

Budgetary Impact of Generalized Pustular Psoriasis (GPP) in the Brazilian Private Healthcare System: A Real-World Data Analysis

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Carlos F. S. De Santana¹, Cinara Soares¹, MD, Juliana Nascimento², Mariana Araujo², Taís B. T. Fernandes².

¹Boehringer Ingelheim Brazil, São Paulo, Brazil; ²Orizon Healthtech, Barueri, Brazil.

Introduction

Generalized pustular psoriasis (GPP) is a rare, chronic, and potentially life-threatening neutrophilic dermatosis, characterized by the sudden onset of widespread, sterile pustules on erythematous and inflamed skin, often associated with systemic manifestations such as fever, fatigue, leukocytosis, and elevated inflammatory markers^{1,2,3}. The condition follows a relapsing-remitting or persistent clinical course and can occur independently or in conjunction with plaque psoriasis^{3,4}. The pathogenesis of GPP involves complex immune dysregulation, with a growing body of evidence implicating mutations in the IL36RN gene and aberrant IL-36 signaling pathways^{5,6,7}.

Due to its rarity, GPP is poorly recognized in clinical settings, with low diagnosis rates and underreporting. This results in fragmented care, delayed interventions, and a lack of standardized treatment pathways^{1,2,8,9}.

Objectives

In Brazil, where 25% of the population is covered by private health, the economic impact of GPP remains largely unexplored. Understanding the real-world clinical trajectory and associated direct healthcare costs is critical to informing health policy, optimizing resource allocation, and improving access to appropriate therapies.

This study aimed to describe the clinical journey and estimate the direct economic burden of generalized pustular psoriasis (GPP) within Brazil's private healthcare system:

Characterizing the epidemiological profile of GPP patients in the private system and assess healthcare utilization and costs before and after diagnosis, including consultations, emergency visits, hospitalizations, ICU admissions, diagnostics, and treatments identifying the most frequent medications and procedures.

Methods

- A retrospective cohort study was conducted using real-world data from a private administrative claims database, which comprises transactional healthcare data from over 11 million covered by private health plans in Brazil—equivalent to approximately 23% of the national population covered by supplementary health.
- Patients were identified based on the presence of the ICD-10 code L40.1 (generalized pustular psoriasis) recorded in any claim between January 1, 2012, and December 31, 2021.
- For the purpose of this study, the first occurrence of L40.1 in medical expenses was used as a proxy for the diagnosis of GPP. Although L40.1 may encompass other pustular variants, it remains the best available code to approximate GPP in administrative data.
- For methodological this alignment, healthcare resource utilization and direct medical costs were analyzed consistency, all patients were aligned to a common reference point (T0), defined as the first recorded ICD-10 L40.1 event. Following this definition, will be followed the journey of those patients by 2 years before and after the main event. This structure allowed for longitudinal assessment of healthcare utilization patterns, patient journey, and economic impact related to GPP.
- All direct medical claims were categorized and aggregated based on hospital-based care across different modalities of service: hospitalizations, ICU admissions, exams and pharmacological treatments.
- Costs were calculated as the total sum of reimbursement values recorded for each medical utilization item. All cost estimates were inflation-adjusted using the Brazilian Consumer Price Index (IPC-A) and reported in December 2023 values (R\$).

Results

Main Event

- A total of 77 beneficiaries were identified with at least one event of Generalized Pustular Psoriasis (GPP, ICD-10 L40.1) between 2012 and 2021.
- Nearly half of the identified patients (49%) lacked information on age and sex - a recurrent challenge in administrative claims data in Brazil, where such fields are not mandatory. Among the patients with available data, 29% were female and 22% male. Geographically, cases were highly concentrated in the Southeast region (71%), especially in São Paulo state (60%) and its metropolitan area (52%), followed by the Northeast (23%). This pattern reflects both the regional distribution of privately insured populations and the potential influence of healthcare access and diagnostic awareness across regions.

Patient Journey

- Regarding the journey, 58% required hospitalization, with a mean cost of BRL 140,213. Hospitalizations directly related to GPP accounted for 78% of all inpatient episodes. 36% of patients required ICU care at least once, and 13% had ICU admissions specifically due to GPP.
- A total of seven in-hospital deaths (9.1%) were identified, of these, one death (1.3%) occurred during a hospitalization explicitly coded as GPP-related. Considering only hospitalized patients (58% of the cohort), this represents an overall in-hospital mortality rate of approximately 15.6%, and 2.2% when restricted to hospitalizations directly attributed to GPP.

