



## Patients quality of life while coping with their Psoriasis - Qualitative Research

Dr.Tshetiz Dahal, Dr.Rishna Malla

General Physician/Clinical Researcher and Writer, Lugansk State Medical University, Luhansk Oblast, 93000,  
Ukraine

Medical Resident, Dermatology Dept, Tianjin Medical University, Wuqing District, Tianjin, China, 301700

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### ABSTRACT

**Background:**A multi-factorial inflammatory condition that is common in dermatology is psoriasis. Our goal was to comprehend how psoriasis sufferers felt about their quality of life and to explore ways to make it better.

**Methods:**This qualitative study involved 81 psoriasis patients who were treated as outpatients at the STNM Hospital in Sikkim, India. The Discourse of the Collective Subject approach was used to transcribe and analyse the interviews (DCS).

**Results:**Well-being, happiness, leisure, wholesome eating, and financial security were all associated with high quality of life. However, their perspectives were significantly impacted by sickness symptoms, social and clothing restrictions, limitations on their professional pursuits, and the lack of a remedy. Increased public knowledge, stress reduction, disease acceptance, and interdisciplinary care were among the suggested changes.

**Conclusion:**The participants' interpretations of quality of life are individualized, complex, based on their personal experiences, and connected to the progression of health and sickness. Improvements in QoL in psoriasis can be attributed to public health policies that support lowering social stigma and stress as well as interdisciplinary approaches to care.

### I. INTRODUCTION

Psoriasis is a long-lasting inflammatory dermatosis that manifests as symmetrical, erythematous-desquamative plaques with white-silver desquamation. It can also include extra-cutaneous symptoms as uveitis and arthritis. Its prevalence in India is estimated to be between 1.1 and 1.5%, accounting for 4.8% to 5.0% of dermatological consultations. Health practitioners frequently underestimate the social and psychological effects of psoriasis [5]. Psoriasis, like other immune-mediated complex illnesses, has no known cure, and current therapies only lessen disease activity and ameliorate symptoms [3]. The

quality of life is negatively impacted by psoriasis, a chronic and recurrent condition that affects joints and visible areas [6].

The World Health Organization (WHO) defines quality of life as an individual's sense of their place in life in relation to their objectives, aspirations, standards, and concerns in the context of the culture and value system in which they live [7]. However, subjectivity, dimensionality, and bipolarity are three features that all definitions share [8]. Dermatoses may lead to emotions like anxiety, melancholy, or even depressive symptoms on the theory that they might alter self-image and have a high potential for initiating processes that impair self-esteem. As a result, in dermatology, the perception of quality of life is regarded as a crucial factor [9]. Since the causes and limitations of the health-disease process are diverse and complicated, quality of life evaluation has evolved into an indicator used to direct healthcare practices and aid in the formulation of public policy solutions.

To better understand the issues that matter to psoriasis patients, such as disease stigma and prejudice, among others, quality of life measurements need to be improved. These are frequently absent from the quality of life instruments listed in the literature. Therefore, the purpose of the current study was to comprehend how psoriasis patients perceive their quality of life and to pinpoint any prospective areas for improvement. In order to further understanding in a neglected field of dermatology, this study will examine the unique experiences of psoriasis patients.

### II. METHODS

An exploratory descriptive study using a qualitative methodology was conducted at a dermatological outpatient of the STNM Hospital in Sikkim, India, the study involved psoriasis patients. The following eligibility requirements were adopted: psoriasis patients who were 18 years of age or older, of both sexes, and gave their



agreement to participate. Participants who said they were too emotionally fragile to participate or continue the interview were not allowed to participate. 81 patients who visited the outpatient dermatology from December 2019 to May 2021 made up the non-probabilistic sample. This sample matched the total number of patients who visited the hospital during the data collection period. There were no refusals or breaks in the interview process without any connection to the participants, two medical nurses and a doctor performed the interviews. The interviewees could not receive the transcripts of the interviews for feedback. Semi-structured face-to-face interviews were used to gather data, which also included sociodemographic information and the following guiding questions: What does "quality of life" mean to you? Does psoriasis, in your opinion, affect your quality of life? If so, in what ways? How, in your opinion, could the impact of psoriasis be lessened on your quality of life? Before the medical consultation, one of the researchers who was thoroughly trained in the technique utilised for data collection performed individual, audio-graphed interviews in a confidential location. The average interview lasted 20 minutes.

