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The Management of Pediatric Hidradenitis Suppurativa Differs Between Dermatologic and Non-Dermatologic Providers: A Retrospective Review

Kelly M. Atherton, MD, MSCR[1], **Chelsea N. Shope, MD, MSCR**[1], **Laura A. Andrews, MD, MSCR**[1], **India S. Robinson-Pirotte, MD, MSCR**[1], **Lara Wine Lee, MD, PhD**[2], **Colleen H. Cotton, MD**[3,4]

[1]College of Medicine, Medical University of South Carolina, Charleston, SC

[2]Department of Dermatology & Dermatologic Surgery, Medical University of South Carolina, Charleston, SC

[3]Division of Dermatology, Children's National Hospital, Washington, DC

[4]Department of Dermatology, George Washington School of Medicine and Health Sciences, Washington, DC

Abstract

Background/Objectives: There is a paucity of pediatric hidradenitis suppurativa (HS) literature. The objective of this study was to characterize differences in management of pediatric HS patients by dermatology vs. non-dermatology clinicians.

Methods: We examined a retrospective cohort of 195 pediatric patients with HS seen at our institution (3/1/19–3/1/20). Two-sample t-tests and two-proportion z-tests were performed.

Results: A total of 76.1% of subjects were seen by dermatology at least once, and of these, 79.1% were referred. HS diagnosis was most often made by dermatology (36.6%), followed by pediatrics (21.6%). Patients managed by dermatology were significantly more likely to have used standard of care therapies (p<0.001). Of dermatology-managed patients, 19.7% were currently

Corresponding Author: Chelsea Shope, MD, MSCR, 171 Rutledge Ave, 11th Floor, Department of Dermatology, Medical University of South Carolina, Charleston, SC 29403, Phone: 843-754-9577, shopec@musc.edu.

Author Contributions:

Kelly Atherton, Chelsea Shope, and Laura Andrews were responsible for the investigation, data curation, formal analysis, and writing of the original manuscript draft.

India Robinson-Pirotte was responsible for investigation, data curation, and reviewing and editing of the manuscript draft.

Lara Wine Lee was responsible for the conceptualization and supervision of this project. She was also responsible for reviewing and editing the manuscript draft.

Colleen Cotton was responsible for the conceptualization, methodology, and formal analysis of this project. She was also responsible for reviewing and editing the manuscript draft.

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prescribed a biologic, as compared with zero patients not managed by dermatology. Those managed by dermatology were less likely to undergo surgical excision (13.3% vs 25.5%, p=0.04).

Conclusions: Our results support increased likelihood of treatment escalation with medical management by dermatologists. Relatively high utilization of referral to dermatology exists, but with only moderate patient adherence. There is a need for improved access to dermatologic care, and prospective studies to determine if differences in specialty management translate to improved patient outcomes.

Keywords

hidradenitis suppurativa; management; pediatric; therapy; outcomes

Introduction

Hidradenitis suppurativa (HS) is a chronic, inflammatory skin condition in which characteristic occlusion of hair follicles is associated with recurrent cycles of inflammation, healing, and scarring.[1] Commonly affected sites include the axilla and inframammary, inguinal, pubic, gluteal, and perianal regions. A recent survey of patients with HS who self-reported the onset of their symptoms demonstrated a bimodal age of onset, peaking in the late teens and mid 40s.[2] Further, a 2021 study showed that up to 50% of HS patients have symptoms between the ages of 10 and 21 years.[3] HS is relatively uncommon, with an estimated prevalence of 0.4% worldwide.[1]

Characterizing HS remains elusive due to lag time between symptom onset and diagnosis, gaps in understanding pathophysiology, lack of standardized treatment protocols, and difficulties in measuring meaningful outcomes of treatment success. Management of adult patients with HS by dermatologists has been associated with treatment escalation from topical therapies to oral medications, biologics, and multimodal treatments,[4] which may improve clinical outcomes and prevent long-term complications of disease. However, utilization of outpatient dermatology services remains poor.[5]

Characterizing presentation, management, and outcomes associated with HS in pediatric patients is even more difficult. Direct comparisons between the variety of specialties which manage pediatric HS are lacking. We aim to identify differences in clinical management and treatment regimens for pediatric HS patients who are primarily managed by dermatology as compared to another specialty.

