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Experiences of Drainage and Associated Impacts: A Qualitative Study Among Patients With Hidradenitis Suppurativa

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ABSTRACT

Background: Hidradenitis suppurativa (HS) is a chronic, debilitating inflammatory skin condition often accompanied by malodorous drainage. Drainage affects quality of life, contributing to stigma, emotional distress, and physical challenges. Recognising the role of drainage in HS, the HiSTORIC (Hidradenitis SuppuraTiva cORe outcomes set International Collaboration) initiative identified it as a key symptom in clinical trials and developed the The HIdradenitis suppurativa DrainagE (HIDE) Scale.

Objectives: This study aimed to explore patients' experiences of drainage to guide person-centred care approaches.

Methods: A qualitative secondary analysis was conducted using data from the parent study on The HIDE Scale©. The data included 38 interviews with patients aged ≥ 18 years, diagnosed with HS, and experiencing drainage. Reflexive thematic analysis was applied using an inductive and semantic approach, guided by person-centred theoretical perspectives.

Results: Three overarching themes emerged: *(1) Drainage is difficult to explain* due to its unpredictable and complex nature; *(2) Drainage impacts mental well-being*, contributing to feelings of social stigma, frustration, and emotional distress; and *(3) Drainage involves significant physical difficulties*, including malodour, frequent dressing changes, and daily activity disruption. Patients described drainage by volume, consistency, colour, and location, emphasising its multidimensional impact. Despite these challenges, pain was identified as the most debilitating symptom of HS.

Conclusions: This study highlights the physical, psychological, and social impact of drainage in HS, emphasising its complexity and unpredictability. Patients described drainage as a multifaceted experience that profoundly affects their quality of life. To improve care, healthcare providers should integrate an assessment of drainage into clinical practice, utilising standardised tools like The HIDE Scale©. Addressing physical and psychosocial aspects of drainage through open and empathetic discussions can reduce stigma, foster a sense of support, and enhance patient–clinician relationships. Adopting person-centred approaches validates patients' experiences and holistic assessment is essential for improving care strategies and the well-being of individuals living with HS.

1 | Introduction

Hidradenitis suppurativa (HS) is a chronic inflammatory skin condition, widely regarded as one of the most debilitating dermatological diseases [1–3]. The significant disability associated with HS primarily stems from the intense pain and subsequent loss of mobility it causes [4]. However, another critical factor contributing to the disease's impact is the frequent drainage from active HS lesions, which typically involves the discharge of pus, blood, and/or wound fluids. This drainage, and the often accompanying malodour, is often cited as a major source of embarrassment for patients, leading to profound social stigma, diminished self-esteem, with severe negative consequences for interpersonal relationships, education, and employment [1, 5–9]. A recent survey of incision and drainage procedures in HS highlighted patient dread, pain and the importance of provider compassion [10], but little is known about how patients experience spontaneous drainage in daily life.

The Hidradenitis SuppuraTiva cORe outcomes set International Collaboration (HISTORIC) was established with the primary aim of developing a Core Outcome Set (COS) for HS [11]. A key objective of the COS was to reduce the substantial variability in outcome measures that had been observed in HS clinical trials. By seeking global consensus, HiSTORIC aimed to identify core domains that should be consistently measured in all future HS trials. Another equally important goal was to ensure the inclusion of outcome measures deemed critical by all major stakeholders, including patients with HS [12].

HiSTORIC successfully reached consensus among an international group of patients with HS and healthcare professionals on six core domains relevant to all types of clinical trials for HS. These domains include pain (as a stand-alone measure), physical signs, HS specific quality-of-life, global assessment, disease progression, and symptoms (specifically drainage and fatigue) [12].

As part of this initiative, The HIdradenitis suppurativa DrainagE (HIDE) Scale© was developed to provide a validated tool for measuring drainage in HS, independent of its impact on quality of life [1]. While the scale was designed to provide a standardised measure of this symptom for clinical trials, the development process also highlighted the need to better understand patients' lived experiences of drainage. The study accompanying the scale's development offered critical insights into the ways drainage affects individuals with HS, uncovering dimensions that remain underexplored in the current literature.

