

CLINICAL REPORT

Determinants of Quality of Life in a Psoriasis Population in Northern Sweden

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The aim of this study was to assess possible determinants of quality of life in psoriasis patients in northern Sweden, and to analyse the association between these determinants and quality of life. A questionnaire was mailed to 1,707 subjects, resulting in a response rate of 74%. The study is therefore based on 1,060 subjects, since 195 denied having psoriasis. Quality of life was measured using a version of the Dermatology Life Quality Index. The extent of the disease was estimated using the patients' sketches. The association between determinants and quality of life was calculated in a risk analysis using logistic regression. Large disease extent and joint symptoms were the strongest indicators for impaired quality of life. Other indicators were withdrawal from medical treatment due to distance to treatment facilities, which strongly influenced the quality of life and choice of treatment. Key words: age; cost; distance; extension; gender; joint symptoms.

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Psoriasis is a common skin disease which has a considerable impact on the patient's quality of life (QoL) (1–5). QoL has been studied from different perspectives (6). A health-related QoL (HRQoL) approach focuses on daily functioning and disability (6). Many tools used in QoL studies in dermatology are of this kind; for example the Dermatology Life Quality Index (DLQI) (7, 8). A needs-based approach is derived from the patient's motivation and possibilities of satisfying basic needs (6, 9). An individualistic approach is taken in studies designed to describe QoL in the individual's own words (6, 10).

A recent Swedish study of HRQoL, using the DLQI as one instrument, found that in patients with psoriatic arthritis perceived HRQoL was lower than it was in patients with either psoriasis or atopic dermatitis. No gender differences in total DLQI score were found (11).

In northern Sweden, summers are short and ultra-violet (UV) light treatment for psoriasis is an important remedy. In the county of Västerbotten, a large and sparsely populated area, treatment facilities are restricted to a few urban centres.

In an effort to improve the quality and availability of psoriasis care in the county of Västerbotten, a project was initiated in May 1997. It includes studies on the economic and social consequences of the disease, determinants of perceived QoL and the views of patients, professionals, administrators and politicians about how psoriasis care can be improved. This article reports the determinants of perceived QoL in the patient group.

The aims were to study the distribution of possible determinants of QoL in persons with psoriasis and to assess the association between these determinants and perceived QoL as measured with a health-based instrument. In order to obtain a more extensive description of individuals' perception of QoL and the determinants, this study will be followed by qualitative research interviews in which needs-based, individualistic and health-based aspects of QoL in combination will be considered.

MATERIAL AND METHODS

Study population

All persons with psoriasis in the county of Västerbotten formed the study base. With a population of 250,000 and a suggested prevalence of psoriasis of 2% (12) there should be approximately 5,000 psoriasis patients in the county. Out of the 36 local health care centres 15 were unable to provide patient data because there were no registers of diagnoses or the staff did not have time, and 11 did not reply. The remaining 10 health care centres sent a list of their patients with psoriasis. Patients who were diagnosed with psoriasis and visited one of these 10 care centres or the Clinical Department of Dermatology in Umeå during 1995–1996 and/or who were members of the Swedish Psoriasis Association (SPA) were included in the database. Patients who had visited one of the non-participating care centres and who had not visited the Department of Dermatology or become members of the SPA were lost to the study. We do not know the size of this dropout population or the characteristics of these patients. We can only assume that most patients in this group probably have a mild form of psoriasis as they were not found in the hospital or SPA registers.

Of 1,737 patients registered, 30 could not be contacted (because their address was not known or they had deceased). A questionnaire was mailed to 1,707 subjects in May 1997.

After two reminders the response rate was 74% ($n=1,255$). Out of these 1,255 respondents, 195 were excluded as they denied having psoriasis. Some were probably supporting members of the SPA. The results are therefore based on 1,060 completed questionnaires.

An analysis of non-respondents showed a similar distribution of sex, age and living area as among respondents. Fifty randomly selected non-respondents were interviewed by telephone. The most common reason for not responding was that the questionnaire was "too extensive". When asked about the extent of the disease, 35% assessed their present condition as "very annoying". A valid comparison of extent data from the questionnaire cannot be done, but we believe that extent of the disease among non-respondents was not different from that of the respondents in any apparent way. We conclude that the non-participation of these patients has not induced any significant selection bias with respect to sex, age or living area.

This study has been approved by the Regional Research Ethics Committee.

