

The Personal Impact of Daily Wound Care for Hidradenitis Suppurativa

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Keywords

Hidradenitis suppurativa · Non-surgical wounds · Personal impact · Frequency of dressing changes · Acne inversa · Wound care · Quality of life · Chronic wounds

Abstract

Background: Recurring nodules, abscesses, and lesions characterise hidradenitis suppurativa (HS): a chronic, inflammatory skin disorder. Globally the prevalence of HS is estimated to be around 1% of the population. Leakage, pain, and odour from HS wounds require substantial management. Little is known of the personal burdens that routine wound management imposes on the patient. **Objectives:** To evaluate how routine HS wound management impacts patients in terms of the time spent changing dressings, the number of dressings required per day, pain experienced during dressing changes, and negative impact on various domains of their personal lives. **Methods:** An anonymous online questionnaire was posted on closed social media patient support groups between April and May 2019. Pearson χ^2 test was used to evaluate if Hurley stages influenced the personal impact of wound care routines on patients. Statistical significance was determined as p value <0.05 . **Results:** In total,

908 people from 28 countries responded. Of these, 81% ($n = 734$) reported that regular dressing changes negatively impacted on their quality of life. Most patients, 82% ($n = 744$), experience pain during dressing changes. 16% ($n = 142$) of patients required five or more dressings daily, and 12% ($n = 108$) spend over 30 min daily tending to wounds. Patients indicated high levels of dissatisfaction with currently available wound dressings. **Conclusion:** HS wound management imposes a substantial personal burden on patients. There is a clear unmet need for HS-specific wound dressings and wound care provisions, and a greater awareness of the condition and its impact is needed among clinicians.

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Introduction

Chronic wound care management imposes substantial economic burdens on healthcare systems, societies, and individuals [1]. Recently, there has been increased attention on the health-related quality of life impacts of chronic wounds on the patient [2]. It is now well established that chronic wound care can have a negative impact on patient quality of life, and on family members [3].

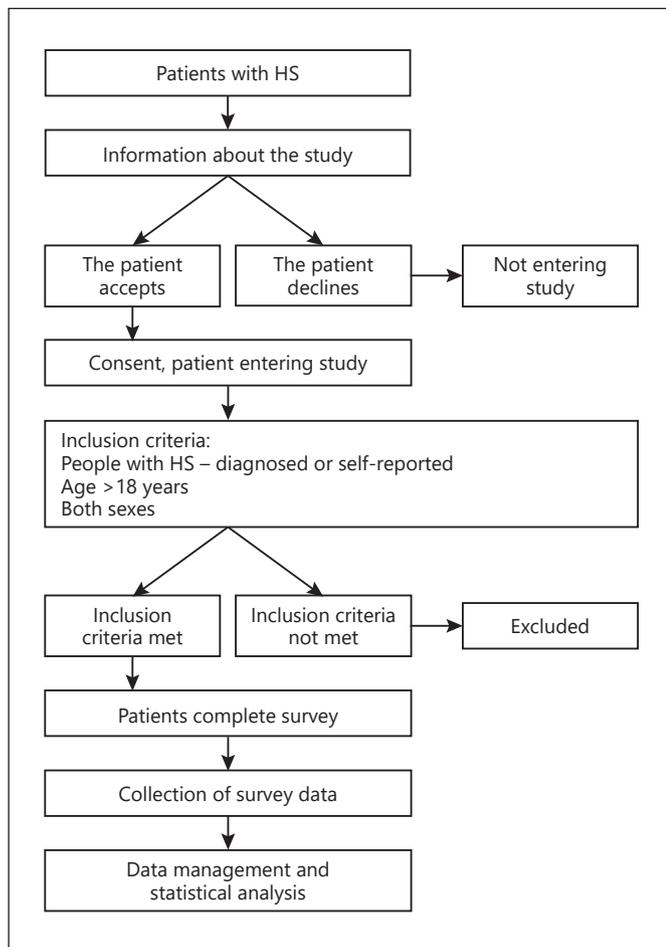


Fig. 1. Flow diagram showing study method.

Hidradenitis suppurativa (HS) is a chronic inflammatory scarring follicular disorder that manifests as painful nodules, abscesses, and draining tunnels at anatomical locations including, but not limited to, the axillae, perianal area, perineum, breasts, and inguinal areas [4]. Among the many challenges facing HS patients is the effective management of malodorous discharge from affected areas. HS often begins at or after puberty, thereby frequently imposing a lifelong burden to the patient in terms of wound management.