Methods

After institutional review board approval was received, we conducted a search of the electronic medical record (EMR) at the Medical University of South Carolina to identify all pediatric patients seen between 3/1/2019 and 3/1/2020 who had an ICD-10 diagnosis code of HS (L73.2) documented. Patients up to age 20 were included in the analysis.

Retrospective chart review was conducted to collect baseline demographic data as well as information pertaining to HS disease course and severity, including Hurley stage. For patients without Hurley staging documented in the EMR, a board-certified dermatologist

(C.H.C.) determined likely Hurley stage based on the documented physical exam at time of initial presentation for HS, in accordance with previously published methods.[6] Information pertaining to disease management, including timing and number of healthcare visits, provider specialty, medical treatments, surgical treatments, and emergency service utilization, were also collected.

Descriptive statistics were used to characterize the study population. Two-sample t-tests and two-proportion z-tests were performed for continuous variables. Categorical variables were analyzed using two-sided Pearson for Fisher's exact or Fisher-Freeman-Halton exact for X^2 testing. A significance level of 0.05 was used in all analyses. Statistical analysis was completed using SAS/STAT® software (SAS Institute Inc., Cary, NC, USA).

Results

A cohort of 195 patients met inclusion criteria, of whom 80.5% were female (Table 1). Average age of first presentation for HS was 14.9 years. Racial composition was 72.8% Black, 17.9% White, and 6.7% other, with 7.2% identifying as having Hispanic ethnicity. Family history of HS was negative in most patients (84.3%). Patients had an average body mass index of 33.2 (± 8.8). Insurance status included 68.2% Medicaid, 29.2% private, and 2.6% self-pay or uninsured, consistent with the insurance status of pediatric dermatology patients overall at our institution.

About one-third (34.9%) of patients had at least one other dermatologic comorbidity, the most common of which was acne (29.2%), followed by pilonidal cysts (5.1%), folliculitis (4.6%), pyoderma gangrenosum (PG, 1.0%), and dissecting cellulitis (0.5%). Over half of patients were diagnosed with a concomitant metabolic abnormality (56.9%), including hypertension (7.2%), polycystic ovarian syndrome (6.4%), inflammatory bowel disease (IBD, 1.5%), and inflammatory arthritis (1.5%). Menstrual irregularities, precocious puberty, or premature menarche was present in 6.4% of female patients included. Patients were also often diagnosed with psychiatric comorbidities (19.7%), including major depressive disorder (MDD,12.3%), anxiety (8.1%), and suicidal or homicidal ideation (SI/HI, 3.1%) (Table 1).

Most subjects (76.1%) were seen by dermatology at least once, with most referred by another provider (79.1%). Of the 47 subjects never seen by dermatology, 42.6% were referred, but were not seen. This was due to parents/patients canceling their visit (47.8%) or never having a visit scheduled (34.8%). Duration of symptoms before initial presentation was often 1–2 years (19.1%). Initial diagnosis of HS was most frequently given at a dermatology (36.6%) or pediatric visit (21.6%). The largest proportion of referrals came from pediatrics (43.2%) and family medicine (15.1%). Patients first diagnosed by a non-dermatologist were treated for a median of 89 days prior to referral to dermatology.

Several differences existed in population characteristics and physical exam between the dermatology and non-dermatology managed patients (Table 2). Family history of HS was present in 17.1% of dermatology-managed patients vs. 4.3% of non-dermatology managed patients (p=0.029). Patients managed by dermatology were more likely to be diagnosed with another dermatologic comorbidity (40.8% vs 17.0%, p=0.005), especially acne (36.1% vs

8.5%, $p<0.001$). No differences in demographics, insurance type, smoking status, metabolic comorbidities, or psychiatric comorbidities were observed.

