## INVESTIGATIVE REPORT

# Clinical Characteristics Associated with Illness Perception in Psoriasis

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**Knowledge of illness perception may aid the identification of groups of patients with a higher risk of coping poorly with the demands of their illness. This study aims to investigate associations between illness perception, clinical characteristics, patient knowledge, quality of life and subjective health in persons with psoriasis. The present study was based on cross-sectional data from patients awaiting climate therapy in Gran Canaria. We included 254 eligible patients (74%) who completed a questionnaire including the revised Illness Perception Questionnaire, the Psoriasis Knowledge Questionnaire, and the Dermatological Life Quality Index. Disease severity was measured using the Psoriasis Area and Severity Index. Several statistically significant associations between clinical characteristics, knowledge and various illness perception dimensions were found. Illness perception was also significantly related to disease-specific quality of life and subjective health. These findings contradict previous findings, which suggested that objective disease factors are not relevant to illness perception in psoriasis.** *Key words: psoriasis; illness perception; clinical characteristics; climate therapy.*

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Research has shown that patients with psoriasis report physical discomfort, impaired emotional functioning, a negative body and self-image, and limitations in their daily activities, social contacts and skin-exposing activities, and work. The severity of psoriasis was shown to be negatively associated with quality of life (QoL) (1). However, research has also shown that factors such as social stigmatization, high stress levels, physical limitations, depression, employment problems and other psychosocial comorbidities experienced by patients with psoriasis are not uniformly proportional to, or indeed predicted by, various measures of disease severity, such as the body surface area involvement or plaque severity (2, 3).

According to Warren et al. (4), psoriasis may affect major life-changing decisions and alter the course of patients' lives. Patients often believe that their lives would have taken a different course if they did not have psoriasis. Indeed, patients' beliefs about their illness may have major effects on how they live with their illness. The illness perception perspective aims to understand how patients evaluate threats to their health by constructing their own thoughts and perceptions. The evaluation of health threats may be conceptualized along dimensions such as identity, the causes of the disease and its consequences, the development of the disease and the extent to which it is controllable (5–7).

Understanding the key risk factors for patient illness perception may help physicians to identify patients who are more vulnerable to the cumulative impact of psoriasis, thereby resulting in more appropriate treatment decisions early in the course of the disease. A recent study by Nelson et al. (8) suggested that the complexity of psoriasis (involving physical, psychological and social challenges, as well as issues of control) was largely unacknowledged by practitioners in healthcare consultations. Practitioners are often perceived as lacking in knowledge and expertise in the management of psoriasis, lacking in understanding and empathy with the effects of psoriasis, and failing to manage psoriasis as a long-term condition (8).

Previous research has identified several aspects of illness perception in subjects with psoriasis. Fortune et al. (9) found that the most commonly reported or putative causal agents were stress and genetic factors. Forty-six percent of patients believed that their behaviour would improve or worsen their psoriasis, whereas 32% believed that the treatment would be curative. Furthermore, the overall clinical severity of the disease was not associated with any of the beliefs held by patients. Kossakowska et al. (10) found that patients with psoriasis differ significantly from healthy individuals in negative emotional control. Patients with psoriasis control anger, anxiety and depression far more intensively than do control groups. In this study age was revealed as the most important contributor to negative emotion control in psoriasis. According to Fortune et al. (3), illness perceptions were always the most important variables in terms of the variance accounted for by stress, distress and disability.

Scharloo et al. (11) found that a strong illness identity, passive coping, belief in a long illness duration, belief in more severe consequences and the level of disease severity were associated with poor outcomes in terms of disease-specific measures of functioning, and with

respect to general roles and social functioning. Coping by seeking social support and belief in the controllability/curability of the disease were significantly related to better functioning. In a later study, Scharloo et al. (12) found that a strong illness identity was associated with more visits to the outpatient clinic and worse outcomes in terms of physical health, social functioning, mental health, health perceptions and depression.

