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Stigmatization in dermatology with a special focus on psoriatic patients

Stygmatyzacja w dermatologii ze szczególnym uwzględnieniem chorych na łuszczycę

Dimitre Dimitrov[1], **Jacek C. Szepietowski**[2]

[1]Presidential Medical Wing, Al Mafraq and Sheikh Khalifa Medical City, Abu Dhabi, UAE
[2]Department of Dermatology, Venereology and Allergology, University of Medicine, Wroclaw, Poland

Summary

A stigma is currently defined as a discrediting mark, biological or social, that sets a person off from others and disrupts interactions with them. People who differ from social norms in some respect are often negatively labeled. A number of medical conditions are recognized at present as stigmatizing their sufferers and certain skin diseases are among them.

The article aimed to analyze the current understanding about stigmatization among dermatological patients, especially those with psoriasis.

We performed our search on PubMed up to November 2016 and utilized combinations of key phrases containing such words as stigmatization, skin, dermatology, names of various skin conditions (psoriasis, vitiligo, acne, etc.). Following a precise selection process, 58 articles remained.

Stigmatization seems to be a common and important problem in dermatology. Psoriasis appears as the most frequently studied skin disease (37.2% of articles). It was followed by vitiligo (13.7%) and leprosy (8.6%). Mainly, the visibility of skin lesions as well as cultural factors contribute to the feeling of stigmatization. There is a need for more research in the field of stigmatization in dermatological conditions and an urgent need for the creation of special anti-stigmatization program/programs for patients suffering from dermatoses.

Keywords: **stigmatization • quality of life • psoriasis • skin diseases • dermatology**

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Author's address: Prof. dr hab. Jacek C. Szepietowski, Department of Dermatology, Venereology and Allergology. Wroclaw Medical University, Chalubinskiego 1, 50-368 Wroclaw, Poland; e-mail: jacek.szepietowski@umed.wroc.pl

Abbreviations: **DPI –** Disability Psoriasis Index, **EOS –** Experiences of Stigmatization, **HADS –** Hospital Anxiety Depression Scale, **SPQ –** Stigmatization Psoriasis Questionnaire.

INTRODUCTION

The meaning and connotation of the word stigma has varied considerably over the centuries. Originally, the Greek word stigma meant the mark of a pointed instrument. Later on, it referred to the physical signs, cut or burnt into the body, to proclaim that the person was a criminal, traitor, or slave [13]. The term stigma acquired a special meaning from the time of early writings about Christ's Crucifixion. It was a symbol of the wounds on the palms, soles and head that Christ suffered on the cross. It was also divided into religious and nonreligious causes. The former believed them to be supernaturally imposed by God [8].

Nowadays, stigma is defined as a discrediting mark, biological or social, that sets a person off from others and disrupts interactions with them [21]. Stereotyping, distrust, fear, or avoidance are all forms stigma can take. Stigmatization begins when individuals with a discrediting mark are marked by another individual or a group. Individuals become label carriers of the marks they carry [48]. Stigma does not necessary need to be a visible flaw or mark. It can also be a specific feature, situation or past experience, which is usually associated with negative stereotypes, leading to social discrimination [47]. More detailed definitions explain that stigmatization may not only prevent the formation of normal relationships but also lead to social discrimination and alienation. People who differ from social norms in some respect, such as race, appearance, physical, or mental health have often been negatively labeled. In such circumstances stigma can be overlapped with discrimination, reaching the point where the stigmatized ones are denied personal and civil rights [10]. Others comment on the fact how distinguishing characteristics result in social disapproval, noting how the visible lesions become a reason for stigmatization with consequent psychological stress and social withdrawal [16].

In the past two decades, stigmas, especially health-related ones, have been categorized into three main types:

1) experienced or enacted stigma;
2) anticipated, felt, or perceived stigma; and
3) internalized or self-stigma.

A fourth type has been added by authors describing cutaneous leishmaniasis – 4) aesthetic stigma [42]. It has become widely accepted that education, particularly in the childhood years, can significantly increase understanding among the public and lessen discrimination against the mentally ill. For such educational material to be effective, the audience needs to be engaged emotionally as well as intellectually. Some programs will encourage participants to have more contact with stigmatized people in order for them to gain a greater understanding of the similarities and differences in their lives. It has been shown that this increases favorable attitudes and decreases perceived danger from mentally ill people [48].