The questionnaire

The questionnaire contained 62 questions about demographic data, economic and social status, symptoms, treatment, cost of treatment, utilization of psoriasis care, withdrawal from treatment due to distance or cost, the patients' expectations of the medical care and how these expectations have been met, perceived QoL, and extent of the disease as expressed on a sketch showing the maximum area of the skin involved during the last year and the past month.

Hypothesis

Our hypothesis was that perceived QoL is influenced, in a complex manner, by a number of indicators. In this questionnaire we can only study parts of this complex puzzle. Age and gender are basic characteristics, as these have a bearing on biological, social, psychological and cultural factors. Social characteristics such as marital status, employment and profession influence patients' exposure to other people, and may affect their perceptions of disturbances caused by the disease. Lastly, the extent of the disease and indicators affecting its extent, such as the availability of treatment, are potentially important.

Outcome variable

There is an authorized Swedish version of the DLQI (11), but for this analysis we used a modified version, which includes 10 questions focusing on sensory symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. Since we aimed at a more extensive description of perceived QoL with psoriasis, and since some patients may have had more than one skin disease, we explicitly asked in what way they felt their *psoriasis* had affected their daily lives during the previous week. Also, one question specifically asked in what way the disease influenced the patient's choice of clothing. With these few exceptions, our version was practically identical to the authorized version of the DLQI. The questions were coded as in the DLQI (8), giving a maximum index sum of 30. In short, "very much" gave a score of 3, "quite a lot" scored 2, "a little" 1 and "not at all" and "not relevant" scored 0. In the analysis, the sum index was divided into three groups of similar size corresponding to a "low", "medium" and "high" index.

Determinants

A number of variables fitting our hypothesis were selected from the questionnaire. Personal indicators were gender and age. Social indicators influencing patients' exposure to other persons were marital status, gainful employment and profession. Indicators affecting the extent of the disease were economic status, area of residence and distance to UV treatment facilities. We also included withdrawal from treatment as a variable, as this reflected both obstacles to treatment and the patient's priorities. Some characteristics may of course have influenced both exposure and extent of the disease.

Extent of the disease indicators were presence of joint symptoms, maximum skin area affected during the past month and location to the head, hands and anogenital area (marked on a body area sketch by the patient). The area of involvement was calculated by a similar method as used in the Psoriasis Area and Extent Index (PASI) (13). The body was divided into three regions – the upper extremities representing 20% of the body area and the lower extremities 40%. Head (10%) and trunk (30%) were compiled into one region representing 40% of the body area. The scoring ranged from 0 (0% of the region affected), 1 (1–9%), 2 (10–29%), 3 (30–49%), 4 (50–69%), 5 (70–89%) to 6 (90–100%). As upper extremities represent an area half as large as the others, the scoring for this region was multiplied by 0.5. The total score index therefore ranged from 0 to 15. Since the respondents were not examined by a doctor we limited patients' reports to self-described area and did not use all the parameters of PASI. It has been shown that self-reported PASI is an acceptable method and we consider area to be easier for patients to describe than infiltration and erythema (14).

Variables such as age, income, area scores and DLQI scores were divided into categories of similar size in order to optimize the precision of comparisons. Distance to UV treatment facilities was categorized according to recommendations from the SPA, based on experience of "critical" travelling distances.

Statistical methods

The association between determinants and outcome was calculated using logistic regression, and is expressed in terms of odds ratios (OR) and 95% confidence intervals (CIs) to illustrate both the magnitude and precision of the assessment. Results are given both as bivariate and multivariate analysis results in order to control for confounding. The dependent variable, QoL, was dichotomized in order to sort out the group of cases with "high" risk. Calculations were made with SPSS version 10.0 for Windows.

RESULTS

Personal factors and socio-economic indicators

The gender distribution was fairly even, with 51.8% of the study population being male and 48.2% female. The age distribution was similar among women and men (see Table I).

The vast majority of the patients lived in partnership and most of those in work were permanently employed. These indicators had a similar distribution among women and men, but, as expected, they differed in profession. Craft and related trade workers constituted the dominating profession among men, while most women

Table I. Distribution and odds ratios (OR) of personal and socio-economic indicators among psoriasis patients.[#]