To the best of our knowledge, little is known about the effects on the perception of illness as assessed by more objective measures, such as demographic variables, medically related factors and patient knowledge. In addition, there are few studies of associations between the components of illness perception (defined as "emotional representation", "timeline", "consequences" and "illness coherence") and QoL (psoriasis-specific). Therefore, the present study addressed the following research questions:

- To what extent are disease characteristics, such as disease severity (Psoriasis Area and Severity Index: PASI), duration of psoriasis, psoriatic arthritis (PsA), comorbidity and previous climate therapy, associated with the dimensions of the illness perceptions?
- To what extent does the patient's level of knowledge of psoriasis contribute independently to the dimensions of illness perceptions after controlling for clinical variables?
- To what extent are the dimensions of illness perception associated with QoL and subjective health?

## MATERIALS AND METHODS

### Study design and population

The present study has a cross-sectional design. However, it was part of a longitudinal pre-post study of Norwegian patients with psoriasis aged ≥20 years who were offered 3 weeks of climate therapy (CT) in Gran Canaria from late April 2009 to early January 2010. The programme comprised sun and sea treatment, with patient education. Patients were recruited to the study when they arrived at the treatment centre in Gran Canaria. Data (medical record and questionnaire) collected on arrival were used in the present study.

Of 343 eligible patients, 254 (74%) agreed to participate and were included at baseline. The reasons for not being willing to participate were not assessed.

The sample comprised 40% females and the mean ± SD age was 47 ± 12 years, while 60% of the sample reported <12 years of education and 69% were in paid work. The mean ± SD PASI score at baseline was 7.5 ± 4.1. Comorbidity was reported by 44%, and the mean ± SD duration of psoriasis was 24 ± 13. Further information on the demographic characteristics is provided in Table I. The study was approved by the hospital administration and Norwegian Social Science Data Service, and recommended by the Regional Committee for Medical Research Ethics for Southern Norway. The protocol complied with the Declaration of Helsinki.

### Instruments

*Illness perception.* The revised Illness Perception Questionnaire (IPQ-R) was used to measure illness perceptions (6, 7). The IPQ-R contains 38 items with 8 components: identity – the label of the illness and the symptoms the patient views as part of the disease; timeline – beliefs about the relative chronicity of the illness (acute/chronic, 6 items); consequences – expected effects and outcomes of the illness (6 items); personal control (6 items); treat-

Table I. *Descriptive data*

| Characteristics | Total | |
|---|---|---|
| Age, years, mean (SD) [range] | 254 | 47 (12) [20–80] |
| Years with psoriasis, mean (SD) [range] | 245 | 24 (13) [1–60] |
| Body mass index, mean (SD) [range] | 251 | 28 (5) [17–49] |
| PASI score pretreatment, mean (SD) [range] | 253 | 7.5 (4.1) [0.4–26.1] |
| Sex, women, *n* (%) | 254 | 102 (40) |
| Education, *n* (%) | 254 | |
| Primary school ≤12 years | | 153 (60) |
| University <4 years | | 52 (20) |
| University ≥4 years | | 49 (19) |
| Employed, yes, *n* (%) | 254 | 174 (69) |
| Living alone, yes, *n* (%) | 250 | 70 (28) |
| Comorbidity, yes, *n* (%) | 254 | 111 (44) |
| PsA verified by doctor, yes, *n* (%) | 252 | 64 (25) |
| Previous climate therapy, yes, *n* (%) | 252 | 140 (55) |

PASI: Psoriasis Area and Severity Index; PsA: psoriatic arthritis.

ment control – beliefs about the personal capacity for controlling the illness and the efficacy of treatment used to cure or manage the illness (5 items); illness coherence – the overall meaning of the illness to the patient (5 items); timeline cyclical – beliefs about fluctuations in the symptoms and the temporal variability of the illness (4 items); and emotional representations – the emotional responses generated by the illness (6 items). Each item were rated from strongly disagree to strongly agree on a 5-point Likert scale. High scores for the components of timeline, consequences and cyclical dimensions means strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness and the cyclical nature of the condition. Furthermore, high scores for the components personal control, treatment control and coherence dimensions means positive beliefs about the controllability of the illness and a personal understanding of the condition. The low Cronbach's α scores in the present sample for the components personal control (α=0.56), treatment control (α=0.36) and timeline cyclical (α=0.61) meant we had to exclude these components from further analyses.

