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ORIGINAL RESEARCH ARTICLE

Identifying Unmet Care Needs and Important Treatment Attributes in the Management of Hidradenitis Suppurativa: A Qualitative Interview Study

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Abstract

Background and Objective Hidradenitis suppurativa (HS) is an inflammatory skin disease with a profound effect on patients' quality of life. The patient's journey to manage HS is often complex and unsuccessful, which motivates the aim of this research to gain insight into unmet needs and relevant treatment considerations from the perspective of patients and healthcare professionals (HCPs).

Methods Individual semi-structured interviews were conducted with patients and HCPs experienced in treating HS to understand the perceived unmet care needs and to identify important treatment attributes. Prioritization of the five most important treatment attributes allowed elicitation of their relative importance.

Results Interviews with 12 patients and 16 HCPs revealed 16 areas of unmet needs either related to treatment outcomes or the care process and 13 important treatment attributes. The most frequently reported unmet needs by patients and HCPs were lacking quality-of-life improvement, low treatment effectiveness, inadequate pain control, low disease awareness, and delayed diagnosis. Patients expressed unique concerns relating to pain management, access to HS specialists, and wound care guidance and costs, which HCPs did not. Treatment attributes related to effectiveness were considered most important by patients and HCPs. Patients additionally emphasized a strong preference for improved pain management.

Conclusions Current HS treatments and care processes leave patients and HCPs with a high level of unmet need. It is critical to consider patients' and HCPs' perspectives when designing appropriate HS care as perceived unmet needs differ. Further quantitative preference elicitation studies are needed to assess the trade-offs between important care needs and treatment attributes.

Key Points for Decision Makers

Current hidradenitis suppurativa treatments and care processes were revealed to leave patients and healthcare professionals with a high level of unmet need due to low treatment effectiveness and inadequate pain management and further identified key challenges related to delayed diagnosis, access to hidradenitis suppurativa specialists, and wound care.

While patients and healthcare professionals both desire treatments with greater effectiveness, patients expressed a strong need to achieve better pain reduction and avoidance of surgery.

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1 Introduction

Hidradenitis suppurativa (HS), also known as acne inversa, is a chronic, debilitating inflammatory skin disease with an overall prevalence range of 0.03–1% and an average age of disease onset of 22 years [1]. The disease involves chronic or recurring inflamed lesions with suppuration, which cause pain and scars in predominantly inverse body areas [2–5]. Although HS itself causes substantial morbidity, recent evidence has shown that HS is a systemic inflammatory disease with multiple associated comorbidities that collectively decrease the quality of life (QoL) of patients [6]. Patients with HS frequently suffer from conditions such as obesity and metabolic syndrome as well as psychologic problems such as depression, tobacco dependency, and social stigmatization, which add to the disease burden [7–12]. Such disease consequences have a substantial negative impact on general and skin-specific QoL [13, 14]. Hidradenitis suppurativa is frequently misdiagnosed with an average duration from manifestation of first symptoms until diagnosis reported of 10.0 ± 9.6 (mean ± standard deviation) years despite the existence of published diagnostic criteria [5, 15–17]. Because of the multifaceted nature of the disease, its course can be unpredictable, which poses challenges for patients and healthcare professionals (HCPs) in the management of the disease [16]. Guidelines suggest the use of antibacterial treatment for mild-to-moderate HS and anti-inflammatory treatments for more severe HS, with surgery recommended to manage sinus tracts, scars, and anatomic changes that have manifested [3]. The tumor necrosis factor-α inhibitor adalimumab is to date the only approved biologic therapy in the European Union and USA. Despite treatment, only approximately one-third of patients experience remission of their disease over time with currently available treatment options and almost half of treated patients with HS remain dissatisfied because of poor efficacy, undesirable adverse effects, inconvenience, or invasiveness [2, 16, 18]. Many patients therefore experience a disease that continues to progress over years, which implies that there is still a significant unmet need for additional effective management options [18]. Other biologics targeting tumor necrosis factor-α, interleukin-17, interleukin-23, and other cytokines have been reported in smaller studies and may potentially have efficacy for the treatment of HS [3, 18–21]. There is a potential influx of additional treatments with over ten small-molecule or biological treatments in clinical development for HS, with only bimekizumab and secukinumab (both monoclonal antibodies against interleukin-17) currently being tested in phase III clinical trials [19, 22].

Studies exploring patient perspectives and preferences have gained increasing importance in clinical, regulatory, and reimbursement decision making as they can differ from HCPs. Agencies such as the US Food and Drug Administration and health technology assessment authorities such as the National Institute for Health and Care Excellence in the UK are advocating the incorporation of patient preferences in the value assessment of treatments [23–26]. Evidence has demonstrated that accounting for patient preferences in decision making can positively influence treatment outcomes such as treatment satisfaction and adherence [27, 28]. Improved treatment adherence in turn can have positive economic implications as reported in a recent study suggesting that published economic evaluations in HS to date consistently reported treatment (dis)-continuation to be an important driver of the cost-effectiveness of HS therapies [29, 30].

