

The Burden of Psoriasis Is Not Determined by Disease Severity Only

Vera M.R. Heydendael,* Corianne A.J.M. de Borgie,† Phyllis I. Spuls,* Patrick M.M. Bossuyt,† Jan D. Bos,* and Menno A. de Rie*

*Department of Dermatology and †Department of Clinical Epidemiology and Biostatistics, Academic Medical Center, University of Amsterdam, the Netherlands

Psoriasis is a chronic scaling and inflammatory skin disease that can affect patients' quality of life and daily functioning. We studied the scores of 85 patients suffering from moderate to severe plaque-type psoriasis, participating in a randomized controlled trial. We compared their scores on a generic quality-of-life instrument with data from two reference populations. We examined associations between clinical severity, as measured by the components of the Psoriasis Area and Severity Index (PASI), and the respective quality-of-life subdimensions, measured by the Medical Outcome Survey Short Form 36 (SF-36), to find out what elements of disease activity are related with impaired quality of life. Compared to the reference population, quality of life was impaired in terms of bodily pain and social functioning. There were no significant correlations between overall disease severity, as measured by PASI, and the SF-36 subdimensions. When examining the PASI components, we found significant correlations between desquamation on the upper limbs and mental health and bodily pain ($r = -0.23$ and $r = -0.28$, respectively) and between desquamation on the scalp and mental health ($r = -0.29$). In conclusion, we found that psoriasis patients had a lower quality of life than a reference population, without a significant relation between disease severity or disease area and quality of life. Yet psoriasis lesions located on visible body parts are significantly correlated with aspects of quality of life.

Key words: SF-36/PASI/quality of life
J Investig Dermatol Symp Proc 9:131-135, 2004

Psoriasis is a chronic scaling and inflammatory skin disease that, like other chronic (skin) diseases, can affect patients' quality of life and daily functioning (Finlay and Coles, 1995). The extent and severity of the disease varies between patients and fluctuates over time.

Based on a large mail survey among members of the National Psoriasis Foundation in the United States (N = 17488), Krueger and coworkers (2001) argued that patients feel that their disease has an impact on the social, physical, and emotional quality of their lives. Recent investigations show that these patients suffer as much disability than others with chronic illnesses (Nichol *et al*, 1996; Rapp *et al*, 1998; Wahl *et al*, 1999, 2000). Earlier analyses in patients with mild and moderate psoriasis showed that disease severity significantly correlates with and can even predict the effect on patients' quality of life (Leary *et al*, 1998; Nichol *et al*, 1996).

Quality of life is known to be influenced by a large number of factors, including age and comorbidity. On the other hand, severe psoriasis is reflected in a number of ways, including erythema, infiltration, and desquamation. When measured by the Psoriasis Activity and Severity Index

(PASI), several quite different patterns of psoriasis can lead to similar PASI.

To further clarify associations between disease severity and quality of life, we studied a group of patients all suffering from moderate to severe psoriasis. We compared their scores on a generic quality-of-life instrument with data from two reference populations, examining associations between clinical severity, as measured by the different PASI components, and the respective Medical Outcome Survey Short Form 36 item (SF-36) subdimensions, to find out what elements of disease activity are related with impaired quality of life.

Results

Patient characteristics Characteristics of the 85 patients (57 men, 28 women) are presented in Table I. The number of patients with moderate psoriasis was 41 (mean PASI, 9.9 ± 0.2 SEM), with 44 suffering from severe psoriasis (mean PASI, 17.2 ± 0.8 SEM). Demographic characteristics (such as marital status, income, and education) between these two groups were comparable. Although more men than women participated in this study, the patient characteristics between men and women did not differ significantly.

Four (3.4%) patients had been diagnosed earlier as having psoriasis arthropatica. Their SF-36 scores did not

Abbreviations: AMC, Academic Medical Center; PASI, Psoriasis Area and Severity Index; SF-36, Medical Outcome Survey Short Form 36 item; USC, University of Southern California

Table I. Patient characteristics

Total	N = 85
PASI (range)	13.7 ± 0.4 ^a (7.6 ^b –38.4)
Sex	
Male	57
Female	28
Ethnic background	
Caucasian	70
Mediterranean	3
Asian	6
Other	6
Age at inclusion, years (range)	39.9 ± 12.7 ^c (19–71)
Age at disease onset, years (range)	24.7 ± 13.8 ^c (3–64)
Duration of disease, years (range)	15.2 ± 9.5 ^c (1–46)
Previous therapies	
UVB	53
PUVA	18
Neotigason	10
Fumaric acid	3
Only topical treatments	22
Other chronic diseases	
None	77
1	6
> 1	2

^aMean ± SEM.
^bThe PASI from one patient at randomization was falsely calculated as higher than 8. Upon recalculation the patient's correct PASI appeared to be 7.6. For the purpose of this study, the patient was chosen to remain included.
^cMean ± SD.

differ from the other included patients. Six patients suffered from other chronic diseases; 3 patients had hypertension (controlled by medication), 2 patients suffered from non-insulin-dependent-diabetes, and 1 patient had rheumatoid arthritis.

