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Research Article
***Comparing Maximum and Average Numerical rating Scale Pain Scores
in Hidradenitis Suppurativa***

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Short Title: Maximum and average pain scores in HS

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Key Message: Either maximum or average numerical rating scale scores can be used to measure pain in HS, however results from the two methods cannot be pooled in meta-analyses because maximum scores are significantly higher than average scores.

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Abstract

Background: Pain is the most impactful and burdensome symptom of hidradenitis suppurativa (HS) and profoundly affects patients' quality of life. There is variation in how trials measure HS pain, with some reporting maximum and others reporting average 7-day pain. It remains unknown whether there is a difference between these measures and which is more strongly associated with quality of life in HS. **Methods:** This is a retrospective cross-sectional study of 257 adults with HS who received care in an HS Specialty Clinic from January 2019 to August 2021. Patients self-reported their average pain and maximum pain severity in the past 7 days measured on a numerical rating scale (0-10). The absolute difference between patient-reported average and maximum pain was calculated and assessed for statistical differences using a paired t-test. Multivariable linear regression was used to assess the correlation between the average versus maximum pain score with Skindex-16 quality of life (QoL) score. **Results:** The maximum pain scores were significantly higher than the average, with a mean absolute difference of 0.83 points (95% CI: 0.74, 0.92) ($p < 0.0001$). The association between Skindex-16 QoL and average pain was not significantly different from Skindex-16 QoL correlation with maximum pain severity ($p = 0.52$). **Conclusion:** This study highlights a small but statistically significant difference in HS patients' maximum and average 7-day pain severities. Both maximum and average 7-day score correlated with skin-related QoL, suggesting equipoise as outcome measures for clinical HS studies.

Introduction

Hidradenitis suppurativa (HS) is a chronic, inflammatory skin condition marked by recurrent painful nodules, abscesses, and draining tunnels, primarily in an intertriginous distribution [1, 2]. HS significantly impairs patients' quality of life, making it one of the most debilitating dermatological diseases [3-5]. Pain, the most frequently reported and distressing symptom in HS, is a major concern for approximately 85% of patients with HS [6, 7]. A global survey reported two-thirds of HS patients experienced moderate-to-severe pain in the preceding week [8].

The evaluation of pain severity in HS typically relies on patient-reported measures such as the Numerical Rating Scale (NRS) and the Visual Analog Scale (VAS)[9], reporting pain scores over specified timeframes. However, discrepancies in pain measurement practices across studies, including varying frequency of assessments and unclear definitions of how pain was measured, pose challenges in standardizing pain evaluation [10]. In a systematic review of 58 observational studies on patient-reported outcomes in HS patients, the Dermatology Life Quality Index (DLQI) was the most commonly used instrument, reported in 57% of the studies. Mean pain score was separately assessed in 43% (25 studies), with the NRS and VAS used by 22.5% (13 studies) and 17% (10 studies), respectively[11]. A review of randomized controlled trials for painful skin conditions revealed that NRS and VAS were utilized in 68% of trials, with 33% measuring maximum pain intensity and 3% reporting average pain intensity. Most studies, however, lacked detail regarding the frequency of pain measurement and recall window[10]. Establishing a consensus is important for enabling the comparison of pain intensity outcomes across studies. This study aims to compare the self-reported maximum pain and average pain in the past 7 days in patients with HS to aid in developing a standardized approach for comparing pain scores across different pain assessment approaches.

Materials and Methods

This retrospective cross-sectional study included patients with HS ≥ 18 years-old who received treatment at an academic HS Specialty Clinic between January 2019 and August 2021 (**Figure 1**). To assess pain severity, patients were asked to rate their pain on a 0-10 numerical rating scale in response to two questions: "On average, how painful has your skin felt in the past 7 days?" and "During the past 7 days, how would you rate your worst/maximum skin pain?" The absolute difference between the patient-reported average and maximum pain was calculated for each patient and paired t-test was performed to determine statistical differences. Multivariable linear regression analysis was applied to evaluate the relationships between the average versus maximum pain score with Skindex-16 quality of life (QoL) total score and estimate the difference between them. QoL was assigned as the dependent variable in our analysis. Pain scores were used as the continuous

independent variables, differentiated into two categories: Average Pain and Maximum Pain. An additional categorical variable was included in the model to indicate whether the independent variable being analyzed at any point was Average Pain or Maximum Pain. Analyses were performed using SAS Analytics software (SAS® 9.4) with P-values ≤ 0.05 considered statistically significant.