Hurley stage was documented in 46.9% of dermatology managed versus 12.0% of non-dermatology managed patients. At their most recent visit, patients managed by dermatology were more likely to have key HS morphologic features documented in their physical exam, including inflammatory nodules (44.2% vs 19.1%, $p<0.001$) and scarring (39.5% vs 8.5%, $p<0.001$). Patients in the dermatology cohort were also more likely to have axillary (51.0% vs 27.7%, $p<0.001$) and groin involvement (30.6% vs 8.5%, $p<0.001$) at their most recent HS visit.

Patients managed by dermatology were more likely to have ever used chlorhexidine gluconate (65.3% vs 10.6%, $p<0.001$), benzoyl peroxide (41.3% vs 2.1%, $p<0.001$), doxycycline (70.0% vs 19.2%, $p<0.001$), and topical clindamycin (89.3% vs 27.7%, $p<0.001$). Dermatology-managed patients were also more likely to be prescribed medication to manage their HS at their most recent visit, including topicals (83.6% vs 31.3%, $p<0.001$), oral antibiotics (53.7% vs 12.5%, $p<0.001$), and other systemic treatments (27.6% vs 3.1%, $p=0.004$). Of those managed by dermatology, 19.7% were prescribed a biologic at their most recent visit, compared with zero patients who were non-dermatology managed (Table 3).

Patients managed by dermatology were more likely to receive intralesional steroids (40.0% vs 0.0%, $p<0.001$), equally likely to undergo incision and drainage (24.0% vs 25.5%, p=0.83), and less likely to undergo surgical excision (13.3% vs 25.5%, p=0.04). There was no difference in the utilization of emergency department (ED), urgent care, or after-hours clinic services by managing specialty (Table 3).

Median duration of management for the dermatology cohort was 7.3 months vs. 0.77 months for the non-dermatology cohort (p=0.01). Median number of HS visits was 3.0 for dermatology-managed patients vs 2.0 for non-dermatology managed (p=0.01). A novel ratio was created to assess the number of visits per month, comparing the median duration of management for HS (months) by the median number of HS visits. Patients managed by dermatology were treated for 1.6 months per each HS-related visit with a dermatologist vs 0.27 months for non-dermatology managed patients for every HS-related visit with a provider (p=0.01).

Discussion

Despite an increasing level of interest and research over the past decade, HS remains a poorly characterized disease. Knowledge about HS in the pediatric population is particularly limited and often extrapolated from basic science and clinical studies in adults. A recent update contradicted the popular belief that HS is a rare disease and one that primarily affects the adult population.[7] Barriers to care exist for HS patients and serve to perpetuate the lack of data characterizing this disease: practitioners' lack of knowledge about HS, difficulty accessing specialists knowledgeable about HS, poor communication, distrust of the medical community, and patients' experiences of their disease.[8]

The tendency of providers to misdiagnose HS may be attributed to unfamiliarity with the disease, and result in lag times between symptom onset and diagnosis.[9] Prompt diagnosis of HS can prevent progression of disease if an appropriate treatment regimen is started early in the disease course.[10] While patients may appropriately be referred to dermatology for further management, they may have difficulty accessing dermatologic care or never attend their referral appointment.

