

Quality of Life of Patients With Hidradenitis Suppurativa in Jeddah, Saudi Arabia

Awadh M. Alamri¹, Abeer A. Alzahrani², Anan M. Aldakhil², Heba E. Alharbi², Farah A. Yahya²

Review began 12/01/2021

Review ended 12/05/2021

Published 12/07/2021

© Copyright 2021

Alamri et al. This is an open access article distributed under the terms of the Creative Commons Attribution License CC-BY 4.0., which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

1. Dermatology, King Abdulaziz Medical City, Ministry of National Guards - Health Affairs, Jeddah, SAU 2. College of Medicine, King Saud Bin Abdulaziz University for Health Sciences, Jeddah, SAU

Corresponding author: Abeer A. Alzahrani, abeerahmedx2020@gmail.com

Abstract

Background

Hidradenitis suppurativa (HS) is a chronic inflammatory skin condition that affects the apocrine gland-bearing areas of the body. It initially presents as painful nodules that eventually develop into abscesses, draining sinuses, and scarring. These manifestations have physical and psychological impacts, which lead to poor quality of life. This study examined the association between quality of life and disease severity, as well as identified the areas of the body most affected by HS among patients in Saudi Arabia.

Methods

This cross-sectional study examined patients with HS who were seen at two dermatology outpatient clinics between December 2018 and March 2019. The patients completed a self-administered standardized questionnaire on the Dermatology Life Quality Index (DLQI).

Results

The average DLQI score was 15.39 ± 8.37 . The majority of patients were classified as stage 3, which indicated that HS has a very large effect on quality of life. The right and left axillae were the most commonly affected areas of the body, with 80.6% of patients noting involvement. While the mean DLQI score was higher in males compared to females, there was no significant difference between the two groups (16.44 ± 9.01 vs. 13.08 ± 6.65 ; $P = 0.248$).

Conclusion

HS caused significant impairment in the quality of life of patients with HS in Saudi Arabia. The mean DLQI score in our study was higher than the score previously reported in the literature. Further studies may identify opportunities to provide additional awareness, care, and support for patients with HS in Saudi Arabia.

Categories: Dermatology

Keywords: patient-reported outcome, health related quality of life, acne, acne inversa, hidradenitis suppurativa

Introduction

Hidradenitis suppurativa (HS) is a chronic inflammatory condition of the apocrine glands that is characterized by hair follicle inflammation, abscess formation, and scarring [1]. HS most commonly affects the axillae, breasts, and genital area [2]. The physical symptoms of HS may prompt feelings of embarrassment, self-consciousness, isolation, and depression, which interfere with quality of life [3,4]. Studies in Greece, Poland, Denmark, and Canada demonstrated that HS significantly influenced the quality of life [3-6]. Assessment of the quality of life is essential to determine the impact of the disease on the patients. However, there are no research papers conducted to estimate the impact of HS on the patients' quality of life in the middle eastern region. Therefore, this study helps in understanding the impact of HS on the patients more. Finally, the results of this study help to improve the health care for HS patients by determining their specific needs for further educational and psychological support, self-management, treatment modalities, and multidisciplinary care.

Materials And Methods

This cross-sectional, multicenter study was conducted in the dermatology department's outpatient clinics of two tertiary hospitals which are King Fahad General Hospital and King Abdulaziz Medical City, Jeddah, Saudi Arabia. This study was approved by the institutional review board (IRB) at King Abdullah International Medical Research Center (KAIMRC) with an approval number RYD-18-417780-141769. Consecutive sampling technique was used, and the patients diagnosed with HS who consulted between December 2018 and March 2019 were included in this study. The patients who participated in the study were all diagnosed with HS clinically and the diagnosis was documented in their medical files. We excluded patients with other

How to cite this article

Alamri A M, Alzahrani A A, Aldakhil A M, et al. (December 07, 2021) Quality of Life of Patients With Hidradenitis Suppurativa in Jeddah, Saudi Arabia. Cureus 13(12): e20234. DOI 10.7759/cureus.20234

skin diseases, such as folliculitis, furunculosis, psoriasis, vitiligo, severe eczema, alopecia, and skin cancers. All patients with mental or psychological illnesses were excluded. All the patients who participated in the study have signed a consent form.

Patients completed a previously validated self-administered standardized questionnaire on the Dermatology Life Quality Index (DLQI) [7]. The questionnaire is composed of three parts and includes sections on demographic data, disease characteristics (with an illustration of a human body to document the affected regions) and the Hurley staging classification [8], and the DLQI. The DLQI scores were interpreted as follows: 0-1, no effect at all on the patient's life; 2-5, small effect on the patient's life; 6-10, moderate effect on the patient's life; 11-20, very large effect on the patient's life; and 21-30, extremely large effect on the patient's life. The daily clinic nurses in both outpatient clinics were trained to deliver this survey.