Most widely available wound dressings have been developed for use on flat or convex body surfaces, whereas HS predominantly affects concave surfaces that are in frequent motion. Managing wounds and applying and retaining dressings in the locations typically affected by HS can therefore be challenging [5]. Furthermore, the odour, pain, and leakage from lesions can unpredictably fluctuate. Consequently, wound management requirements

may change, requiring different dressing types over time [5–8].

Since 2015, various international guidelines on managing and treating HS have been published; all recognising the importance of wound care management in the daily lives of HS patients [9]. Within these guidelines, however, the evidence supporting specific recommendations on dressings for HS are lacking [10–12]. In the literature, there are just a few recent reports examining dressing types specifically for HS wounds [5–8].

There is a lack of understanding of the impact of the daily management of wounds on the individual with HS. This study aimed to address this gap, and to describe the real-life experiences of HS patients with wound care regimes.

Materials and Methods

A survey comprising 26 questions was posted online into HS patient support groups via the group administrators.

Inclusion criteria: participants must be >18 years old and be living with HS, diagnosed or self-reported. Both sexes were included.

Exclusion criteria: <18 years old, not living with HS.

The survey link was live for 1 month. Survey response data was analysed for statistical significance.

The flow diagram for the study is provided in Figure 1.

Results

A total of 908 respondents from 28 countries completed the survey, which was conducted between April and May 2019.

Demographics

Demographic details of respondents are shown in Table 1. The respondents were predominantly female (95%, $n = 865$); with 6% ($n = 58$) in the 18–24 years age bracket; 66% ($n = 596$) were 25–44 years old, and 20% ($n = 182$) in 45–54 years category. A total of 25% ($n = 227$) did not know their current Hurley stage. While 39% ($n = 353$) reported their HS Hurley stage at III, with 30% ($n = 271$) at stage II, 6% ($n = 56$) at stage I.

As Table 2 shows, the majority of patients are affected by HS on 2–4 areas of their body, and as shown in Table 3, the most commonly affected areas are the groin/thigh and armpit.

Most survey respondents were from North America (50%, $n = 457$), followed by Europe (44%, $n = 398$) and

Table 1. Demographics of those who responded to the study survey

Demographics	N (%)
Gender	(n = 908)
Female	865 (95.3)
Male	43 (4.7)
Age	(n = 905)
18–24	58 (6.4)
25–34	268 (29.6)
35–44	328 (36.2)
45–54	182 (20.1)
55–64	57 (6.3)
65+	12 (1.3)
Hurley stage	(n = 907)
I	56 (6.2)
II	271 (29.8)
III	353 (38.9)
Did not know	227 (25)
Location	(n = 907)
USA	399 (44.0)
UK	294 (32.4)
Canada	58 (6.4)
Ireland	47 (5.2)
Australia	26 (2.9)
Denmark	22 (2.4)
Sweden	16 (1.8)
India, The Netherlands	5 (0.6) each
Israel, New Zealand	3 (0.3) each
Belgium, Brazil, Germany, Poland, Slovenia, South Africa, Switzerland	2 (0.2) each
Austria, Costa Rica, Czech Republic, Eritrea, Greece, Italy	1 (0.1) each

the remainder from the rest of the world (6%, $n = 53$). Countries represented by >10 respondents include USA ($n = 399$), Canada ($n = 58$), UK ($n = 293$), Australia ($n = 26$), Denmark ($n = 22$), Ireland ($n = 47$), and Sweden ($n = 16$). Countries represented by <10 respondents include Austria ($n = 1$), Belgium ($n = 2$), Brazil ($n = 2$), Costa Rica ($n = 1$), Croatia ($n = 2$), Czech Republic ($n = 1$), Eritrea ($n = 1$), Germany ($n = 2$), Greece ($n = 1$), India ($n = 5$), Israel ($n = 3$), Italy ($n = 1$), Lebanon ($n = 1$), the Netherlands ($n = 5$), New Zealand ($n = 3$), Philippines ($n = 1$), Poland ($n = 2$), Portugal ($n = 2$), Slovenia ($n = 2$), South Africa ($n = 2$), Switzerland ($n = 2$). One participant did not provide country information.

