

# Examining the lived-experience of psoriasis in Brazil: findings from an online Global Psoriasis Atlas survey

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on behalf of the Global Psoriasis Atlas

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## Introduction

- There is a paucity of data on the epidemiology of psoriasis in Brazil.
- The aim of this study was to better understand the burden of psoriasis experienced by people in Brazil.

## Methods

- We conducted an online survey of 563 Brazilian residents aged  $\geq 18$  years (mean age  $42.1 \pm 12.4$  years) with literacy proficiency who had been diagnosed with psoriasis.
- Data on psoriasis severity, health-related quality of life measures (QoL), capability measures, treatments, comorbidities, and free-text responses on the lived-experience were collected.
- Psoriasis severity was defined using the aggregated self-assessment Simplified Psoriasis Index (SPI) severity score, calculated as the product of 2 scores: the extent score and the average plaque severity score.
- Spearman's correlation (Rho,  $r$ ) was used to test the correlation between SPI and QoL (Hernandez EQ-5D utility score: score of 1 means perfect health) and capability (ICECAP-A: score of 1 means full capability across all attributes) measures.
- A thematic analysis approach was conducted to examine the free-text responses from participants to identify patterns and common themes.

## Discussion

- We found that psoriasis, its clinical features, severity, and associated comorbidities, negatively impact health-related quality of life and capability in the surveyed Brazilian population.
- This is accompanied by feelings of social stigma and prejudice, and inadequate availability of specialist physicians to diagnose and manage psoriasis and access to appropriate and effective treatment.
- To improve the lives of people living with psoriasis in Brazil, there is a need for better access to care and awareness of the disease.

## Results

Figure 1. Self-assessment of extent of psoriasis

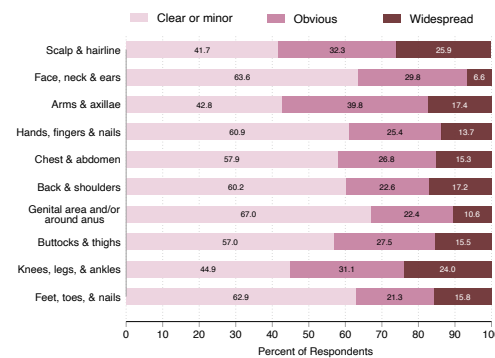


Figure 2. Patient responses on the Quality of Life measures

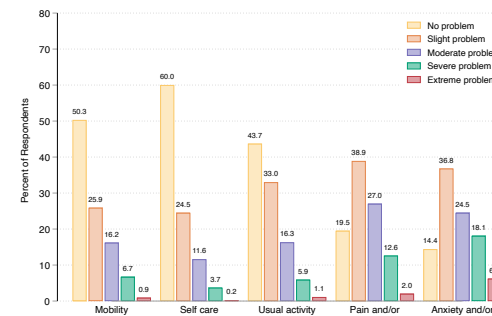


Figure 3. Patient responses on the capability measures

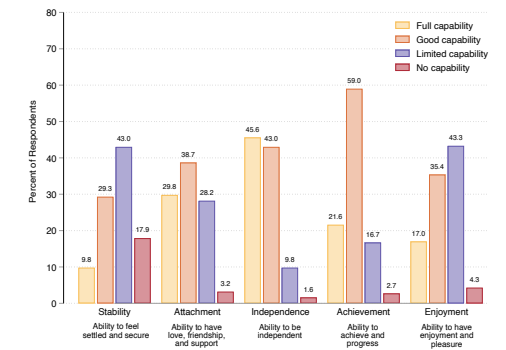


Figure 4. Patient experiences of living with psoriasis

**Stigma/Prejudice**

"It is difficult! I've witnessed many **exclusions**, when I was a teenager I was **bullied**, in college I felt people were aloof or [had] a **look of disgust**."

"People feel **uncomfortable** being close to me because of the skin lesions."

"Aesthetically and emotionally affects. Those who don't know think it's **transmissible**."

**Education**

"Living with psoriasis is very difficult due to **people's lack of knowledge**, there is a lot of **prejudice** ... that ends up affecting the emotional side of people with this disease."

"There is still a **lack of publicity** about psoriasis. [People believe it is] **contagious** and very **disgusting**."

**Trapped/Powerless**

"Discomfort and insecurity define those who live with psoriasis."

"... it is very difficult to live with this disease. I even thought about **suicide**."

"I feel like I'm not living, **just existing**."

"I dream of the day when I will no longer be **hostage to this disease**."

**Access to care**

"We have **many people without treatment** and still lost."

"... it took me a long time to find a dermatologist who had the courage to recommend me **[biologics]**."

"[There is] **difficulty in finding specialized professionals** for the treatment of [psoriasis]. It has improved a lot in recent years, but it is still difficult to diagnose."

## Demographics

- Most respondents had been diagnosed with psoriasis for more than 6 years (81%) with 83% using prescribed or other non-prescribed treatments (<50% felt treatments were effective).
- 52% reported having at least one long-term condition; common comorbidities were mental health conditions (33%), arthritis (30%), hypertension (16%), kidney or liver disease (8%), and diabetes (7%).

## Psoriasis severity

- Moderate or widespread involvement of the scalp & hairline was the most frequently reported area of the body affected (58.2%), followed by the arms & axillae (57.2%), and knees, legs & ankles (55.1%); Fig 1.
- Mean SPI was  $7.8 \pm 8.6$  with a third of respondents considered to have moderate-to-severe psoriasis.

## QoL and capability

- Mean quality of life utility score was  $0.59 \pm 0.25$  with respondents mainly affected by pain/discomfort and anxiety/depression associated with their psoriasis; Fig 2.
- Mean capability score was  $0.71 \pm 0.21$  with ability to feel settled and secure and have enjoyment and pleasure most affected by psoriasis; Fig 3.
- SPI was negatively correlated with health-related QoL ( $r = -0.49$ ,  $P < 0.05$ ) and capability ( $r = -0.44$ ,  $P < 0.05$ ).