impairment of arthritis-related quality of life were pain, number of affected joints, and restriction of joint mobility. These data show, that the prevalence of arthritis in psoriasis may be significantly higher than the previously accepted average of 7%. The results demonstrate that when studying quality of life in psoriasis, arthritis and arthralgia are important independent factors to be included in the evaluation. ***Key words: psoriasis; arthritis; arthralgia; Nordic countries; quality of life.***

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Quality of life (QOL) assessment is receiving increasing attention as an outcome measure in a number of diseases, psoriasis being no exception. The most commonly used disease-specific measures in this respect are the Psoriasis Disability Index (PDI) (1), which reflects the impact of psoriasis on the daily life and activities of the respondent, and the Psoriasis Life Stress Index (PLSI) (2), which measures the degree of subjective stress related to psoriasis experienced by the patient. In none of these measures has the impact of accompanying arthritis been substantially taken into consideration. When following an initiative from the Nordic Psoriasis Associations to study QOL in a large sample of their members (3), we therefore found it important to include an evaluation of the possible influence of arthritis.

Collection of data and analyses from our study has been completed (3) and an overall presentation of the results will appear elsewhere. We have, however, found it important to report separately on the specific data relating to therapy (4), lifestyle, and arthritis.

The present article reports on possible arthritis-related QOL in a total of 5,795 members from the Nordic Psoriasis Associations and for comparison in 702 patients recruited from Nordic dermatologists or Nordic University Clinics. We also present data on the prevalence of reported arthritis in this large outpatient sample of members from several countries. Although there is general consensus on the prevalence of psoriasis being between 2% and 3% in the Western World, there has been no agreement with respect to the prevalence of arthritis in psoriatic patients. Ranges have been reported from 5.4 to 40% (5–10).

MATERIAL AND METHODS

Patients

A questionnaire package was mailed to randomly selected members of the psoriasis associations from Denmark, Finland, Norway, and Sweden and to all members of the associations from Iceland and the Faeroe Islands. The selection included 4,000 members from Sweden, 2,000 from each of Denmark, Norway, and Finland, 1,127 from Iceland and 173 from the Faeroe Islands. Patients were excluded if they were under 18 years of age. Only patients who had diagnosis of psoriasis

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confirmed by a dermatologist were included in the study. The response rates were 67.8% from Denmark, 56.3% from Finland, 40.0% from Iceland, 45.2% from Norway, 45.7% from Sweden, and 44.0% from the Faeroe Islands. To control for possible seasonal variations, an additional 800 questionnaires were mailed out 6 months later to randomly selected members of the Danish, Norwegian, Swedish, and Finnish psoriasis associations. Of these psoriatic patients, 42.6% returned the questionnaires, bringing the total number of qualified members to 5,795.

Dermatologists from all the Nordic countries were invited to participate, with up to 5 consecutive patients each, and each university clinic in the same manner with 10 consecutive psoriatic patients from their outpatients clinics and 10 from the wards. The dermatologist visiting the main hospital in Thorshavn on the Faeroe Islands and the dermatologist in charge of patients from these islands referred to balneotreatment in Iceland were also asked to contribute with patients from their institutions. A total of 702 patients recruited at the dermatology departments or by dermatologists completed the questionnaires. The total number of patients with psoriasis included in the study was 6,497. The number of dropouts in departments and among members has not been recorded.

Questionnaires

All subjects received a questionnaire package, which included the PDI, the PLSI, the Arthritis Disability Index (ADI) form, and additional questions regarding their own evaluation of severity of disease, family history, current and previous treatment, use of alternative treatments, educational status, employment, drinking- and smoking habits, hospitalizations, and other chronic diseases. Prior to the start of the project, both the PDI and the PLSI had been translated into the Nordic languages, i.e. Danish, Swedish, Norwegian, Finnish, and Icelandic. For practical reasons, the members from the Faeroe Islands completed the Danish version of the PDI. The translation procedure was carried out using the translation-back translation method (11). The procedure will be published in detail elsewhere. The 5 Nordic versions of the questionnaire were then completed by a preliminary sample of 147 psoriasis patients from all 6 countries. Total scores and score distributions of the individual items were studied and internal consistencies were found to be acceptable with reliability coefficients.