AIM OF THE PAPER

The aim of this paper was to analyze and describe the current understanding and knowledge about stigmatization process in dermatological patients, especially those suffering from psoriasis.

METHODOLOGY

In order to collect the necessary data, we performed our search on the scientific web site engine PubMed up to November 2016. The following key words, terms and phrases were used to obtain the most complete information: stigmatization and dermatology, stigmatization and skin, stigmatization and psoriasis, stigmatization and atopic dermatitis, stigmatization and vitiligo, stigmatization and other skin problems including acne, hidradenitis suppurativa, rosacea, eczema, genetic skin disorder, ichthyosis, scars, hair loss and birth mark. The search found huge number of articles. In PubMed, using the key word "stigmatization and dermatology" we found 65 articles and selected 14 (not all obtained articles related to the searched topic/title; for that reason we are giving the number of the selected articles, i.e. the articles with contents corresponding to our search); using the key word "stigmatization and skin" – 158 articles, selected 24; "stigmatization and psoriasis" – 53 articles, selected 8; "stigmatization and acne" – 9 articles, selected 1; "stigmatization and hidradenitis suppurativa" – 3 articles, selected 2; "stigmatization and rosacea" – 5 articles, selected 2; "stigmatization and eczema" – 6 articles, selected 1; and "stigmatization and ichthyosis – 2 articles, selected 1. During the selection process we tried to avoid duplication: for instance, from the articles related to psoriasis, under "stigmatization and psoriasis" search, only were 8 taken into final analysis, as most of them were selected previously during the search using "stigmatization and dermatology" and "stigmatization and skin" key words. Despite our effort, some duplication was found and corrected later. After a precise process of verification and selection, a short list of 58 articles directly related to the topic of the current paper was finally selected for the detailed review; of them 19 dealed with the problem of stigmatization in psoriatic patients.

STIGMATIZATION IN VARIOUS DERMATOSES

The emotional burden of patient with skin diseases is enormous. In fact, the visibility of skin lesions plays an important role in this burden. For instance, it was found that patients with fingernail onychomycosis experienced greater stigmatization compared to those with toenail onychomycosis [54]. In an article analyzing the stigmatization in psoriatic patients, the authors described their surprising findings that having facial psoriasis did not influence patients' stigmatization, keeping in mind the face is the most visible area of our body [16]. They explained this with the possibility that patients might also have lesions on other visible areas, for instance hands. In the study analyzing the stigmatization experience in patients with hidradenitis suppurativa, results for the "6-Item Stigmatization Scale" [29] demonstrated that disease involvement in exposed skin areas played a crucial role in the level of stigmatization [34]. Patients with rosacea were also evaluated and the result indicated that the visibility of symptoms was certainly a factor explaining stigmatization process [4]. The facial difference and its impact have been studied and the authors concluded that the risk of stigmatization was greater in disabled children than among non-disabled children and increased with the size of the facial difference and the age of the child [32]. A study analyzing hair loss in children with cancer found the thought of all the hair falling out may initially have a greater impact than the diagnosis itself [44]. The location of the lesion may have a different influence on the different psychological characteristic. For instance, the anogenital localization in hidradenitis suppurativa contributed to the impaired quality of life, but not to a high stigmatization level [34].

The attitude to people with skin problems can vary in different countries and cultures. For instance, in an article about cutaneous leishmaniasis in Pakistan and Afghanistan the authors commented on the common practice to isolate affected people during the course of active lesions [22]. They reported that usually parents isolate their children from others, including their siblings and even themselves. Moreover, women with this skin disease are considered ineligible for marriage and are not even accepted by their own family. Even though the disease is treatable, the disfigurement and social stigmatization may become the reason for psychological disturbances and may be even associated with a higher risk of psychiatric disorders.