Addressing the gaps in understanding drainage in HS is important for advancing care that extends beyond the condition's physical manifestations. Recognising the physical, psychological, and social challenges associated with drainage can support the development of more person-centred care and help ensure that treatment strategies are aligned with the lived realities of those affected.

This study aims to explore patients' experiences of drainage in HS, providing valuable insights to inform and improve person-centred care practices.

2 | Patients and Methods

2.1 | Study Design

This study used a qualitative research design based on interviews, conducted as a secondary analysis of data collected during the parent study, titled 'The HIdradenitis suppurativa DrainagE (HIDE) Scale: development and content validation of a patient-reported outcome measure'. The researchers conducting this secondary data analysis were also lead investigators in the parent study. Their involvement in data collection and initial thematic analysis provided them with in-depth contextual knowledge, enabling a comprehensive re-analysis while maintaining methodological rigour. The study follows the EQUATOR network's recommendations and adheres to the Standards for Reporting Qualitative Research (SRQR) [13]. The use of SRQR ensures transparency and rigour in the design, analysis, and reporting of qualitative findings, contributing to the credibility and reliability of the results.

2.2 | Setting and Participants

This study was conducted at specialised outpatient clinics. Participants were purposefully recruited from the Department of Dermatology, Zealand University Hospital in Roskilde in Denmark, and in the United States at the Department of Dermatology, Penn State Health Milton S. Hershey Medical Center in the United States.

Eligibility criteria required participants to be 18 years or older, have a physician-confirmed diagnosis of HS, and have experienced draining lesions. To enhance diversity in the sample, recruitment was carried out using purposive strategies at both sites. Clinicians were encouraged to invite patients representing variation in age, gender, ethnicity, and Hurley stage during routine clinical visits, and clinic staff monitored ongoing enrolment to identify underrepresented subgroups and direct further invitations accordingly.

Summary

- **Why was the study undertaken?** To explore the complex and under-investigated symptom of drainage in hidradenitis suppurativa (HS), including its physical, emotional, and social dimensions, and to inform more patient-centred assessment and management approaches.
- **What does this study add?** By focusing solely on the symptom of HS drainage, the study provides new and detailed insights into its multifaceted and unpredictable nature, highlights its substantial psychosocial impacts, and supports the use of standardised tools such as the HIdradenitis suppurativa DrainagE (HIDE) Scale.
- **What are the implications of this study for disease understanding and/or clinical care?** Highlights the need for holistic, individualised care strategies that integrate standardised drainage assessment with attention to psychosocial burdens, fostering better patient–clinician communication and improving overall quality of life in HS management.

2.3 | Data Collection

A total of 38 interviews were conducted between December 2022 and October 2023. These included nine concept elicitation interviews and 29 cognitive interviews, with 24 conducted in Denmark and 14 in the United States. All interviews were conducted by experienced interviewers using an identical interview guide available in both English and Danish, ensuring consistency across the two sites.

Interviews were conducted individually with a mixture of in-person and virtual formats to accommodate participants. Data collection continued until saturation was achieved at both sites, meaning no new themes emerged in subsequent interviews. All interviews were recorded and transcribed verbatim to ensure accuracy and reliability in the analysis.

2.4 | Data Analysis

Data from the concept elicitation interviews and cognitive interviews were combined for this secondary analysis, See Figure 1. Secondary analyses involve using existing data from a prior study to address questions not initially envisioned during the primary investigation [14, 15]. While the primary analysis focused on developing an outcome measure, this secondary analysis aimed to explore patients' experiences of drainage through a person-centred theoretical perspective. This underscores the iterative nature of qualitative research and highlights the unique purpose and implications of the re-analysis.

