

The burden of perineo-gluteal hidradenitis suppurativa on patients' quality of life: A Moroccan study

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Abstract

Perineo-gluteal hidradenitis suppurativa (HS) is a severe and disabling form of HS due to its painful lesions, anatomical location, and impact on daily activities. This study aimed to evaluate its effect on patients' quality of life in a Moroccan population, while accounting for cultural factors. A retrospective cohort with prospective cross-sectional analysis was conducted at our dermatology department. Patients with perineo-gluteal HS who had been followed since 2012 were contacted between 2022 and 2024. Quality of life was assessed using the Arabic version of the Dermatology Life Quality Index (DLQI), along with psychological evaluations: Beck Depression Inventory (BDI), Rosenberg Self-Esteem Scale, and Body Image Questionnaire (BIQ). Out of 60 patients with HS, 51 (85%) had perineo-gluteal involvement. Chronic smoking and prolonged sitting were frequent aggravating factors. The mean DLQI score was 11.5, indicating a very large impact on quality of life. Depression was found in 50% of patients, low self-esteem in 66.6%, and negative body image in 61%. Nearly 59% avoided hammams and had difficulty performing ablutions; 9.8% used diapers due to incontinence. Higher DLQI scores were significantly associated with disease severity and smoking. Perineo-gluteal HS severely affects patients' physical, psychological, and social well-being. Its intimate location, combined with pain and cultural constraints, contributes to a profound quality-of-life burden. Effective care requires a multidisciplinary, culturally sensitive approach tailored to this challenging HS presentation.

Keywords: Hidradenitis suppurativa; Perineum; Quality of life; Dermatology life quality index; Morocco

1. Introduction

Hidradenitis suppurativa (HS) is a chronic inflammatory disease characterized by recurrent inflammatory lesions, abscesses, and draining fistulas that often lead to disfiguring scars [1]. It represents a challenging condition due to its complex pathophysiology, chronicity, and frequent resistance to treatment.

The axillary, inguinal, gluteal, and perianal regions are most commonly affected; however, the inner thighs, perineal, sub- and inframammary areas may also be involved [1].

Beyond physical symptoms and aesthetic disfigurement, HS imposes a significant emotional and psychological burden on patients, even at early stages of the disease [2].

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In our clinical setting, we observe a predominance of perineo-gluteal forms, which are particularly debilitating due to their localization [3]. This specific distribution is associated with increased pain, odor, and interference with daily activities such as sitting, walking, and sexual function, resulting in a further deterioration of quality of life. To date, few studies have specifically focused on this form of hidradenitis suppurativa, despite its particularly disabling impact.

This study aimed to assess the impact of perineo-gluteal hidradenitis suppurativa on quality of life in our patient population, while accounting for sociocultural habits specific to Moroccan patients.

2. Methods:

This study is a retrospective cohort study with a prospective cross-sectional assessment conducted at our department. We identified all patients diagnosed with perineo-gluteal hidradenitis suppurativa who had been followed in our department since 2012. Between 2022 and 2024, these patients were contacted and invited to participate in the study.

The diagnosis of perineo-gluteal HS was made clinically by an experienced dermatologist, based on characteristic features such as recurrent inflammatory nodules, abscesses, draining sinuses, and scarring in typical anatomical locations. No histopathological confirmation was required.

Inclusion criteria included all patients with a confirmed diagnosis of perineo-gluteal hidradenitis suppurativa followed at our center. Exclusion criteria were patients lost to follow-up, those who refused to participate, and patients who were unreachable after repeated contact attempts.

Data were collected using a standardized extraction form. Anonymity and confidentiality were ensured, and informed consent was obtained from all participants included in the study.

Quality of life was assessed with a validated Arabic version of the Dermatology Life Quality Index (DLQI). The total score ranges from 0 to 30, with higher scores indicating greater impairment. Interpretation was based on standard categories: a score of 0–1 indicates no effect on the patient's life; 2–5 corresponds to a small effect; 6–10 reflects a moderate effect; 11–20 indicates a very large effect; and 21–30 represents an extremely large impact [4].

Psychological assessments included the Beck Depression Inventory (BDI) [5], the Rosenberg Self-Esteem Scale [6], and the Body Image Questionnaire (BIQ) [7]. ~~Informed consent was obtained from all individual participants included in the study.~~

Statistical analyses were performed using Jamovi and Microsoft Excel software. Univariate analysis was performed using the chi-squared test. The multivariate analysis was performed using logistic regression (stepwise descending method). The p-value of less than 0.05 was considered statistically significant, and 95% confidence intervals (CI) were calculated where appropriate.

3. Results

Out of 60 patients, 51 (85%) presented with perineo-gluteal involvement. The average age was 40 years, with a male predominance of 78.4%.

