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# Perception of dermatologists on the influence of psoriasis on quality of life of patients

# Percepção de dermatologistas sobre a influência da psoríase na qualidade de vida dos pacientes

# Percepción de los dermatólogos sobre el impacto de la psoriasis en la calidad de vida de los pacientes

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**Abstract:** Objective: to know how psoriasis affects the quality of life of patients in the perception of dermatologists and identify strategies for improving it and reorganizing care. Methods: Descriptive, exploratory study research conducted in a public hospital in the countryside of São Paulo, from December 2017 to March 2018, with six dermatologists. The interviews were transcribed and analyzed using the methodological strategy of the Collective Subject Discourse. Results: Psoriasis is a disease, which affects the quality of life because it is associated with psychosocial disorders, shame, stigma and loss of self-esteem. Reducing injuries and symptoms, improving appearance, having an effective medication coupled with humanized care are fundamental for improving the quality of life of these patients. Conclusion: It was observed that for dermatologists, psoriasis is a chronic disease that interferes with the quality of life, due to the prejudice felt by patients, the psychosocial disorders and negative feelings that arise, as well as the social difficulties faced, by them.

**Keywords:** psoriasis; quality of life; dermatology; nursing.

**Resumo:** Objetivo: Conhecer como a psoríase interfere na qualidade de vida dos pacientes na percepção de dermatologistas e identificar estratégias para melhoria e reorganização da assistência. Métodos: Pesquisa exploratória e descritiva, realizada em hospital público do interior de São

Paulo, no período de dezembro de 2017 a março de 2018, com seis dermatologistas. As entrevistas foram transcritas e analisadas utilizando-se a estratégia metodológica do Discurso do Sujeito Coletivo. Resultados: Psoríase é uma doença que inflige prejuízo à qualidade de vida por estar associada a transtornos psicossociais, estigma, vergonha e perda da autoestima. Reduzir lesões e sintomas, melhorar a aparência, disponibilizar medicamento eficaz e oferecer atendimento humanizado são aspectos fundamentais para melhoria da qualidade de vida destes pacientes. Conclusão: Para os profissionais dermatologistas, a psoríase é uma doença crônica, que interfere na qualidade de vida dos pacientes, em virtude do preconceito sentido, dos transtornos psicossociais e sentimentos negativos que afloram, bem como das dificuldades sociais enfrentadas.

**Palavras-chave:** psoríase; qualidade de vida; dermatologia; enfermagem.

**Resumen:** Objetivos: conocer cómo la psoriasis afecta la calidad de vida de los pacientes en la percepción de los dermatólogos e identificar estrategias para mejorarla y reorganizar la atención. Métodos: Investigación descriptiva y exploratoria realizada en un hospital público del interior de São Paulo, de diciembre de 2017 a marzo de 2018, con seis dermatólogos. Las entrevistas fueron transcritas y analizadas utilizando la estrategia metodológica del Discurso Colectivo del Sujeto. Resultados: En opinión de los participantes, la psoriasis es una enfermedad que daña la calidad de vida por estar asociada a trastornos psicosociales, estigma, vergüenza y pérdida de la autoestima. Reducir lesiones y síntomas, mejorar la apariencia, disponer de una medicación eficaz vinculada a la atención humanizada son fundamentales para mejorar la calidad de vida de estos pacientes. Conclusión: Se observó que, para los dermatólogos, la psoriasis es una enfermedad crónica que interfiere con la calidad de vida, debido al prejuicio sentido, los trastornos psicosociales y sentimientos negativos que surgen, así como las dificultades sociales que enfrentan los pacientes.

**Palabras clave:** psoriais; calidad de vida; dermatología; enfermería.

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## Introduction

Psoriasis is a chronic inflammatory disease characterized by a form of inflammation of the skin (psoriasis) and joints (inflammatory arthritis), immune-mediated, influenced by genetic and environmental factors, which affects patients of all age groups and both sexes.(1-3) Presenting with erythematous-desquamative plaques with overlapping white crusts varying sizes, discoids or already complete or incomplete circles.(4-5)

As a general rule, the evolution of psoriasis lasts for many years. However, there is a frequent change in its shape and even its disappearance, followed by the relapse of the disease.(6)

Despite the great impact caused by this dermatosis on quality of life, only in the last 20 years have health professionals been concerned with the systemic repercussions caused in patients' lives.(7)

