

During my dermatology inpatient consults rotation, I helped take care of a mother of four admitted for bloody and purulent drainage from painful wounds on her bilateral inner thighs. Before interviewing her, I quickly scanned through her medical record. She had been seen in the emergency department and admitted to the hospital many times and practically all of her hospital encounters were coded for hidradenitis suppurativa (HS) flares, surgical HS excisions, and incision and drainage of groin and gluteal abscesses. Pelvic imaging this admission showed developing fluid collections, inflammatory changes and fistula formation within the inguinal, inner thigh and rectal regions, respectively. An “acute on chronic exacerbation of HS” as it would be succinctly summarized in medical-speak.

The patient lay in her bed with her legs separated as to not touch her inner thighs together. A sheet with serosanguinous splotches draped over her lower body, as an IV in her arm delivered tramadol and antibiotics.

I had often heard how difficult HS was to treat because the current treatment modalities were often inadequate and focused on helping control symptoms and preventing complications.

“I’ve been dealing with these boils since I was 12 years old. Back then,” she recounted, “there was no other name for it. Nobody called it ‘hidradenitis’. I would just get them lanced in the ED”. They start out as “little red pimples” but then they become “huge and painful just overnight”.

Periodically throughout our chat, she would pause mid-sentence and wince in pain: “Every month or so... it comes back... is so painful... and I’m in bed for one or two weeks.” She tells me that she sleeps with her legs apart or with a pillow in between every night to prevent friction, which could trigger a flare.

“I had surgery on my armpits and thankfully it hasn’t come back here,” pointing to the scars and hyperpigmentation under her arms. “Even though I got surgery down here, I feel like it just keeps coming back in a different area,” motioning to the 10cm ulcerated plaques mirrored on each of her inner thighs. The eroded plaques glistened with purulent and hemorrhagic discharge surrounded by an irregular violaceous heaped border.

She used to work as a nursing assistant, but has not been able to keep a steady job. She has been out of work for the last year because “an episode can be up to two weeks or more.” Her father and sister also suffer from HS. Her close family members know what she deals with, but she feels like it’s not worth explaining to work what’s going on “in between her legs”. She’ll often simply say that she’s not feeling well when she calls out from work to avoid further questions or embarrassment.

“I don’t wear nice skirts or pants unless I bandage myself up real good. My clothes get bloody a lot.” This time, she came to the ED with just a bath towel wrapped around her waist because putting on clothes was too painful.

When kids ask her for money for snacks, she sometimes jokes that “I’m wearing it” because the “those bandage costs add up!” When I ask her what she hopes to be able to do when her feels better, she tells me that she really misses being able to bicycle with her children. As I looked at my patient, I felt a sinking feeling of wanting to be helpful and provide relief and a sense of normalcy, but also a sense of helplessness washed over me, as I thought of the efficacy of treatment options. At the end of our conversation, she thanked me for spending time with her and I thanked her for sharing her story and helping me understand the burden of her disease course through the lens of her life.