The main comorbidities and contributing lifestyle factors observed in the study population are summarized in **Table 1**.

Table 1 Comorbidities in patients with perineo-gluteal hidradenitis suppurativa

Comorbidities	Number of Patients (n)	Percentage (%)
Chronic smoking	40	78,4
Occupations with prolonged sitting positions	20	39,2
Unbalanced diet	36	70,5
Family history of hidradenitis suppurativa	14	27,4

Chronic smoking was the most frequent comorbidity, followed by unbalanced diet and occupations involving prolonged sitting.

The most common clinical presentation consisted of suppurative nodular lesions with retractile scarring, observed in 73% of patients (**Fig. 1**).



Figure 1 Perineo-gluteal hidradenitis suppurativa in a male patient

Hurley stage 3 was the most frequent disease severity, present in 62.7% of cases. Two patients developed carcinomatous degeneration (**Fig. 2**).



Figure 2 Squamous cell carcinoma arising on hidradenitis suppurativa associated with Crohn's disease

A majority of patients (88.8%) experienced pain severe enough to cause insomnia, with a mean Visual Analog Scale (VAS) score of 8.

Perineo-gluteal involvement was associated with a higher mean DLQI score (11.5; range: 1–29) compared to other sites (**Fig. 3**).

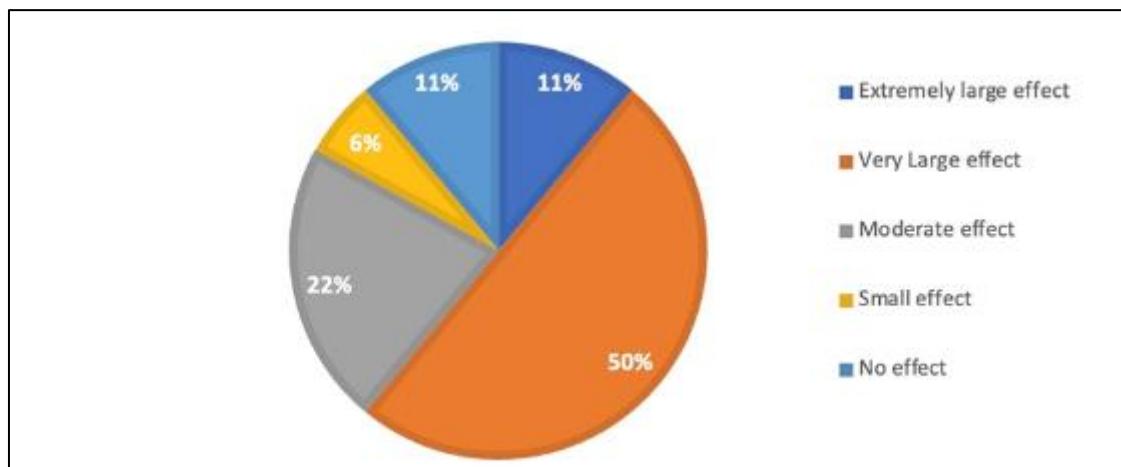


Figure 3 Distribution of DLQI scores among our patients

According to the Beck Depression Inventory, 50% of patients exhibited extreme levels of depression. Self-esteem was very low in 66.6% of patients as measured by the Rosenberg Self-Esteem Scale, and 61% reported a negative body image based on the Body Image Questionnaire (BIQ).

Thirty patients (58.8%) reported difficulties performing ablutions and avoided attending hammams due to their skin condition. Five patients (9.8%) used diapers due to fecal incontinence.

Eight patients (13.6%) underwent surgical deroofing, with one patient requiring a permanent colostomy and an indwelling urinary catheter (**Fig.4**).

