A visit guide for hidradenitis suppurativa—Managing a complex disease in a busy clinic

To the Editor: As highlighted in the continuing medical education article by Goldburg et al,[1] hidradenitis suppurativa (HS) is a complex disease with varied clinical presentations, many comorbidities, and important psychosocial ramifications. HS can be a difficult disease to manage, especially in a busy clinic. Lack of exposure to HS in medical training may compound these challenges, leaving providers feeling less than ideally prepared to treat patients with HS. Moreover, patients with HS frequently have questions requiring extensive counseling on topics such as wound care, how to manage acute flares, diet, and exercise, among other topics. These factors culminate in a time-intensive visit that may seem stressful to manage and perhaps even intimidating to providers who infrequently encounter HS. That said, not everything can be or has to be assessed at an initial visit. Given these challenges, we provide a framework that providers may consider to facilitate evaluation and care delivery throughout the first year of management of a new patient with HS (Table I[2]).

Another important tool in managing HS is patient education. In our specialty HS clinic, we use a patient handout that contains key information presented on a single page in a condensed, bulleted format that serves as a quick reference guide for patients (Fig 1). Topics include exercise, cosmetic and hygiene practices, contraceptive counseling, and evidence behind diets as well as information on patient support groups and national organizations, such as the HS Foundation.

Finally, education of clinic support staff can be instrumental. In our clinic, training of staff members who receive patient calls enables the efficient triaging of new patients and patients with flares. Our nurse performs a basic disease assessment of new patients via telephone that facilitates patient scheduling, prioritizing patients with greater disease burden. When patients have disease flares, these calls are triaged to the physician to ascertain if a clinic visit is necessary. In our clinic, we routinely prescribe topical steroids, prednisone, or oral antibiotics over the phone for management of flares. Holding a few 10-minute appointment slots for urgent intralesional triamcinolone injections weekly is useful and may keep patients with flares out of the emergency room. We have recently found telehealth to be highly effective in treating patients as well.

The objective of this guide is to make treating HS manageable in both academic and private practice settings. The interventions and sample management schedule provided in this visit guide may be helpful to providers who treat patients with HS. Emphasizing patient education and providing resources on support groups to patients will enable them to feel empowered between visits. Finally, education of clinical staff and triaging of acute flare visits are easy interventions that may facilitate clinic workflow.

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Table I. Visit guide to the treatment of patients with HS in the first year*

Visit objective	Baseline visit	3 months	6 months	9 months	Annual examination	Acute flare
Establish the diagnosis						
Evaluate for classic features of HS based on history and examination	x					
Counsel on disease etiology and prognosis	x					
Discuss expectations†	x					
Disease severity assessment						
Hurley stage	x				x	
Lesion count	x	x	x	x	x	x
Pain	x	x	x	x	x	x
Dermatology Life Quality Index		x			x	
Management and treatment						
Counsel broadly on treatment options	x					
Gauge patient interest‡	x					
Elect initial treatment	x					
Answer patient questions about treatment after they have had the opportunity to do their own research		x				
More in-depth discussion of treatment options		x				
Consider initiating more aggressive therapy if (1) deferred at initial visit because of patient preference or (2) no response to initial therapy		x				
Assess response to treatment; consider escalating or de-escalating therapy			x		x	
Schedule close follow-up	x	x	x	x	x	x

Counseling						
Assess for tobacco use and counsel on smoking cessation (if applicable)	x	x	x	x	x	
Substance abuse screening	x				x	
Provide patient handout	x					
Educate on local support group and national organizations		x				
Review clothing, hair care, and skin care tips	x					
Review evidence behind diet interventions		x				
Diet and exercise counseling		x			x	
Contraception and pregnancy counseling						
Discuss contraceptive use; suggest change in agent if appropriate	x				x	
Review with patient if they have plans for pregnancy in the next year	x				x	
If patient plans to become pregnant, discuss pregnancy management in HS and consider reaching out to OB/GYN	x	x	x	x	x	x
Review teratogenicity and lactation safety of prescribed medications; ensure appropriate contraception use	x	x	x	x	x	x
Laboratory test monitoring						
Tuberculosis screening	If needed based on therapy				If needed based on therapy	
Hepatitis B and C screening	If needed based on therapy					
Kidney and liver function tests	If needed based on therapy	If needed based on therapy	If needed based on therapy	If needed based on therapy	If needed based on therapy	

Continued

Table I. Cont'd

Visit objective	Baseline visit	3 months	6 months	9 months	Annual examination	Acute flare
Complete blood count	Consider based on (1) therapy and (2) also for baseline assessment of blood dyscrasias (often helpful in patients with severe disease)	If needed based on therapy	If needed based on therapy	If needed based on therapy	x	Consider
Erythrocyte sedimentation rate	x				x	Consider
C-reactive protein	x				x	Consider
Comorbidity monitoring[2]						
Tobacco and substance use	x					
Polycystic ovarian syndrome		x				
Obesity	x					
Follicular occlusion tetrad	x					
Acne	x					
Inflammatory bowel disease		x				
Skin cancer screening					Consider[‖]	
Pyoderma gangrenosum and autoinflammatory syndromes	Recommend screening 1 time early in care[§]					
Arthropathies	Recommend screening 1 time early in care[§]					
Metabolic syndrome	Recommend screening 1 time early in care[§]					
Impaired sexual health	Recommend screening 1 time early in care[§]					
Diabetes	Recommend screening 1 time early in care[§]					
Anxiety	Recommend screening 1 time early in care[§]					
Depression	Recommend screening 1 time early in care[§]					
Flare management options						
Discuss flare management strategies	x					

Phone-triage flare to ascertain if patient needs to be seen	x
Over-the-phone interventions	Oral steroids Topical steroids Acetaminophen (McNeil Consumer Healthcare, Fort Washington, PA) Nonsteroidal anti-inflammatory drugs Warm compresses Antibiotics
Flare interventions (clinic visit)	As in the previous row, as well as intralesional triamcinolone, incision and drainage

HS, Hidradenitis suppurativa; *OB/GYN*, obstetrician/gynecologist.

