How patients experience psoriasis: results from a European survey

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ABSTRACT

Background Most of the psoriasis that affects the European population is treated with topical preparations. Compliance rates, however, are known to be quite low.

Objective To provide an update on how psoriasis is experienced by patients and how well these patients comply with prescribed topical treatment.

Methods This was an observational and transversal survey conducted in 1281 patients with psoriasis. Patient input alone formed the basis of the study. Participants were contacted through the national psoriasis patient associations in France, the United Kingdom, Belgium, Germany and the Netherlands.

Results The study showed that 32% of the patients suffer currently from psoriasis in the face, skin folds and genital areas – areas very sensitive to topical treatments. Most of the patients (74%) considered their psoriasis as at least moderately severe, and 73% stated not to comply with their current treatment. Lack of efficacy and messiness of the treatment were the main reasons for non-compliance, an element that is especially important for the use in sensitive areas such as the face, skin folds and genitalia.

Conclusion The present survey confirmed that cosmetic acceptability is, together with efficacy and safety, a very important aspect of a successful treatment of psoriasis.

Key words: compliance, inflammatory skin disease, psoriasis, quality of life, topical treatments

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Introduction

Psoriasis affects 1–5% of Europeans overall, with rates as high as 6% in France and Germany.1–3 The disease afflicts men and women equally and is present in all races and socio-economic classes and usually begins in the early adulthood.4,5 Heredity is strongly involved in the pathogenesis, and a series of genetic susceptibility loci have been described.4–6

Psoriatic affliction varies greatly among patients, and over time in the same patient. It is thus very difficult to quantify, especially for its psychological impact.

The disease complicates millions of daily lives and disrupts countless interpersonal relationships.6,7 Hence efforts are ongoing to find suitable instruments to measure psoriasis impact in patients’ quality of life8 including numerous severity-scoring indices. These scores, however, do not relate to the patients’ personal history with psoriasis and they tell us nothing about their perception of treatment.

For instance, it is of notice that even if most patients qualify their psoriasis as severe, the non-compliance rate with treatments is currently estimated as close to 40%.8,9

The reasons for such a discrepancy have not been investigated so far, yet it is crucial to understand them to provide patients with more acceptable treatments or regimens.

In order to shed light on these ill-understood aspects of psoriasis, we undertook a patient’s survey addressing these aspects of disease history and treatment perception generally overlooked by studies of different methodology.

Methods

A master questionnaire was prepared in French and translated into German, English and Dutch, and was sent to psoriasis patient associations in the United Kingdom, Germany, the Netherlands, Belgium and France. The national associations offered the questionnaires randomly, with an introductory letter,
to their members. All answers were translated into English and entered into a specifically designed database for this study.

The survey asked about sociodemographic variables (age, sex, family, living arrangements and education level), medical data (history, location, duration and perceived severity of psoriasis) and treatment data (current and past treatments, compliance with these treatments as measured against the PMAQ-3w scale used already by Duong et al. and Child et al. reasons for non-compliance, perceived necessary measures to implement in order to increase compliance). 

All statistical tests were two-sided, with a significance level of 5%. Continuous variables grouped by country and overall were described using the mean, median, standard deviation and extreme values. Discontinuous variables were described by the documented frequency of each modality, both in individual countries and overall. Quantitative data were first checked for normality and homoscedasticity of residues, and an analysis of variance was performed on data that were both normal and homoscedastic. For data that were non-normal and non-homoscedastic, the non-parametric Wilcoxon and Kruskall, and Wallis tests were employed. Qualitative group data were compared using a chi-squared test, when the data were reasonably approximated by a normal function. Fisher’s exact test was performed on non-normal data.

Results

The survey was conducted between November 2002 and February 2003.

One thousand two hundred and eighty-one (1281) patients responded, representing more than 50% of the patients initially contacted. This rate was more or less the same for all five countries. Demographic information is depicted in Table 1.

The mean age of patients was 51.7 ± 12 years.

