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Published in	International Journal of Dermatology
Publication Date	2007
Document Version	publishersversion
Link	https://research.tilburguniversity.edu/en/publications/edbe4b34-537d-4192-8546-0aebd71155f5
Citation	Reimus, J L M, Vingerhoets, A J J M, Soons, P H G M & Korstanje, M J 2007, 'Suffering in psoriasis patients : Its relation with illness severity and subjective well-being', International Journal of Dermatology, vol. 46, no. 10, pp. 1042-1045.
Download Date	2026-05-11 02:37:11
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Report

Suffering in psoriasis patients: its relation with illness severity and subjective well-being

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Abstract

Objective The aim of the present study was to explore the relationship among subjective illness impact, subjective well-being, and psoriasis severity as assessed by dermatologists. Furthermore, subjective well-being of psoriasis patients was compared to available norm data.

Methods Fifty-nine psoriasis patients participated in this study. The following measures were administered: (a) the Pictorial Representation of Illness and Self Measure – Revised (PRISM-R), yielding Self-Illness Separation (SIS), and Illness Perception Measure (IPM); (b) subjective health status; (c) life satisfaction, and (d) psychological well-being. In addition, the Psoriasis Area and Severity Index (PASI) was determined by dermatologists.

Results Psoriasis patients scored significantly below the norm data on subjective health status and psychological well-being. No differences were found concerning life satisfaction.

PASI failed to correlate significantly with any of the disease impact and subjective health measures. Neither did SIS correlate significantly with any of the subjective health measures, whereas IPM was negatively associated with subjective health status, life satisfaction, and psychological well-being. In a regression analysis with PASI as the dependent measures, none of the subjective health measures showed up as a relevant predictor.

Conclusion In comparison with the norm data, psoriasis patients report less subjective health status and well-being whereas their life satisfaction is not affected. There is no clear association among illness impact, subjective well-being, and illness severity as assessed by dermatologists.

Introduction

A growing awareness that skin disease in general and psoriasis in particular may have a strong impact on the psychologic status, social relations, and daily activities of patients has resulted in several recent quality of life (QoL) studies (for review see Haliouna *et al.*).¹

Although many measures claim to assess QoL, many actually concern health status measures that focus on the influence of disease on a person's physical, psychologic, and social functioning. A serious problem when studying QoL in this manner is that lower levels of functioning are equated with lower QoL, resulting in a confounding between disease-related changes and QoL as an indicator of subjective satisfaction with life.² For example, a patient can learn to adapt to the disease in a way that is satisfying despite his/her low health status.

Measuring a patients' perceived burden of suffering as a result of illness in addition to health-related QoL and life satisfaction may yield valuable information about the actual subjective evaluation of the impact that psoriasis has on patients' lives. Cassell³ defined suffering as a specific state of

distress that occurs when the intactness or integrity of the person is threatened or disrupted. According to this author, the extent of suffering associated with illness is not only determined by the illness itself, but also by the meaning an individual gives to the threat to his or her "personhood." In other words, the intensity and duration of suffering also depends on the personal characteristics of the sufferer.

In the present pilot study, the relationship between suffering as a result of psoriasis, subjective well-being, and illness severity as assessed by clinicians in psoriasis patients is examined. Furthermore, data on health status, life satisfaction, and psychologic well-being obtained from the psoriasis sample will be compared to available norm data

Methods

Patients

Participants were recruited from the Dermatology Department of the Sint Anna Hospital Geldrop (The Netherlands). A total of 59 psoriasis patients (33 men/25 women/1 sex unknown) participated in the study. Age range of the participants was 14–83 years (M = 48.6; sd = 15.4).

Measures

The Pictorial Representation of Illness and Self Measure – Revised (prism-r)

Suffering was measured with a revised version of the PRISM.⁴ This revision was subsequently used to study suffering in a variety of other patient groups like lung disease (former breast cancer, whiplash, and fertility problems (Reimus *et al.* in preparation). The participants received a white A4-size paper sheet with a fixed yellow disk 52 mm in diameter in the bottom right-hand corner. The patient was asked in a printed instruction to imagine that the paper sheet represents his/her life at the moment, whereas the yellow disk represented the patient. The patient had to choose out of three differently sized red disks (stickers), representing his/her medical problem, the one that fits best the patients' view of his/her illness. The red disks were, respectively, smaller than, equal to, and larger than (35 mm, 52 and 65 mm in diameter) the self disk. After having chosen one of the disks, the patient had to place it on the paper sheet, in such a way that it represented the participant's view of his/her medical problem at the current moment.

