Perspectives of psoriasis patients in Turkey

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ABSTRACT

Background: Psoriasis is a chronic skin disease that can have severe psychosocial effects. The aim of this study was to assess the perspectives of psoriasis patients regarding their illness. 

Methods: One hundred and ten psoriasis patients in the 18–65 age group were included. Data were collected via a “face to face interview” method. The questionnaire included mainly three topics (socio-demographic characteristics of patients; self-evaluations of patients about their disease; knowledge and attitudes about psoriasis).

Results: The majority of the patients stated that psoriasis as a socially troubling disease. Almost half of them believed that “stress and unhappiness” was a predisposing factor of their illness. Belief that the occurrence of the disease was due to a contagious infectious agent was the second most frequent factor that patients emphasized. “Signs and symptoms of psoriasis” was the most frequent difficulty patients faced because of psoriasis. Most of the patients who still have their parents, those who have a closest friend in life, and more than half of the patients who have their closest friend at work all stated that there was a change in social relations, mostly arising from their counterparts. More than half of the married patients stated that there was a change in social relations, mostly arising from their spouses.

Conclusion: Psoriasis is more than a cosmetic nuisance and can be associated with psychosocial effects that seriously affect patients’ lives and social relations. Increasing the patients’ knowledge of the disease could have a positive effect on the relations the psoriasis patients have within their social environment.

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Introduction

Psoriasis is one of the most common dermatological diseases. According to various reports, it appears in ~1–5% of the human population. Some authors report that more than 5% of people suffer from psoriasis; this is because many may hide the disease and/or seek unconventional treatments.¹ Albeit primarily a disease of the skin, psoriasis patients have been shown to suffer from such disability as other patients with chronic illnesses, such as heart disease, diabetes, cancer, arthritis, hypertension, and depression.² Because psoriasis is non-fatal, its profound impact on overall patient well-being is often underestimated.³ Psoriasis has a negative impact on physical, emotional, social, sexual, and financial well-being.² Most studies have been conducted among inpatients or outpatients with severe disease, and there has been less research of patients’ own assessments of the impact of psoriasis, although it is agreed that patients are in the best position to assess their quality of life.⁴ To date there has also been less research investigating patient perspectives on other aspects of their psoriasis, such as treatment satisfaction, healthcare consulting behavior, disease education and support. It has been proven in previous studies that patients with psoriasis see the need to improve their knowledge of the disease and self-care methods.⁵

The aim of this study was to assess the perspectives of psoriasis patients regarding their illness through the determination of their opinions: if they consider psoriasis as socially troubling or not; their beliefs about the predisposing factor of their illness; their opinions about the most important difficulty they have faced because of psoriasis; and their perception of changes in their social relations.

Materials and methods

This study included 110 psoriasis patients in the 18–65 age group who attended the Ankara Numune Education and Research Hospital’s Department of First Dermatology between May 2008 and May 2009. All subjects participated after giving their informed consent. Patients with erythrodermic psoriasis, guttate psoriasis, or with only palmoplantar lesions were excluded. Data were collected...
via a “face to face interview” method. The questionnaire included three main topics: socio-demographic characteristics of patients; self-evaluations of patients about their disease; and knowledge and attitudes about psoriasis. The age, gender, marital status, health insurance, occupation, duration of disease, and Psoriasis Area and Severity Index (PASI) scores were noted. Patients were asked to state their opinions about various diseases, most of which were known to be socially troubling (leprosy, syphilis, Behçet’s disease, AIDS, cancer, gonorrhea, tuberculosis, and psoriasis). In order to assess their knowledge of psoriasis, we asked them what they believe are the predisposing factors of their illness (stress and unhappiness, drugs, having underlying diseases, undernourishment and poverty, smoking, drinking alcohol, contagious infectious agents, dust and air pollution, genetic factors, immunity, other factors, or whether they have no idea). The patients were asked about the most frequent difficulty they faced because of psoriasis (financial problems, hospitalization, stress, anxiety and other negative feelings, signs and symptoms of psoriasis, going to public places, if they had no significant difficulty, or if they had no idea).

The patients’ beliefs regarding the predisposing factors of their illness, and their opinions about the most important difficulty that they face because of psoriasis, were also assessed according to the gender, status of education, PASI scores and duration of disease. To do this, PASI scores and duration of disease were divided into three groups (PASI 8.0–10: Group 1; 10.1–15: Group 2; >15.1: Group 3), (duration of disease <7 years: Group 1; 7.1–15 years: Group 2; >15 years: Group 3).