The difficulty in managing pediatric HS is multifactorial. Data are lacking, outcomes are difficult to interpret, and a balance between treatment efficacy and toxicity must be maintained. There is a paucity of efficacy and safety data on systemic treatments in the pediatric population, leaving treatment to be based largely on studies in adults.[11] Disease outcomes are both difficult to define and subjective in nature, as the assessment of disease flares is neither standardized nor validated.[12] Providers must also be cognizant of the scarring and fibrosis that occurs as a result of the inflammatory lesions of HS, as it may make active lesions more difficult to differentiate.[11]

Perhaps one of the most significant burdens of HS is its psychological impact on pediatric patients.[12] Patients in this population are particularly susceptible to the adverse impacts of chronic illnesses, including skin disorders, which can disrupt the developmental period.[13] Patients with HS experience chronic pain and face significant challenges, including bullying, self-isolation, and negative thinking.[11] Psychiatric comorbidities, including anxiety and depression, are increased in this population.[14] Our data show these comorbidities are increased regardless of managing clinician specialty. Ideally, management would include access to patient support groups, and referral to pediatric psychological and psychiatric professionals.[11,15]

Most referrals came from pediatric clinicians, indicating that these providers are often encountering HS patients first in their practices. Thus, it is imperative that these providers have the knowledge to promptly recognize and appropriately treat HS. Our data indicates a 1–2-year lag time prior to patients receiving an HS diagnosis. However, about 20% of all HS diagnoses were ultimately made by pediatric providers, indicating that the lag time is not solely representative of time it took a patient to see a dermatologist following referral.

Dermatologists and non-dermatologists manage pediatric HS differently. Non-dermatologists tend to skip topical treatments, which may be effective as maintenance therapy.[16] Dermatologists prescribe more medications of all types to their HS patients and are more likely to prescribe biologic therapy. Currently, adalimumab is the only approved biologic medication for HS. This approval includes pediatric patients over 12 years who weigh at least 30 kg.[16] When managed by a dermatologist, the number of visits is higher, and duration of management is longer. It remains to be seen whether this correlates with improved disease control and flare prevention.

Inflammatory lesions and their resultant scarring and fibrosis may interfere with patients' activities of daily living, and result in undesirable aesthetic outcomes.[11] Once scarred, lesions are difficult to remove without procedural intervention. For these reasons, management should aim to prevent early scarring through prevention of disease flares.

Surgery, although a viable option in some cases, is associated with a high prevalence of postoperative complications.[17] In our study, dermatology managed patients were less likely to undergo surgical excision than non-dermatology managed patients, which may indicate more reliance on medical management.

The main limitation of our study is its retrospective nature. Not all patients had documentation of Hurley staging or other disease activity, and although we extrapolated from the physical exam, this may have impacted the results. We are also unable to assess patients with HS who did not seek care in our health system, which could impact the generalizability of our findings. Inclusion of patients with a family history of HS may also be a confounding factor, as the guardians of these patients may more readily seek care given their knowledge of the diagnosis. Another limitation may be population-based race. While most studies do show increased rates of HS among African Americans and Latinos, it is unclear whether this is significantly greater than the incidence of these races in our general population. Prospective studies are needed to determine if the differences in specialty management translate to differences in patient outcomes. Potential surrogates for clinical outcomes in the two groups could include ED, urgent care, and after-hours clinic utilization (not significantly different in this study), as well as long-term progression of Hurley staging.

Our results support an increased likelihood of medical management by dermatology and suggest that surgical excision may be avoided with optimal medical management. Our results also demonstrate relatively high utilization of referral to dermatology, but only moderate patient adherence. Management of HS in the pediatric population should balance the avoidance of unnecessary toxicity with efficacy of therapy and adequate disease control to prevent lasting sequelae of disease. Educating pediatric clinicians and validating outcome measurement tools will be critical steps in improvement of disease management.

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Data Availability:

Data available upon reasonable request to the authors.