Comparison with reference populations Table II shows the mean scores on the respective SF-36 subdimensions and those of the reference groups. Compared to the Dutch reference sample, the psoriasis patients in our study perceived their quality of life more impaired on two quality-of-life subdimensions, bodily pain and social functioning, with a better physical functioning.

PASI compared to SF-36 in the AMC study group All correlations between the total PASI and the seven SF-36 subdimensions scores were very small and none reached statistical significance. No correlation or relevant trend was found between the two summary scores of the SF-36, mental component and physical component summary score (Fig 1).

Examining the specific elements of the PASI (erythema, infiltration, and desquamation) we observed small but significant correlations between mental health and desquamation located on the scalp ($R = -0.287$, $p < 0.01$), mental health and desquamation on the upper limbs ($R = -0.228$, $p = 0.04$), and bodily pain and desquamation on the upper limbs ($R = -0.280$, $p < 0.01$).

When the severity of the disease was classified into moderate and severe, most mean SF-36 subdimensions scores in the severe psoriasis group were lower than the corresponding scores in the moderate psoriasis group, but none of these differences was significant (Table III).

Correlation among demographic variables, total PASI, and SF-36 in the AMC study sample A significant correlation was found between age and physical functioning

Table II. Mean SF-36 scores for the AMC psoriasis study patients and the USC and Dutch reference (DR) population samples

SF-36 subdimension	Study sample		
	AMC patients (n = 85)	USC population (n = 644)	DR population (n = 1742)
Age at inclusion (years)	39.9 ± 12.7 ^a	48.2 ± 15.1 ^a	47.6 ± 18.0 ^a
Age at disease onset (years)	24.7 ± 13.8 [*]	30.4 ± 15.4 ^a	Not described
Physical functioning ^b	88.9 ± 16.1 ^a	85.9 ± 19.7 ^a	83.0 ± 22.8 ^a
Social functioning ^c	77.1 ± 24.5	89.2 ± 18.8	84.0 ± 22.4
Role: physical	75.3 ± 35.9	85.5 ± 29.0	76.4 ± 36.3
Bodily pain ^c	67.8 ± 24.5	76.7 ± 22.2	74.9 ± 23.4
Mental health	71.7 ± 19.4	74.1 ± 17.2	76.8 ± 17.4
Role: emotional	78.2 ± 36.8	85.3 ± 29.8	82.3 ± 32.9
Vitality	68.7 ± 19.1	66.5 ± 18.2	68.6 ± 19.3

^aMean ± SD.

^b $p < 0.05$ compared to DR population.

^c $p < 0.05$ compared to USC and DR population.