In this study we assessed patients’ perceptions of their social relations within their social environment, dividing these into four different categories (closest friend at work, closest friend in life, parents, spouse); the patients were asked if there had been a change in these social relations or not after being diagnosed with psoriasis. For each category, the patients reported whether the perception of change arose either from themselves, from both sides or from their counterparts alone.

**Results**

One hundred and ten patients with plaque-type psoriasis were included in this study. The minimum age was 18 and the maximum age was 65. The mean age of the patients was 39.2 (SD: 12.8) years. The mean duration of disease was 14.1 years (SD: 10.4), and the mean PASI was 14.3 (SD: 5.1). The number of patients was 26, 45, and 39 in the PASI groups 1, 2, and 3 respectively. According to the duration of disease, there were 39 patients in group 1, 35 patients in group 2, and 36 patients in group 3.

There were 50 female (45.4%) and 60 male (54.5%) patients. Seventy-nine patients (72.7%) were married, 32 patients (29.9%) had no formal education, and 44 patients (40.0%) were graduates of primary school. The majority of the patients (96.3%) were covered by a government health insurance system.

The patients were asked to state their opinions about various diseases, most of which were known to be socially troubling. The majority of the patients regarded psoriasis as a socially troubling disease (94.5%); however, the percentage of patients who thought AIDS was a troubling disease was lower (46.3%). A total of 29.09% of the patients did not regard tuberculosis as a socially troubling disease and 34.5% of the patients had no opinion about tuberculosis. Nearly one out of two patients (47.2%) had no idea what leprosy was (Table 1).

Almost half of the patients (43.6%) believed that “stress and unhappiness” was a predisposing factor of their illness. Occurrence of the disease due to a contagious infectious agent was the second most significant item that the patients emphasized (24.5%). The other beliefs (and their percentage occurrence) that the patients had regarding any predisposing factor were as follows: drugs (7.2%), undernourishment and poverty (4.5%), genetic factors (4.5%), smoking or drinking alcohol (3.6%), dust and air pollution (2.7%), having underlying diseases (1.8%), immunity (0%). Eight patients (7.2%) had no opinion regarding a predisposing factor. There were no patients who suggested any other predisposing factors not mentioned above.

“Signs and symptoms of psoriasis” was the most frequent difficulty that patients faced because of psoriasis (49.09%), especially the cosmetic concern. The second most frequent difficulty was “stress, anxiety, and other negative feelings” (20.0%). However, “no significant difficulty” was the second most frequent perception in both the patients with no formal education and those in PASI group 3. The other difficulties stated by the patients were financial problems (12.7%) and going to public places (6.3%). No patients stated hospitalization as the most frequent difficulty. Thirteen patients (11.8%) mentioned that they had no significant difficulties. The distribution of patients’ beliefs about the predisposing factor of their disease according to gender, status of education, duration of disease, and PASI were similar; “stress and unhappiness” and occurrence of the disease due to a contagious infectious agent were the first two items stated.

Nineteen out of 34 patients (55.8%) who have their closest friend at work, 42 out of 79 married patients (53.1%), 45 out of 87 patients (51.7%) who still have their parents, and 15 out of 29 patients (51.7%) who have a closest friend in life perceived a change in relations generally arising from their counterparts (Table 2).

We also assessed the social relations of married patients with their spouses; 24 married patients thought that a contagious infectious agent was the causative factor of their illness. Most of them (37.5%) stated that there was a behavioral change arising from themselves, and 29.1% perceived a change arising from their partners.

**Discussion**

Psoriasis is a chronic skin disease that can have severe psychosocial effects. Its chronicity, frequent relapses, the absence of a permanent cure, and symptoms such as pruritus make it hard to live with. Furthermore, the cosmetic disfigurement of psoriasis has a negative

### Table 1 The percentage of psoriasis patients who find various diseases socially troubling.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Do not know (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leprosy</td>
<td>33.6</td>
<td>19.0</td>
<td>47.2</td>
</tr>
<tr>
<td>Syphilis</td>
<td>16.3</td>
<td>23.6</td>
<td>60.0</td>
</tr>
<tr>
<td>AIDS</td>
<td>46.3</td>
<td>36.3</td>
<td>17.2</td>
</tr>
<tr>
<td>Cancer</td>
<td>65.4</td>
<td>34.5</td>
<td>0.0</td>
</tr>
<tr>
<td>Gonorrhea</td>
<td>28.1</td>
<td>37.2</td>
<td>34.5</td>
</tr>
<tr>
<td>Behçet’s disease</td>
<td>55.4</td>
<td>30.9</td>
<td>13.6</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>36.3</td>
<td>29.0</td>
<td>34.5</td>
</tr>
<tr>
<td>Psoriasis</td>
<td>94.5</td>
<td>5.4</td>
<td>0.0</td>
</tr>
</tbody>
</table>