In total, 90% ($n = 820$) of respondents reported that their HS lesions require wound dressings. Patients report using a combination of different dressing types to manage their lesions. As shown in Table 4, some 49% ($n = 445$) use adhesive island dressings, 59% use non-adhesive dressings with tape or bandages. Further, 44% ($n = 397$) improvise with items such as sanitary towels, kitchen

Table 2. The numbers of anatomical areas affected by HS, as reported by the survey respondents

No. of areas affected	Percentage of patients	N
1	7.9%	72
2	11.8%	107
3	20.6%	187
4	26.9%	244
5	18.5%	168
6+	14.3%	130

Table 3. The areas of the body affected by HS, as reported by the survey respondents

Area affected	Percentage of patients affected	N
Armpit	79%	720
Groin/thigh	91%	828
Perineum/perianal skin	30%	276
Genitals	57%	516
Buttocks	59%	536
Breasts	56%	512
Other	7.6%	69

Table 4. Types of dressings used as reported by survey responses, and experience of current dressings

	Percentage of patients	N
Type of dressing		
Adhesive dressing	49%	443
Non-adhesive with tape	36%	329
Non-adhesive with bandage	22%	201
Improvised dressings	44%	397
Other	14%	124
Experience leaks or lost dressings	93%	843
Experience adhesive sensitivity	84%	767

towel, and tissue paper. Participants had the option to provide multiple answers to this question. Most (85%, $n = 769$) respondents reported adhesive sensitivity, and 93% ($n = 845$) of patients have experienced a dressing leak or fall-off.

Areas of Life Impacted by Dressings

As shown in Figure 2, 81% ($n = 734$) of patients believe that tending to their wounds and dressing changes are a contributing factor to a reduced quality of life ($p < 0.001$) (Table 5).

Table 5. χ^2 test showing perceived negative impact on quality of life (p value <0.0001) – the proportion of survey respondents reporting that wound care/dressing changes are/are not a contributing factor to a reduced quality of life

	Response				Overall p value
	Don't know (frequency)	No (frequency)	Yes (frequency)	N/A (frequency)	
No. of respondents	102 (11.2%)	68 (7.5%)	734 (80.8%)	4 (0.4%)	<0.0001

Table 6. Assessing the most affected aspects of patient's lives based on varied criteria. Participants were asked to select which areas of their life was negatively impacted by daily HS wound management

Criteria	No	Freq (%)	Yes	Freq (%)	Overall p value
Work Life	278	(30.6%)	630	(69.4%)	<0.0001
Social Life and Hobbies	149	(16.4%)	759	(83.6%)	<0.0001
Relationships and Sex Life	119	(13.1%)	789	(86.9%)	<0.0001
Day to Day activities	165	(18.2%)	743	(81.8%)	<0.0001
Mental Health	142	(15.6%)	766	(84.4%)	<0.0001
Financial Wellbeing	528	(58.1%)	380	(41.9%)	<0.0001
General Wellbeing	249	(27.4%)	659	(72.6%)	<0.0001

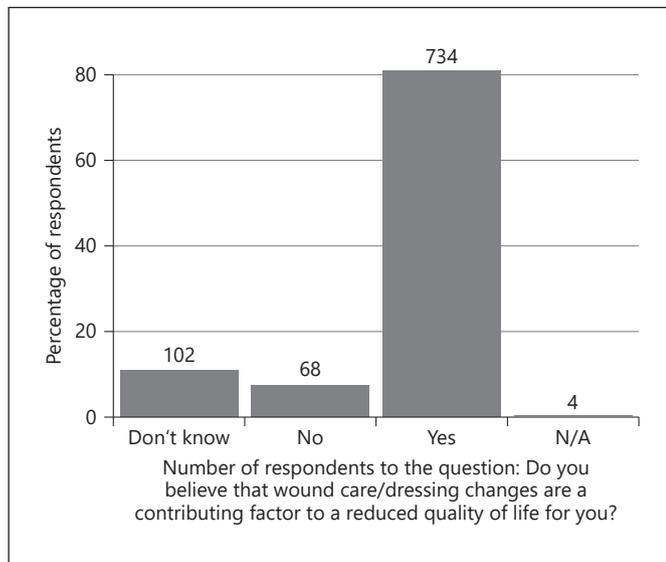


Fig. 2. The plot shows the proportion of HS patient respondents reporting on wound care/dressing changes and the impact on quality of life.

