

Quality of Life in Hidradenitis Suppurativa: A Scoping Review

1. Introduction

Hidradenitis Suppurativa (HS) also referred to as acne inversa is a common, chronic, relapsing, inflammatory skin condition and is physically, psychologically and socially disabling disease.¹ Lesions of HS are associated with extreme pain, pus and odour and therefore can potentially lead to significant psychological impact and greatly affect quality of life (QoL).² QoL is a multidimensional construct, which can be measured in various ways. There are some common generic QoL tools that are widely used in dermatology to assess QoL in patients with skin diseases. However, generic or dermatological QoL measures may not capture changes in QoL particularly in HS because of severity of disease.²

2. Aims

1. To illuminate the importance of HS specific QoL tools by identifying and examining those in use.
2. To identify the valid and reliable disease specific QoL tools.
3. If valid and reliable generic or disease specific QoL tool exist to capture any change in QoL for HS patients.

3. Methods

This Systematic Review (SR) was performed using a systematic keyword search strategy of 10 electronic databases including a search for grey literature. . Figure 1. (PRISMA flow diagram) depicts the detailed search process and reasoning for exclusion of sources. Literature screening and data analysis was guided by Joanna Briggs Institute manual and Arsky & O'Malley framework. The psychometric properties of these tools included reliability, validity, and sensitivity measurement.

4. Images of common areas involved in HS



5. Results

There is a paucity of validated tools for evaluation of QoL in HS. Dermatology Quality of Life Index (DLQI) along with visual analogue pain scores are widely used to assess QoL but fail to capture the full impact of this disease on patients' lives. DLQI is not fully validated for HS. HS specific QoL assessment tools have been developed. Six tools were identified in this SR however they lack full psychometric evaluation except one (HSQoL-24).

1. **HISQoL** (Kirby et al., 2019)
2. **HSQoL-24** (Marron et al., 2019)
3. **HIDRADisk** (Peris et al., 2019)
4. **HISQOL-23** (Thorlacius et al., 2019).
5. **HSBOD** (Pinard et al., 2018).
6. **HS-QoL** (Sisic et al., 2017).

There is currently no external validation available on any of these tools.



PRISMA 2009 Flow Diagram

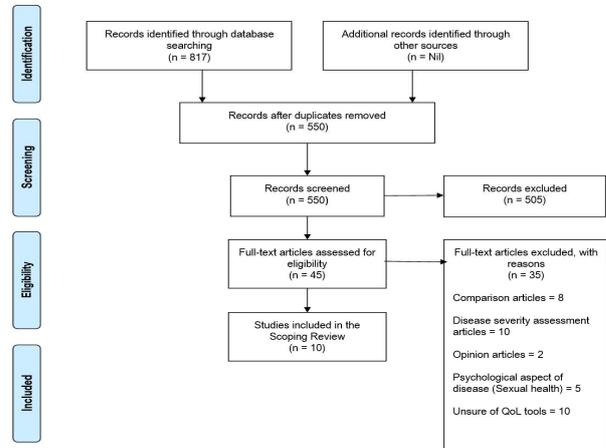


Figure 1. PRISMA flow diagram depicting search process and reasons for exclusion; modified from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

6. Discussion

Although, **Dermatology Quality of Life Index (DLQI)** is not HS specific QoL tool, it is most widely used QoL assessment tool in dermatology. It has been the most popular and most accepted tool over the years. It has been used in almost every skin condition including HS over the years and favoured by patients and dermatology practitioners. Reliability, consistency and sensitivity of DLQI was found to be high according to the study by Basra et al., 2008. However, external validation remained pending.

HISQOL by Kirby et al. (2019) is an acceptable QoL assessment tool, but cross-cultural validity needs to be confirmed and its certain properties need to be elucidated. **VAS** like **HSBOD** and **HIDRADisk** can be effective but some people might find abstract thinking hard. **HIDRADisk** need to be translated into different languages. There is no external validation available on any QoL tools for HS.

7. Conclusion

This review indicates that there is very little research in the field of QoL tools for HS. From a scientific point of view, it is important to develop and validate disease specific tools to measure the real impact of disease on patients QoL. These disease QoL instruments can evaluate changes in QoL of a HS patient thus helping improved intervention and management of disease.

8. References

- Dufour, D.N., Emtestam, L. & Jemec, G.B. (2014) Hidradenitis suppurativa: a common and burdensome, yet under-recognised inflammatory skin disease, Post graduate Medical journal 90, 216-221.
- Thorlacius, L., Asmann, S., Miller, I., Vinding, G. & Jemec, G.B.E. (2019) Development of HISQOL: A Hidradenitis Suppurativa – Specific quality of life instrument. Journal of Skin Appendages Disorders 221-229.