The Discourse of the Collective Subject (DCS) technique, which is based on the theory of social representations, was used to analyse the data [10]. The DCS aims to address the difficulty of individual or group idea or opinion expression while respecting both their dual qualitative and quantitative conditions. Given that the concretized idea of the discourse's form constitutes a type of qualitative variable, it must be afterwards qualified. Although it does not violate the theoretical saturation criterion to end an interview, this collective idea is also a quantitative variable insofar as it conveys the opinions held by individuals [11]. In our study, all outpatient dermatology patients who showed up and consented to an interview throughout the data collection period were questioned. The option to comprehend the meanings, reasons, desires, attitudes, and beliefs supported by the nature of the study object was what led to the selection of this type of technique [12]. From obtaining the interviews to synthesizing the speeches, the methodological steps of this technique included reading the set of testimonies gathered in the interviews, marking the selected key expressions in each response, identifying the central ideas of each response, analyzing all key expressions and central ideas, grouping the similarities into homogeneous sets, and identifying and naming the central idea of the homogeneous sets.

A consent form was signed by each participant. The researchers outlined all measures to protect confidentiality in this permission, including their agreement to handle, keep, and exchange research data to maintain the confidentiality of information learned from and about research participants.

### III. RESULTS

The majority of the 81 participants (54%) were male, (70%) were married or cohabitating, and (60%) had at least completed their primary school. The disease began to manifest in patients when they were 36 years old, making their average age 50. The monthly household income for 61% of the sample ranged from \$200 to \$560. The three themes' discourses emerged from the leading questions after the central concepts and key phrases from the interviews' transcription analysis were determined. The fundamental concepts and patients' DCS for the ensuing topics are shown.

#### Theme 1 - Meaning of Quality of Life - Central Ideas:

- A. Well-being
- B. Solidarity
- C. Financial stability
- D. Good nutrition
- E. Do not have stress and concerns
- F. Be happy
- G. Having leisure and practicing physical activity
- H. Being employed

**DCS:** In my opinion, having a decent quality of life means having the freedom to go outside and stroll, to have a nice home, leisure time, and a life. It is my welfare to be able to live joyfully. I also think it's critical to be physically and mentally well, so I make an effort to eat well and exercise. I try not to worry about small things and drink a lot of water. In addition to being honest, having a solid work, and enjoying what you do, I believe that having excellent relationships with everyone is crucial. Faith and a close-knit family are what really matter. No, I don't require a lot of money to live a decent life. Having friends is a vital part of my quality of life, but it differs from person to person since as we experience some life events, other things lose their significance. Everyone leads very busy lives, therefore I believe that if we take a time to pause and think about others, things will go better for everyone. If you understand others, quality of life improves regardless of financial elements. A disease-free life, or one where you can afford medicine if you do, is what many people consider to be a high quality of life. And it's not enough just



to come to the hospital, but you have to follow the doctor's recommendations at home too.

### **Theme 2 - Impact of Psoriasis on Quality of Life - Central ideas:**

- A. Symptoms of the disease (pain and itching)
- B. Behaviour (shame)
- C. Increased stress
- D. Frustration and suffering
- E. Link inseparable from treatment
- F. Commitment to professional activities
- G. Stigma of disease
- H. Contagiousness
- I. Restriction on clothing

**DCS** - For me, it obstructs everything. Psoriasis aches, especially when it itches and becomes worse while I'm around other people. The plaques upset me when I scratch too much and come off. It's really irritating and addictive, and once you lay your palm on it, the itching doesn't stop. I believe that it is irrelevant when I am inside my home, but on the street it is difficult since we are ashamed. I try to avoid crowded areas since I feel uncomfortable there, and if someone looks at me, I find myself itch-scratching. There isn't a lot of freedom for you. You cannot feel at ease when swimming since some individuals understand, while others do not. They believe they can capture it. It was challenging at first because I didn't want to wear shorts, people kept staring at me, and I felt self-conscious. I still find it difficult to wear low-cut clothing nowadays since everyone is staring and asking what it is. In fact, there are times when I'd rather wear a full-sleeved blouse just to avoid questions because if I try to respond, I might come across like a complete moron. I am also unable to have long, gorgeous hair, which annoys me greatly because I am constantly trimming and maintaining it. I have trouble even getting a job, which keeps me from succeeding professionally. After all, you still have to be under treatment, and I cannot do other things that I like. We often need injections, spending a lot of time here at the clinic. Every day you have to put ointment on instead of doing other things. Psoriasis takes people out of social life, so we go into depression. It's complicated, I'm really depressed, really down.