The data were collected and analyzed using SPSS for Windows version 21.0 (IBM, Armonk, New York, USA). The demographic characteristics of the patients were presented with descriptive statistics, such as mean, standard deviation, frequencies, and percentages. Associations between variables were tested with the Student's t-test, analysis of variance test, and chi-square test, as necessary. We examined whether there was a significant difference in the quality of life among patients with different severities of HS. We further analyzed whether there was an association between disease severity and quality of life.

Results

A total of 36 patients were included in this study. Twenty-four (66.7%) patients were men, and 12 (33.3%) patients were women. The mean age of the participants was 35.9 ± 10.7 years (range, 18-65). The mean Hurley staging score was 16.1 ± 8.7 , which classified most patients with stage 3 HS. The average DLQI score was 15.3 ± 8.3 , which indicated that HS has a "very large effect on the patient's life" (Table 1). The right and left axillae were the most commonly affected areas; right and left axillary involvement was each noted in 80.6% of all respondents (Figure 1).

| Variables | Patients (N = 36) |
|--------------------------------------|-------------------|
| Age in years | 35.9 ± 10.7 |
| Gender | |
| Male | 24 (66.7) |
| Female | 12 (33.3) |
| Hurley Stages | |
| Stage 1 | 7 (21.1) |
| Stage 2 | 9 (27.3) |
| Stage 3 | 17 (51.5) |
| Dermatology Life Quality Index score | 15.3 ± 8.3 |

TABLE 1: Demographic and clinical characteristics of the study population

Data were presented as mean \pm standard deviation or numbers with percentages.

Affected Anatomical Regions %

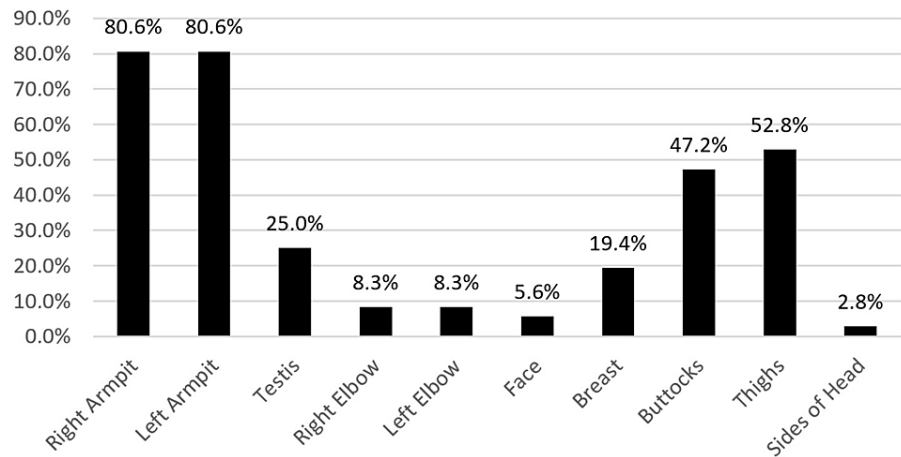


FIGURE 1: Multiple response analysis of affected anatomical regions

Involved sites in our study population

The mean DLQI score in male and female patients was 16.4 ± 9.01 and 13.08 ± 6.6 , respectively; however, there was no significant difference between these two groups ($P = 0.248$). There was also no significant association between age and disease burden ($P = 0.580$). There was no significant difference in DLQI scores among the Hurley stages and no significant association between the Hurley stage and DLQI score ($P = 0.416$) (Tables 2, 3). Three participants were unstagable; thus, they were not included in the Hurley staging and DLQI comparison.

| Hurley Stage | DLQI Score | P-value |
|--------------|------------|---------|
| Stage 1 | 11.1 ± 7.3 | 0.416 |
| Stage 2 | 15.3 ± 8.2 | |
| Stage 3 | 16.1 ± 8.7 | |

TABLE 2: Comparison between the Hurley stage and Dermatology Life Quality Index (DLQI) scores

| DLQI Score Interpretation | Hurley Stage | | |
|-------------------------------|--------------|-----------|-----------|
| | Stage 1 | Stage 2 | Stage 3 |
| Effect on the Quality of Life | | | |
| No to small effect | 2 (33.3%) | 1 (16.7%) | 3 (50%) |
| Moderate to very large effect | 4 (23.5%) | 5 (29.4%) | 8 (47.1%) |
| Extremely large effect | 1 (10%) | 3 (30%) | 6 (60%) |