Psoriasis Disability Index and Psoriasis Life Stress Index

The PDI consists of 15 disease-specific items rated on a 4-point Likert scale with scores from 0 to 3 corresponding to 0 = "not at all", 1 = "a little", 2 = "a lot", and 3 = "very much". The total score (ranging from 0 to 45) reflects the impact psoriasis has on the daily life and activities of the respondent, in this case over the previous month. The items of the original version of the PDI are rated on a 7-point Likert scale. To increase the comparability with the other questionnaires used in the study, the Nordic translations of the PDI are rated on a 4-point Likert scale (see above). As in the original version, the total scores (ranging from 0 to 45) are then calculated as percentage scores (0–100%).

In contrast to the PDI, which measures the impact of psoriasis on specific aspects of daily living, the PLSI[2] measures the degree of subjective stress related to psoriasis experienced by the respondent within the last month. The PLSI consists of 15 items, which cover different aspects of psoriasis-related stress. The score reflects the degree of stress experienced by the respondent for each of these items as rated on a 4-point scale, with scores ranging from 0 to 3 corresponding to 0 = "not at all", 1 = "slight degree", 2 = "moderate degree", and 3 = "a great deal". The total scores of PLSI are also presented as percentage scores (0–100%).

Arthritis Disability Index

To investigate the impact of arthritis on QOL, we constructed an arthritis disability index (ADI) (see Table III below), which consisted of items 1, 6a, 7a, 6b, 7b, 8, 9, 10, 11, 12, and 14 from the PDI with the word "psoriasis" substituted with "psoriatic arthritis". Two additional items rating the degree of pain and the degree to which assistance was required for washing or going to the toilet were also included. In this way, using the PDI as a frame, we could obtain an impression of the importance arthritis may have had on previously reported data. The impact of arthritis was scored on a 4-point scale similar to that used in the PDI. Possible total score range of the 11 items was 0 to 33. Only patients who had been given a diagnosis of arthritis by a rheumatologist or a dermatologist were asked to complete the arthritis QOL section of the questionnaire. However, 582 members claiming to suffer from arthritis without a diagnosis given by a specialist also filled out an ADI. These answers have been treated separately under the heading "Arthritis undiagnosed". When calculating the internal consistencies from the responses of a total sample of respondents, who initially had completed the ADI, the reliability coefficients ranged from 0.88 (Finland) to 0.94 (Sweden). Total ADI scores are presented as percentage scores.

Disease severity

The respondents were asked to rate their subjective experience of the degree of psoriasis severity, including the degree of erythema, scaling, plaque thickness, and itching as well as their general assessment of severity on 11-point scales with endpoints representing "not at all" (0) and "to a very high degree" (11). They were also asked to rate the area of their psoriasis on a scale from 0 to 100%. Respondents to both psoriasis and arthritis were asked to indicate which parts of their body were afflicted. Respondents with arthritis were also asked to rate the degree of pain and the degree to which they felt bothered by their pain on 11-point scales, as described above. For the 702 psoriatic patients studied by dermatologists or at dermatology departments, disease severity was also assessed by the physician, using the PASI scoring system (12), where the area involved together with severity of erythema, infiltration, and desquamation are graded, resulting in range of total scores from 0 to 72.

Statistical analyses

Proportions and ordinal data were analyzed with χ^2 tests and other non-parametric tests, including the Mann Whitney and Friedman tests. Continuous data were analyzed with *t*-tests for independent samples, analyses of variance (ANOVAs), and analyses of covariance (ANCOVAs). Further analyses were conducted with multiple linear regression analyses. All significance levels reported are two-tailed.