For the World Health Organization (WHO), quality of life is defined as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”.(8) Although it is a comprehensive and broad concept, it reflects the subjective and multidimensional aspects that permeate the construct.(9)

People with chronic diseases can have their quality of life changed since they need to modify habits and develop adaptive processes to the disease. In addition to the direct impacts on QOL, dermatoses can promote psychological problems such as changes in self-image, damage to self-esteem and social interactions, as well as trigger symptoms of depression and anxiety.(10-11) These implications have contributed to arouse the interest of researchers who study the repercussions on QOL caused by chronic diseases such as hypertension, diabetes, rheumatological and cardiovascular diseases.(12-13)

Instruments that use psychometric parameters to measure QOL can assist in decisions that involve, for example, the administration or not of high-cost or high-risk drugs. The use of simple measures to assess quality of life is well accepted by patients who wish to express their anxieties and concerns.(6)

However, there is a scarcity of studies that evaluate the perception of specialists in dermatology regarding the quality of life of patients with psoriasis, since most studies assess the quality of life from the patient's perspective.(14-15) Given the above, the purpose of this study was to answer the following guiding questions: What is the influence of psoriasis on the QOL of patients in the perception of dermatologists? How to provide QOL for these patients? How could this assistance be improved?

To fulfil this knowledge gap, the present study sought to understand how psoriasis interferes with the quality of patients in the perception of dermatologists and to identify strategies for improving and reorganizing care.

## Methods

This is an exploratory and descriptive study that used the Collective Subject Discourse (CSD) technique, based on the theory of Social Representations. The DSC seeks to answer and get to know the thoughts, representations, beliefs and values of a community on a given topic by applying scientific methods.(16)

In empirical research, thinking, materialized in the form of discourse, is a qualitative variable. But being this collective thought, it is also configured as a quantitative variable, as it expresses the opinions shared by individuals.(17)

The study site took place at the dermatology outpatient clinic of a public university institution, located in a city on the interior of the state of São Paulo. Inclusion criteria were established: being a dermatology specialist doctor, of both sexes, being a member of the Brazilian Society of Dermatology and providing care at the research site. Initially, specialists were invited to participate in the study and their inclusion only began after reading and signing the Free and Informed Consent Form.

Data were collected through semi-structured interviews, carried out individually in a private environment, from December 2017 to March 2018. Was used a semi-structured interview script, developed by the researchers, consisting of three guiding questions. Such questions were applied to six dermatologists who provide care to patients diagnosed with psoriasis at the dermatology outpatient clinic of the institution where the research was carried out, namely: “In your opinion, does psoriasis interfere with patients' quality of life? If so, how? In your opinion, what does it mean to provide quality of life for patients with psoriasis? How could the quality of life of these patients be improved?”. At the end of the interviews, the speeches were transcribed and submitted to manual analysis by one of the researchers with experience in operationalizing the methodological strategy of the Collective Subject Discourse (CSD).

The methodological steps of this technique, which must be followed from obtaining the interviews to the synthesis of the speeches, include: reading the set of statements collected in the interviews; reading the answer to each particular question, marking the selected key expressions; identification of the central ideas of each answer; analysis of all key expressions and central ideas, grouping the similarities into homogeneous sets; identification and naming of the central idea of the homogeneous ensemble, which will be a synthesis of the central ideas of each discourse; construction of the speeches of the collective subject after the identification of the central ideas and key expressions that named the speeches of the collective subject.(16)

In this study, we chose to assign the identification of the interviewees' testimonies by the letter "M" (interviewee) followed by the numbering that was assigned to them in the interview transcript. The project was approved by the Research Ethics Committee of the Faculty of Medicine of Botucatu (FMB), under the nº 2,392,601, according to Resolution nº 466/2012 of the National Health Council.(18)

## Results

The sample was composed by six dermatologists. After transcribing the interviews, the central ideas and key expressions were identified, and the speeches of the three themes, which emerged from the interview's guiding questions, were organized. Table 1 summarizes the central ideas and the CSD regarding the first theme, “Impact of psoriasis on quality of life”.