TABLE 3: Association between the Hurley stage and Dermatology Life Quality Index (DLQI) scores

Discussion

HS is a chronic inflammatory skin disease of the pilosebaceous unit. It affects intertriginous areas of the body such as the axillae, buttocks, groins, and submammary folds [9]. Tzellos et al. demonstrated that HS impacts the physical and psychological aspects of quality of life [3,10,11]. HS begins with blockage of the hair follicle, which promotes inflammation, dysregulation of the immune system, and eventual bacterial

infection. Infected hair follicles are likely to rupture, which releases bacteria and keratin into the dermis layer of the skin. This activates immune cells in the dermis, resulting in abscess formation [2].

Our data correlated well with previous literature on the chronicity and impact of HS. Among patients with HS in Saudi Arabia, HS had a very high impact on the quality of life at all stages of the disease. The mean DLQI score in our study population was 15.39 ± 8.37 , which indicated that the disease had a great impact on the quality of life regardless of the Hurley stage. The mean DLQI in our study was comparable to those reported by Matusiak et al. 12.7 ± 7.7 , Frings et al. 12 ± 7.0 , Jorgensen et al. 11.9 ± 7.6 , Kourins et al. 11.43 ± 6.61 , and Schneider-Burrus et al. 13.18 ± 0.37 [4,7,12-14].

While previous studies showed a female predominance, HS preferentially affected males in our study population. However, this observation could be limited by the small sample size included in the study. In our study, there was no association between disease severity and age. Similarly, Schneider-Burrus et al. demonstrated no actual relation between the patient's age and the impact of HS on the quality of life [14].

The most burdensome characteristics of HS are the pain that is experienced by 97% of the patients diagnosed with HS. The patients report that it limits their daily physical activities including household chores and exercising. As a result of the recurrent painful abscesses, the lesions may result in malodorous discharge which the patients are conscious of, and they often fear others' reactions. Additionally, the patients might feel embarrassed about visible active lesions or scars, and HS may, therefore, lead to stigma [15]. HS can affect all aspects of the patient's life and it has been associated with feelings of distress, depression, and other psychological symptoms. The physical symptoms of HS also lead to feelings of shame and social isolation [5,16]. The decrease in quality of life might be different depending on the affected anatomical region. HS with genital localization was associated with the strongest negative impact on quality of life and causes great disability affecting the patient's intimate relationships and sexual function. A study conducted in 13 European countries reported that sexual dysfunction was higher in HS patients compared to various other dermatological diseases [7,17]. However, our study demonstrated that the most affected anatomical regions by HS were the right and left armpits both of which had a percentage of 80.6%.

Moreover, the nature of the disease and its recurrent flares can have a great impact on work as well leading to absent days and increased burden. Matusiak conducted a survey, which demonstrated that approximately 58% of patients with HS lost 34 days of work annually due to HS [7]. A Polish study done by Kaaz et al. showed that HS is also associated with a poorer quality of sleep compared to control [18].

Conclusions

In conclusion, HS is a serious chronic skin condition with physical and psychological implications. It clearly causes a significant impairment in quality of life among patients in Saudi Arabia. HS is a rare condition, and the small sample size of our study, despite data being collected from two centers, was a significant limitation of this study. We recommend conducting further multicenter studies with larger sample sizes. Future studies should examine the factors that could provide additional awareness, support, and care for patients with HS.

Appendices

Dermatology Life Quality Index (DLQI)

DERMATOLOGY LIFE QUALITY INDEX (DLQI)

Hospital No: Date:
 Name: Score:
 Address: Diagnosis:

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick (✓) one box for each question.

- | | | | |
|--------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|---------------------------------------|--|
| 1. Over the last week, how itchy, sore, painful or stinging has your skin been? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | | |
| 2. Over the last week, how embarrassed or self conscious have you been because of your skin? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | | |
| 3. Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> | |
| 4. Over the last week, how much has your skin influenced the clothes you wear? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> | |
| 5. Over the last week, how much has your skin affected any social or leisure activities? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> | |
| 6. Over the last week, how much has your skin made it difficult for you to do any sport? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> | |
| 7. Over the last week, has your skin prevented you from working or studying? | Yes <input type="checkbox"/> | | |
| | No <input type="checkbox"/> | Not relevant <input type="checkbox"/> | |
| If "No", over the last week how much has your skin been a problem at work or studying? | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | | |
| 8. Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> | |
| 9. Over the last week, how much has your skin caused any sexual difficulties? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> | |
| 10. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time? | Very much <input type="checkbox"/> | | |
| | A lot <input type="checkbox"/> | | |
| | A little <input type="checkbox"/> | | |
| | Not at all <input type="checkbox"/> | Not relevant <input type="checkbox"/> | |

Please check you have answered EVERY question. Thank you.