Variable	Distribution (%)		Crude OR (95% CI)		Adjusted OR* (95% CI)	
	Women	Men	Women	Men	Women	Men
Gender: Women/Men	48.2	51.8	1.0	1.03 (0.77–1.37)	1.0	1.01 (0.74–1.39)
Age group: 0–39 years	27.3	23.5	1.0	1.0	1.0	1.0
40–49 years	21.3	24.1	0.89 (0.48–1.64)	1.75 (0.99–3.09)	0.84 (0.44–1.62)	1.84 (1.00–3.39)
50–59 years	22.3	23.5	1.79 (1.00–3.22)	1.69 (0.95–3.01)	1.97 (1.03–3.79)	1.65 (0.89–3.06)
60+ years	29.1	28.9	0.86 (0.49–1.53)	0.82 (0.46–1.47)	1.21 (0.64–2.29)	0.93 (0.49–1.76)
Marital status: Single	12.9	16.9	1.0	1.0	1.0	1.0
Married/cohabitant	78.3	75.4	0.97 (0.52–1.84)	1.51 (0.85–2.67)	1.13 (0.57–2.29)	1.48 (0.80–2.74)
Divorced	8.7	7.7	1.11 (0.45–2.75)	1.50 (0.62–3.64)	0.95 (0.33–2.72)	1.15 (0.43–3.07)
Employment: Permanently employed	59.4	58.1	1.0	1.0	1.0	1.0
Substitute	5.0	5.9	0.83 (0.28–2.48)	2.36 (0.99–5.60)	0.98 (0.26–3.70)	2.59 (0.98–6.72)
Self-employed	3.2	8.6	1.86 (0.82–4.21)	2.34 (1.02–5.39)	2.26 (0.94–5.46)	2.25 (0.91–5.58)
Unemployed	8.7	6.3	1.60 (0.41–6.19)	1.54 (0.75–3.17)	1.26 (0.26–6.07)	1.35 (0.61–2.99)
Other (e.g. student, pensioner)	23.7	21.1	0.88 (0.49–1.59)	1.10 (0.65–1.87)	0.90 (0.47–1.70)	0.90 (0.50–1.61)
Profession: Legislators, senior officials and managers	3.1	6.8	1.0	1.0	1.0	1.0
Professionals with university degree	12.4	19.7	3.15 (0.34–29.53)	0.40 (0.14–1.08)	1.51 (0.14–16.31)	0.39 (0.13–1.18)
Technicians and officers	15.8	12.5	4.67 (0.52–41.64)	0.77 (0.27–2.22)	2.90 (0.29–28.78)	0.81 (0.26–2.54)
Clerks	14.8	8.0	4.42 (0.48–40.76)	0.65 (0.21–2.07)	2.86 (0.28–29.34)	0.85 (0.25–2.95)
Service workers and shop sales workers	34.7	5.4	3.37 (0.39–28.84)	0.55 (0.15–2.02)	2.45 (0.26–23.12)	0.52 (0.13–2.13)
Skilled agricultural and fishery workers	0.3	4.8	–	0.28 (0.06–1.27)	–	0.44 (0.09–2.14)
Craft and related trades workers	1.4	21.7	3.50 (0.14–84.69)	0.50 (0.19–1.33)	2.03 (0.07–55.60)	0.57 (0.20–1.63)
Plant and machine operators and assemblers	2.1	14.8	2.33 (0.11–50.99)	0.46 (0.16–1.30)	0.83 (0.03–20.08)	0.60 (0.20–1.85)
Workers in occupations, for which no training is requested	15.5	6.0	3.08 (0.34–28.13)	0.21 (0.05–0.95)	1.71 (0.17–17.42)	0.17 (0.03–1.01)
Members of the armed forces	–	0.3	–	–	–	–
Income group ¹ : >200,000 SEK	10.0	39.0	1.0	1.0	1.0	1.0
150,001–200,000 SEK	29.6	32.5	2.21 (0.91–5.38)	0.93 (0.57–1.52)	2.13 (0.80–5.67)	1.15 (0.67–1.97)
100,001–150,000 SEK	25.9	14.6	1.62 (0.65–4.08)	1.24 (0.65–2.36)	1.84 (0.67–5.05)	1.36 (0.67–2.76)
<100,000 SEK	34.5	14.0	1.71 (0.71–4.15)	1.67 (0.87–3.20)	1.63 (0.62–4.30)	1.56 (0.77–3.15)
Living area: Urban centre	48.9	43.6	1.0	1.0	1.0	1.0
Rural area	51.1	56.4	1.13 (0.74–1.72)	1.20 (0.81–1.79)	1.27 (0.80–2.01)	1.35 (0.88–2.09)
Distance to UV facilities: 0–20 km	63.7	62.4	1.0	1.0	1.0	1.0
21–60 km	21.2	19.2	0.78 (0.45–1.37)	1.41 (0.83–2.41)	0.89 (0.48–1.62)	1.79 (1.00–3.22)
61–100 km	8.3	9.6	0.41 (0.15–1.13)	1.87 (0.95–3.69)	0.45 (0.16–1.30)	2.11 (1.01–4.44)
101–150 km	3.3	5.3	1.16 (0.32–4.21)	0.82 (0.29–2.35)	1.78 (0.46–6.81)	0.86 (0.29–2.59)
>150 km	3.5	3.5	2.60 (0.71–9.47)	2.29 (0.72–7.32)	2.32 (0.59–9.10)	4.21 (1.07–16.60)