**Table 1-** Synthesis of the central ideas and the collective subject's discourse regarding the theme impact of psoriasis on quality of life

| **Central Ideas** | **DSC** |
|---|---|
| Appearance | *I believe that the quality of life depends a lot on the patient, on the degree of involvement, on the severity of the disease and, mainly, on the aesthetics. Physical aspects, such as itching, pain, cracks and joint impairment, also influence it. Scales are also annoying, they stay on clothes and people think it is personal carelessness (M1, M3, M4, M5).* |
| Misinformation about the disease | *As we end up treating patients with a low level of education, the concern with the transmission of the disease prevails and interferes in many aspects of life, as they feel uncomfortable thinking about what others will think, because they think it is a contagious disease (M2, M4).* |
| Stigmatizing disease | *This helps the patient with skin lesions to hide or hide the lesions, which affects social and family life and contributes to the stigma of the disease (M3, M4, M5 M6).* |
| Psychosocial disorders (anxiety / depression) | *In my opinion, psoriasis can trigger anxiety symptoms in some patients, a fact that can lead to worsening of the lesions (M4, M6).* |
| Compromise of professional activities | *Psoriasis also interferes with emotional and professional relationships, which contributes to some patients requesting secondary benefits, due to being away from work, because of the injury (M5, M6).* |
| Loss of self-esteem<br>Negative feelings | *In addition, psoriasis, being a chronic disease, ends up contributing to the loss of self-esteem, which can lead, in the long run, to a feeling of helplessness, incapacity, hopelessness and even depression (M1, M2, M3).* |

Table 2 presents the central ideas and speeches related to the second theme, “How to provide quality of life for patients with psoriasis”.

**Table 2 -** Synthesis of the central ideas and the collective subject's discourse regarding the theme how to provide quality of life for patients with psoriasis

| Central Ideas | DSC |
|---|---|
| Reducing injuries and symptoms | *The right answer is to cure the disease, but unfortunately, we do not have a cure. It depends a lot on each patient; sometimes what is quality of life for one is not for the other. To provide quality of life, for me, would be to have the greatest possible reduction in the number of injuries and improvement in appearance, being able to offer an acceptable type of treatment, with a minimum of side effect, and resulting in a lower number of injuries. The most important thing is for the patient to see himself without injuries and to be in good health, but this is always very difficult (M1, M2, M4, M5).* |
| Understanding the impact of the disease on the patient's life | *In my view, I provide quality of life when I understand the extent to which the disease affects it. And that does not mean that he is free of the disease, but that he gets a little better, with relief from the itching, the improvement in the aspect of the lesions and, mainly, with the improvement of the areas where the lesion is more exposed, more visible, facilitating social interaction (M1, M3, M4, M6).* |
| Clarifying the patient about the disease | *It is also our job to provide clarification to patients about the disease, because many think it is transmissible, that it can become a cancer, and inform that Medicine is striving to achieve improvements that are more efficient in treatment (M1, M3, M4, M6).* |
| Humanizing service | *If we can provide a good reception, good service and make sure that we are offering our best, I believe that we can improve the impact on QOL (M2, M3, M5).* |
| Understanding the patient’s needs | *We, dermatologists, have to be sensitive to understand the needs of each patient, ask if that patient is sleeping well, how is the love life, if he is enjoying things, in short, and not only worrying about treating psoriasis (M1, M2, M3, M4).* |

Table 3 presents the central ideas and speeches related to the third theme, “Interventions to improve the quality of life of patients with psoriasis”.

**Table 3 -** Synthesis of the central ideas and discourse of the collective subject regarding the theme interventions to improve the quality of life of patients with psoriasis

| Central Ideas | DSC |
|---|---|
| Reduce injuries and symptoms | *I think that if we contribute to reducing the number of injuries, pain, itching, this will undoubtedly have a positive impact on quality of life (M2, M3, M4).* |
| Clarify the population and patients | *Informing the population, family and the patient himself may be a therapeutic resource that reduces the stigma of the disease (M1, M2, M4, M5, M6).* |
| Welcoming | *In addition, we must also welcome the patient and understand the representation of the disease in his life (M2, M3).* |
| Trying to provide multidisciplinary care | *Every chronic disease, in general, consumes our mental health. So, I think we need to pay special attention to that too. If we could count on a multidisciplinary treatment, with nutritionists, cardiologists and psychologists, we could certainly offer a better quality of life to these patients (M1, M2, M4, M5, M6).* |
| Offer supporting treatments | *Offer creams, moisturizers, not only the medication that exists at high cost, but the adjuvants. All of this will cooperate so that it is put back in society, resulting in a better quality of life (M3, M5, M6).* |