Given the complexity of the patient journey and profound impact on QoL, it is critical to understand key challenges from the patient perspective to bring greater awareness and understanding among HCPs who treat patients with HS [31]. However, patient perspectives in the context of HS have hardly been investigated. Although the Global Survey Of Impact and Healthcare Needs Project augmented the currently low understanding of unmet care needs for patients with HS, further qualitative work can improve understanding of the unmet care needs and potential differences in perceptions between patients and HCPs to contribute to the optimization of HS management [16]. Furthermore, no high-quality patient preference research in the form of a conjoint analysis or discrete-choice experiment (DCE) has been published with patients or HCPs in HS to date. Preliminary qualitative research aiming to identify and prioritize important treatment considerations from the perspective of patients and HCPs forms part of the process to design conjoint analyses or DCEs that are currently commonly used to elicit and quantify treatment preferences of patients and HCPs. Understanding and comparing perspectives of patients and HCPs may provide important insights on common misconceptions in the care provision and reveal opportunities for better harmonization in the future.

The objectives of this research are two-fold: (1) to reveal and prioritize the unmet care needs perceived by patients and HCPs, with the term "unmet care needs" relating to the adequacy of available treatments and disease severity or disease burden according to the characterization suggested by Vreman et al. [32] and (2) to identify relevant treatment attributes and assess their relative importance in the context of HS management.

2 Materials and Methods

This study consisted of qualitative interviews with adult patients with HS and HCPs with experience treating patients with HS. The semi-structured interviews assessed the

perceived unmet care needs and identified treatment attributes that patients and HCPs consider most important in the management of HS.

2.1 Population

The group of HCPs consisted of accredited dermatologists or surgeons experienced with HS; general practitioners (GPs) and nurses were not included because of low overall disease awareness. Healthcare professionals were identified through their presence in HS-specific literature or conference activities (European Hidradenitis Suppurativa Foundation and Symposium on Hidradenitis Suppurativa Advances) and were recruited by e-mail. Snowball sampling was deemed most appropriate for this research given the disease rarity and associated difficulties of using stricter purposeful sampling techniques [33, 34]. Participating patients were identified and contacted through participating HCPs or patient advocacy groups (Irish Skin Foundation, Hidradenitis Patiënten Vereniging, Hope for HS, Patientforeningen HS Danmark & Association Acne Inversa SchwAIz). Key participant inclusion criteria for patients were aged ≥ 18 years and a confirmed medical diagnosis of HS; participation was not restricted by HS disease severity. The study allowed participation of subjects located in Europe or North America. All participants were made aware of the objectives of the research and provided consent to use their anonymized responses for this study. There was no compensation of any type for participation in this study. Prior to enrollment, the required sample size was estimated between 15 and 20 for each group based on published qualitative research with a similar purpose [35, 36]. During the study, enrollment of participants in either group was pre-determined to be finished as soon as three consecutive interviews did not provide substantially new information (defined as no new unmet care need or treatment attribute), which is suggested by Moser and Korstjens to indicate data saturation [37–39].

2.2 Semi-Structured Interviews

A literature search in MEDLINE was conducted in May 2020 to identify important themes and select relevant items for the qualitative interview guide [40]. The search revealed only seven studies in HS that were deemed relevant for development of the interview guides, which were aimed to be designed in accordance with previously published patient and HCP perspectives and insights into the context of HS management [16, 41–46]. The interview guides (Appendix) were jointly developed by the authors, who have experience with patient preference research or are HCPs with experience in treating HS. All one-to-one interviews were conducted online using the same semi-structured interview guides, which were pilot tested among the authors, between June 2020 and January 2021 by two male student researchers with MSc in health sciences in English, German, Dutch, Portuguese, or French language and were audio-recorded in digital format to allow accurate data processing. Both interviewers had formal academic education for the conduct of qualitative interviews, but limited practical experience, which was addressed by training of the co-authors who are very experienced in qualitative research, by pilot testing and by previous secondary research into patient preference studies and HS. No particular characteristic of interviewers' profiles was expected to lead to any form of bias in the conduct and analysis of the qualitative interviews. Participants were made aware of the interviewer's background at the start of the interview as no participant had familiarity with the interviewers prior to the interview. Prompts were only used to advance the discussion if the participant finished elaborating on a question. Rates of non-participation or discontinuation during the interview were noted. Because of the ongoing global COVID-19 pandemic at the time of this research, physical interviews or focus groups were not considered appropriate. All procedures performed in this study involving human participants were in accordance with the ethical standards of Maastricht University and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