For the secondary analysis, reflexive thematic analysis was employed using an inductive and semantic approach. The epistemological stance adopted was situated between critical realism and constructivism, balancing scientific description with interpretive insight. This approach acknowledges the

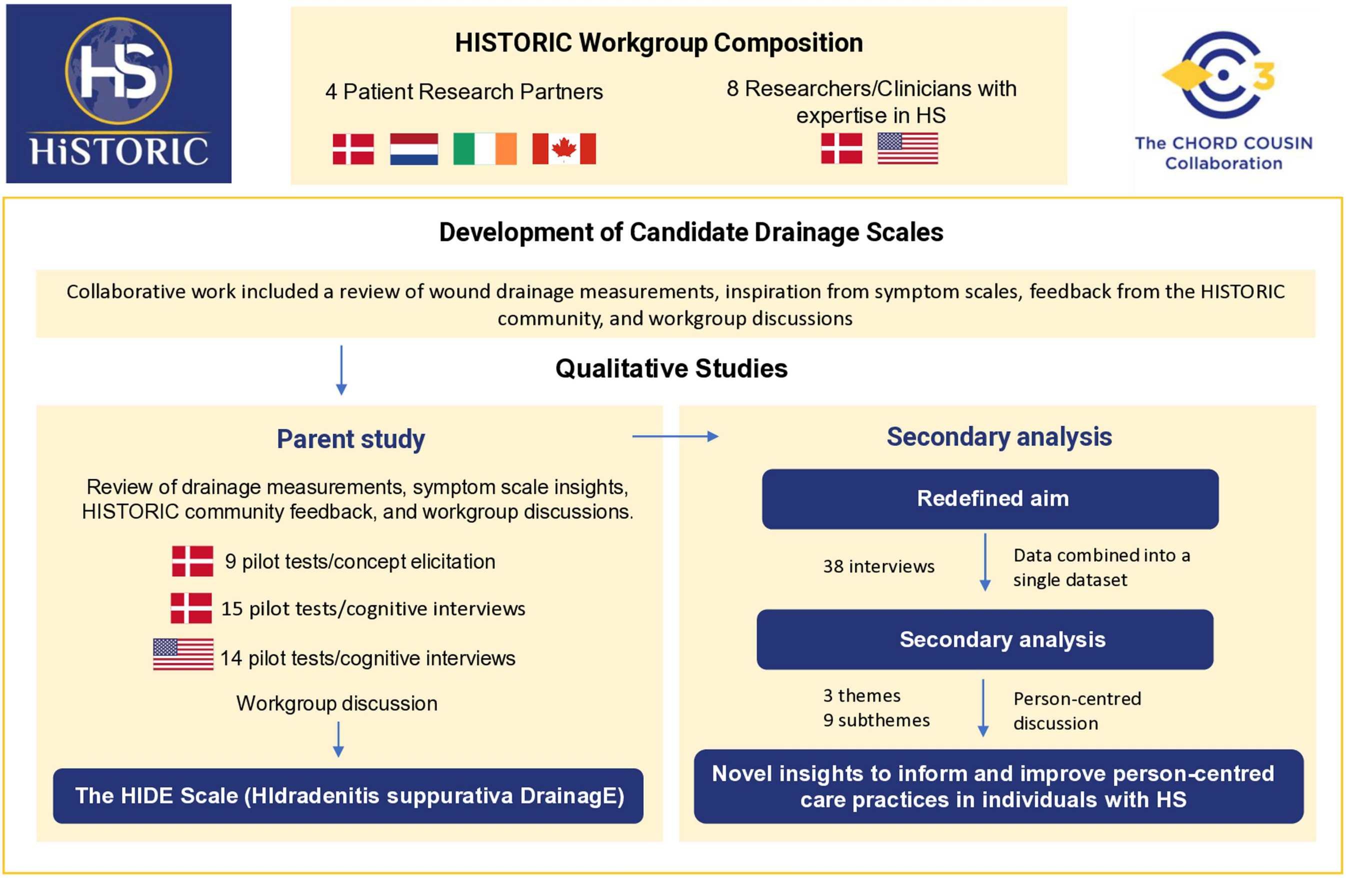

FIGURE 1 | Overview of study methods and results.

TABLE 1 | Demographic and disease characteristics of patients in the qualitative study, adapted from the original publication by Thorlacius et al. [27].

