

Living With Hidradenitis Suppurativa

Shari Tosk Solarski

Dermatology nurses and other health care professionals may sometimes fail to appreciate and recognize the physical and emotional challenges faced by patients with a particular chronic dermatologic disease or condition. To better bring patients' feelings and perceptions into focus, the Dermatology Nursing Editorial Board is excited to introduce a new series, "Patients' Perspectives: Living With..."

The goal is that these important patient views and comments will improve patient care. If you know of a patient who would be interested in sharing his/her experiences with the dermatology nursing community, please ask him/her to briefly answer (3-5 sentences) the questions as outlined here. Submissions can be sent via e-mail to the journal office at dnjrnrl@ajj.com or mailed to Patients' Perspectives, Dermatology Nursing, East Holly Avenue Box 56, Pitman, NJ 08071-0056.

When were you diagnosed with your disease/condition?

I was diagnosed with hidradenitis suppurativa (HS) sometime around 1989 or 1990. However, I have suffered with this disease since 1978, not including the pilonidal cyst I had as a teenager.

When and how did you find out you had the disease/condition?

Looking back, now I see that the pilonidal cyst may have been the first of many cysts which are part of the progression of HS. The first huge cyst that appeared on my upper thigh during the summer of 1978 was treated as a boil. The local doctor cut it open (without any local anesthetic), drained it a bit, and covered it with gauze. I was told to put black salve on it, to wash more frequently, and to stop wearing jeans. Since that time, I have had HS cysts come and go under both arms, on both upper thighs, in the panty lines, in my C-section scar, under my breasts, on my face (2 days before my wedding), on my labia, and on the crack of my buttocks. I am at stage 2 or 3 with scarring and sinus tracts.

How would you describe your appearance?

I have always battled with my weight, but was only 5 to 10 pounds overweight at the time of my first outbreak. I am now severely overweight, and suffer from many of the symptoms of hypothyroidism as well.

What kind of education and support were you given at the time of your diagnosis?

None. The doctor who finally did diagnose HS is a wonderful woman, who put a name on these recurrent "boils" or "cysts." She told me that this had nothing to do with cleanliness, and she treated me with respect and efficiency. When my armpit became so inflamed and unresponsive to injections or antibiotics, she referred me to a surgeon, who performed an I & D with packing.

How has your disease/condition affected your life, physically and emotionally?

This is a difficult question to answer. At times, this disease has totally immobilized me. I have been unable to

Shari Tosk Solarski, MA, BS, is a Teacher of English as a Second Language, Minue School, Carteret, NJ.

Figure 1.

HS-USA (www.hs-usa.org) provides a forum for hidradenitis suppurativa patient advocacy and rights, and supports educational outreach to instill awareness and knowledge of HS by the public and private sectors.



Figure 2.

Shari Solarski (2nd from left) has become actively involved with HS-USA, the HS Petition, and the New Jersey Hidradenitis Support Group.



function and perform even the simplest of tasks. After the birth of my first child, the HS flare ups came more frequently and more severely. As you can imagine, as a young mother, this was devastating. I could not hold my infant. I could not take antibiotics and nurse my child. I was totally dependent on my husband and mother for help. Over the years, I have become a recluse at times due to the severity of the disease, and the embarrassment of draining, smelly, disgusting lesions. There were many missed days from work. Emotionally, this disease can be devastating. It becomes a terrible cycle: stress leads to outbreaks, which lead to missed work, which lead to job loss, which leads to financial hardship, which leads to stress, which leads to more outbreaks, which eventually leads to mental and emotional instability, self-doubt, feelings of poor self-worth, disgusting self-image, and eventually severe depression, including thoughts of suicide.

What would you like health care providers to know about treating people with your disease/condition?

First, I would like to see more dermatologists recognize the symptoms and diagnose HS correctly. (That is, of course, if they have time for medical, not only cosmetic, dermatology.) I would like to see nurses who don't turn away in disgust upon looking at HS cysts. I would like to see doctors and nurses who understand that this is not a cleanliness issue. I would like to see the office staff advised that if a patient with HS calls for an appointment, and asks to be seen same day, it is because a cyst has developed that requires immediate treatment. I would like to see doctors consider pain management along with treatment of symptoms. I would like to see some medical research into the causes and possible cures and/or treatments for HS. I would like the millions of HS sufferers to be able to stop hiding in embarrassment, and find competent doctors who will treat them with respect and dignity.

What worked for you and what didn't (treatments, emotional support, etc.)?

For my HS, I take Cipro[®] antibiotics only when absolutely necessary, since years of progressively stronger and stronger antibiotics have left me immune to their benefits. I use ClindaMax[®] topical right now, which is helping if I catch them in time. I get Kenalog[®] injections when needed. I hot compress constantly when lesions are open and draining. To try to prevent outbreaks, I try to stay out of the heat since sweating aggravates the condition. I try to keep the areas dry by using only cornstarch powder numerous times a day. I do not shave under my arms or on the bikini line. I no longer enjoy summertime activities with my children.

Emotionally, the best thing that happened to me, was finding the organization HS-USA, Inc., a 501-c-3 charitable organization (www.hs-usa.org) (see Figures 1 & 2). I discovered that I was not the only person to have this disgusting disease. I found a group of supportive, helpful people, and I became proactive. This has helped me gain a tiny bit of control over this disease, because I feel like I am finally able to *do something* to help myself and others. I have gone public with this disease to my family and friends. I have become a New Jersey state contact person, and lead the New Jersey Hidradenitis Support Group, which has met three times in the past year. I am involved on the national and local levels, and have been working to generate awareness and support through the HS Petition, and to educate the local medical community.

What do you wish society knew about your disease/condition?

I wish society knew how devastating this disease is for sufferers. I wish society made it a little easier for people with true debilitating illnesses to get assistance. I wish society knew that each and every person has the

M ***My biggest fear for the future is that one or both of my children will develop this disease.***

capacity to help in even a small way. I wish one celebrity, one famous person, or one doctor would get over the embarrassment and “come out” with this disease to help us raise awareness and support for funding and research.

What would you tell other people who are newly diagnosed with this disease/condition?

I would tell newly diagnosed people to check out the HS-USA Web site (www.hs-usa.org), and the various worldwide online support groups. You are *not* alone. We know what you go through on a daily basis. We are here for you. If new people do not have Internet access, I would give them my own phone number and the number of the HS crisis hotline. I would drive for hours to meet them. I would offer my friendship and hope. I would remind them to read, read, read, everything they can find about the disease and possible treatments. I would remind them that every body responds differently to different things, so keep trying until something is found that works for them!

How do you think living with this disease/condition will affect your life in the future?

My biggest fear for the future is that one or both of my children will develop this disease. There are many, many cases of familial HS, and some doctors believe it may be genetic. If this gene can be identified and isolated, a whole area of treatment and prevention could be researched. I hope that this disease, which I believe to be definitely hormonal, and probably an androgen dysfunction problem, does not get worse as I reach menopause. I am starting to develop some arthritis and scalp problems, which may also be related. I am hoping that I won't have to block the door to ask questions at the endocrinologist's office as I did for my early dermatologist visits! ❑

Reprinted from ***Dermatology Nursing***, 2004, Volume 16, Number 5, pp.447-449. Reprinted with permission of the publisher, Jannetti Publications, Inc., East Holly Avenue Box 56, Pitman, NJ 08071-0056. Phone (856)256-2300; FAX (856) 589-7463. (For a sample issue of the Journal visit the www.dermatologynursing.net <<http://www.dermatologynursing.net/>>).

Visit the Dermatology Nurses Association website at www.dnanurse.org <<http://www.dnanurse.org/>>