RESULTS

The following analyses have been conducted for the total group of psoriasis association members (*member group*) and the group of psoriatic patients recruited at dermatology departments and by practicing dermatologists (*patient group*). The difference between the mean degree of severity of self-reported psoriasis in the member group (4.9 ± 2.6) and in the seasonal control group (4.6 ± 2.6) did not reach statistical significance ($p = 0.17$; *t*-test for independent samples). The two

Table I. *Total number and percentage with self-reported and diagnosed arthritis, mean self-reported psoriasis severity, and mean arthritis disability index (ADI) of Nordic psoriasis association members*

		Arthritis				Mean self-reported psoriasis disease severity (0–10) (SD)			Mean ADI (SD) percent scores
	Total	Total self-reported		Diagnosed by specialist		Without arthritis	Arthritis diagnosed	Total member sample	Athritis diagnosed
	n	*n*	%	*n*	%				
Denmark	1,422	503	35.4	378	26.6	5.0 (2.6)	5.6 (2.7)	5.2 (2.6)	22.5 (19.3)
Finland	1,136	452	39.8	370	32.6	4.3 (2.5)	5.2 (2.6)	4.6 (2.6)	18.6 (14.2)
Iceland	398	144	36.2	115	28.9	4.3 (2.9)	4.9 (2.7)	4.7 (2.8)	19.2 (16.1)
Norway	960	441	45.9	324	33.8	5.0 (2.4)	5.9 (2.4)	5.3 (2.4)	25.1 (18.0)
Sweden	1,811	780	43.1	556	30.7	4.2 (2.5)	4.9 (2.6)	4.5 (2.6)	21.2 (18.2)
Faeroe Islands	68	11	16.2	6	8.8	4.7 (2.4)	5.2 (2.8)	4.9 (2.4)	13.4 (11.6)
Total	5,795	2,331	40.2%	1,749	30.2%	4.5 (2.6)	5.3 (2.6)	4.8 (2.6)	21.7 (17.6)

groups of members were therefore pooled in the subsequent analyses.

Forty percent of all members responded that they had arthritis, and 75% of these subjects reported that a rheumatologist or dermatologist had diagnosed this condition. The percentage of subjects diagnosed with arthritis by a rheumatologist or dermatologist differed significantly between countries in the member group ($\chi^2 = 32.9$; $p < 0.001$). More members from Norway, Sweden, and Finland were diagnosed with arthritis than members from Denmark and Iceland, who had more members with arthritis than the Faeroe Island sample (Table II). The differences between countries in the percentage of patients recruited by dermatologists and departments diagnosed with arthritis did not reach statistical significance ($\chi^2 = 7.7$; $p = 0.17$).

Thirty-nine percent of the member group reported that they had been hospitalized previously for psoriasis or arthritis. Finland and Norway had the highest rates of hospitalizations (74.3 and 62.7%, respectively), Sweden the lowest (37.3%). When members who reported that at some point in their lives they had been hospitalized for psoriasis or arthritis were compared with those without a history of these hospitalizations (Table III), it was found that more of the previously hospitalized members had arthritis than those without a history of hospitalization ($\chi^2 = 211.1$; $p < 0.0001$). There was no difference in the proportion of subjects having been diagnosed with arthritis between the member group and the two patient groups taken as a whole.

PDI, PLSI, disease severity scores, cigarettes per day, and alcohol consumption per day of subjects with diagnosed arthritis, "undiagnosed arthritis" and without arthritis were compared with one-way ANOVAs. Significant ($0.002 < p < 0.0001$) differences between groups were found for all measures analyzed, with the exception of number of cigarettes per day. Subjects with diagnosed arthritis generally exhibited greater impairment of psoriasis QOL (PDI and PLSI), longer disease duration, and greater self-reported disease severity, but consumed less alcohol than subjects without arthritis.