Characteristic	Denmark ($n = 24$)	USA ($n = 14$)
Age, years, mean (SD)	46.9 (14.1)	41.3 (13.7)
Female, *n* (%)	17 (79%)	13 (93%)
Race, *n* (%)		
White	23 (96%)	7 (50%)
Black or African American	0	6 (42%)
Asian	1 (4%)	0
Other or Mixed	0	1 (7%)
Hurley Stage, *n* (%)		
I	1 (4%)	1 (7%)
II	19 (79%)	8 (57%)
III	4 (17%)	5 (36%)

active role of the researcher in co-constructing meaning alongside participants [16, 17].

Data were coded and analysed by the first author at the Danish site using the NVivo software system [18]. The findings were interpreted and discussed through the lens of person-centred theory, which emphasises understanding patients' lived experiences and perspectives [19].

2.5 | Ethical Considerations

The study was approved by The Danish Data Protection Agency. No involvement of the Medical Research Ethics committee is required for qualitative interviews and questionnaire studies in Denmark. In the Unites States, the study was approved by the institutional review board at Penn State University (registration number STUDY00022216). The study was performed according to The Declaration of Helsinki [20]. The patients in this manuscript have given written informed consent to publication of their case details.

3 | Results

Patient demographics are summarised in Table 1. Three overarching themes emerged from the analysis: (1) Drainage is difficult to explain, (2) Drainage impacts mental well-being, and (3) Drainage involves physical difficulties. These themes are detailed below, based on patients' perspectives. Themes and subthemes are illustrated in Table 2.

3.1 | Drainage Is Difficult to Explain

This theme highlights the challenges patients with HS face in articulating their experiences with drainage. The complex, unpredictable nature of the symptom, coupled with the stigma of discussing intimate and distressing symptoms, often made it difficult for patients to describe.

Patients were unfamiliar with the term ‘drainage’ and requested clarification. It was not a term they were familiar with or one they were accustomed to discussing, either with family or healthcare professionals. Once explained as ‘discharge of pus, blood, and/or wound fluids’ patients were able to recognise and articulate their experiences with drainage.

Patients described drainage as both a persistent symptom and a process, encompassing the accumulation of fluid, the rupture of lesions, and the subsequent release and resolution of fluid. Some experienced constant seeping, while others described sudden ‘explosions’ of fluid. In severe cases, drainage necessitated emergency surgical intervention to alleviate discomfort, often disrupting patients' lives for weeks.

When describing drainage, patients used terms like ‘boil-like lumps’, which varied in size from peas to golf balls. The fluid ranged in consistency and colour, including descriptions of cottage cheese-like pus, gel, liquid, or blood, with shades ranging from white, yellow, greenish to red and black. Patients also described drainage as a process that typically began with the expulsion of pus and gradually transitioned to blood, before the cyst could eventually resolve itself.

In addition to the amount of fluid, patients emphasised the importance of describing drainage's colour, consistency, and location. Many suggested visual aids, like diagrams or avatars, to better convey the extent and impact of drainage.

Patients generally agreed that estimating the amount of drainage was relevant for describing their experiences. However, accurately quantifying the drainage proved challenging. While patients intuitively conceptualised it in measurable terms, such as volumes or amounts, they recognised that realistically measuring these volumes was impractical. Some hypothetically suggested using tools like measuring spoons to approximate the amount, but this approach was deemed neither feasible nor relevant in daily life. As a result, patients supported a patient-reported estimation of the amount, viewing it as a more practical and realistic method.

The severity of drainage's impact was closely linked to the lesion's location. Lesions in intimate areas, such as between the buttocks, on the genitals, and under the arms, were particularly disruptive, affecting patients' mobility and intimacy.

Patients often linked the most severe instances of drainage to specific lesions they had experienced over time, describing these as particularly challenging and significantly impactful on their daily lives. These findings underscore the complexity of drainage as a symptom, requiring healthcare professionals to consider volume, appearance, consistency, and location when addressing patients' experiences holistically.

3.2 | Drainage Impacts Mental Well-Being

The psychological toll of recurrent drainage episodes emerged as a key theme. Patients described living with HS as a ‘rollercoaster’ of pain and relief, with symptoms fluctuating over time. Many women noted worsening symptoms before menstruation, while others identified stress as a trigger for flare-ups, including drainage.