## Discussion

Dermatosis impairs self-image and has great potential to trigger processes that affect self-esteem. In addition, they contribute to intensify the feeling of rejection caused by skin diseases and can trigger negative feelings in relation to body image and fear of possible body exposure.(10,19)

Aspects observed in the speeches of the experts interviewed suggest that the patients' perception of physical appearance is associated with greater impairment in daily activities and social exclusion, which can compromise daily activities and quality of life in general. Studies show that individuals affected by psoriasis worldwide experience social stigmatization, often related to work, discrimination by society, in addition to pain, itching and bleeding.(20-21)

A qualitative research carried out in Denmark with patients with psoriasis showed that they develop strategies to avoid public exposure on social occasions due to the stigmatization of the disease.(22) The discomfort generated by the disease helps them to avoid other people or camouflage the injuries, which can favor the loss of self-esteem and even trigger symptoms of anxiety and depression.(23)

According to the participants in this study, negative feelings about the disease and the appearance of injuries can also interfere with work activities. Therefore, some seek to obtain secondary benefits resulting from illness, such as being away from work. A study carried out in Germany showed that patients with psoriasis lost, on average, 4.9 days of work per year due to the disease.(24)

Authors emphasize the presence of several variables that can impact the lives of patients with psoriasis. They include personality characteristics, character, values, life situation, meanings attributed to society's life and attitudes, which vary from person to person. (25)

The data collected in the study showed that providing a better quality of life for patients demands welcoming and sensitivity from the team to understand each individual's needs. In addition, the need to provide clarifications to patients and society was emphasized, so that they can understand better the representation of this disease in the lives of affected individuals. From the interviewees' perspective, providing adequate treatment and reducing side effects caused by medications can also contribute to improving QOL. The literature has highlighted specific therapies, especially with the use of biological drugs, which allow total or partial stabilization of the disease.(26-27)

The care of patients with psoriasis does not only require the treatment of injuries and joint implications, but also the identification and treatment of comorbidities that already exist or are likely to develop. This includes paying attention to possible cardiovascular, metabolic and psychological diseases, with a multidisciplinary team.(28)

In another study carried out in Denmark, patients who received support from a nutritionist or participated in research on the relationship between weight and psoriasis considered this follow-up to be highly beneficial. However, when this support from another professional ended, the follow-up with a specialist doctor became more difficult. (22)

However, a study conducted in England demonstrated the importance of psoriasis patients being monitored by specialist doctors. The research suggested that the current routine practice for the treatment of psoriasis in primary care performed by clinicians is incompatible with the real needs of these patients. Therefore, in order to improve this assistance, psoriasis would need to be recognized as a complex long-term condition that involves deep physical, psychological and social demands.(29)

Providing specialized care to restore health in all aspects, without worrying only about the integrity of the skin but also with psychosocial issues, can reduce the negative impact of the disease on the patients' lives.(30)

Nursing consultations and other integrated health actions can also contribute to improving QOL, but it is essential that interventions do not focus only on physical illness. The team must be sensitive to the health and social problems of patients seeking alternative interventions that have a positive impact.(31)

The nursing consultation is an effective strategy for improving the patient's quality of life, as it allows nurses to systematically organize their care with the aim of providing care that involves not only the biological aspect, but also the understanding of the patient as a social being during the health-disease process. Such an approach would allow nurses to be part of the process of identifying possible problems and decisions to be made during care.(32)

The scarcity of studies in the literature with a qualitative approach to investigate the experts' perception of the impact of psoriasis on patients' quality of life was a limitation of the study, in addition to being carried out in a single hospital.

## Conclusion

The results of this study demonstrate that psoriasis, from the perspective of dermatologists, is a disease that negatively impacts on the quality of life of patients due to prejudice, psychosocial disorders and negative feelings triggered by it.

The testimonies of the dermatologist professionals revealed that the improvement in the quality of life of these patients involves the establishment of bonds with the team, humanized assistance, and reduction of symptoms resulting from skin lesions, with a consequent improvement in appearance.

Lastly, the present analysis offers important subsidies to health professionals for the improvement of care strategies through the implementation of actions based on an interdisciplinary and comprehensive approach to health care. It is necessary to offer assistance that addresses the real psychological and social needs of these patients, who often go unnoticed in their usual care.

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**Contribution of the authors:** a) Study conception and design, b) Data acquisition, c) Data analysis and interpretation, d) Writing of the manuscript, e) Critical review of the manuscript.

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