[#]Crude and adjusted odds ratios (ORs) with a 95% confidence interval (CI) for a “high quality of life (QoL) index” with respect to these factors. Where not indicated, reference is a complementary category.

*Adjusted for extent index during the past month.

¹Annual income before tax. The exchange rate in 1995 was 10.785 SEK per £. The income given includes salary and pension.

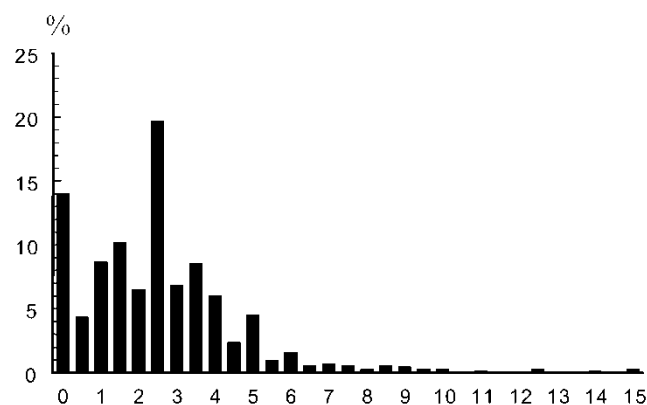


Fig. 1. Distribution (%) of extent index among psoriasis patients. Score 0–1 means low extent, score between 1–3 medium extent, and above 3 large extent.

worked as service workers or shop assistants. More women than men had a profession with exposure to customers and women had a lower income than men (Table I).

Similar proportions of patients lived in urban centres and rural areas [9,056 or more inhabitants (1996.12.31) and less than 9,056 inhabitants, respectively]. Two-thirds of the patients lived within 20 km of UV treatment facilities. When this study was performed, there were only three UV treatment facilities located in the three cities in the county. An investigation of the utilization of the UV treatment facilities revealed that when the distance from the patients' home to the treatment facility increased from 30 km to 80 km,

utilization dropped from 31.6% to 8.3%. At a distance of 100 km it was reduced to 3.2%.

Extent of the disease

Almost half of the study population stated that they had joint symptoms; this was reported more frequently by women. Involvement of the head/scalp was reported by more than half of the patients, while hand and/or anogenital involvement was reported by a smaller proportion. The extent index is illustrated in Fig. 1. The clinical expression of psoriasis was similar among women and men (Table II).

For the analysis of determinants of QoL, the total extent index was separated into three groups of similar size. A "low" index includes values of 0–1, a "medium" index of 1.5–3 and a "high" index, of >3.

Perceived quality of life

The QoL index is given in Fig. 2. The total index was separated into two groups for the risk analysis. A "high" index includes values above 6. This group comprised about 30% of the patients. In the following risk analysis a "case" is a patient belonging to this group.

Risk analysis

The results of the bivariate analysis of risk indicators for impaired QoL, stratified for gender, are given in Tables I and II. Reference categories were formed because of what in general are considered to be

Table II. Distribution and odds ratios (OR) of clinical characteristics, extent of the disease, and quality of life (QoL) among psoriasis patients.[#]