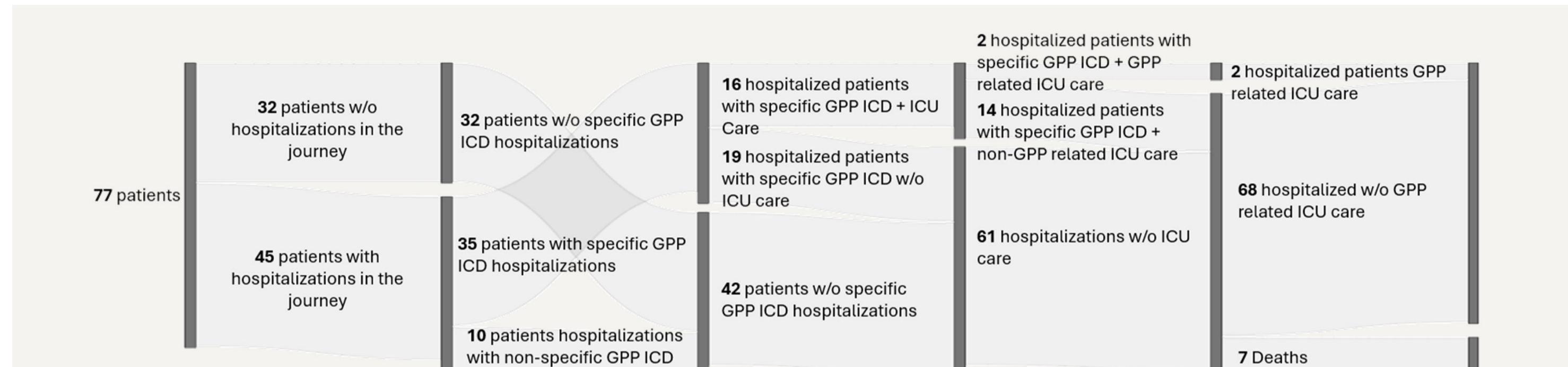


Figure 1. Patient Journey Mapping of GPP Cases in the Brazilian Private Healthcare System

Healthcare resource utilization

• Pre-diagnosis

Two years before the first recorded diagnosis, 12% of patients were hospitalized, with a mean of 1.4 admissions and a mean cost of R\$ 19,204.88 per admission. ICU admissions occurred at lower frequency, with mean ICU costs of R\$ 9,332.03. In the year immediately preceding diagnosis, hospitalization rates rose to 20%, and mean costs increased by 132% to R\$ 44,668.99, indicating progressive clinical deterioration and high pre-diagnostic disease activity.

- Post-diagnosis (+1 to +2 years) Following diagnosis, hospitalization rates remained high (21% in the first year), and 16% of patients required ICU care.
- The mean hospitalization cost peaked at R\$ 115,649.68, a 159% increase compared with the year prior to diagnosis. ICU-related costs reached R\$ 182,496.93, a 71% escalation, reflecting critical disease exacerbations requiring intensive support.
- Two years post-diagnosis, both utilization and cost indices declined: hospitalizations decreased to 10%, with an average cost of R\$ 29,057.68, and ICU costs fell dramatically to R\$ 3,855.36, suggesting stabilization and more effective disease management.
- Overall, mean cumulative hospitalization costs per patient totaled R\$ 140,213.12, and mean ICU costs R\$ 136,931.56, confirming inpatient care as the major cost driver in the GPP patient journey.