For some, drainage episodes were likened to the buildup of a boil, where the anticipation of its release felt like a mental rollercoaster, oscillating between the intense pain of the

TABLE 2 | Overview of themes, subthemes, and illustrative data extracts on experiences of drainage.

Themes	Dimensions and excerpts
Theme 1: **Drainage is difficult to explain**	**Dimension 1: Drainage is hard to describe and rarely discussed** *The word drainage... well, I don't know what it means. But there is an explanation in parentheses of what it could be. Not everyone knows it, you know... I would have understood it better if it had been called "fluids" instead of "drainage." I didn't even know it was called "drainage" until last year when I started coming here to the hospital.* (Patient 19, DK)
	Dimension 2: Like an egg *There's the drainage that's you know, a combination of like, red mixed with white, it's just like everything is coming out all at once. I also have seen, like almost black, which to me is less severe, but it's blood, but I can tell there's still is some infection floating around in there, but it's on the downside, or, or maybe it's coming up but I'm catching it early. And then there's red, which is, it's coming out, but most of the infectious stuff has gone and it's just, I'm just bleeding.* (Patient 4, US)
	Dimension 3: It is all about those individual draining lessons *Thinking of the worst amount of drainage I have experienced, I think of a specific day, episode, or something similar.* (Patient 2, DK)
Theme 2: **Drainage impacts mental well-being**	**Dimension 1: A rollercoaster experience of pain and relief** *That lesion is gone now, but it was terrible and completely impacted my quality of life. It wouldn't heal on its own and kept draining—sometimes blood, sometimes pus. I had to change bandages multiple times a day, every day. It was messy, painful, and exhausting, especially because it was between my buttocks, making walking, sitting, and everything else incredibly painful.* (Patient 13, US)
	Dimension 2: Drainage as a manifestation of loss of control *A few years ago, we were on vacation in Germany, and I had a lesion just under my breast I lifted my shirt to check in the mirror, and suddenly it burst everywhere—sink, mirror, walls. My boyfriend rushed over, asking what happened because it sounded like a gunshot. It left me feeling faint and sick, especially with the awful smell. He told me to sit and relax while he cleaned up, even though it was unpleasant. Knowing I had that big hole under my chest was unsettling.* (Patient 2, DK)
	Dimension 3: The drainage is not the worst *Once they start to drain, they are no longer a problem for me.* (Patient 13, DK) *I feel like drainage is an annoyance, but it's not painful. I can manage that. Whereas the pain is different—it's like I can't move, I can't put my arm down because my underarm is, you know, so inflamed. That's the worst for me.* (Patient 8, US)
Theme 3: **Drainage involves physical difficulties**	**Dimension 1: Drainage equals malodor challenges** *Right now, I have one under my arm, and I'm waiting for it to drain. When it bursts, there's a horrible smell, and it keeps draining—white at first, then red with blood as it finishes. While there's some relief afterward, the smell can be awful. I use Hibiclens, boil-ease, and Period to manage it and catch the drainage.* (Patient 6, US)
	Dimension 2: Large amounts of clothing and wound dressings *For me, it's this white fluid and blood, and then it just gushes out. Suddenly, I can feel that my underwear has gotten a bit wet, and it's just fluid. Even though I don't have as much now, it still happens constantly. I always feel dirty and have to change clothes all the time.* (Patient 7, DK)
	Dimension 3: Never knowing when drainage will start *For example, when I've been out and suddenly feel that it has burst, even though I didn't think it was there. You can't think about anything else until you get home. It takes up so much space mentally as well.* (Patient 4, DK)

condition and the temporary relief that came with drainage. Some patients described experiencing dark periods in their lives where HS and its associated drainage were overwhelming.

The experience of drainage was often seen as a manifestation of losing control. Despite their best efforts at self-care to prevent the progression of HS, outbreaks would occur unpredictably, reinforcing a sense of powerlessness in managing the disease. This recurring pattern of unexpected flare-ups led to feelings of frustration and defeat, emphasising the emotional and physical challenges of living with HS. Patients found drainage particularly disabling, as it disrupted their social interactions and daily routines. Many referred to specific episodes, highlighting moments when drainage was at its peak.