Variable	Distribution (%)		Crude OR (95% CI)		Adjusted OR* (95% CI)	
	Women	Men	Women	Men	Women	Men
Joint symptoms	46.6	42.7	2.89 (1.85–4.52)	4.15 (2.72–6.35)	3.15 (1.92–5.36)	3.55 (2.25–5.59)
Body area involved						
Head	56.4	56.2	1.45 (0.92–2.28)	1.76 (1.16–2.67)	1.07 (0.65–1.75)	1.30 (0.83–2.03)
Hands	30.6	28.8	2.43 (1.51–3.90)	1.94 (1.25–2.98)	1.99 (1.20–3.29)	1.53 (0.97–2.43)
Anogenital area	26.7	27.4	1.89 (1.16–3.08)	1.94 (1.24–3.04)	1.28 (0.75–2.18)	1.53 (0.95–2.45)
Extent index during past month						
Low	29.3	25.0	1.0	1.0	–	–
Medium	33.9	38.7	2.19 (1.13–4.22)	1.95 (1.07–3.55)	–	–
High	36.8	36.3	5.58 (2.89–10.77)	5.03 (2.78–9.10)	–	–
Withdrawal due to distance	15.6	15.1	3.29 (1.83–5.90)	2.69 (1.53–4.73)	2.36 (1.24–4.47)	2.27 (1.23–4.20)
Withdrawal due to cost	17.4	15.2	3.97 (2.35–6.69)	2.06 (1.21–3.52)	2.55 (1.43–4.53)	1.49 (0.83–2.66)
Withdrawal for other reasons	17.7	17.0	1.61 (0.99–2.62)	1.89 (1.18–3.03)	1.27 (0.74–2.16)	1.62 (0.98–2.68)
QoL index						
Low	38.2	36.6				
Medium	27.4	28.4				
High	34.4	35.0				

[#]Crude and adjusted odds ratios (ORs) with a 95% confidence interval (CI) for a "high quality of life (QoL) index" with respect to these factors. Where not indicated, reference is a complementary category.

*Adjusted for extent index during the past month.

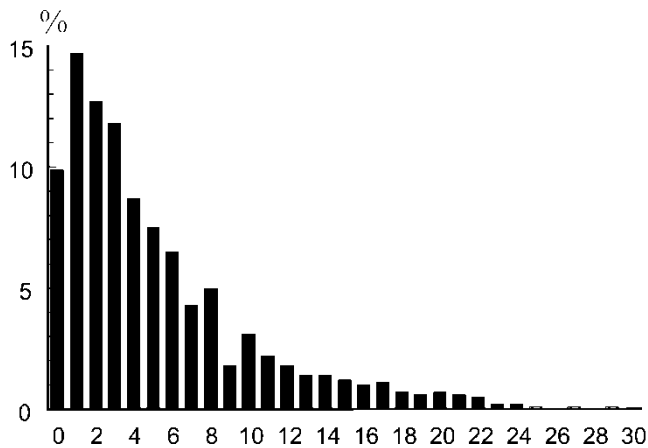


Fig. 2. Distribution (%) of perceived quality of life among psoriasis patients. Score 6 and more means a high risk of having an impaired quality of life due to psoriasis.

favourable indicators for a high QoL (small disease extent, proximity to treatment facility, high income, young age). The extent of the body area affected by psoriasis was the strongest risk indicator. Joint symptoms and involvement of the hands and anogenital area were likewise strong risk indicators. Other risk indicators were withdrawal from UV treatment or medical care due to cost or distance. The pattern was similar among women and men.

Gender itself was not a risk indicator. Involvement of the head/scalp and withdrawal from medical treatment for other reasons (such as resignation, lack of time, work, family, sensitivity to light, not wanting to be a burden, mild disease or limited opening hours at the UV treatment centres) were significant for impaired QoL among men. With few exceptions, socio-economic indicators did not appear to be risk indicators. Age between 50 and 59 years was a risk indicator among women and self-employment was a risk indicator among men. There was also a discrepant pattern among women and men regarding profession. Though the results were not significant and there were few respondents in each group, there was a consistent pattern showing that all professions were associated with a better QoL compared with legislators, senior officials and managers among men, and that the reverse was seen among women.

A multivariate analysis of the determinants was performed with adjustment for extent of the disease in order to control for confounding from this indicator. The results are given in Tables I and II. In this analysis, reported joint symptoms kept a position as a strong risk indicator among both men and women. Another risk indicator for both genders was the decision not to undergo UV treatment due to distance. Age between 40 and 49 and long distance to the UV treatment facilities were other risk indicators among men. Involvement of the hands, the decision not to be treated due to high treatment costs and age 50–59 were other risk

indicators among women. The risk pattern that emerged in the bivariate analysis with regard to profession was maintained in the multivariate analysis.

DISCUSSION

As expected, the extent of the disease was the most important indicator for impaired QoL in our study, and in agreement with other studies (15, 16). The importance of joint symptoms was not surprising (15). In the analysis, we used patients' self-reports of joint symptoms which they attributed to their psoriasis. It is known that the prevalence of joint pain is high among persons with psoriasis, but that only a proportion of these findings are due to true arthritis (17).