Figure 2. Healthcare Utilization Over Time in GPP: emergency vs. elective visits

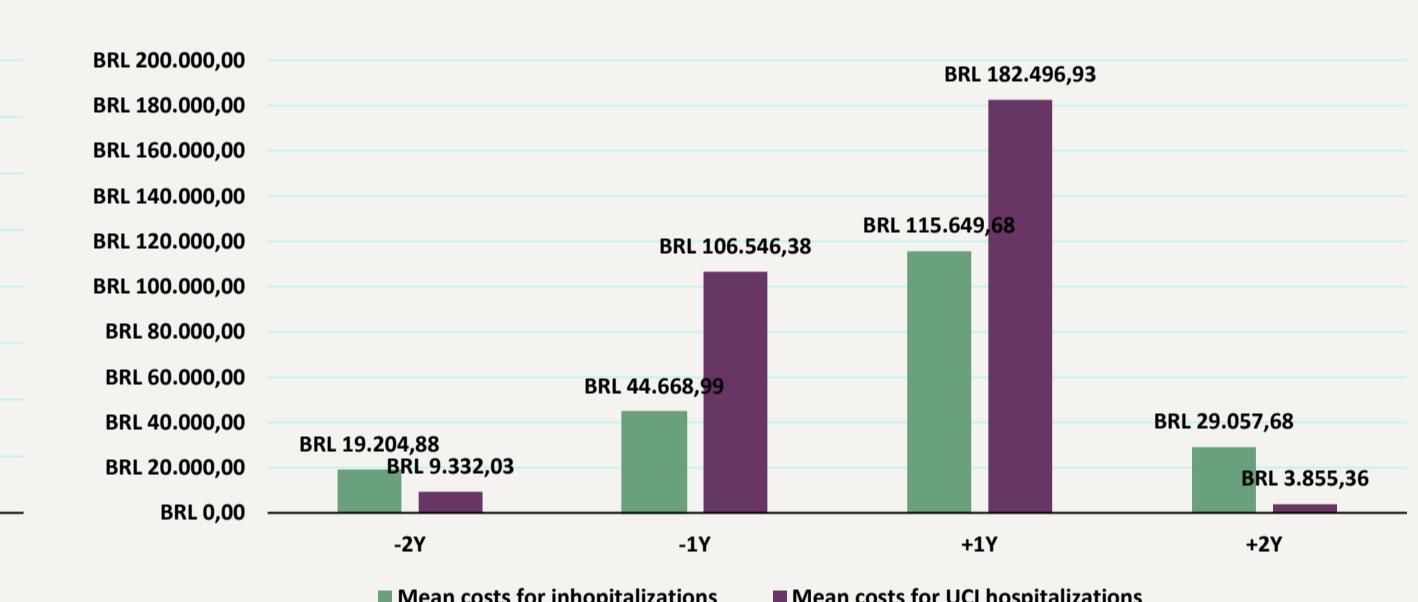


Figure 3. Average Inpatient and ICU Costs Across the GPP Patient Journey

Pharmacological treatment patterns

- Medication utilization analysis revealed 18 of the 77 patients (23%) used systemic agents directly associated with GPP management. Biologic therapies (anti-IL12/23, anti-IL17, anti-TNF) were used by 14 patients, accumulating R\$ 3,171,883.83, representing the largest expenditure segment. Systemic non-biologics (acitretin, methotrexate, cyclosporine) were used by 13 patients, totaling R\$ 5,921.12. Supportive medications (analgesics, corticosteroids, anti-inflammatories, sedatives) accounted for R\$ 179,205.01, highlighting the chronic symptomatic burden.
- Expenditure profile indicates that, biologics dominated cost composition, but their use was limited to a minority of patients, reflecting restricted access, late diagnosis, or off-label use barriers. The low overall uptake of systemic and biologic therapies suggests gaps in treatment and clinical awareness across private healthcare settings.

Procedures and Exams

- The majority of procedures addressed, particularly targeting systemic inflammation and organ function monitoring. The most common procedures included regular complete blood count (C-reactive protein, creatinine, urea, and electrolytes), Cardiopulmonary assessments, such as chest X-rays and transthoracic echocardiograms—aligned with the high prevalence of respiratory (42%) and cardiovascular (35%) comorbidities observed in this population.
- The total cost associated with the 30 most utilized diagnostic procedures amounted to approximately BRL 240,000. This reflects both the intensity of medical monitoring and the recurrent use of tests throughout the patient journey. Many of these procedures occurred during hospitalizations or acute episodes, contributing significantly to the overall cost burden.
- These findings suggest that the clinical management of GPP in the Brazilian private healthcare system requires a multidisciplinary and resource-intensive approach, even in the absence of standardized treatment protocols. The high frequency and cumulative cost of procedures underscore the complexity of GPP and highlight the need for evidence-based guidelines to optimize clinical decision-making and healthcare resource utilization.

Conclusions

The absence of nationally established treatment protocols or standardized clinical algorithms contributes to fragmented care and therapeutic heterogeneity. As a result, patients may receive suboptimal or off-label therapies that fail to control disease activity effectively—ultimately prolonging hospital stays and increasing overall costs. Inappropriate or delayed treatment decisions may also hinder the efficient use of healthcare resources. These findings underscore the urgent need for earlier diagnosis, the implementation of evidence-based care pathways, and improved access to appropriate therapies to optimize both resource utilization and patient outcomes.

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Disclosures

1. The authors meet criteria for authorship as recommended by the ICMJE.
2. The authors did not receive payment related to the development of the poster.
3. Boehringer Ingelheim A/S and LEO Pharma A/S were given the opportunity to review the poster for medical and scientific accuracy as well as intellectual property considerations.
4. The study was supported and funded by Boehringer Ingelheim and LEO Pharma A/S

Poster presented at ISPOR EUROPE 2025 -Glasgow