*Knowledge.* The Psoriasis Knowledge Questionnaire (PKQ) was developed in a Norwegian dermatology context. It contains 49 questions about psoriasis (its aetiology, development and treatments) that patients are required to answer. The questionnaire constitutes an additive index that contains 49 items related to issues such as disease characteristics, causes and effects on disease development, treatment and the characteristics of prevalence. There are 3 response options for each statement: "valid", "uncertain" and "invalid". The total score is calculated based on the number of correct responses, with a possible range of 0–49. Since the PKQ is an additive index (13), assessments of dimensionality (factor analysis) is not considered appropriate psychometric approaches. Higher scores indicate higher levels of knowledge.

*Quality of life (disease-related).* The Dermatological Life Quality Index, Norwegian version (DLQI-N) is a dermatology-specific QoL form that contains 10 questions related to a patient's personal experience of the effects of skin problems on their symptoms, feelings, daily activities, leisure activities, work and school, personal relationships and treatment (14). DLQI has been used in many studies to describe the QoL in various dermatological disease groups and it has satisfactory reliability and validity in a study of Norwegian psoriasis patients (15). The total score is calculated by summing the scores for each question and higher scores represent greater impairment of QoL.

*Subjective health.* Subjective health was measured using a single-item question from Short Form SF-36 that asked: "Would you say your health is excellent (1), very good (2), good (3), quite good (4), poor (5)?" Higher scores indicate poorer subjective health (16).

*Medical factors*

The following clinical variables were used in the analyses: duration of psoriasis (years), previous CTs (1=no, 2=yes), comorbidities (1=no, 2=yes) and the disease severity (PASI where higher scores=more severe (17)). The diagnosis of PsA (1=no, 2=yes) was confirmed by patient records.

*Demographic variables*

The following demographic variables were used in the analyses: age (years), sex (1=men, 2=women), and formal education (1=7–10 years; 2=middle school and 1 or 2 years of high school; 3=high school or secondary school; 4=college or university for less than 4 years; 5=college or university for 4 years or more).

*Statistical analysis*

SPSS PC version 19.0 was used for the statistical analyses. Descriptive analyses were performed to determine the frequency, mean, SD and range of scores (minimum to maximum). Cronbach's $\alpha$ was used to estimate the internal consistency of the scales (reliability). Correlational analyses (Pearson's $r$) and multiple linear block-wise regression analyses were performed to estimate the relationships between variables. The moderating effects of illness perceptions were tested by entering interaction terms involving each of the socio-demographic variables, the other clinical variables and knowledge, one at a time (while retaining the main effects in the model). The moderating effects on QoL and subjective health were tested in the same manner, using interaction terms between illness perceptions and socio-demographics. $p < 0.05$ was considered significant. Table SI[1] shows the characteristics of the different scales that were used. Cronbach's $\alpha$ ranged from 0.87 to 0.76.

RESULTS

*Associations between socio-demographic and clinical variables, knowledge and illness perceptions*

Bivariate analyses detected a number of statistically significant associations between variables, which are

shown in column $r$ for each illness perception dimension in Table II.

The multiple linear regression analyses detected statistically significant associations between clinical variables, knowledge of psoriasis and the different dimensions of illness perceptions. Higher PASI scores were significantly associated with higher scores on the timeline (standard (std.) $\beta$=0.19, $p$=0.006), consequences (std. $\beta$=0.22, $p < 0.001$) and emotional representation (std. $\beta$=0.16, $p$=0.020). Higher knowledge scores were significantly associated with lower consequences scores (std. $\beta$=–0.16, $p$=0.028). Longer duration of disease was significantly related to lower scores for emotional representation (std. $\beta$=–0.27, $p$=0.020) and higher scores for timeline (std. $\beta$=0.21, $p$=0.007) and illness coherence (std. $\beta$=0.22, $p$=0.003). There was a significant association between comorbidity and consequences (std. $\beta$=–0.17, $p$=0.011). PsA was significantly associated with lower scores for consequences (std. $\beta$=–0.13, $p$=0.049). Previous climate therapy was associated with higher scores for illness coherence (std. $\beta$=0.14, $p$=0.037). A higher educational level was significantly associated with higher scores for illness coherence (std. $\beta$=0.20, $p$=0.002). Female gender was associated with higher scores for emotional representation (std. $\beta$=0.14, $p$=0.039).