### **Theme 3 - Contributions to Improve Quality of Life in Psoriasis - Central ideas:**

- A. More efficient drugs
- B. Clarification of the lay population
- C. Acceptance of disease
- D. Possibility of healing
- E. Treatment adherence

- F. Have multidisciplinary service
- G. Stress reduction

**DCS** - Quality of life could be improved by making other people aware that a person with psoriasis on their skin does not have a disease transmitted by sight, by clothing, by soap, in any way ... Because people stare and are disgusted and scared, but that is a problem that person has. I think that is the reason why a lot of people suffer ... to see the prejudice of others. There comes a time when we stop suffering from these hardships, but for those who are sick at the beginning, they will still have to go through all of this ... Because others look and judge, they are afraid to touch and to be touched. Also, if the treatment advances and they found a cure for it, it would be better, of course ... if you had a medication that would end psoriasis tomorrow, a more direct treatment instead of a weak one. Let's suppose, I'm here today because it's my appointment, but if I did not have to come here, I'd be at work. Now, if I did not have psoriasis, it would be better. It's been a long time since I've had it, that I've lived with it, for about 30 years. With psoriasis, one even forgets what is good. When people do not have this disease it is very good, I still remember how it was... you do not scratch, worry about your appearance, you will be able to be free, going to the beach and pool without thinking. However, I think that this is impossible, that only God can do that at the moment, because for this disease there is no cure. And since this is the reality, what can improve it is to have better control of psoriasis. A control that would minimize the appearance of the lesions on the skin, where there is no more pain. And for this we need to do the right follow-up, more often, because I have a weight problem as well. So, I need an endocrinologist, a nutritionist ... because of the medication, I had side effects in other parts of my body that need to be monitored by other professionals, not just the dermatologist. And not having that makes me a little nervous. This is another thing that would certainly improve quality of life, calm the nerves a bit. It is no use doing the treatment right and not calm down.

## **IV. DISCUSSION**

Since psychometric tools frequently cannot accurately translate the degree of the damage imposed by any condition on an individual's life, evaluating quality of life in healthcare settings is problematic. In the instance of psoriasis, this challenge is framed by the chronic and intractable nature of a skin condition



characterized by social limitations, unfavourable emotions, and treatment dependence.

Due to the fact that identity formation incorporates appearance, people with dermatological illnesses must consider how their skin looks on a fundamental social level. This study demonstrates that the skin is frequently the point of touch when meeting someone new [13]. Failure to meet the demands and expectations of others results in a great deal of personal unhappiness, which ultimately affects one's quality of life (QoL) and interpersonal relationships [13]. A research with 41 patients in the UK revealed that people's restricted social interaction and inadequate comprehension of their condition interfered with their relationships [14]. This conclusion was supported by a qualitative study involving 16 patients at an outpatient dermatology clinic at a hospital in Denmark, where the participants developed avoidance tactics due to the stigma associated with their illness [15]. For instance, some participants claimed to disguise their skin lesions with clothing to avoid having to explain them. We discovered the identical method that was mentioned in our study. A multicenter research of 35 patients revealed that the majority of them experienced social discrimination as a result of their illness, which led some people to conceal and lie about it [16]. The accounts of the participants in the current study revealed the discrimination and rejection that psoriasis patients encounter, which has a detrimental effect on how they perceive their quality of life. This bias is frequently so strong that it prevents people from engaging in social activities as well as achieving their full potential in the workplace [17]. Psychological tension and body dissatisfaction levels are also elevated by psoriasis [17]. The majority of those who have this disorder try to avoid feeling worried, but this is quite challenging given how many negative thoughts it brings on. The participants' treatment regimen already causes them stress because they are unable to engage in activities they find enjoyable.

A study conducted in the United States with 18,000 members of the National Psoriasis Foundation has shown that people with psoriasis believe that physicians quite often underestimate the impact of the disease on patients' lives. Furthermore, what is perceived by psoriasis patients as severe is often not valued by the physician [18]. There is evidence that patients prefer a customized approach to their care. They desire to be treated as individuals rather than as psoriasis cases. Some patients claim that their treatment is hampered since the doctors do not listen to their issues. They claim that doctors

undervalue the severity of their difficulties and are ill-equipped to deal with the situation, which leaves patients feeling rejected. Supporting their unique challenges in their lives outside of their illnesses is crucial for them [15]. This method is intricate and demonstrates how seeing each patient as a person and seeing them holistically is the biggest challenge for healthcare providers caring for these individuals. It's critical to pay attention to their complaints, value them, and avoid concentrating just on their skin's outward appearance. This study discovered that there is a need and desire to involve input from other health experts in addition to the medical professional, as seen in the DCS. This result is consistent with earlier research showing the value of professional support [15].