© AY Finlay, GK Khan, April 1992 www.dermatology.org.uk, this must not be copied without the permission of the authors.

FIGURE 2: Dermatology Life Quality Index (DLQI)

DERMATOLOGY LIFE QUALITY INDEX (DLQI) - INSTRUCTIONS FOR USE

The Dermatology Life Quality Index questionnaire is designed for use in adults, i.e. patients over the age of 16. It is self explanatory and can be simply handed to the patient who is asked to fill it in without the need for detailed explanation. It is usually completed in one or two minutes.

SCORING

The scoring of each question is as follows:

| | |
|------------------------------------------|----------|
| Very much | scored 3 |
| A lot | scored 2 |
| A little | scored 1 |
| Not at all | scored 0 |
| Not relevant | scored 0 |
| Question 7, 'prevented work or studying' | scored 3 |

The DLQI is calculated by summing the score of each question resulting in a maximum of 30 and a minimum of 0. The higher the score, the more quality of life is impaired.

HOW TO INTERPRET MEANING OF DLQI SCORES

| | |
|---------|------------------------------------------|
| 0 – 1 | no effect at all on patient's life |
| 2 – 5 | small effect on patient's life |
| 6 – 10 | moderate effect on patient's life |
| 11 – 20 | very large effect on patient's life |
| 21 – 30 | extremely large effect on patient's life |

REFERENCES

Finlay AY and Khan GK. Dermatology Life Quality Index (DLQI): a simple practical measure for routine clinical use. *Clin Exp Dermatol* 1994; **19**:210-216.

Basra MK, Fenech R, Gatt RM, Salek MS and Finlay AY. The Dermatology Life Quality Index 1994-2007: a comprehensive review of validation data and clinical results. *Br J Dermatol* 2008; **159**:997-1035.

Hongbo Y, Thomas CL, Harrison MA, Salek MS and Finlay AY. Translating the science of quality of life into practice: What do dermatology life quality index scores mean? *J Invest Dermatol* 2005; **125**:659-64.

There is more information about the DLQI, including over 85 translations, at www.dermatology.org.uk. The DLQI is copyright but may be used without seeking permission by clinicians for routine clinical purposes. For other purposes, please contact the copyright owners.

©AY Finlay, GK Khan, April 1992 www.dermatology.org.uk, this must not be copied without the permission of the authors.

FIGURE 3: Dermatology Life Quality Index (DLQI) (Continued)

Additional Information

Disclosures

Human subjects: Consent was obtained or waived by all participants in this study. King Abdullah International Medical Research Center issued approval RYD-18-417780-141769. Dear Dr. Awadh Mohammed Alamri Assistant Professor & Consultant Dermatologist, Department of Medicine, KAMC-Jeddah Ministry of National Guard - Health Affairs Sub-investigators: Abeer Alzahrani, Anan Aldakhil, Farah Yahya and Heba Aiharbi After reviewing your submitted research proposal/protocol and related documents, the IRB has APPROVED the submission. **Animal subjects:** All authors have confirmed that this study did not involve animal subjects or tissue. **Conflicts of interest:** In compliance with the ICMJE uniform disclosure form, all authors declare the following: **Payment/services info:** All authors have declared that no financial support was received from any organization for the submitted work. **Financial relationships:** All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. **Other relationships:** All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