The first part of the interview included questions on participants' demographic information in which patients were asked about their geographic location, age, gender, and disease experience, characterized by disease severity using Hurley staging, time since diagnosis, and treatment experience. Participating HCPs were asked about their geographic location, medical specialization and experience treating patients with HS by the number of years of treating patients with HS, frequency of consulting patients with HS, disease severity range of patients with HS consulted, and types of HS treatments applied [47]. Categorization of participants' responses in both groups regarding their experience with HS, i.e., disease severity and type of interventions used, were not mutually exclusive as respondents could have experience with more than one classification. In the second part, to reveal the perceived unmet care needs in HS, participants were asked open-ended questions such as "What is your view on the unmet care need in the management of HS?" to learn about their experiences with the management of the patient's condition in terms of treatment outcomes and treatment processes. All participants were neutrally asked to quantify the level of unmet care need they perceive themselves on a 7-point Likert-scale (0 = lowest level of unmet care need to 7 = highest level of unmet care need). Participating HCPs were additionally asked if the perceived level of unmet care need is correlated to a patient's disease severity. In the third part, treatment attributes that are influential to treatment decision making were first elicited in an

exhaustive manner from participants and HCPs. Participants were then asked to prioritize the five most important treatment attributes out of all previously mentioned treatment attributes to elicit their relative importance.

2.3 Analysis and Presentation of Results

Descriptive statistics were used to characterize the sample and mean values with ranges were presented for continuous variables. Frequencies expressed as percentages were presented for categorical variables. Results for identified unmet care needs and identified treatment attributes were analyzed in a qualitative and quantitative manner. Coding using content analysis methods was used to analyze the qualitative interviews. For the qualitative analysis, all participants' responses were exhaustively listed and subsequently categorized; in the case of conflict during the categorization process, joint decisions between the authors (including HCPs experienced in treating HS) were made. For the quantitative analyses, the proportion of participants reporting each item of unmet care need or treatment attribute was calculated and visualized in Microsoft Excel 2013. The first five interviews were jointly analyzed by two researchers to agree on a consistent analysis and classification approach for the remaining interviews, which were individually analyzed. The presentation of the results adheres to reporting guidelines by Hollin et al. to enhance the transparency and trustworthiness of published qualitative methods and evidence [48]. Patients' and HCPs' responses are separately presented. The unmet care needs attributes are divided into treatment outcome-specific and care process-specific items.

All unmet care needs and treatment attributes mentioned by participants were either reported individually if mentioned by at least three respondents or otherwise grouped by theme. Themes to categorize unmet care needs and treatment attributes that were reported by fewer than three respondents were defined based on similar studies identified in the literature search or based on author experience (including HCPs experienced in treating HS). All items were listed and ranked by frequency of being reported. Relevant qualitative interview findings, for example, quotations of respondents, were added in the body text to aid the interpretation of the quantitative results.

3 Results

3.1 Study Sample

Interviews were conducted with a total of 28 participants, 16 HS-experienced HCPs, and 12 adult patients as the predetermined level of data saturation was achieved (no new unmet care need or treatment attribute emerging in three consecutive interviews). Interview duration was on average 30 minutes for both groups, with a range from 23 minutes to 54 minutes and 17 minutes to 45 minutes with patients and HCPs, respectively. The response rate was not possible to assess as snowballing sampling was applied, but no participant who expressed initial interest to participate refused, or discontinued participation afterwards. The sample of participating HCPs consisted of 15 dermatologists and one surgeon. Participating HCPs' experience treating patients with HS ranged from 3 to 40 years with an average of 10.7 years. Participating patients were on average 41.6 (28–64) years old, mostly white/Caucasian (93%), female (75%), and based in five European countries (83%) or USA (17%). Time since patients' medical diagnosis of HS was on average 11.2 (2–30) years. In addition to the demographics, Table 1 also depicts HCPs' and patients' experience with HS by the frequency of HS-specific consultations, disease severity spectrum, and types of interventions used. Most participants had experience across all the HS severity stages defined by Hurley and had experience with the range of interventions available to treat HS, including biological therapies. The majority of both groups (> 58%) indicated to have experience using off-label treatments to treat HS.

3.2 Unmet Care Needs

A total of 16 unmet care themes were identified through interviews and classified to be either treatment outcome-related [8] and care process-related [8]. Participating HCPs and patients most frequently reported the negative QoL as an unmet care need, which patients explained to be driven by the lacking improvement of general or skin-specific QoL, productivity levels, fatigue, leisure activities, mental health, intimacy issues, and social life including stigmatization of available treatment options.