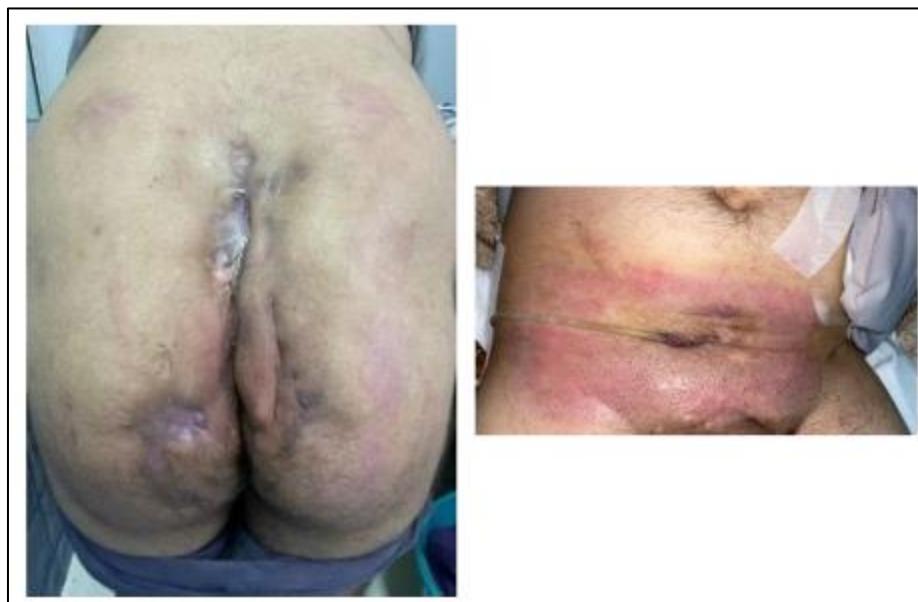


Figure 4 Perineal involvement with placement of an indwelling catheter

Higher DLQI scores were correlated with disease severity and chronic smoking (**Table 2**).

Table 2 Association between DLQI scores and clinical variables in patients with HS

	Disease severity (Hurley >3)	Chronic smoking
Higher DLQI scores (> 11)	p=0,049*	p=0,035*

DLQI: Dermatology Life Quality Index, *Significant value p<0.05

4. Discussion

The present study highlights the significant impact of perineo-gluteal hidradenitis suppurativa (HS) on patients' quality of life.

Likely, many studies assessing the impact of HS on quality of life will continue to be conducted, as the rate of publication on this topic has dramatically increased, from virtually none or one per year in the 1990s to around 90 studies published in 2019 alone [8]. This growing body of research highlights the expanding recognition of HS as a disease with profound psychosocial and physical burdens, further emphasizing the need for comprehensive assessment tools and tailored management approaches.

The Dermatology Life Quality Index (DLQI) remains a pivotal and widely accepted tool for assessing the burden of chronic dermatological diseases, including HS.

In the systematic review conducted by Kimball et al., total DLQI scores were above 10 in all studies reviewed, except for one [9].

Our findings are consistent with the existing literature, which **consistently** demonstrates a profound negative effect of HS on patients' daily functioning and well-being [2,8,10-15].

In our study, although the population is predominantly male, quality of life remains significantly impaired according to the DLQI score. Since a very high impact on quality of life is generally more frequent in women than in men (25% vs. 16%, p < 0.001), this suggests that the degree of DLQI impairment in our cohort may not be directly related to sex [15].

Psychological comorbidities, such as depression and sexual dysfunction, are also highly prevalent in HS patients. Lifestyle factors, including smoking and alcohol consumption, further exacerbate the quality of life deterioration by impairing sleep quality and promoting mood disorders [11,16]. Our data emphasize that smoking, in particular, aggravates the impact of HS on quality of life.

In the literature, a higher Hurley stage has been associated with a greater negative impact on quality of life across all DLQI items and domains [15], as also demonstrated in our study.

In our population, perineo-gluteal hidradenitis suppurativa (HS) is highly prevalent. This localization profoundly impacts quality of life due to its anatomical proximity to the anal canal and external genitalia, which can compromise continence and sexual function [11]. Moreover, as reported by Jemec et al., mechanical factors such as prolonged sitting and friction may trigger or worsen HS lesions in the gluteal area [17].

Surgical management of HS in this region remains challenging because of the area's complex anatomy and high risk of postoperative complications, including wound healing difficulties and the potential need for permanent colostomy in severe cases. This necessitates a cautious, multidisciplinary approach aimed at balancing disease control with preservation of function.

Surgical management of HS, particularly in the perineo-gluteal region, remains challenging due to the area's complex anatomy, the chronic inflammatory nature of the disease, the potential for recurrence, and the high risk of postoperative complications, including wound healing difficulties and the possible need for permanent colostomy in severe cases. These factors necessitate a cautious, multidisciplinary approach aimed at balancing effective disease control with preservation of function [18].

5. Conclusion

This study highlights the severe impact of perineo-gluteal hidradenitis suppurativa on patients' quality of life, affecting not only physical well-being but also psychological and social health. The observed male predominance does not fully explain the degree of quality-of-life impairment, emphasizing the significant roles of disease severity. The perineo-gluteal localization, compounded by mechanical factors such as prolonged sitting and friction, complicates management. Although surgical treatment is often necessary, it remains challenging due to the region's complex anatomy and high risk of postoperative complications, requiring a careful multidisciplinary approach. These findings underscore the importance of comprehensive and personalized assessment to optimize the management of this severe HS form, integrating medical, psychological, and sociocultural aspects.

Compliance with ethical standards

Disclosure of conflict of interest

The authors declare that they have no conflict of interest

Statement of ethical approval

This study was conducted in accordance with the ethical standards of the Helsinki Declaration.

Statement of informed consent

Informed consent was obtained from all individual participants included in the study.

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