References

1. Dufour DN, Emtestam L, Jemec GB: Hidradenitis suppurativa: a common and burdensome, yet under-recognised, inflammatory skin disease. *Postgrad Med J*. 2014, 90:216-21; quiz 220. [10.1136/postgradmedj-2013-131994](https://doi.org/10.1136/postgradmedj-2013-131994)
2. Napolitano M, Megna M, Timoshchuk EA, Patruno C, Balato N, Fabbrocini G, Monfrecola G: Hidradenitis suppurativa: from pathogenesis to diagnosis and treatment. *Clin Cosmet Investig Dermatol*. 2017, 10:105-15. [10.2147/CCID.S111019](https://doi.org/10.2147/CCID.S111019)
3. Esmann S, Jemec GB: Psychosocial impact of hidradenitis suppurativa: a qualitative study. *Acta Derm Venereol*. 2011, 91:328-32. [10.2340/00015555-1082](https://doi.org/10.2340/00015555-1082)
4. Kouris A, Platsidaki E, Christodoulou C, et al.: Quality of life and psychosocial implications in patients with hidradenitis suppurativa. *Dermatology*. 2016, 232:687-91. [10.1159/000453355](https://doi.org/10.1159/000453355)
5. Matusiak L, Bieniek A, Szepletowski JC: Psychophysical aspects of hidradenitis suppurativa. *Acta Derm Venereol*. 2010, 90:264-8. [10.2340/00015555-0866](https://doi.org/10.2340/00015555-0866)
6. Alavi A, Anooshirvani N, Kim WB, Coutts P, Sibbald RG: Quality-of-life impairment in patients with hidradenitis suppurativa: a Canadian study. *Am J Clin Dermatol*. 2015, 16:61-5. [10.1007/s40257-014-0105-5](https://doi.org/10.1007/s40257-014-0105-5)
7. Finlay AY: Quality of life measurement in dermatology: a practical guide. *Br J Dermatol*. 1997, 136:305-14.
8. Hurley HJ: Axillary hyperhidrosis, apocrine bromhidrosis, hidradenitis suppurativa, and familial benign pemphigus: surgical approach. *Dermatologic Surgery*. Roenigk RK, Roenigk HH (ed): Marcel Dekker, New York; 1996. 623-645.
9. Krajewski PK, Matusiak Ł, von Stebut E, Schultheis M, Kirschner U, Nikolakis G, Szepletowski JC: Quality-of-life impairment among patients with hidradenitis suppurativa: a cross-sectional study of 1795 patients. *Life (Basel)*. 2021, 11:[10.3390/life11010034](https://doi.org/10.3390/life11010034)
10. Wolkenstein P, Loundou A, Barrau K, Auquier P, Revuz J: Quality of life impairment in hidradenitis suppurativa: a study of 61 cases. *J Am Acad Dermatol*. 2007, 56:621-3. [10.1016/j.jaad.2006.08.061](https://doi.org/10.1016/j.jaad.2006.08.061)
11. Nazary M, van der Zee HH, Prens EP, Folkerts G, Boer J: Pathogenesis and pharmacotherapy of hidradenitis suppurativa. *Eur J Pharmacol*. 2011, 672:1-8. [10.1016/j.ejphar.2011.08.047](https://doi.org/10.1016/j.ejphar.2011.08.047)
12. Frings VG, Bauer B, Glöditzsch M, Goebeler M, Presser D: Assessing the psychological burden of patients with hidradenitis suppurativa. *Eur J Dermatol*. 2019, 29:294-301. [10.1684/ejd.2019.3552](https://doi.org/10.1684/ejd.2019.3552)
13. Jørgensen AR, Holm JG, Ghazanfar MN, Yao Y, Ring HC, Thomsen SF: Factors affecting quality of life in patients with hidradenitis suppurativa. *Arch Dermatol Res*. 2020, 312:427-36. [10.1007/s00403-019-02025-5](https://doi.org/10.1007/s00403-019-02025-5)
14. Schneider-Burrus S, Tsaousi A, Barbus S, et al.: Features associated with quality of life impairment in hidradenitis suppurativa patients. *Front Med (Lausanne)*. 2021, 8:676241. [10.3389/fmed.2021.676241](https://doi.org/10.3389/fmed.2021.676241)
15. Thorlacius L, Esmann S, Miller I, Vinding G, Jemec GB: Development of HiSQOL: A Hidradenitis Suppurativa-Specific Quality of Life Instrument. *Skin Appendage Disord*. 2019, 5:221-9. [10.1159/000496234](https://doi.org/10.1159/000496234)
16. Miller IM, McAndrew RJ, Hamzavi I: Prevalence, risk factors, and comorbidities of hidradenitis suppurativa. *Dermatol Clin*. 2016, 34:7-16. [10.1016/j.det.2015.08.002](https://doi.org/10.1016/j.det.2015.08.002)
17. Sampogna F, Abeni D, Gieler U, et al.: Impairment of sexual life in 3,485 dermatological outpatients from a multicentre study in 13 European countries. *Acta Derm Venereol*. 2017, 97:478-82. [10.2340/00015555-2561](https://doi.org/10.2340/00015555-2561)
18. Kaaz K, Szepletowski JC, Matusiak Ł: Influence of itch and pain on sleep quality in patients with hidradenitis suppurativa. *Acta Derm Venereol*. 2018, 98:757-61. [10.2340/00015555-2967](https://doi.org/10.2340/00015555-2967)