Although drainage could feel overwhelming at times, patients often stated that it was not the worst aspect of living with HS. They described drainage as an unpleasant but manageable aspect of the condition, recognising it as a persistent challenge that they had to cope with in their daily lives. However, many emphasised that the most debilitating symptom was the persistent and intense pain. The pain was particularly severe during the buildup phase of the lesions, especially when accompanied by accumulating drainage that caused tissue tension. The pain often overshadowed the inconvenience of drainage, significantly affecting patients' ability to perform daily activities, maintain relationships, and preserve emotional well-being, making it the most invalidating aspect of their experience with HS. These findings illustrate how drainage and mental well-being are interconnected. Stress and emotional distress not only result from drainage but also exacerbate the condition itself.

3.3 | Drainage Involves Physical Difficulties

The physical difficulties of managing drainage were a significant burden for patients. The volume, frequency, and duration of drainage episodes were key factors contributing to the overall symptom burden.

Malodour was frequently mentioned as one of the most distressing aspects. Despite rigorous hygiene efforts, the smell was persistent and often socially isolating. Patients described feelings of shame and self-consciousness, noting the impact on their relationships and social lives.

Managing the drainage required a significant reliance on wound dressings and frequent clothing changes, which patients described as a labour-intensive aspect of their daily routines. They described using large quantities of dressings, often layering them to adequately absorb the persistent and unpredictable fluid. Some patients recounted changing dressings and clothes multiple times a day, and in severe cases, even hourly. The effort to keep the lesion areas clean and dry was relentless, with many carrying spare dressings wherever they went to avoid potential leaks or stains. This constant focus on managing drainage not only created a physical burden but also led to feelings of frustration and emotional exhaustion.

The unpredictable timing of drainage added another layer of difficulty. Some lesions developed without warning, leaving patients unprepared and embarrassed in public situations. Despite these challenges, the burden of drainage varied between individuals, emphasising the need for personalised care and longitudinal monitoring to address this symptom effectively.

4 | Discussion

This study examined the experiences of patients with HS regarding drainage, a common but insufficiently researched symptom, with the aim of informing person-centred care strategies. The findings revealed that drainage is a multifaceted and distressing experience, presenting challenges in articulation, significant impacts on mental well-being, and considerable physical difficulties. Patients described drainage as unpredictable and difficult to quantify, noting variations in its volume, consistency, and appearance as key aspects shaping their experiences.

Beyond the physical burden, drainage was closely linked to emotional distress, social stigma, and reduced quality of life, exacerbated by malodour and the labour-intensive management of wound care. Despite these challenges, patients consistently identified the persistent and intense pain of HS as their most debilitating symptom. This finding aligns with previous research, which highlights pain as a primary concern for individuals living with HS [4, 21].

The findings of our study align with existing literature that underscores the profound impact of HS on patients' quality of life, particularly in relation to drainage. Previous research has highlighted the significant physical and psychological burdens of HS, including pain, malodour, and social stigma, which contribute to emotional distress and reduced quality of life [8, 22–25]. The unpredictability and variability of drainage, as reported by participants, further supports findings from earlier studies that emphasise the challenges of managing this symptom within the context of wound care [26]. The fluctuating volume, consistency, and appearance of drainage complicate both wound management and daily activities, exacerbating the physical burden on patients.

This study adds depth and nuance to the understanding of drainage as a multidimensional experience. Patients' perspectives reveal that drainage extends beyond the quantification of fluid output. Reporting drainage involves not only estimating the volume over a defined period, such as the past week, but also reflecting on broader aspects of their lived experience since the last clinical consultation. This includes subjective elements such as the psychological and emotional toll of recurrent drainage episodes. Patients expressed the need to describe drainage in greater detail, incorporating specific attributes such as the type (e.g., pus, blood, serous fluid), anatomical location, colour, malodour, and the shape or nature of the lesion. These findings complement survey-based research on incision and drainage [10], by extending the perspective to the everyday, multidimensional burden of spontaneous drainage.