Patients were asked to indicate what areas of their lives they felt were impacted by the need to apply dressings and were offered seven options (Table 6). As shown, most respondents answered that tending to their HS wounds

Table 7. The financial impact of HS wound care

	Percentage of respondents	Number of patients
Amount in Euro (Euro respondents, $n = 55$)		
EUR 10 or less per week	49%	27
EUR 11–30 per week	47%	26
EUR 31–45 per week	1.5%	1
Over EUR 45 per week	1.5%	1
Amount in Sterling (UK respondents, $n = 237$)		
GBP 10 or less per week	74%	175
GBP 11–30 per week	23.6%	56
GBP 31–45 per week	0.8%	2
Over GBP 45 per week	1.6%	4
Amount in USD (USA respondents, $n = 375$)		
USD 10 or less per week	55.5%	208
USD 11–30 per week	36.5%	137
USD 31–45 per week	6.1%	23
Over USD 45 per week	1.9%	7

does negatively impact their daily lives to varying extents (Table 6) in almost all options available.

The only exception to this was “financial well-being,” where 58% ($n = 528$) indicated that application of dressings did not negatively impact them financially. Some 79% ($n = 726$) of participants purchase their wound dressings at the pharmacy. Only 8% ($n = 75$) had

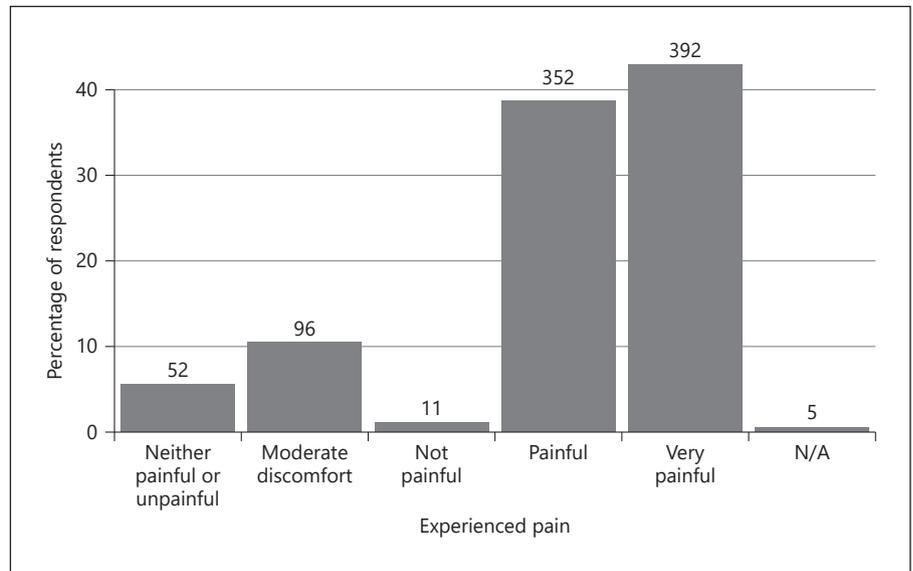


Fig. 3. The plot shows the proportion of HS patient respondents who reported on dressing-related pain experienced.

no out-of-pocket expenses relating to wound dressings. A summary of out-of-pocket expense is shown in Table 7.

Pain during Dressing Changes

We explored the proportion of HS patients who experienced pain when applying their dressings (Fig. 3). A total of 82% ($n = 744$) reported that tending to dressings was a painful experience, with 43% ($n = 392$) reporting it as very painful (Table 8). Furthermore, dissatisfaction with dressing leaks, comfort, and ease of use were reported but rates of dissatisfaction were not influenced by Hurley stage.

Frequency of Dressing Changes

The association between the self-reported Hurley stage and the number of dressings used on a typical day were analysed. As shown in Figure 4 there were considerable differences in the number of dressings required on a typical day. In total, 17% ($n = 156$) of patients reported using just one dressing per day, 24% ($n = 214$) use three dressings per day, 13% ($n = 114$) use four dressings daily, while 16% ($n = 142$) use five or more dressings daily. Over the course of a month, this translates to 90 dressings for 24% of patients, 120 dressings for almost 13% of patients, and more than 150 dressings for almost 16% of HS patients.

The frequency of dressing changes differed significantly ($p < 0.001$) depending on Hurley stage (Table 9); the majority (>90%) of stage I used one to three dressings daily, whereas >27% of stage III patients reported using on average five or more dressings in a day.