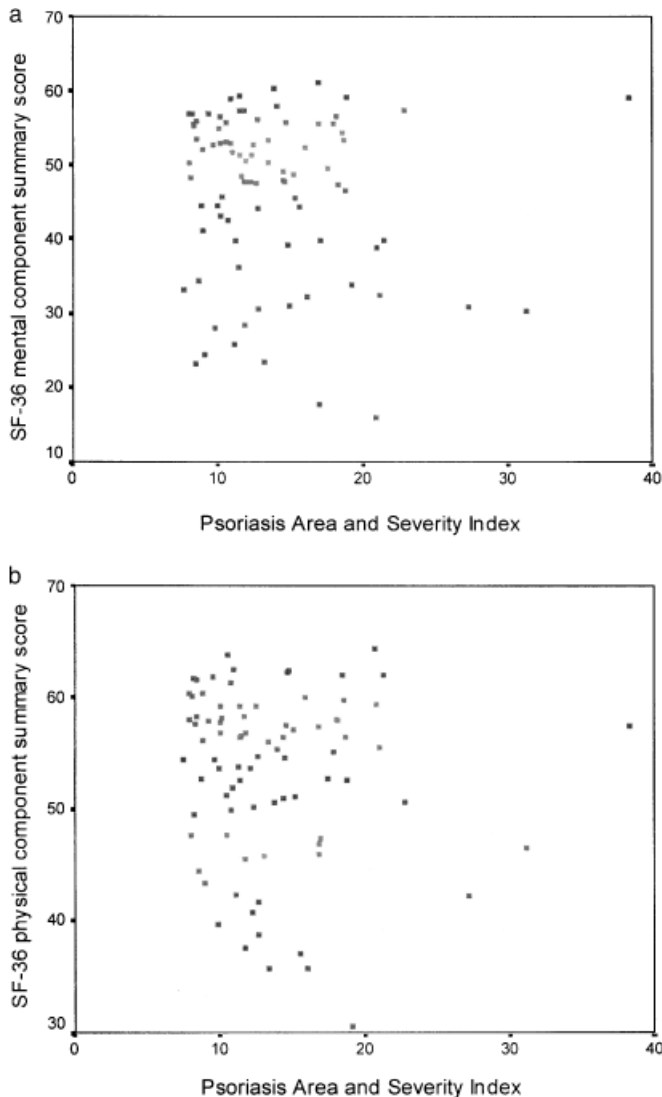


Figure 1
Psoriasis Area and Severity Index: (a) in relation to SF-36 mental component summary score and (b) in relation to SF-36 physical component summary score.

($p = 0.016$, $R = 0.262$). No statistically significant correlation was found between other demographic variables (such as ethnic background, education, marital status), previous used therapies, and total PASI and SF-36 subdimensions.

Discussion

We confirmed the finding that a general instrument (SF-36) finds major impact of psoriasis on patients lives even though this instrument was not especially designed to detect burden of skin disease. In this study of quality of life in patients with moderate to severe psoriasis, we found more bodily pain and a lower social functioning than in a large Dutch reference population. There was no significant correlation between disease severity and disease area, as measured by PASI, and SF-36 scores, but moderate relations between specific elements of the PASI and quality of life. In particular, psoriasis lesions located on visible body

Table III. SF-36 scores in patients suffering from moderate psoriasis ($n = 41$) compared to patients suffering from severe psoriasis ($n = 44$), within the AMC study group

SF-36 subdimension	Moderate	Severe
Physical functioning	91.3 \pm 2.2 ^a	86.6 \pm 2.7 ^a
Social functioning ^b	79.6 \pm 3.8	74.7 \pm 3.7
Role: physical	78.7 \pm 5.7	72.1 \pm 5.8
Bodily pain	71.2 \pm 3.9	64.7 \pm 3.6
Mental health	72.9 \pm 2.9	70.5 \pm 2.9
Role: emotional	80.0 \pm 5.4	76.5 \pm 5.9
Vitality ^c	72.7 \pm 2.7	65.0 \pm 3.1

^aMean \pm SEM.
^b $p = 0.09$.
^c $p = 0.06$.

parts are significantly correlated with aspects of quality of life, in particular mental health.

This study is limited because most of the patients did have quite extensive disease and because of relative homogeneity of the study population. This might have had an influence on identifying a variation in burden of disease. This in contrast to earlier investigations in which patients with a wider range of psoriasis severity were examined.

Because of the study design, in which patients had a wash-out period of 2 to 4 wk, we could not completely rule out an influence of this wash-out period on the disease severity. Therefore, we compared the PASI before and after the wash-out period and found no relevant differences (data not shown).

A small number of patients ($n = 4$) suffered from psoriasis arthropatica. Analysis of the SF-36 outcome showed no significant differences between this subpopulation and the patients without psoriasis arthropatica.

Using a generic quality-of-life instrument, comparisons with other populations can be made. Earlier other investigators recommended a combination of generic and dermatology-specific instruments to assess quality of life in patients with skin diseases (Chren *et al*, 1997; De Korte *et al*, 2002). It is very well possible that a dermatology or psoriasis-specific instrument had been able to detect more variation in our study population.

We were unable to use age-matched control data when comparing quality of life of the psoriasis patients in our study with the Dutch reference population. The fact that our group was younger than the comparator group can explain the better scores for physical functioning and may have obscured minor differences on other subdimensions.