The answers given to the questions in the ADI are presented in Table III and the mean ADI scores can be found in Table I. A one-way ANOVA showed a significant effect of country ($F(5,2330) = 5.5$; $p < 0.001$). Norwegians had significantly higher scores than members from the remaining countries ($p < 0.05$; Scheffe *post-hoc* tests). When comparing the total ADI scores of members diagnosed by a specialist (mean: 7.9 ± 6.4) and "undiagnosed subjects (mean: 4.1 ± 4.6) complaining of arthritis" with a

Table II. *Percentage of 6,497 Nordic psoriatic patients diagnosed with arthritis by a dermatologist or a rheumatologist*

	Members total sample		Members never hospitalized for psoriasis or arthritis		Members having been hospitalized for psoriasis or arthritis		Patients recruited by dermatologists or departments	
	n	Arthritis diagnosis (%)	*n*	Arthritis diagnosis (%)	*n*	Arthritis diagnosis (%)	*n*	Arthritis diagnosis (%)
Denmark	1,422	26.6	940	18.7	482	41.9	219	29.2
Finland	1,136	32.6	412	22.8	724	38.1	115	26.1
Iceland	398	28.9	61	23.1	134	40.3	19	31.6
Norway	960	33.8	122	21.4	391	51.7	161	33.5
Sweden	1,811	30.7	1,307	27.5	504	38.9	165	33.3
Faeroe Islands	68	8.8	36	11.1	32	6.3	23	8.7
Total	5,795	30.2%	3,528	23.2%	2,267	41.1%	702	30.1%

Table III. *Responses to the individual items of the Arthritis Disability Index (ADI) presented as the percentage of 1,749 subjects having an arthritis diagnosed by a specialist and responding to each of the 4 response categories. The items referred to activities within the last 4 weeks*

		Response (%)			
	Items	"Very much"	"A lot"	"A little"	"Not at all"
1	How much have you suffered from joint pains?	10.9	32.6	43.2	13.3
2	How much has your arthritis interfered with your carrying out work around the house?	10.2	22.4	35.3	32.1
3A	How much has your arthritis kept you away from work? – Or	2.7	2.6	5.5	89.1
3B	How much has your arthritis affected the way you work?	2.3	4.1	13.3	80.2
4A	How much has your arthritis prevented you from carrying out your daily activities? – Or	4.5	11.4	17.8	66.3
4B	How much has your arthritis altered the way you carry out your normal daily activities?	4.9	12.2	17.6	65.3
5	Has your career been affected by your arthritis?	8.8	7.1	9.4	74.7
6	Has your arthritis resulted in sexual difficulties?	2.3	6.5	19.2	72.1
7	Has your arthritis created problems with your partner or any of your close friends?	1.5	4.8	21.1	72.6
8	How much has your arthritis stopped you going out socially or to any function?	3.1	10.3	23.6	63.0
9	Has your arthritis made it difficult for you to do any sport?	13.2	21.6	33.3	31.8
10	Has your arthritis resulted in you smoking or drinking alcohol more than you would normally?	0.5	1.1	6.6	91.8
11	How much has your arthritis required you to have assistance when taking a bath or going to the toilet?	0.6	2.7	14.1	82.6

t-test for independent samples, a significant ($t = 16.9$; $p < 0.001$) difference was found. Subjects with diagnosed arthritis had significantly more areas (roughly more joints) affected (4.1 ± 2.1) vs. (2.7 ± 1.7); ($t = 17.3$; $p < 0.001$), reported significantly more sensory pain (5.1 ± 2.6) vs. (3.9 ± 2.3); ($t = 11.6$; $p < 0.001$), reported significantly greater unpleasantness (affective pain) (5.2 ± 2.9) vs. (3.8 ± 2.6); ($t = 11.4$; $p < 0.001$), and reported significantly greater restriction of movement because of arthritis (4.4 ± 2.9) vs. (2.8 ± 2.4); ($t = 13.7$; $p < 0.001$) than subjects with "undiagnosed arthritis".