Table 8. χ^2 test assessing dressing-related pain (p value <0.0001)

Response	No. of respondents	Frequency	p value
Neither painful or unpainful	52	5.7%	<0.001
Moderate discomfort	96	10.6%	<0.001
Not painful	11	1.2%	<0.001
Yes, painful	352	38.8%	<0.001
Yes, very painful	392	43.2%	<0.001
N/A	5	0.6%	<0.001

Time Spent Changing Dressings

We explored the relationship between the amount of time patients spent per day on their dressings and assessed the association between this and the self-reported HS Hurley stage. As illustrated in Figure 5, for all Hurley stages including respondents who do not know the Hurley stage, 59% ($n = 530$) indicated that they were spending up to 15 min per day on their HS dressings, while there were considerable differences when Hurley stages were compared. Additionally, 29% ($n = 261$) reported they spent from 16 to 30 min per day on their dressings. The Pearson χ^2 test confirmed a significant association between the Hurley stage and the time spent on dressing (shown in Table 10), where patients spent significantly more time tending to dressings depending on disease severity ($p < 0.001$). Notably, 11% ($n = 95$) who reported Hurley stage, and 1% ($n = 13$) who did not know their Hurley stage, indicated they were spending over 30 min per day on their dressings.

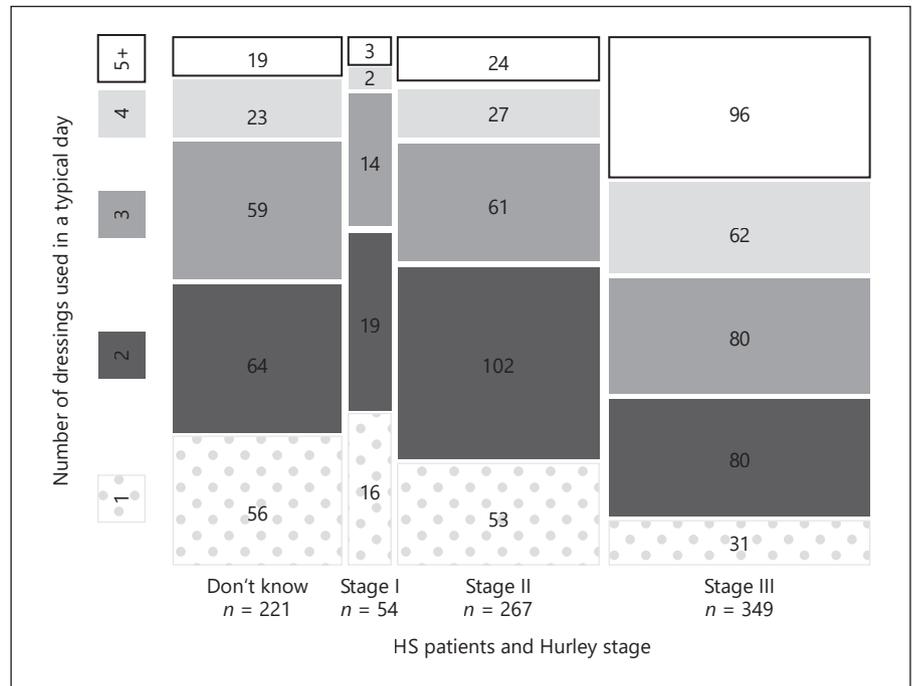


Fig. 4. The plot shows the association between Hurley stage and number of dressings used on a typical day.

Table 9. χ^2 test demonstrating the association between Hurley stage and the number of dressings used ($p < 0.001$)

	No. of respondents				Overall p value
	Don't know	Stage I	Stage II	Stage III	
No. of dressings used daily					
1	56	16	53	31	<0.001
2	64	19	102	80	<0.001
3	59	14	61	80	<0.001
4	23	2	27	62	<0.001
5+	19	3	24	96	<0.001

Discussion/Conclusion

Our results imply that wound care management imposes substantial burdens on HS patients in relation to the patient's quality of life, dressing-related pain, frequency of dressing changes, and time constraints.

Areas of Life Impacted by Dressings

Most HS patients indicated that managing their wounds had negative impacts on multiple areas of their lives, including mental health, work, sex life, and relationships. Loneliness, separation from an active social life, and depression are just some of the negative mental health impacts associated with chronic wounds [13, 14], and de-

pression [15], social isolation [16], and loneliness [17] have all been associated with HS. There have been several recent reports associating HS with impaired work productivity [18–20]. In addition, HS has been demonstrated to negatively impact on a patient's ability to form intimate relationships [21, 22].

