

A protocol for a systematic review: a qualitative synthesis of the experiences of people with Hidradenitis Suppurativa

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Background

Hidradenitis Suppurativa (HS) is a complex long-term condition that causes abscesses on the skin, which usually occur around the groin, buttocks, breasts and armpits. It is estimated to affect around 1% of the population (1). It is often difficult to manage and with limited evidence-based treatment options (2). There is evidence of poor quality of life, psychological impact and disability associated with HS (3). Cardiovascular, endocrine, gastrointestinal, rheumatologic, and psychiatric comorbidity burden has been associated with HS (4). Obesity and smoking are risk factors associated with both the prevalence and severity of HS (5).

An initial scoping review has suggested that although qualitative research exploring the experiences of this population is still somewhat limited, there is an opportunity to gain greater clarity on these experiences through synthesising the available literature. Grasping what is already known about people's experiences of living with and treating HS would provide a useful framework for the study team to progress research into people's experiences of the treatment of HS.

Aims and Objectives

AIM: To systematically review the qualitative literature reporting the experiences of people living with HS.

Objectives:

- 1) To synthesis what is known about the experience of people living with HS.
- 2) To synthesis what is known about the experience of treatment for HS.
- 3) To develop an analytic framework for analysing further qualitative data about experiences of HS treatment.

Methods

Protocol registration

This current protocol has been registered in the International Prospective Register of Systematic Reviews (PROSPERO).

Literature search strategy

A systematic literature search will be carried out in MEDLINE, PSYCHinfo, PSYCHextra and CINHAL.

The search was developed based on the PICO approach:

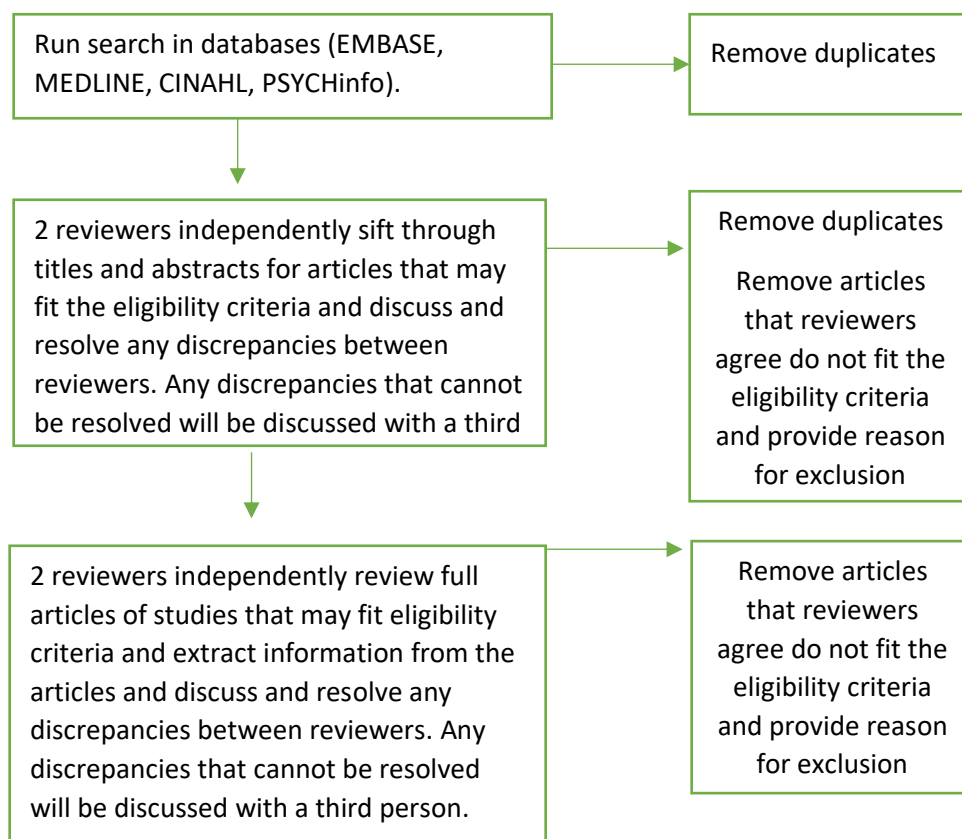
Population	Hidradenitis Suppurativa
Interest	Experiences – not specified as number of results manageable without this filter and want to ensure maximum sensitivity.
Context	All – not specified in search as not required.

This search strategy was developed by LH, supported by the information specialist DG. It was subsequently reviewed by the rest of the team. Appendix 1 provides the full search strategy.

Inclusion/Exclusion Criteria

	Inclusion criteria
Population	Population includes people who have HS. All ages and countries included.
Study design	Any qualitative approach to data collection and analysis.
Language	All languages where authors able source a translation of key information into English.
Topic	Findings are relevant to understanding the experiences of living with / treating HS
Publication type	Articles with available full text

Design of study



Data extraction

Information will be extracted by two reviewers independently. A data extraction form has been developed (Appendix 2). The data extraction process will be piloted and adapted if required.

Evidence synthesis

Evidence will be synthesised using a thematic synthesis approach (6). This will involve three key steps:

1. coding findings line by line to translate the concepts between studies and begin process of synthesis. This will also involve axial coding (checking consistency of interpretation and appropriate levels of coding).
2. Develop descriptive themes by looking for similarities and differences between codes group them into a hierarchical tree structure.
3. Generate analytical themes by considering how the descriptive themes answer the review questions. This process aims to generate additional understanding / hypotheses.