> "I have made career choices and avoided greater work responsibilities just to accommodate my HS because I cannot have others relying on my ability to work." US patient, female, age 38 years, white skin color with moderate HS.
>
> "I was unable to walk on bad days prior to receiving a series of excisional surgeries combined with biologic therapy ten years ago. When the therapies worked, I got back control over my life and underwent a huge life transformation, but in the past 6 months it started going wrong again after many good years and I suffered from new lesions in new body areas." Irish patient, male, age 46 years, white skin color with moderate HS

Poor effectiveness of available interventions, in particular a low response rate or likelihood of response, was emphasized by ten patients and 14 HCPs, with the latter group

Table 1 Demographic characteristics of the study sample and their experience with HS

Characteristic	Classification	Patients ($n = 12$)	HCPs ($n = 16$)
Age, mean (range)	Years	41.6 (28–64)	N/A
Gender, *n* (%)	Female	9 (75)	2 (12)
Race, *n* (%)	White or Caucasian	11 (92)	N/A
	Black or African American	1 (8)	N/A
Location, *n* (%)	Europe	10 (83)	14 (88)
	North America	2 (17)	2 (12)
Experience with HS, mean (range)	Years	11.2 (2–30)	10.7 (3–40)
Consultations for HS[a], *n* (%)	0–9	8 (67)	2 (12)
	10–29	4 (33)	9 (56)
	30–50	–	3 (19)
	> 50	–	2 (12)
Disease severity, *n* (%)	Mild	11 (92)	16 (100)
	Moderate	10 (83)	14 (88)
	Severe	8 (67)	14 (88)
Interventions used, *n* (%)	Minor surgery	9 (75)	13 (81)
	Excisional surgery	7 (58)	7 (44)
	Antibiotic treatment	10 (83)	16 (100)
	Biological treatment	6 (50)	14 (88)
	Off-label treatment	7 (58)	13 (81)

HCP healthcare professional, *HS* hidradenitis suppurativa, *N/A* not applicable

[a]Per week (HCPs) and per year (patients)

frequently noting that current interventions do not provide sufficient patient satisfaction and durable inflammation control.

> "It's a huge unmet need that the available treatments often lose effect over time which is aggravated by the limited number of alternatives to switch patients to." US dermatologist, male, with over 10 years of experience treating patients with mild-to-severe HS

Inadequate pain management was perceived by both groups as an important unmet care need that is often overlooked because of prioritizing improvement in visual or inflammatory signs of HS.

> "Pain management is non-existent despite it having the biggest impact on my quality of life. A lot of dermatologists don't even ask you if you are in pain or how you are managing it because it doesn't even occur to them that HS may be painful." US patient, female, age 39 years, white skin color with severe HS.

Eleven HCPs highlighted the low durability of treatment effectiveness of current interventions and the inability to halt disease progression in patients, with some in particular concerned for patients at risk of progression from mild to moderate or severe stages of HS. Eight respondents in both groups stated concerns regarding the side effects of available antibiotic or biological therapies, drug–drug interactions, and the high burden of undergoing surgery. Perceptions of unmet care needs were mostly similar between patients and HCPs, though patients more frequently emphasized the inability of current care options to improve visual appearance or prevent scarring. Table 2 presents the unmet care needs relating to treatment outcomes, including respondents' characterization of each unmet need and the frequency of being reported.

Table 3 portrays the perceived unmet care needs relating to the care process; including respondents' characterization of each unmet need and the frequency of being reported. Patients frequently reported delays in receiving a correct medical diagnosis, thought to be caused by low disease awareness in GPs and dermatologists. Fourteen HCPs confirmed this issue by explaining that patients often experience multiple unsuccessful referrals, wrong diagnoses, and ineffective treatment intimations until HS is correctly diagnosed by a specialist.

> "It took me twenty years to get a correct diagnosis and I had to see a lot of specialists before I found someone in Ireland who is familiar with this condition." Irish patient, age 46 years, male, white skin color with moderate HS.

Fragmentation of care delivery concerned ten HCPs who admitted suboptimal collaboration and patient follow-up between GPs, dermatologists, surgeons, pharmacists, and nurses. Eight patients shared concerns regarding the