Our research indicates the value of following a specialist appointment with a nurse consultation. Specialists and nurses could collaborate more closely and give the necessary assistance for one another. The quality of life would be enhanced through nursing consultations, follow-ups, integrated health initiatives, and suggested measures. Interventions shouldn't just target the physical illness. Patients seeking effective alternative interventions should have their social and health issues taken into consideration [19]. In order to provide care that would encompass not just the biological side but also a knowledge of the patient as a social being during the health-disease process, a nurse can organize their care in a methodical manner through the use of nursing consultations. Such a strategy would enable a nurse to participate in the process of spotting possible issues and making care-related decisions [20]. Having a nurse consult with patients throughout their care has been rated favourably in the current study by our patients. Additionally, current research demonstrates that a nurse consultation is advantageous to the community and may lead to good and suitable measures that are adapted to the specific needs of patients in terms of care [21, 22].

To that end, the literature highlights the significance of professionals paying close attention and actively listening to patients in order to determine their true needs and then to provide the necessary solutions [23]. Active listening entails letting go of preconceived notions [24] and calls for health workers to be willing to adapt, assist, and make a difference. Finally, public health policies to increase knowledge and awareness of the general population about psoriasis are needed. This approach will help to explain the impact of psoriasis on a person's life and, hopefully, reduce the prejudice surrounding it and facilitate social





inclusion. After all, what defines a person goes far beyond their skin.

## V. CONCLUSION

The results of this study show not only how patients with psoriasis perceive their quality of life, but also the stigma, prejudice, and social challenges they experience. For these individuals, quality of life is a multifaceted, subjective concept that frequently revolves around an individual's ability to meet their most fundamental requirements. From the perspectives captured by the interviews, the recommendations to enhance quality of life centred on the necessity of raising general public awareness about the disease, the acquisition of more effective medications that enable healing, acceptance of the disease, care by a multidisciplinary team, and stress reduction. The fact that we did not consider the study's impacts on the participants before, during, or after the interview and should be included in follow-up

research using our approach is a potential weakness of our study. Last but not least, the current analysis provides critical insights to healthcare professionals to enhance care strategies through the implementation of actions based on an interdisciplinary care approach, targeted at the true psychological and social needs of these patients, which frequently go unnoticed.

## Availability of Data and Materials

The data that support the findings of this study are not publicly available because they contain information that compromise the privacy of research participants. However, an anonymous dataset can be made available from the corresponding author under reasonable request.

## Additional information

Additional file 1 of Quality of life of patients living with psoriasis: a qualitative study.

**Part 1**  
**Clinical and Sociodemographic Information**

1. Name: _____	2. Phone number: _____
3. Date of Birth: ____/____/____	4. Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male
5. Marital Status: <input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Divorced/ Widower	
6. Education: <input type="checkbox"/> Up to Elementary <input type="checkbox"/> Middle and High school <input type="checkbox"/> Higher education	
7. Age of disease onset: _____	
8. Occupation: _____	
9. Number of people in the family: _____	
10. Monthly family income: 1- <input type="checkbox"/> Up to R\$ 1,000.00 2- <input type="checkbox"/> R\$ 1,100.00 to R\$ 3,000.00 3- <input type="checkbox"/> R\$ 3,100.00 to R\$ 5,000.00 4- <input type="checkbox"/> Over R\$ 5,000.00	
11. Length of psoriasis treatment: <input type="checkbox"/> less than a year <input type="checkbox"/> between 5 and 10 years <input type="checkbox"/> more than 10 years	
12. Are you a smoker? <input type="checkbox"/> Yes <input type="checkbox"/> No	
13. If yes, how many cigarettes do you smoke per day? _____	
14. How long have you been smoking? _____	
15. If no, how long have you stopped smoking? _____	
16. Do you drink alcohol? <input type="checkbox"/> Yes <input type="checkbox"/> No	
17. If yes, how often do you drink? _____	
18. If no, when have you stopped drinking alcohol? _____	

## Part 2 - Guided questions applied to patients

1. What do you understand by quality of life?
2. In your opinion, does psoriasis interfere with your quality of life? If yes, in what aspects?
3. In your perception, how could your quality of life be improved in relation to psoriasis?

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#### Competing interests

The authors declare that this research was conducted in the absence of any commercial or financial relationships that could be construed as potential conflicts of interest.