Two quantitative measures were derived from the PRISM-R:¹ Self-Illness Separation (SIS), i.e., the distance between the centers of the self and the medical problem disk (ranging from 0 to 202 mm) and² Illness Perception Measure (IPM), the size of the medical problem disk (with a range of 1–3). The latter measure is included as an additional variable to the original PRISM. In this revised form, SIS is assumed to represent suffering, whereas IPM represents subjective illness severity.

Health Monitor Questionnaire

The Health Monitor Questionnaire⁵ is a general instrument to assess subjective aspects of health and well-being. It consists of three summary scales: 1) subjective health status (eight items), 2) life satisfaction (five items) and 3) psychologic well-being (five items), each scored on a five point scale. All summary scales were rated so that higher values indicate better well-being. Items used in this questionnaire had been derived from existing questionnaires like the General Health Perception Questionnaire, the CES-D and the WHOQOL-100.^{6,7} Unpublished findings indicate that correlations between the scales and the subscales Depression and Anxiety of the Hospital Anxiety and Depression Scale (Dutch version)⁸ and the WHO-Five Well-being Index⁹ are fairly high, ranging from -0.42 to -0.71.

The Health Monitor Questionnaire is administered repeatedly to a representative sample of the Dutch population. For the current study, we used the results obtained from 828 men and 673 women as norm data. Internal consistencies of the summary scales are fairly high. Alpha coefficients for subjective health status, life satisfaction, and psychologic

well-being typically vary between 0.85 and 0.90, between 0.75 and 0.80, and between 0.80 and 0.85, respectively.

Psoriasis Area and Severity Index (PASI)

The PASI index¹⁰ is considered a standard method for evaluation of therapeutic success under practical conditions in clinical dermatologic studies. It takes into account the localization, extent, and severity of psoriasis and is based on a subjective evaluation of the clinician. In this study, the PASI scores of 42 patients were collected.

Procedure

Psoriasis patients were asked by nurses at the dermatologic day care center of the Sint Anna hospital to participate in the study. The Health Monitor Questionnaire and PRISM-R were administered to patients on one of their visits to the day care center.

Statistical procedures

All data were analyzed using SPSS 11.0.1. One sample *t*-tests were performed to make comparisons between the psoriasis sample and the norm data. To assess bivariate correlations of the three summary scales of the Health Monitor Questionnaire and the PRISM outcome variables with the PASI scores, Pearson product-moment correlations were calculated. Linear regression analysis was used to estimate the predictive value of the questionnaire measures and PRISM-R variables on PASI scores.

Results

Table 1 summarizes the descriptive statistics of the psoriasis patients and the norm data. Psoriasis patients scored significantly below the norm data on subjective health status ($t = -2.91$; $P < 0.01$) and psychologic well-being ($t = -2.96$; $P < 0.01$). Life satisfaction, however, did not differ significantly.

Table 2 represents the within-group correlations among PRISM-R measures, subjective health measures, and PASI scores. Significant negative correlations were found between IPM and subjective health status ($r = -0.51$, $P < 0.01$), life satisfaction ($r = -0.33$, $P < 0.05$) and psychologic well-being ($r = -0.54$, $P < 0.01$). In contrast, SIS did not correlate significantly with any subjective health measure. Finally, no significant associations were found between the PASI score and any of the disease impact and subjective health measures. In a regression analysis with PASI as the dependent measures, none of the subjective health measures showed up as a relevant predictor.