Results

In this single-center retrospective study, 257 unique patients accounted for 510 dermatology encounters. Of these patients, 61.5% were female and 72.8% identified as Black, with the mean age being 37.6 years (95% CI: 36.5-38.7) as shown in Table 1. The mean Average Pain Score was 4.9 (95% CI: 2.7, 5.2), while the mean Maximum Pain Score was 5.3 (95% CI: 4.2, 6.7). The mean absolute difference between the Maximum and Average Pain Scores was 0.83 (95% CI: 0.74, 0.92, $p < 0.0001$). The association between Skindex-16 QoL and Average Pain was not significantly different from Skindex-16 QoL correlation with Maximum Pain severity ($\beta = -0.7$, 95% CI: -3.0, 1.5, $p = 0.5$).

Discussion

This study shows a small but significant difference between maximum and average 7-day pain scores in HS. Our analysis showed both Maximum and Average 7-day scores correlated with skin-related QoL, suggesting equipoise as outcome measures for clinical HS studies. However, our findings highlight that results from studies using maximum scores cannot be directly compared with those using average scores due to the significant difference of approximately 0.83 points between these measures, on a 0-10 scale.

Pain is a key domain measured in clinical trial outcomes [12]. No single pain measurement technique is consistently shown to be superior across different patient groups [13, 14]. Studies indicate that real-time pain assessments often record lower scores than those recalled from memory [15]. Recording the maximum pain score at multiple intervals within a set period may yield more reliable and consistent results than a single, average evaluation [16]. A review article suggests using composite scores from multiple days of various pain intensities—current, average, maximum, and minimum—offers the greatest reliability and validity, while minimizing assessment burden in clinical trials [14]. This method becomes particularly relevant for HS, where pain intensity can fluctuate due to factors such as the lesion location. For example, individuals with lesions on their buttocks might report different levels of pain depending on their activity, highlighting the dynamic nature of pain in HS.

Several limitations are present in our study which should be taken into account when interpreting the findings. First, the retrospective design of the study may have introduced selection bias and limited the ability to control for confounding factors that may affect pain perception. Second, our study was conducted at a single academic HS specialty clinic, which may not be representative of the broader HS population. Third, we did not collect data on the use of analgesic medications, which may have affected the patient-reported pain perception in our study population. In addition, it might have been useful to compare pain scores with a patient global assessment of disease severity as well as QoL.

Conclusion

This study highlights a small but statistically significant difference in HS patients' maximum and average 7-day pain severities. Future research is needed to understand the complexity of pain assessment and management in patients with HS.

Statements

Statement of Ethics

Study approval statement: This study protocol was reviewed and approved by Emory University Institutional Review Board. The initial approval was granted on July 1, 2020, and a subsequent amendment was reviewed and approved on October 4, 2021.

Consent to participate statement: Written informed consent was obtained from participants to participate in the study.

Conflict of Interest Statement

Lauren Orenstein has been a consultant to ChemoCentryx, UCB, and Novartis, participated in clinical trials with ChemoCentryx, and received grants from Pfizer.

JRI receives a stipend as Editor-in-Chief of the British Journal of Dermatology and an authorship honorarium from UpToDate. He is a consultant for Abbvie, Boehringer Ingelheim, ChemoCentryx, Citryll, Insmmed, Kymera Therapeutics, MoonLake, Novartis, UCB Pharma, UNION Therapeutics, and Viela Bio. He is co-copyright holder of HiSQOL, Investigator Global Assessment and Patient Global Assessment instruments for HS. His department receives income from copyright of the Dermatology Life Quality Index (DLQI) and related instruments.

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Author Contributions

Concept and design: Ingram, Orenstein, Li.

Acquisition, analysis, or interpretation of data: Orenstein, Li, Speck.

Drafting of the manuscript: Li.

Critical revision of the manuscript for important intellectual content: Orenstein, Ingram, Li.

Statistical analysis: Orenstein, Li.

Supervision: Orenstein.

Responsibility for integrity: Li, Orenstein.

Data Availability Statement

All data generated or analysed during this study are included in this article. Further inquiries for data generated and analyzed during this study can be directed to the corresponding author.

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Table 1: Characteristics of 257 unique participants with Hidradenitis Suppurativa

Variables	n (%)
Age – mean (95% CI)	37.6 (36.5-38.7)
Sex	Female – 205 (79.8%)
	Male – 52 (20.2%)
Self-identified Race	Black – 158 (61.5%)
	White – 47 (18.3%)
	Asian – 12 (4.7%)
	Not reported – 40 (15.5%)