The finding that the AMC study population scored relatively lower on the subdimensions bodily pain and social functioning in comparison with the USC population could be due to a higher disease severity in the AMC population compared to the USC population. In contrast to the AMC population, patients with stable plaque psoriasis not exceeding 20% of total body surface area were included in the USC population. On average, the USC patients had psoriasis covering 7.2% (SD 5.0%) of their bodies. Another

explanation for this difference could be that, in contrast to the USC population, the "actual disease activity" was measured in the AMC population, because at the time of evaluation patients were not treated with active antipsoriatic therapies. Several previous studies have demonstrated that psoriasis located on visible body parts (legs, arms, head) had a greater impact on the quality of life than lesions located on other areas (Finlay and Coles, 1995; O'Neill and Kelly, 1996; Touw *et al*, 2001).

Wahl and coworkers (2000) compared the SF-36 scores of a large Norwegian group of psoriasis patients ($n=283$) with those of a general population and found significantly lower scores on all subdimensions in the psoriasis group. Although age (40:47 y) and disease duration (15.2:19 y) were comparable to our psoriasis study group we found higher scores, indicating better health, in our patients. This difference could be related to the fact that 20% of the study population of Wahl *et al* (2000) was hospitalized, substantially more patients suffered from psoriasis arthropatica and also more comorbidity was reported. Unfortunately, no disease activity was reported by the investigators.

Several studies have examined the association between clinical severity of psoriasis and quality of life, relying on disease-specific instruments (Fortune *et al*, 1997; Kent and al-Abadie, 1993; Touw *et al*, 2001) or evaluations performed by the patients themselves (Rapp *et al*, 1999). To our knowledge, the subscales of the SF-36 were never correlated with disease-specific characteristics such as erythema, infiltration, desquamation, and body surface area.

Our results do not demonstrate a significant correlation between clinical symptoms and quality of life. Nevertheless, patients with severe disease severity did have an inferior quality of life compared to the patients with moderate disease.

It is very well likely that cosmetic disfigurement and itch determine the burden of illness. These are not captured by the disease severity scores, nor by the generic quality-of-life instruments. To measure these, disease-specific instruments can be used, whereas generic quality-of-life measurement enable a comparison with other groups. We think that our results support the decision to use disease-specific instruments (to measure burden of illness) in combination with a generic instrument (to measure general health-related quality of life) in evaluating the impact of disease severity in psoriasis.

Materials and Methods

Patients We used data from 85 patients suffering from moderate to severe plaque-type psoriasis who had given informed consent for a randomized controlled trial comparing methotrexate and cyclosporine. The details of this trial are reported elsewhere (Heydendael *et al*, 2003). Eligible patients had a PASI score of 8 or more, naive to treatment with methotrexate and cyclosporine. They were older than 18 y and had sufficient understanding of the Dutch language.

Patients were included between October 1998 and June 2000 at the outpatient clinic at the Department of Dermatology in the Academic Medical Center (AMC) at the University of Amsterdam, the Netherlands. This center acts as a referral center for the city of Amsterdam (30%), the regional area around Amsterdam (26%),

and the rest of the Netherlands (44%). A wash-out period during which no treatment was permitted lasted 2 wk for patients previously treated with topical therapies and 4 wk for patients previously treated with photo(chemo)therapy and systemic therapies.

Outcome measures

Assessment of disease severity Patients characteristics such as age, sex, age at inclusion, duration of disease, and coexistence of chronic diseases (comorbidity) were recorded. For evaluation of the clinical symptoms the PASI was used (Fredricksson and Petterson, 1978). The PASI takes values in the range 0 to 72 with higher PASI values indicating more severe disease. Moderate psoriasis was classified as a PASI between 8 and 12, and severe psoriasis as a PASI of >12 . The investigators that scored the PASI were trained to reduce intra- and interobserver variability. The reliability of the PASI, as measured by Cronbach's alpha, was high: 0.95.

Quality of life During screening (and before the wash-out period), patients' self-assessment of health-related quality of life was measured by the SF-36 (Aaronson *et al*, 1998). The SF-36 is a generic multidimensional instrument consisting of the following subdimensions: (1) limitations owing to physical problems; (2) limitations in social function; (3) role limitations owing to physical problems; (4) bodily pain; (5) mental health; (6) role limitations owing to emotional problems; and (7) vitality (energy and fatigue). Also, two summary scores can be calculated, mental component and physical component summary score. Scores on the SF-36 were transformed to a 0 to 100 scale, with higher scores indicating a better quality of life.

Analysis Average scores of the psoriasis patients were calculated and compared with reference data from a Dutch reference population of 1742 persons without chronic illness (Aaronson *et al*, 1998). In addition, we compared the averages scores with data from psoriasis patients ($n=644$), studied at the University of Southern California (USC) (Nichol *et al*, 1996). Differences between groups were tested for significance using the *t* statistic.