The adjusted R squared (variance explained) for the different dimensions of illness perceptions varied from 10% (timeline) to 16% (illness coherence).

The tests of the interaction effects showed that the effect of knowledge of psoriasis on illness coherence differed between sexes ($p$=0.007). Thus, there was a strong association between greater knowledge of psoriasis and better personal understanding of the disease in women, whereas this association was not present for men.

*Illness perceptions, quality of life and subjective health*

Table SII[1] shows that the bivariate analyses detected statistically significant associations between the vari-

Table II. *Associations between illness perception components, demographic and clinical variables and patient knowledge, which were tested using multiple linear regression analyses. Pearson's* r*, standardized beta values and exact* p-*values for statistically significant associations are shown*

| | Timeline | | Consequences | | Illness coherence | | Emotional representation | |
|---|---|---|---|---|---|---|---|---|
| | $r$ | Std. beta ($p$) | $r$ | Std. beta ($p$) | $r$ | Std. beta ($p$) | $r$ | Std. beta ($p$) |
| Demographic | | | | | | | | |
| Age, years | | | | | | | –0.20 (0.002) | |
| Sex[a] | | | | | 0.15 (0.018) | | | 0.14 (0.039) |
| Education[b] | | | | | 0.23 (0.000) | 0.20 (0.002) | –0.17 (0.008) | |
| Clinical | | | | | | | | |
| PASI (higher score=more severe) | 0.17 (0.008) | 0.19 (0.006) | 0.21 (0.001) | 0.22 (0.001) | | | 0.13 (0.041) | 0.16 (0.020) |
| Duration of disease (years) | 0.25 (0.000) | 0.21 (0.007) | –0.13 (0.047) | | 0.25 (0.000) | 0.22 (0.003) | –0.27 (0.000) | –0.27 (0.020) |
| Comorbidity[c] | | | –0.16 (0.014) | –0.17 (0.011) | | | | |
| Psoriasis arthritis[c] | | | | –0.13 (0.049) | | | | |
| Previous climate therapy[c] | 0.17 (0.007) | | | | 0.18 (0.004) | 0.14 (0.037) | –0.15 (0.016) | |
| Knowledge: PKQ[d] | 0.24 (0.000) | | | –0.16 (0.028) | 0.27 (0.000) | | –0.17 (0.007) | |
| Adjusted R squared (%) | | 10 | | 11 | | 16 | | 13 |

[a] 1=men; 2=women. [b] 1–5; higher score=higher level of education. [c] 1=no; 2=yes. [d] higher score=more knowledge.
Std.: Standard; PASI: Psoriasis Area and Severity Index; PKQ: Psoriasis Knowledge Questionnaire.

ables shown in column *r* for the QoL and subjective health.

Higher scores for consequences (std. β = 0.41, *p* < 0.001) and emotional representation (std. β = 0.23, *p* = 0.002) were significantly associated with higher scores for QoL, after controlling for age, sex and education. The amount of variance explained for QoL was 28%.

Higher scores for consequences (std. β = 0.22, *p* = 0.002) and emotional representation (std. β = 0.24, *p* = 0.002) were significantly associated with lower subjective health, after controlling for age, sex and education. A lower level of education was significantly associated with lower subjective health (std. β = –0.14, *p* = 0.023). The amount of variance explained for subjective health was 17%.

No statistically significant interaction effects were found between socio-demographic variables (age, sex and education) and the illness dimensions (timeline, consequences, illness coherence and emotional representation) with respect to QoL and subjective health.

## DISCUSSION

To the best of our knowledge, this study is one of the few to elucidate illness perceptions in patients with psoriasis. Understanding illness perceptions in psoriasis is critical for providing effective treatment. Patients with chronic conditions may actively construct their own personal models of illness in an attempt to deal with the impact of their condition (18).