### Table 2 Psoriasis patients’ perceptions of the source of the change in social relations.

<table>
<thead>
<tr>
<th>Social relations with:</th>
<th>Change arising from both sides (%)</th>
<th>No change arising from either side (%)</th>
<th>Change arising from the patient (%)</th>
<th>Change arising from the counterpart (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closest friend at work</td>
<td>5.8</td>
<td>44.1</td>
<td>17.6</td>
<td>32.3</td>
</tr>
<tr>
<td>(n = 34)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closest friend in life</td>
<td>6.8</td>
<td>48.2</td>
<td>20.6</td>
<td>24.1</td>
</tr>
<tr>
<td>(n – 29)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>6.8</td>
<td>48.2</td>
<td>6.8</td>
<td>37.9</td>
</tr>
<tr>
<td>(n = 87)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>16.4</td>
<td>46.8</td>
<td>13.9</td>
<td>22.7</td>
</tr>
<tr>
<td>(n = 79)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
impact on the quality of life by causing psychological stress, disruption of social relationships and difficulties in daily life. It may cause as much disability as debilitating and life-threatening diseases, even though it is confined to the skin. Embarrassment, stigmatization, depression, problems of self-esteem and body image are frequent in patients with psoriasis. It may also interfere with various aspects of the quality of life such as personal relationships, sports, sexuality, self-care activity, and activities at work or school.6

The disability caused by psoriasis has been investigated in several studies in the past decade.4,7–11 There are also studies that aim to determine the need for health education among patients with psoriasis through the determination of gaps most frequently occurring in this type of knowledge.2 It has been proven in previous studies that patients with psoriasis see the need to improve their knowledge of the disease and of their self-care activities.12–14

The aim of this study was to assess the perspectives of psoriasis patients regarding their illness. In this study we use the term “illness” instead of “disease”, even though the diagnosis of all cases was proved clinically and/or histopathologically. The term “disease” is assumed to be more medical and universal. However, “illness”, defined as the subjective response of an individual suffering from the symptoms of a disease, is usually affected by the backgrounds and emotional characteristics of individuals as well as personal, social, physical, environmental, and cultural values. Being ill usually correlates with perceived changes in bodily appearance, excessive and emotional stress, and behavioral changes in relation to others. People generally perceive themselves as being ill when they find answers to a series of questions such as “what has happened?”, “why has it happened?”, “why has it happened to me and why now?”, “what should I do about it?”, etc.15

The characteristics of the patients in this study give us strong clues about the patient profile of other psoriasis patients in Turkey. Importantly, the hospital in which the present study was carried out is one of the major hospitals in the country. Many patients from other regions are referred to and utilize this hospital.

Almost all of the patients regarded psoriasis as a socially troubling disease. Remarkably, the percentage of patients who considered AIDS a socially troubling disease was lower. In general AIDS is a very troubling and traumatizing disease, but patients in this study may have prioritized psoriasis because of their own illness. We were surprised that, not only did 29.09% of the patients not regard tuberculosis as a socially troubling disease (when in Turkey it remains an important public health concern), 34.5% of them had no idea about tuberculosis. A relatively high percentage of the patients had no idea about other socially troubling diseases. It is reasonable that people prioritize their own illness/disease, and it is clear in our study that most of the patients prioritize psoriasis.

Psoriasis patients experience a degree of morbidity as severe as that faced by patients with other chronic medical illnesses. In a study by Rapp et al,7 46%, 42%, and 32% of psoriasis patients believe that it would be the same as having, or better to have, diabetes, asthma, or bronchitis (respectively). Although the majority of the patients regarded psoriasis as a socially troubling disease, not all of them thinking like this stated “significant difficulty” as the most frequent difficulty they faced. The conflict in this result may be explained by the results of PASI Group 3 and the group of patients with no formal education, as this perception had the second highest frequency in these groups.