The mean duration of the respondents’ psoriasis was 25.2 (± 12.79) years overall. The mean age for psoriasis onset was with 26.48 ± 16.38 years, more or less the same throughout the five countries.

As expected, most patients reported suffering from psoriasis on their scalp, elbows, knees, ears, nails and backs. National variations were not generally wide: more than 60% of UK patients had nail psoriasis, compared with 40% of French and Belgian patients, whereas no Dutch patient reported psoriasis on the buttocks, an area affected in about 10% of patients from other countries. Interestingly, 32% of patients reported psoriasis of the genitals and 29% on the face. Psoriasis inversa was prevalent, with a mean 36% for skinfolds involvement.

On a psychological level, 28% of all patients thought they had ‘very severe’ psoriasis, and another 46% judged it ‘somewhat severe’. French patients were the most anxious, with only 14% saying their disease was ‘not severe’ and with the British patients being the least worried: 45% qualified their psoriasis as ‘not severe’. Results for the physical impact were similar to the above findings, corroborating the belief that physical impact has a direct influence on the psychological level (Table 2).

Sixty-seven percent (67%) of all treatments were prescribed by dermatologists; generalists (GPs) accounted for 28% of all prescriptions except in the UK, where more prescriptions (60% vs. 34% by dermatologists) were written by GPs. Detailed results are shown in Table 3.

Seventy percent (70%) of all patients used a topical preparation. The most widely prescribed topical treatments were vitamin D analogues (63%), corticosteroids (57%), salicylic acid (17%) and retinoids (4%). These results include topical treatments used alone or in combination with other topical treatments. Forty-two percent (42%) used a topical treatment in combination with other therapies: phototherapy (36%), oral drugs (38%) or alternative treatments such as sun–sea stays or baths. Table 4 provides further information.

<table>
<thead>
<tr>
<th>Table 1 Patient demographics</th>
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<tbody>
<tr>
<td></td>
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<tr>
<td>Total number of patients</td>
</tr>
<tr>
<td>Mean age (years)</td>
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<tr>
<td>(Standard deviation)</td>
</tr>
<tr>
<td>Gender % (N)</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Is cohabiting % (N)</td>
</tr>
<tr>
<td>Has children % (N)</td>
</tr>
<tr>
<td>If yes, is the main child carer % (N)</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>Primary education % (N)</td>
</tr>
<tr>
<td>Secondary education % (N)</td>
</tr>
<tr>
<td>University degree % (N)</td>
</tr>
</tbody>
</table>

n/a, not applicable.
On average, 73% of the patients reported not complying with their treatment. Differences were not significant between countries (Table 5). The compliance was slightly higher for vitamin D derivatives (57%) compared to corticosteroids (50%) and salicylic acid (41%). Seven percent (7%) responded spontaneously in free-text answers that they only applied their medication when they thought they needed it.

Main reasons for non-compliance were:
- low efficacy as rated by 27% of patients;
- poor cosmetic characteristics (sticky sensation after treatment application) as believed by 29%;
- time consuming (long time to rub in the topical treatment) as stated by 26% (fig. 1).

Fifteen percent (15%) of the patients also mentioned that side-effects lead to non-compliance.

Even if the majority of patients were non-compliant with their topical treatment, 61% reported that they were ‘somewhat satisfied’ with their topical treatment and 19% ‘very satisfied’. Twenty percent were ‘not satisfied’.

Patients were asked through an open question to indicate what they would like to see improved in their topical treatment in order to be more compliant. The following proposals were made: better efficacy, less greasy, sticky and smelly treatment and less side-effects.

**Discussion and conclusion**

Psoriasis is still one of the most important diseases in dermatological practice because it is so common, produces significant morbidity and has profound effects on patient’s
How patients experience their psoriasis

Quality of life. Previous research confirmed that more than 80% of patients suffering from the disease expressed difficulties in establishing social contacts and relationships being the worse aspect of their psoriasis. However, until now much more attention has been paid to dermatologists’ views on psoriasis therapy than those of patients. Since several years now, attempts have been made to remedy and the concept of quality of life was developed from an array of information about physical, social and psychological well-being and two categories of questionnaires are currently in use: general health and skin-specific disease surveys. But still, little quantitative information is available on subjects such as body parts affected, satisfaction or non-satisfaction with treatments and reasons thereof, degree of compliance and factors influencing it. Hence, the present survey intended to investigate the actual psoriasis situation from a patient point of view. Observations made about the burden and location of the disease somewhat contradict those made in textbooks, earlier surveys and epidemiological studies.