Pain during Dressing Changes

Survey participants overwhelmingly indicated that they experienced pain during dressing changes. Pain is regularly experienced in the management of chronic wounds, often exacerbated by dressing changes, and damage to peri-wound skin [23]. This pain can take up to 1 h to resolve [23]. Dressing removal is a known contrib-

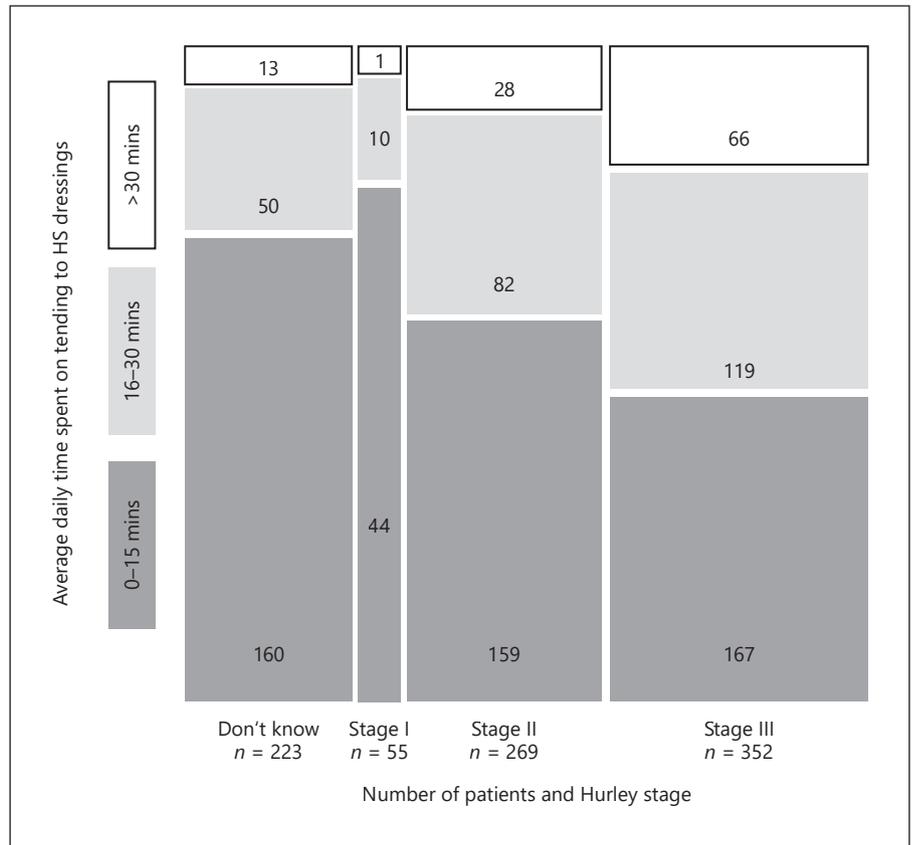


Fig. 5. The plot shows the association between Hurley stage and time spent on dressing changes in an average day.

Table 10. χ^2 test demonstrating the relationship between Hurley stage and time spent on dressings

	No. of respondents				Overall <i>p</i> value
	Do not know	Stage I	Stage II	Stage III	
Average daily time spent on HS dressings					
0-15 min	160	44	159	160	<0.001
16-30 min	53	1	82	119	<0.001
Over 30 min	13	1	28	66	<0.001

utor to wound-related pain, and inappropriate dressing selection is also a contributing factor [23].

The majority of survey respondents report adhesive sensitivity. It is known that improper technique in removing dressings can strip skin, damage skin integrity, cause pain, delay healing, and increase the risk of infection [24].

Top tier dressings such as low adherent silicone or low adherent foam dressings, which can reduce medical adhesive-related skin injury [24], are high cost and typically not available over the counter [8]. In this study the majority of patients do not have access to professional wound care facilities, nor top tier dressings.

Most patients indicated dissatisfaction with comfort, ease of use (applying, adjusting, removing), and confidence that the dressing will not leak or move. HS wound phenotypes change over time; accordingly, so too do the wound care requirements [8].