Positive significant correlations (Pearson's R) were found between total ADI and PDI, and PLSI ($p < 0.001$), with correlations ranging between 0.32 (PLSI) and 0.70 (PDI). A significant correlation ($R = 0.53$; $p < 0.001$) was found between total self-reported psoriasis severity and scores on the PDI. We also found a significant correlation between self-reported severity and ADI ($R = 0.20$; $p < 0.001$). When controlling for ADI scores with a partial correlation, the correlation between severity and ADI remained almost unchanged ($R = 0.51$; $p < 0.001$). Items related to sport, daily activities, and housework (Table III) had an approximately 3 times stronger influence on ADI than on PDI. A higher influence on ADI than on PDI was also, but to a lesser degree, found for items related to work, absence from work, career, and social activities.

Although PASI scores of patients recruited from departments were greater than PASI scores of patients recruited from dermatologists ($p < 0.001$; *t*-test for independent samples), there was no significant difference in the prevalence of arthritis between these two groups, and no correlation was found between ADI and total PASI scores. An index of arthritis severity was computed by adding a score for each area of the body affected. A significant correlation ($R = 0.54$; $p < 0.001$) was found between the arthritis severity index and ADI. Small, but significant, correlations were found between most arthritis-related variables and the use of tranquilizers, sleep medication, and antidepressants.

Psoriasis QOL measures for members, for patients recruited from dermatologists in private practice, and for patients recruited from dermatology departments were compared using one-way ANOVAs. Significant differences ($p < 0.001$) were found for PDI, PLSI, time willing to be spent on an effective treatment, and ADI scores. Post-hoc tests (Scheffe, $p < 0.05$) showed that patients recruited from dermatology departments had a higher rate of hospitalization and higher scores on the

PDI and PLSI than patients recruited from dermatologists, who had higher scores on both measures than members. The percentage of involvement of finger joints was higher among members (73.4%) than among the patient groups (66.8%) ($p < 0.05$), otherwise the groups had an identical distribution of affected joints and a similar mean number of affected.

A linear stepwise multiple regression analysis was conducted with ADI scores as the dependent variable, and sex, age, specific areas affected by arthritis coded as dummy variables, number of areas affected by arthritis (indicating number of joints), sensory pain, affective pain, degree of restriction of movement due to arthritis, and country affiliation coded as dummy variables entered as independent variables. Arthritis-related "affective pain", "number of joints" affected by arthritis, restriction of movement in the Norwegian sample, and arthritis-related sensory pain explained approximately 50% of the variance in ADI scores. Being of younger age, being female, and the back being affected by arthritis was also associated with greater impairment of arthritis-related QOL, explaining a further 0.9% of the variation. There was no difference in the percentage of subjects diagnosed with arthritis between subjects with and those without a family history of psoriasis ($\chi^2 = 3.2$; $p = 0.07$).

When comparing the number of affected joints and ADI scores between single subjects and subjects married or living with a partner, and between subjects with higher and basic education, no significant differences were found. When conducting a multiple linear regression with ADI as the dependent variable, and number of joints affected, and employment status (working, unemployed, at school, on sick leave) recorded as dummy variables entered as independent variables, number of affected joints ($\beta = 0.46$; $p < 0.001$), being on sick leave ($\beta = -0.18$; $p < 0.001$), and working ($\beta = 0.16$; $p < 0.001$) emerged as significant predictors of ADI, with the three variables explaining 25%, 5%, and 2% of the variance respectively.

DISCUSSION

ided the term "psoriatic arthritis" in our presentation, although it was used specifically in the questionnaire. The reason for this is that we had no access to records of members or patients and therefore we were unable to establish that generally accepted criteria for this diagnosis (13, 14) had been used. For the same reason, we restrict ourselves to the term "reported arthritis". In hindsight, it would have been preferable if we had been able to distinguish between members diagnosed by a rheumatologist and those diagnosed by their dermatologist. This distinction was omitted in order to simplify and reduce the number of items in the very large questionnaire (3). Our study showed a high proportion of self-reported arthritis (40%) with 75% of these having had arthritis diagnosed by a dermatologist or a rheumatologist. Whether or not a rheumatologist or a dermatologist had diagnosed arthritis is probably dependent on the local access to specialists and to local tradition. We cannot rule out that a number of patients suffering from osteoarthritis have been included in these figures.