In certain cultures, the fear of stigmatization due to skin disorders can be devastating. Two girls with lamellar ichthyosis, reported in Nigeria, were hidden at home form the time they were born [18]. The authors explained that families with a history of certain diseases, such as leprosy, epilepsy, and disfiguring skin diseases usually have difficulties integrating into society. Such families are considered as ''outcasts'' or as carrying bad genes, and for that reason marriage to any member of such a family is not encouraged. It was clearly underlined that to protect the future of other children, the girls were kept in isolation and denied any education. Consequently, they grew up with no chance of gaining employment and leading a normal life in future.

The relation of stigma and other psychopathological conditions has been described, where the authors conc-

Table 1. Dermatoses and stigmatization: list of investigated skin diseases

Dermatoses in which stigmatization was studied	Number of studies	Percentage of studies	Reference
Psoriasis	19	32.7%	7, 18-32,35,36
Acne	3	5.1%	37,38,39
Atopic Dermatitis	3	5.1%	19,20,40
Facial difference	3	5.1%	13,41,58
Genital herpes	3	5.1%	42,43,44
Hair loss	1	1.7%	14
Hematidrosis	1	1.7%	45
Hidradenitis suppurativa	2	3.4%	11,46
Ichthyosis	1	1.7%	16
Leishmaniasis cutaneous	2	3.4%	8,15
Leprosy	5	8.6%	33,47,48,56,57
Onchocercal skin disease	3	5.1%	34,49,50
Onychomycosis	1	1.7%	9
Port wine stains	1	1.7%	51
Psychogenic dermatosis	1	1.7%	52
Psychosomatic purpuras	1	1.7%	53
Rosacea	2	3.4%	12,54
Skin defect	1	1.7%	55
Trichotillomania	1	1.7%	17
Vitiligo	8	13.7%	18,21,59-64

luded that stigmatization might overlap with trichotillomania and body dysmorphic disorder [32].

Analyzing stigma precipitating factors among stigmatized vitiligo and psoriasis patients with dark skin and Caucasians, it was concluded that the clinical and demographic parameters that are responsible for stigma differ widely between different cultures and skin shades play a major role [43]. The authors emphasized the fact that the clinical and demographic factors that influenced stigma among vitiligo and psoriasis population in brown-black skin shade of South Indian culture is by and large different to that of light-skinned Caucasian societal backgrounds.

Most of the available articles described stigmatization and other psychometric parameters only in one dermatological condition/disease. Our research found only a few studies, where the authors investigated patients with more than one disease, for instance psoriasis and atopic dermatitis [48,51] or psoriasis and vitiligo [40,43]. We identified 58 articles with 20 different skin conditions/diseases where stigmatization was studied. The most commonly investigated skin disease was psoriasis – 18 articles dealing with stigmatization in psoriatic individuals. They constituted more than 30% of all papers on stigmatization in various dermatoses. Table 1 presents dermatoses in which stigmatization level has been assessed and reported in the English literature of the subject.

STIGMATIZATION AND PSORIASIS

As mentioned above, our research found that psoriasis is the most common skin disease, where the stigmatization experience was studied. Therefore, below we present a short description of articles on stigma in psoriatic individuals.

Hrehorow et al. aimed to estimate what level of stigmatization was experienced by psoriatic patients and to analyze the relation between the feeling of stigmatization and some clinical, demographic and psychosocial parameters [16]. The study reported that most of the patients under observation were found to have feelings of stigmatization due to psoriasis. According to 6-Item Stigmatization Scale [29], only 9.8% of patients with psoriasis had no feeling of stigmatization and a further 18.3% were only minimally stigmatized. The rest of the patients had various degrees of stigmatization. Analyzing the questions separately, the most troublesome aspect was having other people stare at at skin changes followed by the fact that some people consider psoriasis to be a contagious disease. The authors compared the above results with the mean level of stigmatization measured with Feeling of Stigmatization Questionnaire [11] and found that anticipation of rejection and feelings of guilt and shame were the most important aspects of stigmatization felt by psoriatic patients. They concluded that the results achieved with the 6-Item Stigmatization Scale [29] correlated highly with the Feelings of Stigmatization Questionnaire [11] ($\rho = 0.68$, $p < 0.001$) as well as with separate dimensions of stigma (anticipation of rejection: $\rho = 0.53$, feeling of being flawed: $\rho = 0.62$, sensitivity to the opinions of others: $\rho = 0.67$, secretiveness: $\rho = 0.35$, positive attitudes: $\rho = 0.41$, $p < 0.001$ for all comparisons) except the dimension of guilt and shame ($\rho = 0.14$, $p = 0.16$). Similarly, total scoring of the Feeling of Stigmatization Questionnaire [22] significantly correlated with all questions of 6-Item Stigmatization Scale [10] analyzed separately (ρ ranging from 0.41 to 0.61, $p < 0.001$). When analyzing the relationship between the level of stigmatization and clinical and socio-demographic parameters, the authors could not find any significant connections. Using the Feeling of Stigmatization Scale [11], they demonstrated that the level of stigmatization was significantly higher in patients with no family history of psoriasis than comparing with subjects whose family members had psoriasis.