Table 2 Identified unmet care needs related to treatment outcomes

Treatment outcome-related unmet care need	Respondents' characterization of unmet care need	Patients ($n = 12$)	HCPs ($n = 16$)
QoL impact	Lacking improvement of general or skin-specific QoL; mental health; productivity; social life; intimacy issues; lifestyle restrictions	11 (92)	14 (88)
Effectiveness	Insufficient control or reduction of lesions, nodules, or draining fistulas; lacking effect on inflammation, flares, or other symptoms; low treatment response rate, efficacy, or likelihood of response; insufficient patient satisfaction	10 (83)	14 (88)
Pain control	Inadequate pain reduction, control, or improvement	9 (75)	11 (69)
Duration of effect	Poor maintenance of effect; low durability of effect; frequent loss of response or disease recurrence	7 (58)	11 (69)
Side effects	Concerning antibiotics or biologic side effects; drug–drug interactions; comorbidity implications; life implications of surgery	8 (67)	8 (50)
Disease progression	Inadequate halting of disease progression or worsening of disease	5 (42)	9 (56)
Skin appearance	Dissatisfying visual or odor appearance of skin affected by disease or scarring	7 (58)	4 (25)
Time to onset	Slow onset of effect or treatment response; difficult early prediction of later treatment success	4 (33)	5 (31)

Data are presented as *n* (%) and sorted by decreasing frequency of being mentioned

HCP healthcare professional, *QoL* quality of life

Table 3 Identified unmet care needs related to care process

Care process-related unmet care need	Respondents' characterization of unmet care need	Patients ($n = 12$)	HCPs ($n = 16$)
Timely diagnosis	Delayed, wrong, or no diagnosis provided	9 (75)	14 (88)
Disease awareness	Poor general awareness or knowledge of HS; inadequate care provision until correct diagnosis	11 (92)	11 (69)
Healthcare system settings	Inadequate healthcare system care set-up; lacking care integration, follow-up, or self-care guidance; long geographic distance to HS specialist; care inefficiencies due to fragmented care provision	6 (50)	10 (63)
Wound care guidance	Insufficient patient and nurse education on HS-specific wound care; lacking published guidance or information	8 (67)	5 (31)
Treatment selection process	Lack of shared decision making, patient involvement	6 (50)	9 (56)
Access to HS specialists	Long waiting times; high number of referrals to consult HS specialist	7 (58)	4 (25)
Wound care costs	High cost for wound dressings, bandages, supplies, or skin/hygiene products; limited reimbursement or coverage of wound care supplies	8 (67)	1 (6)
Treatment costs	High out-of-pocket treatment costs; low coverage or reimbursement; limited possible choice of treatment	4 (33)	5 (31)

Data are presented as *n* (%) and sorted by decreasing frequency of being mentioned

HCP healthcare professional, *HS* hidradenitis suppurativa

insufficient wound care guidance received by nurses and HCPs because of insufficient education provided or guidance published.

> "There is not nearly enough support for the detrimental mental aspects that are involved in living with HS as it is swept under the rug in the United States." US patient, female, age 39 years, white skin color with severe HS.

Many patients further highlighted the very high costs for wound dressings and skin care products as reimbursement is often partially or completely lacking in the USA and some European countries. Costs of medical treatments and consultations were perceived as problematic by US patients while most European respondents reported sufficient medication reimbursement. However, difficulty accessing HS specialists because of waiting times or geographic distance was reported by seven patients across both locations.

> "It usually takes me 8 months to see my specialist for which I also I have extremely high co-payments. Another frustration is getting the care coordinated

between my primary care provider and my specialist because I have multiple conditions whose therapies sometimes conflict each other." US patient, age 38 years, female, white skin color white with severe HS.

"HS is a disease that costs me a lot of money. While out of pocket costs for medical interventions are manageable, the specific products that I need to treat my skin and wounds not always reimbursed and have costed me a lot of money over the long course of my disease." French patient, age 44 years, female, white skin color with moderate HS.

Such access barriers were of particular concern for patients during disease flaring as patients felt most emergency departments are unaware of HS and cannot provide appropriate urgent or emergent care in such occasions.

"I see a frequently underrecognized unmet need in the limited options to treat patients with mild forms of HS. Current treatment options together with delays in diagnosis don't allow us to prevent new inflammation in these patients with mild HS which to me is a great treatment opportunity missed." Dermatologist in The Netherlands, male, with over 10 years of experience treating patients with mild-to-severe HS.

Patients and HCPs scored the level of perceived unmet care needs on a 7-point Likert scale with 4.5 (2–6) and 5.5 (3–7), respectively. Eleven HCPs confirmed greater unmet care needs with increasing disease severity, whilst two HCPs were more concerned about the lack of effective interventions to adequately treat patients with mild HS and prevent disease progression to more severe stages of HS.

3.3 Treatment Attributes

Thirteen treatment attributes were identified that are presented with respondents' characterization and frequency of being reported in Table 4. All patients expressed the importance of treatments leading to an improvement in QoL. More specifically, nine patients expected improvements in productivity levels (including education or work), eight patients expressed expectations for treatments to improve their mental health (including anxiety, depression, stigmatization, or self-realization) and social life (including leisure activities or private relationships), and five patients emphasized the importance of reducing fatigue.