*The information in this visit guide represents our opinions/recommendations, not official guidelines.

†Expectations are important to establish early in care. It is important to counsel patients that there is no cure, that improvement may be slow and studded with periods of disease worsening, and that not all patients with HS progress (ie, patients with Hurley stage I disease are not likely to progress to stage III disease).

‡Patients with HS may have varied approaches to their care; some may elect to pursue lifestyle interventions only; some may prefer to think or read about treatment options; and others may elect early, aggressive therapy. Even though many patients with HS live with severe, untreated disease for a long time, a few more days to months of being untreated while considering different treatment options may not matter to some patients.

§One-time screening early in care (ie, at the second or third visit) should be performed; however, this can be done at any visit if warranted based on patient history, examination findings, and impact of diagnosis on clinical management.

‖Individualize based on disease duration and history of immunosuppression.

HIDRADENITIS SUPPURATIVA(HS): Dr. Kimball's General Treatment Guidelines

General lifestyle changes:
- Wear loose-fitting, breathable clothing to reduce friction on your skin
- Stop smoking- cigarette smoking has been shown to be associated with worse disease
- Weight loss can improve symptoms of HS

Bleach or Vinegar Baths:
- Place ¼ cup of standard bleach or 1 cup of vinegar in a full bathtub of water. Adding salt can reduce stinging (1lb/tub)
- Soak in bath for a few minutes three times a week; rinse afterward.
- If no bathtub at home, can use a washcloth with solution.

Optimal soaps/body washes:
- Head & Shoulders shampoo as a body wash to hair-bearing areas.
- Hibiclens
- No evidence for Zote soap, witch hazel, tea tree oil, PRID

Antiperspirants:*
- Can apply antiperspirant in problem areas (armpits, groin, skin folds)
- Good options: Secret clinical strength, Dove clinical strength

* Be sure to try antiperspirant in small area first to make sure there is no reaction

Diet:
- No specific diet has been shown to cure HS and further research is needed on how food choices affect the condition.
- There is no evidence for improvement with the paleo diet, avoidance of nightshades, vitamin supplementation, or turmeric supplementation.
- Limited evidence suggests that certain steps might be helpful:
  - **Eliminating dairy products**: Milk, cheese and other dairy products can raise insulin levels. This leads to the overproduction of hormones called androgens, which play a role in HS.
  - **Eating less sugar**: When combined with moderate exercise, limiting foods with added sugars and syrups, such as sodas, cereals and candy, might reduce your insulin levels and ease the symptoms of HS.
  - **Avoid whey protein** (powders, bars, protein shakes): If you desire protein supplementation, use soy

Hair Removal:
- Try to avoid waxing, plucking, and shaving in HS areas.
  - These can lead to ingrown hairs, infections and possibly future HS lesions
- If you need to shave, use electric razors or trimmers
- If desire to remove hair entirely we recommend laser hair removal
- Contact information for board-certified dermatologists who are willing to see HS patients for laser hair removal
- At-home device: Iluminage Touch

Hormonal Birth Control:
- Progesterone only birth control can worsen HS
- Speak with your primary care doctor or OB/GYN about changing to a different form of birth control if you are on one of these medications. **These can be BAD for HS**:
  - Depo Provera shot, Nexplanon implant
  - **Progestin IUD** (Mirena, Skyla)
  - Progestin only pill **(norgestimate, norethindrone, levonorgestrel)**, Jolivette, Micronor.

  Most oral contraceptive pills (OCPs) are combination estrogen-progesterone, and they can be evaluated for their androgenicity, which is related to the progesterone component. High androgen OCPs can worsen HS.
- **Low androgen OCPs (typically GOOD for HS):**
  - **Ethinyl estradiol +drospirenone** (Yasmin, Yaz)
  - **Ethinyl estradiol +desogestrel** (Apri, Mircette, Desogen, Reclipsen, Kariva)
  - **Ethinyl estradiol +norgestimate** (Ortho Tri-Cyclen, Estarylla, Trinessa)
  - **Ethinyl estradiol + norethindrone** (Estrostep)

Local Surgeons:
- Names and contact info of surgeons who are experienced with HS and work collaboratively with the dermatology team

Local OB/GYNs:
- Names and contact info of OB/GYNs who are experienced with HS and work collaboratively with the dermatology team

Support groups/Information websites:
- http://www.hs-foundation.org
- http://hopeforhs.org/
- https://www.nobsabouths.com/

Information about local clinical trials and research studies

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Fig 1. General treatment guide handout given to patients at visits. The information in this handout represents our opinions/recommendations, not official guidelines. Additionally, this handout includes brand names for which there may be alternative equivalent products. Brand names were selected because they are easy to find, and we have evaluated them. *HS*, Hidradenitis suppurativa; *IUD*, intrauterine device; *OB/GYN*, Obstetrician/gynecologist.