In a study conducted by Bohm et al., the authors analyzed the perceived relationships between severity of psoriasis symptoms, gender, stigmatization and quality of life among psoriasis patients [5]. They analyzed 381 in-patients diagnosed with psoriasis. Symptom severity and discomfort were measured subjectively with single items. To measure the stigmatization, they employed the Questionnaire on Experience with Skin Complaints [49]. The results found an association between symptom severity and higher discomfort and stigmatization and lower skin-related quality of life. Gender difference was found in relation to experiences of discomfort, stigmatization and mental aspects of quality of life. They concluded that the effect of stigmatization on skin-related quality of life is driven by both symptom severity and stigmatization, but the effect on mental health is driven mostly by stigmatization alone. They noted that, despite the fact that women and men experience the social impact of psoriasis differently, the effect of stigmatization on quality of life is similar for both genders.

In the article entitled “Quality of life in patients with psoriasis and psoriasis arthritis with a special focus on stigmatization experience” the authors discussed how the quality of life of those patients is negatively affected [52]. They underlined the fact that even a small patch of psoriasis is enough for the patient to be felt stigmatized. The authors noted that some of the consequences occurring among psoriatic patients might be disease specific. They stressed on the importance of including also the psychological outcome, and not only physical, from the clinical research that evaluate the results of treatment of patients with psoriasis and psoriasis arthritis. It was also suggested that the well-established fact that the quality of life of psoriatic patients is comparable with other chronic systemic diseases and possibly life threatening ones, can be explained with the high level of stigmatization experienced by those patients. The authors clearly stressed on the fact that both the quality of life and stigmatization should not be underestimated in psoriatic patients and have to be considered in interaction with them.

An in-depth study of stigmatization among psoriasis patients was performed by Ginsburg and Link [11]. They developed the "Feelings of Stigmatization Questionnaire", specifically targeting patients with psoriasis. The following 6 dimensions are analyzed in the questionnaire: "anticipation of rejection", "feelings of being flawed", "sense to the opinion of others", "guilt and shame", "positive attitudes" and "secretiveness". Additional items were included and were called "psoriasis related despair". The authors emphasized the fact that the feeling of stigmatization is not one-dimensional. With the help of this questionnaire, the experience of stigmatization can be differentiated and the relation with other predictors of the disease or sociodemographic variables elements can be evaluated. The most significant results were found concerning age at the onset of the disease. The factors regarding anticipation of rejection, awareness of others' opinions, guilt and shame, and positive attitudes were less distinct in older patients at the onset of psoriasis. In contrast, the influence of "the extension of bleeding lesions" on 2 of the 6 factors, feelings of being flawed and awareness of others' or on the category psoriasis related to despair was clearly higher. Moreover, it was important whether the patient had a job or not; in the latter case, the dimensions such awareness of others', guilt and shame, and psoriasis related despair, were significantly more distinct. As expected, the actual experience of being rejected had an impact on the factors relating to the patient's awareness of others' opinion, in the sense of being reinforced, and positive attitudes, in the sense of being toned down. It is surprising, however, that the actual experience of being rejected had no influence on the domain anticipation of rejection. The extension of the lesions and their visibility were not predictive for the different dimensions of stigmatization.