"It would be great if future treatments could better reduce my pain and help me break away from this vicious circle in which my HS symptoms negatively impact my mental health and social life which in turn negativity influence my condition." Swiss patient, age 28 years, female, white skin color with moderate HS.

Likelihood of response to be achieved was the second most frequently desired treatment attribute by both

Table 4 Identified treatment attributes

Treatment attribute	Respondents' characterization of treatment attribute	Patients ($n = 12$)	HCPs ($n = 16$)
QoL improvement	Mental health improvement (including improved depression, anxiety, psychological problems, mental stability, stigmatization, confidence, or self-realization); greater productivity (including education and work); social life (including leisure activities, sports, private relationships, travel or family activities); fatigue improvement	12 (100)	13 (81)
Effectiveness	Likelihood of response; response rate; chance of response; efficacy	10 (83)	13 (81)
Treatment convenience	Method, location or frequency of administration; contact to healthcare personal	9 (75)	13 (81)
Duration of effect	Response maintenance; duration of effect; avoidance of disease recurrence	10 (83)	10 (63)
Long-term treatment safety	Reduced long-term treatment side effects; reduced drug–drug interactions; avoidance of comorbid complexities	8 (67)	10 (63)
Pain reduction	Pain reduction, control, or improvement	10 (83)	7 (44)
Skin appearance	Improvement of scarring, visual, or odor appearance	10 (83)	7 (44)
Surgery avoidance	Avoidance of surgery	9 (75)	7 (44)
Immunological control	Immunological stability; control of inflammation; avoidance of flares; reduction of nodules/lesions/draining fistulas	5 (42)	9 (56)
Time to effect onset	Time to response; speed of response; predictability of response	5 (42)	8 (50)
Disease progression	Avoiding disease progressing; halting of disease progression	3 (25)	9 (56)
Treatment costs	Low patient out-of-pocket cost; adequate coverage or reimbursement	5 (42)	7 (44)
Treatment satisfaction	Satisfaction with treatment	0 (0)	6 (38)

Data are presented as *n* (%) and sorted by decreasing frequency of being mentioned

HCP healthcare professional, *QoL* quality of life

groups. Patients reported more frequently than HCPs the importance of treatments being able to reduce pain, improve skin appearance or odor, or lead to the avoidance of surgery.

> "If nothing works, you are having a surgery and have to undergo weeks and weeks and weeks of recovery, only for it (HS) to recur in the same place quite quickly. A big thing would be if future treatments can stop it (HS) from coming back, that would be amazing." Irish patient, age 37 years, female, white skin color with severe HS.

Healthcare professionals more frequently than patients cited the importance of treatments being able to control inflammation (including nodules, lesions, and draining fistulas), halt disease progression, and show a fast onset of action enabling earlier treatment success prediction.

> "We need medicines that respond in more patients and have a more profound and consistent effect." US dermatologist, male, with over 10 years of experience treating patients with mild-to-severe HS.

When participants were asked to limit their previously mentioned treatment attributes to the five most important, differences in priorities between patients and HCPs became apparent (Fig. 1). Pain reduction was revealed to have the highest probability of being cited within the five most important attributes by patients, followed by treatment effectiveness. HCPs prioritized effectiveness, immunological control, and QoL improvement. Improvements in visual appearance or odor, surgery avoidance, and mental health were prioritized by patients but not at all by HCPs.

4 Discussion

With evidence on patients' and HCPs' perspectives in the management of patients with HS being scarce to date, this research revealed novel insights on important unmet care needs and treatment considerations from patients and HCPs through the conduct of qualitative interviews. The overall perception of unmet care needs was high in both groups and related to treatment outcomes or care process-related issues. The inability of currently available therapies to show satisfying levels of effectiveness to improve QoL and reduce HS pain was revealed to drive the treatment outcome-related unmet care needs. This is also confirmed by the high number of respondents in both groups reporting experience with "off-label" treatments to manage HS. Both groups were highly concerned about delays in diagnosis, mostly attributable to a low level of disease awareness, leading patients to undergo many unsuccessful referrals and treatment initiations during which the disease can progress; this has been defined as a global problem [17]. Even after a correct diagnosis, both groups emphasized significant inefficiencies in the HS management process due to fragmented care delivery, insufficient HS-specific education, inadequate wound care guidance, and access barriers to HCPs with expertise in HS. The results highlight that for US respondents, costs to the individual is an important concern, which is not surprising given the US multi-payer healthcare system. However, access barriers to HS specialists due to long waiting times and geographic distance were also reported by respondents outside the USA, which is considered problematic because it leads to patients with HS visiting emergency departments for expensive and inefficient treatment and pain relief as Taylor et al. highlight [49]. The views of both groups in our study on unmet care needs were mostly similar, with the exception of patients reporting more concerns around the