A major finding of our study was that persons with greater disease severity had more strongly held beliefs about the chronicity of psoriasis, its negative consequences and its emotional impact. Hence, disease severity may be an indicator of coping. This contrasted with previous studies of the psoriasis population. In a study from 1998, Fortune et al. (9) found that the overall PASI was not associated with patient beliefs about the cause, cure/control, consequences, chronicity/recurrence or symptoms perceived as part of their psoriasis. They argued that the objective severity of a condition was unlikely to be associated with subjective experiences in terms of beliefs, because "patients are little more than passive objects upon which the disease impacts". This lack of association was also confirmed in a later study (3). However, studies of other chronic illness populations have found associations between illness perceptions and the disease severity. For example, Howard et al. (19) found that lower lung function was associated with the experience of greater consequences due to the disease. In a study of coronary heart disease by Aalto et al. (20), those with a more severe illness than in the present study reported stronger illness identity, weaker belief in the controllability of the disease, more severe consequences due to the disease and a longer chronic timeline.

Our study showed that patients who were more knowledgeable about psoriasis had less severe perceived consequences of psoriasis. Those with a higher education had

a better personal understanding of the disease. Attending previous climate therapy was related to a better understanding of the disease and subjects who had had psoriasis for a longer time worried less about psoriasis, had strongly held beliefs about the chronicity of psoriasis and a better personal understanding of the disease. Furthermore, our study showed that the association between knowledge and personal understanding of the disease was strongest among women. Overall, these factors may reflect personal resources, such as experience and competence. Previous coronary heart disease research showed that subjects with a strong perceived competence perceived fewer symptoms, regarded their illness as more under control, perceived less severe consequences and were less likely to make strong assumptions about coronary heart disease. Those who felt competent and with control over their life events may have more effective coping strategies to deal with the challenges posed by a chronic illness, so they may assess the consequences of illness in day-to-day life as less severe and threatening and perceive that they have more control over their illness (20). Research has also shown that although psoriasis patients know many core facts about psoriasis, they do not know several facts about the disease that may be valuable for improving self-management (21). Poor adherence to prescribed treatments is also a major problem in this patient group (22). It is reasonable to consider that focusing on knowledge about the pathogenesis and treatment of psoriasis may increase the patient's perception of their symptom control, which may increase patient compliance with treatments. It is important to understand the factors that affect the adherence of patients to medical regimes or their health behaviour during the management of illness to ensure appropriate interventions (23).

We also found that those with strongly held beliefs about the negative consequences of psoriasis and those who experienced more worry about psoriasis had a poorer QoL. These findings agreed with previous research. The literature suggests that illness perceptions (especially perceived consequences and control) are important factors that affect psychosocial outcomes, such as subjective well-being. Strong illness identity, severe perceived consequences, low perceived controllability and a chronic perceived illness timeline have all been shown to be related to poor well-being in various chronic illnesses (24). Illness perceptions have also been associated with self-care behaviours (25, 26). With respect to psoriasis, Scharloo et al. (11) found that belief in more severe consequences was associated with a worse outcome in terms of disease-specific measures of functioning, as well as the general role and social functioning. According to Fortune et al. (3), illness perceptions were the most important factors that explained variance in psoriasis-related disability. The same pattern is found in other disease groups. For example, a study of coronary heart disease showed that cognitive representations contributed to the global health status and QoL (27).

A possible limitation in the present study is the sample utilized. The participants had embarked on a 3-week treatment programme including sun and relaxation. These are patients who have actively sought treatment and are about to start it, which in turn may have influenced their illness representations and QoL. There may be increased hopefulness associated with such a significant event in the time course of their illness.

In summary, we have found that disease-related factors, such as disease severity and duration of psoriasis, are associated with various illness perceptions in psoriasis. We also showed that knowledge about illness is an important determinant. Furthermore, we also found that strongly held beliefs about the negative consequences of psoriasis and those who experienced more worry about psoriasis had a poorer QoL.

Knowledge of the determinants of illness perceptions may help to identify groups of patients with greater risk of coping poorly with the demands of their illness, so that tailored interventions can be provided to those with low self-management risk profiles. Hence, our findings may have practical implications for rehabilitation and patient counselling in terms of helping patients to cope with their illness by modifying and restructuring their personal models of illness (23).

## ACKNOWLEDGEMENTS

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