Another study ascertained that 1 in 5 patients experienced strong rejection, usually in the following situations: going to the gym, going to the swimming pool, going to the hairdressers, or at a job place [12]. Using multiple regression analysis, the authors found that independent variables for the feeling of stigmatization were sociodemographic data, the severity of psoriasis, the experience of being rejected, and 2 of the following dimensions of the Feelings of Stigmatization Questionnaire [11]: anticipation of rejection and the awareness of others' opinion. As a dependent variable they indicated malfunction at work, seeking professional help, and consumption of alcohol.

A study examining the relationship of moderate to severe psoriasis and touch related stigmatization found that 26.3% of the patients reported having experienced during a previous month a situation in which people made a conscious effort not to touch them because of their psoriasis [13]. Using various questionnaires, the authors analyzed the relation between high depression scores and perceived deprivation of social touch and found that might indicate the stigma experience in psoriasis.

Perrott et al. reported that those who developed psoriasis at a younger age are more likely to experience a feeling of stigmatization [41]. In this study gender-based attitudes in most cases were not a useful predictor of feelings of stigmatization. The study found that physician-rated disease severity is a poor predictor of disease impact. The authors summarized that there is a need for a physician-based severity rating scale that is able to evaluate the physical impact of psoriasis and, at same time, to relate disease severity to the psychological impact and quality of life.

Richards et al. performed a study to analyze both general and disease-specific psychological variables in patients with psoriasis and how they, together with physical status and symptoms, may predict the disability [45]. One hundred fifteen patients with psoriasis participated in this study and were asked to complete 3 psychometric assessment measures: the Psoriasis Disability Index (DPI), Stigmatization and Psoriasis Questionnaire (SPQ) and the Hospital Anxiety and Depression Scale (HADS). According to HADS, 43% of the patients were found to be suffering from depression, and 10% demonstrated anxiety. Analyzing the obtained data, the authors found that psychological factors were stronger determinants of disability in psoriatic patients, compared with clinical severity, visible cosmetic involvement, or duration of the disease.

The study of Vardy et al. aimed to find if patients with psoriasis have higher levels of stigmatization compared with patients with other skin diseases and if their experiences of stigmatization (EOS) affect the impact of severity of psoriasis on the quality of their lives [57]. One hundred patients with psoriasis and 100 with other various skin problems as a control group were included. The authors evaluated EOS by specifying a latent construct, using the following 5 indicators: refusal, retreat, self-esteem, rejection, and concealment. Analyzing the results, the authors ascertained that EOS was an almost full mediator of the association between severity of disease and quality of life in psoriasis; high severity of disease related to increased levels of EOS, which was again associated with decreased levels of quality of life. That was not observed in the control group. The authors believed that the results emphasize the crucial role that EOS plays in the lives of patients with psoriasis.

Schmid-Ott et al. aimed to determine the various dimensions of stigma experience by utilizing Questionnaire on Experience with Skin Complaints (QES) – an adopted and extended German version of the Feeling of Stigmatization Questionnaire [11,49]. The researchers examined 187 in-patients, diagnosed with psoriasis, at the age of 17 to 83 years old. The authors commented that self-esteem, retreat and rejection were mainly influenced by 'problematic regions' affected by psoriasis, rejection also by 'visible parts' and retreat also by 'invisible regions'. At the same time, the influences of age, age at onset and sex on the stigma experience were small but significant. Female and older patients, as well as patients with longer history of psoriasis felt more stigmatized. The authors pointed to the high percentage of suicidal tendencies (4.3%) and suggested an association with stigmatization.

Schmid-Ott et al. followed up on 166 patients during one year to assess changes of stigmatization experience and psoriasis over time [50]. While no significant somatic differences between gender were found, the feeling of stigmatization among women was more emphasized. The results of the study showed a moderate but significant relevance of skin status (disease severity) for the feeling of stigmatization over time only in men, thus suggesting a considerable influence of other psychic variables, probably coping skills, especially in women.