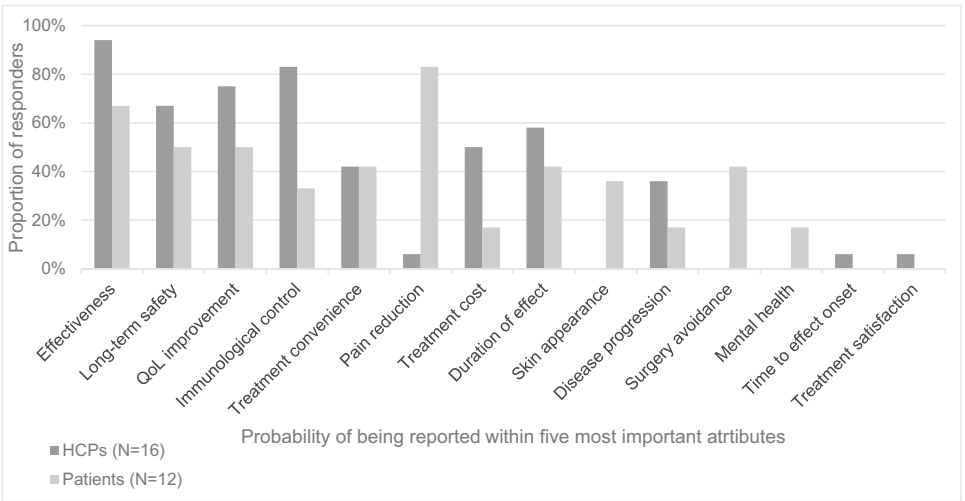

Fig. 1 Probability of treatment attributes being mentioned as one of the five most important. *HCP* healthcare professional, *QoL* quality of life

skin appearance (visual and odor) and guidance on the cost of wound care, which HCPs did not emphasize as strongly.

Unsurprisingly, given the high unmet care needs caused by the limited number of effective treatments available, patients and HCPs prioritized improvements in effectiveness and QoL over safety or convenience as treatment attributes. Improvement in HS pain, appearance of skin, and avoidance of surgery were more frequently considered by patients as the most important treatment attributes, while HCPs more frequently pointed out improved immunological control (reduced level of inflammation) and avoidance of disease progression defined by patients' skin manifestations [47]. There were little to no controversies in the respondents' statements with the exception of some HCPs seeing the greatest need to more successfully prevent disease progression at early stages with more effective treatments, while others emphasized the need to have more effective treatment options for patients with more severe HS who had already exhausted the limited treatment options available. The prespecified target level of data saturation (three consecutive interviews with no new unmet care need or treatment attribute emerging) was achieved with a sample size close to those that can be observed in similar qualitative research [35, 36]. A greater number of interviews with HCPs ($n = 16$) than with patients ($n = 12$) was needed to reach data saturation, which could indicate the responses from HCPs to be more heterogenous than those of patients.

A study by Garg et al. eliciting the identifying care needs of 1299 participants in Europe and North America also revealed that participants were most concerned about delayed diagnoses, HS-related pain, access to dermatology, and extreme QoL impact [16]. Authors of the HIdradenitis SuppuraTiva cORe outcomes set International Collaboration tried to address the current lack of consensus on outcome measures and agreed that pain, physical signs, HS-specific QoL, global assessment, and disease progression should be consistently assessed, which are similar to the domains of unmet care identified in our study [50, 51].

The frequently reported issues in qualitative research on respondents' differing expressions of similar meanings have been addressed in this study by a prior literature search to inform the design of interview guides and by exhaustive listing and subsequent classification of all items reported by participants. However, it cannot fully be dismissed that some unmet need categories or treatment attributes are not mutually exclusive. For example, unmet needs relating to treatment effectiveness can also be closely associated with QoL improvement or treatment satisfaction, Tables 2, 3 and 4 present in detail which aspects of each item were mentioned by the respondents.

Although our study followed good research practices, some limitations may exist. First, potential selection bias and limitations in generalizability due to the sample size may have impacted the study despite respondents' statements becoming repetitive after approximately ten interviews in each group indicating data saturation. The study design and predetermined sample size requirements were targeted to identify strong trends between participants' profiles. Second, GPs and nurses, whose experiences could have brought additional perspectives on the journey of a patient with HS, were not interviewed because of the awareness of HS in these groups reportedly being too low. Third, while this study was able to reveal interesting insights from respondents across multiple countries, a more focused recruitment of participants from only one country would have potentially allowed potential flaws to be revealed of one particular healthcare system in greater detail. Finally, the conduct of physical focus groups could have resulted in insightful exchanges between participants but were not feasible because of the ongoing COVID-19 pandemic at the time of this research.