The multivariate analysis confirmed the result from the bivariate analysis regarding localization of psoriasis to the hands to be significantly associated with impaired QoL in women. This is similar to findings from other studies (16, 18, 19). Localization of the disease to the hands and involvement of head and anogenital area may affect an individual's appearance, self-image and sexuality (19). Hands are main tools in work and physical contact, and having them exposed (16, 18) may awaken fear, i.e. the patients' own feelings of being "unclean" or "untouchable" (4) and uncomfortable when touching other people including partners, and the fear of others that the disease is contagious. The discriminative sensitivity of the hand (20) is an important part of the individual's communication system (21). If use of the hands is reduced because of involvement of psoriasis, the ability to communicate and work is impaired.

Like Lundberg et al. (11), we found no difference between genders regarding total DLQI score, while Zachariae et al. did (15). However, we did find gender differences regarding age and localization of the disease. A woman in her 50s with a large spread of psoriasis working in a service-related occupation, where her hands are exposed and she has physical contact with others, may feel uncomfortable. Self-esteem may be influenced by culture, where youth, beauty and a healthy body are admired and where advertising and the media focus commonly on young women (22). Besides the maximum onset at puberty, there is a smaller peak of onset of psoriasis later in life, especially among women aged 40–50 (23). The impact on QoL can be more distinct during the first years after onset, but this may differ between individuals owing to different coping strategies (5, 24, 25). The occurrence of psoriasis at these ages may concur with other major life changes taking place, such as children moving away from home and a general ageing of the body, and affect the individual (19). A man in his 40s with large areas covered with psoriasis, who works as a manager, may experience his QoL similarly affected. Among men, awareness of the body and of an ideal male image has increased (26).

Our finding that certain age groups are at risk of perceiving a lower QoL is interesting with respect to coping strategies. However, our data do not include the date of onset of the patient's disease. Such data would have strengthened an analysis of the association between age and perceived QoL.

Both women and men incur considerable expense during their treatment for psoriasis (3). Women generally have a lower income and therefore cost may be more important to them (27). Moreover, women with a low income are more frequently married to men with a similarly low income (28).

As expected, we found that with an increased distance to the UV treatment facilities the utilization of such facilities decreased. Distance itself was a risk indicator for men and opting for non-treatment because of distance was a decision made mostly by patients who lived far from these facilities. Some patients living close to treatment facilities, however, also gave distance as a reason for not undergoing treatment. The opposite was also seen. Half of the patients living more than 100 km from UV treatment facilities stated that their withdrawal from treatment was due to factors other than distance. For many the decision to withdraw from treatment probably had a complex background. Besides distance there may have been other obstacles to undergoing treatment. Other basic needs may have become more important (9). There may also be other explanations, such as different coping strategies for learning to live with the disease (24). Over time a process of normalization may take place (25), and the disease become part of everyday life. This is not to say that patients will not feel some degree of chronic, low-grade stress (19), and might have main reactions such as "anticipation of rejection" and "sensitivity to others' attitudes" (5), resulting from living with psoriasis.

There may be other explanations as to why so many of the respondents chose non-treatment over treatment, despite the risk of a worse QoL.

One of the weaknesses of the DLQI index is that it covers only parts of the respondent's life. For this reason we included one open question about the respondent's own views on what constitutes a high QoL, which elicited responses such as having a job, a family, or going for a walk in the forest. This showed that QoL includes aspects of life that are not shown in the DLQI. It remains to be established whether these aspects are affected by psoriasis and, if so, in what way. Some advantages of the DLQI are that it covers different parts of life and can be used in a questionnaire. It can be used to compare different skin diseases and also to compare between patients from different countries and cultures. We used a modified version of the DLQI. Still, we consider the validity of the DLQI to be applicable to our version, as there were only minor changes.

The study population was not representative of all

psoriasis patients in the county. Judging from the dropout analysis, our respondents were representative of the part of the psoriasis population who were, and are, in contact with primary and specialist care. All the patients included verified that they suffered from psoriasis. Of these, 91.4% had had the diagnosis confirmed by a dermatologist. In most cases we consider psoriasis to be quite easy to diagnose in primary care. However, we cannot rule out the possibility that a small number of our patients may have had another skin disease.

This study will be followed by qualitative interviews with which we hope to come to a more extensive understanding of why some patients refrain from undergoing treatment. The result will be useful for improving psoriasis care and, hopefully, the QoL of psoriasis patients.

To summarize, besides extent of the disease and joint involvement, distance to medical treatment facilities influenced the perceived QoL. Distance also had an influence on choice of treatment. There was an effect of age group on perception of QoL. Finally, among women, involvement of hands and cost of treatment also appeared as risk indicators.

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