In the article entitled "The level of stigmatization and depression of patients with psoriasis" the authors analyzed how the psychological status and level of stigmatization are influenced by the demographic variables in patients with psoriasis [20]. They analyzed 202 patients with severe psoriasis. The results revealed that both men and women experienced the greatest discomfort when others were looked at their skin lesions. Also, they found that patients with psoriasis believed that others consider their condition as a contagious disease. The psychological status of the patients was determined with Beck Depression Inventory. The authors found moderate depression, among unemployed and divorced patients. They compared the average scores of the 6-item scale and Beck Depression Inventory according to demographic parameters and characteristics of the disease in well-prepared table. In conclusion, they suggested that psoriatic patients who experience high levels of stigmatization and/or depressiveness should be offered psychological care.

A study measured stigmatization among psoriasis and vitiligo patients by comparing the level of social participation in their domestic and social life [40]. There were 150 cases each with psoriasis and vitiligo. The researchers found that among vitiligo patients 17.3% participated minimally in domestic and social life, whereas 28% of psoriasis patients had this problem (*P*=0.027). At the same time, extreme participation restriction was found only among psoriasis patients (2.7%).

Schmid-Ott G et al. analyzed the stigmatization experiences of patients with atopic dermatitis and psoriasis [51]. They found that patients with psoriasis experienced more stigmatization. Compared with patients with different affected regions, they found that the genital area is especially relevant for the stigmatization experience. The authors suggested that stigmatization should be regarded as possibly the most afflicting feature of these diseases and considered as a secondary source of stress.

ANTI-STIGMA STRATEGIES

While describing, analyzing and commenting on stigmas and other psychological problems among dermatological patients, some of the authors indicated the strategies or programs used for reducing the feeling of stigma.

One of the studies proposed three levels of action [46]. The first is protest through media, from medical professionals, patient associations and patient charities about inaccurate or unhelpful ways of presentation, for instance, disfiguring skin conditions. The second is education, the importance of proper information to be provided to counteract unhelpful stereotyping of stigmatized groups. The third is having contact with people from 'stigmatized' groups in order to initiate and achieve changes about the stigmatization in general. The authors underlined that among people with especially mental health difficulties the third method, i.e. direct contact, demonstrated significant reduction of stigma. They concluded that more research is needed to find how to apply such activities and properly combine them with clinical practice for patients with dermatoses.

The second group raised the question if the already developed stigma reducing intervention for certain target group or condition can be of use or be effective for people with other conditions, including skin problems [30]. It appeared that this might be possible, but may require some special disease-specific modifications. The guidelines to reduce stigma were prepared and published 2011 by the International Federation of Anti-Leprosy Associations and the Netherlands Leprosy Relief [34]. They are designed for health and social professionals who have to deal with stigma in leprosy and other health conditions. Evidence-based and best-practice information from different disciplines is provided, as well recommendations on how to reduce stigma against and among affected persons in the community. First, it recommends to aware that someone may be stigmatized without realizing it; second we have to avoid labeling persons with a certain health condition.

Working with patients suffering from cutaneous leishmaniasis, the experts concluded that multi-dimensional approaches were required [22]. First, they believe the disease has to be eliminated or controlled. The proper education of population concerning, for instance, disease transmission, vectors, prevention, etc. should be brought to the participant's attention. Involving community leaders is another important factor. The authors stressed that visual propaganda, such as posters, public health information has to be distributed around the country. They pointed out on that only a combined approach by general practitioners and all local health care provides could result in the success of anti-stigmatization activity. The role of the media is also emphasized. Since the activity has to be multidimensional, they believe schools should be involved as well. Proper education of children in schools is essential. At the end of their recommendation, they advise that all measures should be in synchrony with socioeconomic development. All those activities have to be completely and integrally supported and facilitated by the local, regional, and country authorities. The authors also advise that one has to search for experience with anti-stigma activity in other diseases and conditions.

CONCLUSIONS

Stigmatization seems to be a common and important problem among dermatological patients. Visibility of skin lesions, as well as cultural factors are the main ones contributing to the feeling of stigmatization. Psoriasis appeared the most frequent disease in which stigmatization was assessed. However, the literature data on stigma in different dermatoses is very limited. Moreover, several different instruments were used to evaluate stigmatization level by different research groups which limits the possibility to make a direct comparison between the studies. Definitely, dermatological patients require holistic therapeutic approach with anti-stigma strategies included. There is a need for more research in the field of stigmatization in dermatological.

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