This study further underpinned that qualitative research is a beneficial step prior to designing quantitative preference elicitation instruments because of familiarization with the target population and its preferences and supporting attribute/level refinement. Our study identified important opportunities for future research to better understand the preferences of patients and HCPs in the management of HS, preferably using quantitative preference elicitation methods. The prioritization exercise of treatment attributes enabled us to identify a range of patient-relevant and HCP-relevant attributes for potential inclusion in future DCEs. Further research is needed to determine which of these attributes are most appropriate for a DCE in HS to ensure the cognitive burden for participants is manageable [52]. Wider contextual issues (delay in diagnosis, access to specialist, fragmented care, wound care issues) were revealed to be of importance to patients and HCPs that require further consideration in the design of future DCEs; this could be done by testing treatment effect attributes more holistically to account for their impact on the care continuum such as for example, reduction in surgery, associated burden of wound care, and number of follow-up visits required, instead of only testing different levels of treatment effect expressed in plain response rates. Assessing the trade-offs and relative importance of treatment attributes in larger samples using a quantitative elicitation approach will allow greater understanding of influential factors of respondents' profiles and improve the generalizability of the findings with the aim to improve future clinical, regulatory, and reimbursement decision making to reduce the currently high level of unmet care needs in HS.

5 Conclusions

This study revealed that current HS treatment options and care processes leave patients and HCPs with a high level of unmet care need. HCPs and patients have mostly similar

views on unmet care needs such as low effectiveness and pain control. Patients emphasized the challenges relating to access to HS specialists and issues relating to guidance and costs of wound care. Treatment effectiveness outcomes were considered as the most important treatment attributes by both groups. Yet, our study highlighted important care process-related considerations that may impact respondents' preferences that should be accounted for in future DCE study designs.

Appendix

Interview guide for HCPs

Background:

1. What is your current job title & role?
2. Do you have experience treating patients diagnosed with HS?
3. How many years of experience do you have treating patients with HS?
4. What is the spectrum of disease severity of HS that you have experience treating?
   (a) Options: mild, moderate, severe (Hurley staging as possible metric)
5. What is the spectrum of treatment interventions you perform on patients with HS?
   (a) Options: minor surgery, excisional surgery, antibiotic treatment, biological treatment, off-label treatment
6. How many consultations on average per week with patients with HS would you estimate to have?
   (a) Options: 0–5, 5–10, 10–30, 30–50, 50 +

Unmet care needs:

1. What is your view on the unmet care need in the management of HS? Please be exhaustive related to treatment outcomes and care process
2. On a 7-point Likert scale with 1 being "no unmet needs at all" and 7 being "greatest level of unmet needs", what do you believe is the level of unmet needs in HS from a HCP perspective (if known)? Please explain your rating.
3. Do you believe this unmet need is different from a patient perspective? If yes, how?

Treatment attributes:

1. Which treatment attributes influence your treatment decision making as HCP? Please be exhaustive.
2. Considering the treatment attributes you recently mentioned, please limit yourself to the five most important attributes for you in medical decision making

Interview guide for patients

Background:

1. What is your gender?
2. What is your age?
3. What is your ethnicity?
4. Did you have a medical diagnosis of HS? If yes, how many years ago
5. Which severity stages of HS have you experienced yourself?
6. What is the spectrum of treatment interventions you have experienced yourself?
   (a) Options: minor surgery, excisional surgery, antibiotic treatment, biological treatment, off-label treatment
7. How many consultations on average per year for HS would you estimate to have?
   (a) Options: 0–5, 5–10, 10–30, 30–50, 50 +

Unmet care needs:

1. What is your view on the unmet care need in the management of HS? Please be exhaustive related to treatment outcomes and care process
2. On a 7-point Likert scale with 1 being "no unmet needs at all" and 7 being "greatest level of unmet needs", what do you believe is the level of unmet needs in HS from a patient's perspective (if known)? Please explain your rating.

Treatment attributes:

1. Which treatment attributes or treatment characteristics would influence your treatment decision making as patient? Please be exhaustive.
2. Considering the treatment attributes you recently mentioned, please limit yourself to the five most important attributes for you in treatment decision-making

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Declarations

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Conflict of interest DW is a registered PhD student at Maastricht University and an employee of UCB Pharma, UCB Pharma had no role in the design, conduct, and analysis of the study, or in the writing/reviewing of this manuscript. All other authors declare no conflict of interest

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Ethics approval All procedures performed in studies involving human participants were in accordance with the ethical standards of Maastricht University and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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

Consent for publication The submission does not include personal details or images that may lead to the identification of participants and all participants gave consent to publish their anonymized data.

Availability of data and material Not applicable.

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