For instance, more than 30% of the patients reported psoriasis of the genitals and nearly 30% reported psoriasis on the face, locations one does not generally consider as frequently affected. Likewise, over a third of patients suffered from psoriasis inversa, which is generally believed to affect less than 10% of psoriasis patients. Most of the patients suffered from psoriasis on their scalp, elbows, knees, ears, nails and back. With 70% of the patients rating their psoriasis as at least somewhat severe, this survey confirms that patient perception of their psoriasis is different from that of their doctors. However, it needs to be indicated that the respondents to our survey were active members of psoriasis associations and therefore probably more concerned by their disease than non-members. This may also explain the ‘high’ mean psoriasis duration (25 years) and the evaluation of their psoriasis as severe.

The present survey further confirmed that adherence to treatment is a prerequisite for good efficacy results and this is particularly true for topical preparations. Moreover, this is especially important for the use in sensitive areas such as the face, skin folds and genitalia: when patients were asked if they complied or not with their treatment, the large majority (73%) reported not to comply. These figures are not in accordance with other studies’ results that generally revolve around a 40–50% rate. In these studies however, the definitions and evaluation tools to measure non-compliance were different from the one we used.

The fact that more than 50% of the patients complied when treated with a vitamin D derivate (57%) or with corticosteroids (50%) seems to indicate that these medications are better accepted than for instance salicylic acid-based specialties or anthralin/dithranol regimens.

The main reasons given by patients for not complying were ‘lack of efficacy’ and ‘poor cosmetic characteristics’ of the treatments.

The cosmetic aspect of treatment is also very important and it has a major impact on the patients’ compliance. When patients were asked to indicate possible solutions to increase their compliance, higher efficacy and lower greasiness were the main suggestions. This is particularly interesting, considering that patients who completed the survey have a long experience of different treatments and are therefore more demanding and critical.

Even if a certain reporting bias was unavoidable in the study, patient-based compliance studies like this are of extreme value. They focus on the day-to-day opinions of psoriasis sufferers themselves and disclose significant elements about current disease and treatment perception, thus indicating future investigation pathways, to design better accepted topical treatments.

### Table 5: Distribution of fully compliant patient* with regard to their compliance for psoriasis topical treatments

<table>
<thead>
<tr>
<th></th>
<th>Germany</th>
<th>UK</th>
<th>France</th>
<th>Belgium</th>
<th>Netherlands</th>
<th>All patients</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number</td>
<td>177</td>
<td>175</td>
<td>235</td>
<td>158</td>
<td>121</td>
<td>866</td>
<td></td>
</tr>
<tr>
<td>NP</td>
<td>85</td>
<td>91</td>
<td>94</td>
<td>83</td>
<td>50</td>
<td>403</td>
<td>0.0658</td>
</tr>
<tr>
<td>No</td>
<td>56 (61%)</td>
<td>60 (71%)</td>
<td>108 (77%)</td>
<td>58 (77%)</td>
<td>54 (76%)</td>
<td>336 (73%)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>36 (39%)</td>
<td>24 (29%)</td>
<td>33 (23%)</td>
<td>17 (23%)</td>
<td>17 (24%)</td>
<td>127 (27%)</td>
<td></td>
</tr>
</tbody>
</table>

*Fully compliant patients were those who strictly respected the prescription during the 3 later days and last weekend.
NP, not provided.
Acknowledgements

We would like to thank the patients for the time they spent completing the survey, the physicians for their participation, the National Psoriasis Associations of Belgium, France, Germany, Netherlands and United Kingdom and their chairmen for their support.

References