Frequency of Dressing Changes

Our study shows the association between the frequency of HS dressing changes and disease severity. Many patients with more advanced HS needed five or more daily dressing changes, clearly imposing a significant personal burden on the patient. Studies on other wound condi-

tions requiring regular dressing changes (such as pressure ulcers) show that on average, approximately three dressing changes per week are needed [13]. A study assessing home care wound management needs in four communities in Denmark reported 3.53 dressing changes per week, with approximately one quarter of the >1,000 patients assessed requiring a daily dressing change [14]. Within the current study, 53% ($n = 470$) require three or more dressings daily, and 16% ($n = 142$) reported needing five or more daily dressing changes, highlighting the personal impact HS can impose on patients.

Time Spent Changing Dressings

A sizeable proportion of HS patients spend the equivalent of almost 1 day (in terms of waking hours) per month tending to their wounds alone. Studies have shown that 70–80% of wound patients in general have their wounds treated by a community nurse [25], imposing significant constraints on healthcare workers and resources [2, 26]. HS patients typically attend a clinical setting for assistance with post-surgical wounds; however, the routine management of their wounds over the course of the illness is largely left to the patient. It is evident that daily management of HS wounds requires a significant investment of time. The majority of respondents report HS lesions affecting two or more anatomical locations, evidently influencing time spent changing dressings. Time spent managing dermatoses impacts economic productivity and potentially impacts the patient's welfare and ability to work. For example, in the treatment of psoriasis, Ring et al. found that an average of 526 min was spent by patients in treatments to reduce the psoriasis area and severity index (PASI) score with one point at an estimated cost to the patient of EUR 285.20 in terms of working hours [27]. Our study only captured the time spent on dressings. Other time-consuming factors that impact psychosocial well-being of the patient, such as doctors visits, and transport [28] or hospitalisation, shopping for clothing, doing laundry, or preparing special diets [29] were not included.

There is a notable lack of wound dressings specifically designed for non-surgical wounds in the HS patient [5, 6, 30] or any evaluations of dressings available for HS patient non-surgical wound management [8]. The current study highlights the unmet need for HS-specific wound care dressings as reported by patients, and the lack of clinical wound management provisions available to HS patients.

In summary, the results illustrate that day-to-day management of non-surgical wounds can have significant negative impacts on the lives of some HS patients.

The data presented herein represent a comprehensive study on the personal impact that wound care can have on HS patients, and patient dissatisfaction with current dressing options. These patient-reported experiences indicate that the daily management of wounds characteristic of this chronic condition can have notable impacts on patients' personal lives.

Study Limitations

We acknowledge the limitations in this study design. These include:

Under-coverage: the survey was not translated into other languages, limiting the study to English speakers. It also captured the experience of only patients who are active in online communities. The patient population in the study may be inadequately represented.

Voluntary response bias: the respondents were self-selected, and the responses were patient reported.

Response bias potentially leading to social desirability wherein respondents wish to present themselves in a favourable light.

The survey link was shared into closed HS support groups, but there was no mechanism to ensure each respondent was a HS patient, as it is self-reported. The link could be accessed more than once. However, duplicate data were removed before analysis.

Key Message

Non-surgical wound care has considerable personal impact on HS patients.

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Statement of Ethics

Informed consent form and all study materials were submitted to the Ethics Committee (EC) at The Hermitage Clinic, Old Dublin Road, Dublin Ireland, for review and approval. Approval of both the documentation (study approval reference number HMC-005/2019) and the consent form was obtained before any subject

was enrolled. Written consent was obtained by participants. The study was conducted in accordance with Good Clinical Practice and the Declaration of Helsinki.

Conflict of Interest Statement

Suzanne Moloney is the founder and a shareholder of HydraMed Solutions, a start-up wound care company creating solutions for people living with HS. Suzanne is also a HS patient. Dr Barry McGrath is a HS patient, co-founder of the nascent patient organisation HS Ireland, manages a HS patient support group, and works as an unpaid scientific advisor and research associate at HydraMed Solutions.

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Author Contributions

All Authors fulfil the ICMJE criteria for authorship. Suzanne Moloney contributed to the questionnaire design, recruitment to the study, data collection, and drafting of the manuscript. Barry McGrath contributed to the data analysis, drafting and review of the manuscript. Davood Roshan contributed to the analysis and interpretation of data for the work, and revision of the manuscript. Georgina Gethin contributed to the questionnaire design and critical review of the manuscript.

Data Availability Statement

The data that supports these findings are not publicly available but can be made available on request. Please contact the author.

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