Data management

References found via searching databases will be stored in an EndNote library. Copies of articles and related materials will be downloaded and transferred to NVivo to code for the thematic synthesis.

References

1. Deckers IE, van der Zee HH, Prens EP. Epidemiology of hidradenitis suppurativa: prevalence, pathogenesis, and factors associated with the development of HS. *Current Dermatology Reports*. 2014;3(1):54-60.
2. Rambhatla PV, Lim HW, Hamzavi I. A systematic review of treatments for hidradenitis suppurativa. *Archives of dermatology*. 2012;148(4):439-46.
3. Patel ZS, Hoffman LK, Buse DC, Grinberg AS, Afifi L, Cohen SR, et al. Pain, psychological comorbidities, disability, and impaired quality of life in hidradenitis suppurativa. *Current pain and headache reports*. 2017;21(12):49.
4. Cartron A, Driscoll MS. Comorbidities of hidradenitis suppurativa: A review of the literature. *International Journal of Women's Dermatology*. 2019;5(5):330.
5. Dufour DN, Emtestam L, Jemec GB. Hidradenitis suppurativa: a common and burdensome, yet under-recognised, inflammatory skin disease. *Postgraduate Medical Journal*. 2014;90(1062):216-21.
6. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*. 2008;8:45-.

Appendix 1: Search strategy

Search strategy in full:

EMBASE:

Step	Terms
1	hidradenitis.mp.
2	acne inversa.mp.
3	exp hidradenitis/
4	1 or 2 or 3

MEDLINE:

Step	Terms
1	hidradenitis.mp.
2	acne inversa.mp.
3	exp hidradenitis/
4	1 or 2 or 3

PSYCinfo

Step	Terms
1	hidradenitis.mp.
2	acne inversa.mp.

CINAHL:

(MH "Hidradenitis+") OR hidradenitis OR "acne inversa"

Appendix 2: Data screening and data extraction

Stage 1 – Full paper screening:

Q		YES	NO
1	Does the article include data collected from people with HS?	Continue	Exclude
2	Was a recognised qualitative approach to data collection and analysis used?	Continue	Exclude
3	Is the full text available?	Continue	Exclude
4	Do you have a translation of the key information into English?	Continue	Exclude
5	Does the article provide information on the experience of living with HS?	Continue	Exclude

DISCUSSION BETWEEN TWO INDEPENDENT REVIEWERS TO TAKE PLACE BEFORE ANY ARTICLES PROCEED TO STAGE 2.

Stage 2 – Study characteristics:

Article Title:	
Authors:	
Author affiliations:	
Year of publication:	
Journal of publication:	
Extracted by:	

1	What is the research question?	
2	Country	
3	Setting	
4	Time frame	
5	Population (number, age, gender, ethnicity, etc)	
6	Recruitment methods	
7	Data collection methods	
8	Data analysis methods	

9	Researcher characteristics (disciplinary background, training in qualitative research, source of funding, COI etc)	
10	Theoretical/conceptual underpinnings	

Stage 3 – Findings:

Themes / Findings identified:	
Data presented to support findings:	
Author's conclusions:	
Reviewer's conclusions:	

Stage 4 – Study quality:

1. Is a qualitative approach appropriate? For example: <ul style="list-style-type: none"> Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? Could a quantitative approach better have addressed the research question? 	Appropriate	Inappropriate	Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: <ul style="list-style-type: none"> Is the purpose of the study discussed – aims/objectives/research question/s? Is there adequate/appropriate reference to the literature? Are underpinning values/assumptions/theory discussed? 	Clear	Unclear	Mixed	Comments:

3. How defensible/rigorous is the research design/methodology? For example: <ul style="list-style-type: none"> • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified? 	Defensible	Indefensible	Not sure	Comments:
4. How well was the data collection carried out? For example: <ul style="list-style-type: none"> • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic? 	Appropriately	Inappropriately	Not sure/inadequately reported	Comments:
5. Is the role of the researcher clearly described? For example: <ul style="list-style-type: none"> • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants? 	Clearly described	Unclear	Not described	Comments:
6. Is the context clearly described? For example:	Clear	Unclear	Not sure	Comments:

<ul style="list-style-type: none"> • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered 				
7. Were the methods reliable? For example: <ul style="list-style-type: none"> • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to? 	Reliable	Unreliable	Not sure	Comments:
8. Is the data analysis sufficiently rigorous? For example: <ul style="list-style-type: none"> • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data? 	Rigorous	Not rigorous	Not sure/not reported	Comments:
9. Is the data 'rich'? For example: <ul style="list-style-type: none"> • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites? 	Rich	Poor	Not sure/not reported	Comments:

10. Is the analysis reliable? For example: <ul style="list-style-type: none"> • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored? 	Reliable	Unreliable	Not sure/not reported	Comments:
11. Are the findings convincing? For example: <ul style="list-style-type: none"> • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent? 	Convincing	Not convincing	Not sure	Comments:
12. Are the findings relevant to the aims of the study?	Relevant	Irrelevant	Partially relevant	Comments:
13. Conclusions Is there adequate discussion of any limitations encountered? For example: <ul style="list-style-type: none"> • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? 	Adequate	Inadequate	Not sure	Comments:

<ul style="list-style-type: none"> • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? 				
14. How clear and coherent is the reporting of ethics? For example: <ul style="list-style-type: none"> • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? Was the study approved by an ethics committee?	Appropriate	Inappropriate	Not sure/not reported	Comments:
OVERALL ASSESSMENT As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++	+	-	Comments:

Guidance for overall assessment

Grade the study according to the list below:

++ All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.

+ Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.

– Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.