Discussion

The aim of the present study was to explore the links among suffering, subjective well-being, and psoriasis severity as

	Mean and standard deviations of									
	Health status		Life satisfaction		Psych. well-being		SIS		IPM	
	M	SD	M	SD	M	SD	M	SD	M	SD
Psoriasis	29.9	6.6	17.7	3.4	18.6	3.8	85.3	59.2	1.6	0.8
Reference group	32.4	5.7	18.2	3.2	19.3	3.2	–	–	–	–

Table 1 Mean and standard deviations of Health Monitor Questionnaire and PRISM-R variables

Table 2 Correlations of Health Monitor Questionnaire and PRISM-R outcome variables with Psoriasis Area and Severity Index (PASI) and intercorrelations of variables

	Correlations with				
	PASI	Health status	Life satisfaction	Psych well-being	SIS
Health status	-0.16	1.0			
Life satisfaction	-0.10	0.43†	1.0		
Well-being	-0.12	0.64†	0.68†	1.0	
SIS	-0.14	0.02	-0.18	0.02	1.0
IPM	0.23	-0.51†	-0.33*	-0.54†	-0.15

* $P \leq 0.05$; † $P \leq 0.01$.

assessed by dermatologists. Additionally, we compared subjective health, well-being, and life satisfaction of psoriasis patients with healthy controls.

Not surprisingly, psoriasis patients scored significantly lower on subjective health status and psychologic well-being than healthy controls. However, life satisfaction did not differ significantly from the norm group. Although psoriasis causes physical and psychologic discomfort, the health problems of these patients apparently generally do not interfere too dramatically with daily activities in everyday life.

None of the disease impact and subjective health measures was significantly associated with the PASI scores. In recent years it has become clearer that perceived illness severity cannot be assessed properly solely by measuring the physical extent of illness severity in psoriasis patients. Kirby *et al.*¹¹ compared several measurements for assessing psoriasis severity for their ability to assess both the physical and psychologic effects of psoriasis. Their results indicated that physical scores of psoriasis severity give a poor indication of psychosocial disability caused by psoriasis. Fortune *et al.*¹² found that overall clinical severity of psoriasis as assessed by the PASI and duration of illness were unrelated to impairment in any areas of QoL. A study on QoL in 6497 Nordic psoriasis patients revealed that although self-reported severity of psoriasis was a significant predictor of psoriasis-related QoL, PASI-scores

were not.¹³ The present findings once more illustrate this lack of association.

Based on the existing literature and the results found in this study, it can be concluded that a more integrative assessment that encompasses physical and psychologic measurements is apparently needed to determine illness severity in psoriasis patients in its full extent. According to Cassell,³ illness or discomfort itself is not the only determinant of suffering but one also has to take into account relevant person features like coping, the subjective importance of physical appearance, illness representation, personality, personal ambitions, and social support. All these features are likely to moderate the relationship between illness severity and subjective well-being.

Also, the specific location of the affected areas (whether it is visible for others or can easily be covered) might play an important role in illness severity. For instance, Fortune *et al.*¹² found that anatomic location (social visibility) of psoriasis predicted self-reported physical health and also a modest association with patients' mental health was found.

In the present study, SIS did not correlate significantly with any subjective health measure, which is in contrast with results that Büchi *et al.*¹⁵ reported. In a validation study involving over 700 patients with different disorders (rheumatoid arthritis, chronic obstructive pulmonary disease, systemic lupus erythematosus), SIS showed significant correlations with Short Form-36 subscales¹⁶ differing in profile from one patient group to another. In addition, significant negative correlations were found between SIS and depressive symptoms and significant positive correlations with coping resilience. The contrasting results found in this study could possibly be explained by the use of the additional IPM measure or the specific characteristics of the psoriasis patient group.

On the other hand, IPM correlated significantly with all subjective health measures. One might hypothesize that this index represents "illness severity." According to Davidoff,¹⁷ severity can be well understood as a blend of the following four aspects of a disease: (a) distress (whatever makes the patient feel unwell); (b) disability (interference with normal function); (c) seriousness (threat to life); and (d) urgency (the immediacy of the need for intervention). It is important to note that severity is considered to be a mixture of both a

patients' experience of illness and physicians' evaluation of disease and that the importance of the different aspects of severity may vary from one disease to another. Distress is probably the most important determinant of illness severity in psoriasis patients. Future validation of this new PRISM-R measure has to be carried out to obtain a better understanding of the factors which determine IPM.

In conclusion, the results of this study once more emphasize the importance of adding subjective measures to existing health-related QoL and illness severity measures when evaluating treatments. The PRISM-R may be expected to really capture the patients' evaluation of the impact psoriasis has on their lives.

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