The average response rate to the questionnaires of 50.2% is comparable to the rates of 40 to 50% generally found in mailed epidemiological questionnaires (15). The higher response rate of Danish members is probably due to the fact that the Danish Psoriasis Association was the only one that followed our recommendation to mail a reminder of the study shortly before mailing the questionnaires (15).

The present study showed no significant differences in prevalence of arthritis between members and other "patient groups". Although in one survey studying inpatient populations (9), almost 40% of patients with psoriasis had inflammatory arthritis, and in another survey of previously hospitalized patients, the figure was 25% (10), the occurrence of arthritis in psoriasis has generally been estimated at approximately 7% (13). According to our data, this estimate could be too low. The figure of 23% cases of claimed arthritis in our never-hospitalized material is the significant factor in this respect.

It has until now been assumed, that the frequency of arthritis would be significantly higher among inpatients than among outpatients (10, 13, 14). This figure still seems valid, as 41% within the group of members having previously been hospitalized for their disease (39% of members) had been diagnosed with arthritis.

Although components of a QOL evaluation have been used for studies of psoriatic patients suffering from arthritis (10), to the best of our knowledge, no other large-scale dermatological surveys on QOL in psoriasis have included an evaluation of the influence of joint symptoms by a specific arthritis QOL scoring system. While it is not surprising that a correlation was found between "arthritis severity" and ADI, and that arthritis-related pain, "number of joints" affected, and restriction of movement were among the most important factors explaining variances in score, we can offer no explanation for why being a Norwegian per se increased the risk of having a high ADI score. It is unlikely that genetic differences are of importance; e.g. a very high proportion of the Icelandic population is of Norwegian origin. The same high risk was also found for Norwegians concerning their psoriasis-related QOL (3), as shown by a high PDI.

Although the differences in prevalence between countries were small, the Norwegians also had the highest frequency of reported arthritis among members of the psoriasis associations. This is in contrast to what is known about rheumatoid arthritis, where the prevalence in Norway is lower than that in the other Nordic countries (16). We have avoided discussing comparisons of patients recruited by dermatologists and departments between countries because the number of dermatological beds differs widely between countries, as probably also do the indications for hospital care.

Correlations were also found between ADI and working status. Psoriatic patients who reported arthritis exhibited greater impairment of psoriasis QOL, longer disease duration, and greater self-reported disease severity, while no correlation was found between "arthritis QOL" and PASI scores. Our results thus confirm that psoriatic patients suffering from arthritis have poorer dermatology-related QOL than psoriatic patients without arthritis. This has recently been shown by a Swedish group (17), which used the Dermatology Life Quality Index DLQI (18) on 234 patients from a dermatology outpatient clinic. The DLQI was developed to be used across skin diseases, and is not specifically oriented towards psoriasis.

The finding that the high correlation between self-reported psoriasis severity and PDI remained almost unchanged, when controlling for ADI with a partial correlation, indicates that the greater impairment of skin-disease-related QOL is likely to be independent of the impact of arthritis on QOL. Other statistically significant findings are mentioned among the results. However, it should be mentioned that the clinical significance of statistically significant results in a large sample like ours should be interpreted with caution.

The results of the present investigation clearly demonstrate that when studying QOL in psoriasis, it is necessary to acknowledge joint disease as an important independent factor. The use of ADI instead of the commonly used Health Assessment Questionnaire (HAQ) for arthritis (19) allows a direct comparison between the many items presently used to evaluate psoriasis QOL. Among these, it has been shown that daily activities such as carrying out work around the house and doing sport should be given special consideration. However, it should also be mandatory to take pain and restriction of movement into account. Although our patients as a whole did not belong to the most severely affected arthritis patients, 43.5% claimed to have suffered from "a lot" or "very much" pain within the previous 4 weeks. In future studies, the QOL evaluation in psoriasis patients with joint disease could very well be performed by incorporating HAQ instead.

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