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Table 1:

Patient Demographics

	Complete Cohort	Dermatology-Managed	Non-Dermatology Managed	p-value
Sex				**1.0**
Female	157 (80.5%)	117 (80.7%)	40 (80.0%)	
Male	38 (19.5%)	28 (19.3%)	10 (20.0%)	
Age at first presentation for HS (years±SD)	14.9 (±2.9)	14.7 (±2.8)	15.7 (±3.2)	0.368
Race				0.805
Black	142 (72.8%)	105 (72.4%)	37 (74.0%)	
White	35 (17.9%)	26 (17.9%)	9 (18.0%)	
Other	13 (6.7%)	9 (6.2%)	4 (8.0%)	
Ethnicity				0.873
Hispanic or Latino	14 (7.2%)	10 (6.9%)	4 (8.0%)	
Not Hispanic or Latino	175 (89.7%)	131 (90.3%)	44 (88.0%)	
Family History of HS	27 (13.9%)	25 (17.1%)	2 (4.3%)	0.029 *
BMI (average ± SD)	33.2 (±8.8)	33.8 (±9.1)	31.7 (±7.6)	0.479
Insurance				0.832
Medicaid	133 (68.2%)	98 (67.6%)	35 (70.0%)	
Private	57 (29.2%)	44 (30.3%)	13 (26.0%)	
Self-pay or uninsured	5 (2.6%)	3 (2.1%)	2 (4.0%)	
Comorbid Conditions				
Dermatologic	68 (34.9%)	58 (40.0%)	10 (20.0%)	0.005 *
Acne	57 (29.2%)	51 (35.2%)	6 (12.0%)	<0.001 *
Pilonidal cysts	10 (5.1%)	6 (4.1%)	4 (8.0%)	0.259
Folliculitis	9 (4.6%)	9 (6.2%)	0 (0.0%)	0.117
Pyoderma gangrenosum	2 (1.0%)	2 (1.4%)	0 (0.0%)	1.000
Dissecting cellulitis	1 (0.5%)	1 (0.7%)	0 (0.0%)	1.000
Metabolic	111 (56.9%)	87 (60.0%)	24 (48.0%)	0.130
HTN	14 (7.2%)	8 (5.5%)	6 (12.0%)	0.199
PCOS	10 (6.4%)	8 (5.5%)	2 (4.0%)	0.887
IBD	3 (1.5%)	1 (0.7%)	2 (4.0%)	0.162
Inflammatory Arthritis	3 (1.5%)	2 (1.4%)	1 (2.0%)	1.000
Psychiatric	39 (19.7%)	26 17.9%)	13 (26.0%)	0.527
MDD	39 (12.3%)	15 (10.3%)	9 (18.0%)	0.605
Anxiety	16 (8.1%)	8 (5.5%)	8 (16.0%)	0.070
SI/HI	6 (3.1%)	4 (2.8%)	2 (4.0%)	1.0

* Indicates a statistically significant result, $p < 0.05$

HTN: Hypertension

PCOS: Polycystic ovarian syndrome

IBD: Inflammatory bowel disease

Table 2:

Documentation by Managing Specialty

	Dermatology-Managed	Non-Dermatology Managed	p-value
Other Dermatologic Comorbidity	40.8%	17.0%	0.005 *
Physical Exam: Most recent visit			
Inflammatory nodules	44.2%	19.1%	<0.001 *
Scarring	39.5%	8.5%	<0.001 *
Axillary Involvement	51.0%	27.7%	<0.001 *
Groin Involvement	30.6%	8.5%	<0.001 *

* Indicates statistically significant result

Table 3:

HS Treatments Prescribed by Provider Specialty

	Dermatology-Managed	Non-Dermatology Managed	p-value
Treatments ever prescribed			
Chlorhexidine gluconate	65.3%	10.6%	<0.001*
Benzoyl peroxide	40.8%	2.1%	<0.001*
Doxycycline	69.4%	19.1%	<0.001*
Topical clindamycin	88.4%	27.7%	<0.001*
Oral clindamycin	38.1%	34.0%	0.729
Current treatment			
Average number	2.66	0.53	<0.001*
Biologic	20.3%	0.0%	0.006
Procedures received			
Intralesional steroids	40.1%	0.0%	<0.001*
Incision and drainage	25.2%	29.8%	0.570
Surgical excision	13.6%	23.4%	0.285
Number of Surgery Visits for HS	0.68	2.38	0.002*

* Indicates statistically significant result, p <0.05