Our findings expand upon existing literature and provide practical insights into the clinical management of HS. This deeper understanding has the potential to guide evidence-based treatment strategies and care practices. Additionally, the study emphasises the importance of holistic and personalised approaches that address not only the physical burden of drainage but also its significant psychosocial impacts. By integrating these dimensions, healthcare providers can better meet the needs of patients with HS and deliver more comprehensive, patient-centred care.

Person-centred practice, as defined by McCormack and McCance, emphasises the importance of fostering meaningful relationships among care providers, patients, and those significant to them. It involves working with patients' beliefs and values, demonstrating a sympathetic presence, engaging in shared decision-making, and providing holistic care [19]. In the context of HS, promoting a person-centred approach requires that clinical discussions about drainage address both its physical and psychosocial dimensions [9, 25]. Holistic assessments of drainage should include detailed descriptions and provide an open, supportive space for patients to share their experiences in their own words. Simultaneously, systematic tools such as standardised drainage outcome scales can enable healthcare providers to monitor and manage HS more effectively over time [27].

These elements are essential for delivering empathetic, comprehensive care and ensuring that patients with HS feel validated in their experiences. When patients feel heard and their challenges are acknowledged, the patient–clinician relationship is strengthened, fostering trust and collaboration throughout the treatment journey [19]. This approach can also be integrated into patient education [28].

4.1 | Strengths and Limitations

Key strengths of this study include the analytic expansion, retrospective interpretation, and broadened sampling to broaden the scope and deepen the understanding of the findings [14].

Challenges inherent to qualitative secondary analysis, such as aligning the data with the new research question, posed potential limitations [15]. These challenges were addressed by explicitly identifying the study as a secondary analysis and discussing its strengths and limitations.

Another limitation of the study is the overrepresentation of patients with severe HS, which may have skewed the narratives toward more severe experiences. Additionally, our study population included a higher percentage of female patients compared to typical HS clinical trials. The sample also lacked ethnic diversity, particularly in the Danish cohort. These factors highlight the need for future research to investigate drainage across a broader spectrum of disease severity and a more balanced demographic representation.

5 | Conclusions

This study provides an in-depth account of patients' experiences with drainage in hidradenitis suppurativa, focusing exclusively on this underexplored symptom. By doing so, it contributes unique patient perspectives that deepen the understanding of drainage as a complex phenomenon with profound physical, psychological, and social impacts. Incorporating standardised tools such as patient-reported outcomes, alongside open and empathetic dialogue, can validate patients' experiences and support holistic, person-centred care. By addressing both the physical and psychosocial dimensions of drainage, healthcare providers can strengthen patient–clinician relationships and ultimately improve the well-being of individuals living with HS.

Author Contributions

Stine Thestrup Hansen: conceptualisation, data curation, formal analysis, investigation, methodology, project administration, resources, software, supervision, validation, visualisation, writing – original draft. **Bente Villumsen:** conceptualisation, supervision, validation, writing – review and editing. **Mina Shereen Khaled:** project administration, validation, writing – review and editing. **Terri Shih:** project administration, validation, writing – review and editing. **Steven Daveluy:** conceptualisation, supervision, validation, writing – review and editing. **Amit Garg:** Conceptualisation, supervision, validation, writing – review and editing. **Susanne de Goeij:** project administration, validation, writing – review and editing. **Barry M. McGrath:** project administration, validation, writing – review and editing. **Peter Theut Riis:** conceptualisation, supervision, validation, writing – review and editing. **Kari Zalik:** project administration, validation, writing – review and editing. **Jennifer L. Hsiao:** project administration, validation, writing – review and editing. **Camilla G. Frederiksen:** project administration, validation, writing – review and editing. **Noor F. Goandal:** project administration, validation, writing – review and editing. **Hans Christian Ring:** project administration, validation, writing – review and editing. **Joseph Dowsett:** project administration, validation, writing – review and editing. **Rahul Masson:** project administration, validation, writing – review and editing. **John R. Ingram:** conceptualisation, supervision, validation, writing – review and editing. **Gregor B.E. Jemec:** conceptualisation, supervision, validation, writing – review and editing. **Joslyn S. Kirby:** conceptualisation, supervision, validation, writing – review and editing. **Linnea Thorlacius:** conceptualisation, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, resources, software, supervision, validation, visualisation, writing – original draft.