Attitudes and perceived causes of the disease may affect patients’ health-seeking behaviors and treatment delays. The beliefs of the patients regarding the underlying factors as their illness were evaluated. Almost half of them believed that “stress and unhappiness” was a predisposing factor for their illness. It is remarkable that nearly one out of five patients believed that the cause was a contagious infectious agent. The other issues that patients emphasized were: having underlying diseases, undernourishment and poverty, drugs, dust and air pollution, smoking, drinking alcohol, and genetic factors. Contrary to our expectations, patients did not worry about the possible genetic impact of psoriasis. Only five patients, all of whom had a formal education, mentioned that item. None of the patients stated immunity, and eight patients had no opinion about any causative factor. The distribution of the patients’ beliefs about the underlying factors of their illness was similar according to gender, status of education, duration of disease, and PASI. In a study carried out by O’Leary et al,10 the causal beliefs of psoriasis patients about their illness were as follows, in descending frequency: hereditary factors, stress/psychological, immunity, lifestyle (smoking, alcohol, diet), uncontrollable factors, and pollution. The patients believing hereditary factors, lifestyle (smoking, alcohol), and pollution are causal factors were in the lower percentages in our study. In contrast again with O’Leary et al’s10 study, and remarkably so, there was a high percentage of patients who regarded contagious infectious agents as causal factors in our study. There are previous research reports17–19 demonstrating that a significant proportion of psoriasis patients believe that stress/psychological factors are causal. In our study the most frequently mentioned item as a causal factor was “stress and unhappiness”.

“Signs and symptoms of psoriasis” was the most frequent difficulty that patients were facing because of psoriasis. Nearly half of the patients stated this item. Only four out of 48 patients were suffering from pruritus, whereas 44 were suffering from the cosmetic aspects of psoriasis. In Gupta and Gupta’s20 report, psoriasis patients reported having the most difficulty on social, occupational, and financial levels. “Stress, anxiety, and other negative feelings” was the second most frequently prioritized perception. However, “no significant difficulty” was the second most frequently prioritized perception in both the patients with no formal education and, surprisingly, those in PASI group 3. Perhaps the patients with severe psoriasis are more accepting of the disease and have learned to cope with it, or they may be more under control in terms of treatment. In the group with no formal education, we were not surprised at the result, because we think that they are probably not too aware of their disease, or rarely attend social events.

The two most frequently prioritized perceptions, “Signs and symptoms of psoriasis” and “Stress, anxiety, and other negative feelings”, bring another important social concept—stigmatization—to mind. Briefly, stigmatization is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from an adverse social judgment about a person or a group. At this point psoriasis becomes very serious for both the patient and others around him/her. Stigmatization can negatively influence the patients' relations with their social settings.21 In addition to physical impairment, psoriasis also exerts a severe and detrimental social impact; many of the patients experience social rejection and stigmatization.22,23 In addition to outright rejection, the anticipation or fear of being rejected or stigmatized disrupts the patients' social experiences to such an extent that they avoid social events.22,24 The perceptions of psoriasis patients regarding their illness can reveal how this “stigmatization” affects their social lives. In this study we assessed the patients' perceptions of their social relations within their social environment in different categories. For each category, patients stated whether the perception of change arose either from themselves, from their counterparts or from both sides. Most of the patients who still have their parents, those who have a closest friend in life, more than half of the patients who have their closest friend at work, and more than half of the married patients all stated that there was a change in social relations, mostly arising from
their counterparts. We also assessed the social relations of married patients who believed that a contagious infectious agent was the causative factor of their illness. Most of the patients stated that there was a behavioral change arising from themselves. This may be due to their perception that psoriasis is an infectious and contagious disease and because of the responsibility they have for their spouses. Psoriasis is still thought to be a contagious disease in the community and this may influence the relations between patients and the social environment. From this point of view, knowledge of the disease for both patients and the persons around them becomes an important issue.

As a result, psoriasis is more than a cosmetic nuisance and can be associated with psychosocial effects that seriously affect patients’ lives and social relations. The impact of psoriasis on the physical, social, psychological, and financial aspects of life should not be trivialized and must be considered with the same importance as other chronic conditions. Patients need information about their condition and how best to manage it. In general, information tends to reduce ignorance and isolation, and patients can learn how to handle social situations in which they are confronted about their skin condition and how not to become “ignited” by others’ ignorance. Increasing the patients’ knowledge of the disease could have a positive effect on the relations the psoriasis patients have within their social environment. We think that social care should also be prioritized as well as physical and biological care in the psoriasis patient.

References