Associations between quality of life and demographic, clinical characteristics, and disease severity were explored using Pearson correlation coefficients. A significance level of 0.05 was used in all statistical tests.

The authors thank G.A.M. Appel, S.F. Langenhuisen-Jongevos, F.M.C. Mombers, Y. Remmelzwaal, and H.J.C. de Vries. The statistical assistance of B.C. Opmeer and W.F.M. Goldschmidt is very much appreciated. We are grateful to J. de Korte, psychologist, for his expertise and advice concerning the quality of life. This study was supported by a grant from the Health Organization (CVZ Grant 97-009).

DOI: 10.1046/j.1087-0024.2003.09115.x

Manuscript received May 30, 2003; revised August 22, 2003; accepted for publication October 8, 2003

Address correspondence to: V.M.R. Heydendael, MD, Department of Dermatology, A0-229, Academic Medical Center, PO Box 22660, 1100DD Amsterdam, the Netherlands. Email: v.m.heydendael@amc.uva.nl

References

- Aaronson NK, Muller M, Cohen PDA, *et al*: Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *J Clin Epidemiol* 51:1055-1068, 1998
- Chren MM, Lasek RJ, Quinn LM, Covinsky KE: Convergent and discriminant validity of a generic and disease-specific instrument to measure quality of life in patients with skin disease. *J Invest Dermatol* 108:103-107, 1997

- De Korte J, Mommers FM, Sprangers MA, Bos JD: The suitability of quality-of-life questionnaires for psoriasis research: A systematic literature review. *Arch Dermatol* 138:1221–1227, 2002
- Finlay AY, Coles EC: The effect of severe psoriasis on the quality of life of 369 patients. *Br J Dermatol* 132:236–244, 1995
- Fortune DG, Main CJ, O'Sullivan TM, Griffiths CE: Quality of life in patients with psoriasis: The contribution of clinical variables and psoriasis-specific stress. *Br J Dermatol* 137:755–760, 1997
- Fredricksson T, Petterson U: Severe psoriasis: Oral therapy with a new retinoid. *Dermatologica* 157:238–244, 1978
- Heydendael VMR, Spuls PhI, Opmeer BC, *et al*: Methotrexate versus cyclosporin in moderate-to-severe chronic plaque psoriasis. *N Engl J Med* 349:658–665, 2003
- Kent G, al-Abadie M: The psoriasis disability index-further analyses. *Clin Exp Dermatol* 18:414–416, 1993
- Krueger G, Koo J, Lebwohl M, Menter A, Stern RS, Rolstad T: The impact of psoriasis on quality of life: Results of a 1998 National Psoriasis Foundation Patient-Membership Survey. *Arch Dermatol* 137:280–284, 2001
- Leary MR, Rapp SR, Herbst KC, Exum ML, Feldman SR: Interpersonal concerns and psychological difficulties of psoriasis: Effects of disease severity and fear of negative evaluation. *Health Psychol* 17:530–536, 1998
- Nichol MB, Margolies JE, Lippa E, Rowe M, Quell J: The application of multiple quality-of-life instruments in individuals with mild-to-moderate psoriasis. *Pharmacoeconomics* 10:644–653, 1996
- O'Neill P, Kelly P: Postal questionnaire study of disability in the community associated with psoriasis. *BMJ* 313:919–921, 1996
- Rapp SR, Feldman SR, Exum L, Fleischer AB, Reboussin DM: Psoriasis causes as much disability as other major medical diseases. *J Am Acad Dermatol* 41:401–407, 1999
- Rapp SR, Feldman SR, Fleischer AB, Reboussin DM, Exum ML: Health related quality of life in psoriasis: A biopsychosocial model and measures. In: *Care Management of Skin Diseases: Life Quality and Economic Impact*. New York: Dekker, 1998; p 125–146
- Touw CR, Hakkaart-van Roijen L, Verboom P, Paul C, Rutten FFH, Finlay AY: Quality of life and clinical outcome in psoriasis patients using intermittent cyclosporin. *Br J Dermatol* 144:967–972, 2001
- Wahl A, Hanestad BR, Wiklund I, Moum T: Coping and quality of life in patients with psoriasis. *Qual Life Res* 8:427–433, 1999
- Wahl A, Loge JH, Wiklund I, Hanestad BR: The burden of psoriasis: A study concerning health-related quality of life among Norwegian adult patients with psoriasis compared with general population norms. *J Am Acad Dermatol* 43:803–808, 2000