Ethics Statement

All patients in this manuscript have given written informed consent for participation in the study and the use of their de-identified, anonymized, aggregated data and their case details for publication. Approved by the Danish Data Protection Agency. Ethical review not required by the Danish Medical Research Ethics Committee for qualitative interviews and questionnaire studies. Approved by the Institutional Review Board at Penn State University (STUDY00022216).

Conflicts of Interest

The following authors declare no conflicts of interest: Stine Thestrup Hansen, Bente Villumsen, Mina Shereen Khaled, Terri Shih, Susanne de Goeij, Kari Zalik, Noor F. Goandal, Joseph Dowsett, Rahul Masson. The following authors report conflicts of interest: **Steven Daveluy**: research funding from Abbvie, Incyte, UCB, Novartis, Pfizer, Moonlake, Regeneron, Sanofi, and Insmed; consulting fees from Abbvie, UCB, Incyte, and Novartis; honoraria from Abbvie, UCB, and Novartis. **Amit Garg**: research grants from AbbVie, UCB, and the CHORD COUSIN Collaboration (C3); co-copyright holder of the HS-IGA and HiSQOL instruments; advisor to AbbVie, Almirall, Boehringer Ingelheim, Engitix, Immunitas Therapeutics, Incyte, Insmed, Navigator Medicines, Novartis, Pfizer, Priovant, Sun Pharma, UCB, Union Therapeutics, and Zura Bio. **Barry M. McGrath**: consultancy and research with Almirall, Incyte, MoonLake, Novartis, and UCB; honoraria from Novartis, UCB, and MoonLake; travel support from Novartis and UCB; member of HS steering committees with Novartis and UCB (paid); unpaid leadership roles with HS Ireland charity board, HISTORIC, H-Strong, BAD HS Guidelines Development Group; Patient Associate Editor, *British Journal of Dermatology* (unpaid); PPI reviewer, Health Research Board Ireland (paid). **Peter Theut Riis**: Advisory Board member for Almirell. **Jennifer L. Hsiao**: grants to institution for clinical trials from Amgen, AstraZeneca, Incyte, and Novartis; consulting fees from AbbVie, Aclaris, Boehringer Ingelheim, Incyte, Navigator Medicines, Novartis, Pfizer, Sanofi, and UCB; honoraria from AbbVie, Galderma, Novartis, Sanofi, Regeneron, and UCB; Board of Directors member, HS Foundation (unpaid). **Camilla Gøtzsche Frederiksen**: ownership of stocks in Novo Nordisk and Bavarian Nordic. **Hans Christian Ring**: Advisory Board member for UCB and Novartis. **John R. Ingram**: co-copyright of HiSQOL, Investigator and Patient Global Assessment instruments for HS; departmental income from DLQI; consulting for AbbVie, Boehringer Ingelheim, Cantargia, ChemoCentryx, Citryll, Elasmogen, Engitix, Incyte, Indero, Insmed, Kymera Therapeutics, MoonLake, Novartis, UCB Pharma, UNION Therapeutics, and Viela Bio; stipend as past Editor-in-Chief of the *British Journal of Dermatology*; authorship honorarium from *UpToDate*. **Gregor B. E. Jemec**: research grants from AbbVie, ChemoCentryx, InflaRx, LEO Pharma, Novartis, and UCB Pharma; consulting fees from Novartis and UCB Pharma; travel support from Sanofi; leadership roles as Vice President, EHSF e.V.; Board Member of C3 and CHORD; Co-coordinator, ALLOCATE group of ERN-Skin; Vice Chair, ARHS Task Force of EADV; Editor-in-Chief, *Dermatology*; co-copyright holder of HiSQOL© and HS-IGA©. **Joslyn S. Kirby**: full-time employee of Incyte Corporation. **Linnea Rishøj Thorlacius**: co-copyright holder of HiSQOL© and HS-IGA©.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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