2. Gherardi G, Marveggio C, Stiglich F. Parotid metastasis of Merkel cell carcinoma in a young patient with ectodermal dysplasia. Diagnosis by fine needle aspiration cytology and immunocytochemistry. *Acta Cytol*. 1990;34:831-836.
3. Schmid C, Beham A, Feichtinger J, Aubock L, Dietze O. Recurrent and subsequently metastasizing Merkel cell carcinoma in a 7-year-old girl. *Histopathology*. 1992;20:437-439.
4. Centers for Disease Control and Prevention National Program of Cancer Registries (NPCR). NPCR and SEER incidence – US cancer statistics public use databases Available at: www.cdc.gov/cancer/npcr/public-use. Accessed June 12, 2018.
5. Martel-Jantin C, Pedergnana V, Nicol JT, et al. Merkel cell polyomavirus infection occurs during early childhood and is transmitted between siblings. *J Clin Virol*. 2013;58:288-291.
6. Schiffman M, Castle PE, Jeronimo J, Rodriguez AC, Wacholder S. Human papillomavirus and cervical cancer. *Lancet*. 2007;370:890-907.
7. Feng H, Shuda M, Chang Y, Moore PS. Clonal integration of a polyomavirus in human Merkel cell carcinoma. *Science*. 2008;319:1096-1100.
8. Paulson KG, Iyer JG, Blom A, et al. Systemic immune suppression predicts diminished Merkel cell carcinoma-specific survival independent of stage. *J Invest Dermatol*. 2013;133:642-646.

https://doi.org/10.1016/j.jaad.2018.08.021

Online communications among hidradenitis suppurativa patients reflect community needs

To the Editor: Patients with hidradenitis suppurativa (HS) often feel embarrassment and may avoid discussing symptoms with physicians, friends, and even family.[1] We studied communications in an online community focused on HS to identify trends.

A search for the term *hidradenitis suppurativa* on Facebook identified the closed Hidradenitis Suppurativa Support Group as the largest support group for individuals with HS, with 12,970 members at the start of the analysis. With permission from the group administrators, an institutional board review–approved retrospective assessment of posted content from 7 randomly selected days from 3 months (November 2017, December 2017, and January 2018) was performed. Posts were assessed for primary content and anonymously categorized. A total of 20 posts were reviewed by 2 investigators for agreement.

The majority of the 1036 messages from 703 unique users sought feedback from other users by requesting information (54%) (Table I) and requesting social support (20%). Fewer inquired about other categories (Fig 1). Nine posts (0.87%) appear to have been made by family or friends, perhaps confirming the hidden nature of the disease.

Limitations include the fact that this group may not be representative of the general population of individuals with HS and the fact that there was no verification of diagnosis or severity of HS. Also, discussion topics may vary by season or news events.

The information exchanged on Facebook forums is not regulated by medical professionals, and some of the home remedies shared in this HS support group, such as dietary recommendations or use of laundry soap as topical treatment for skin lesions

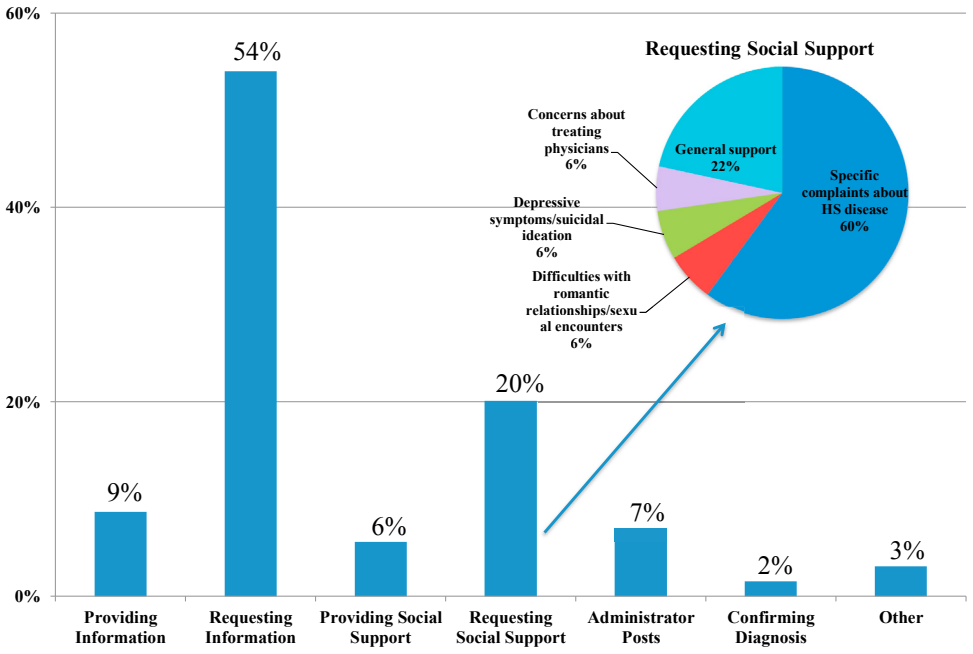

Fig 1. Categories of online posts. *HS*, Hidradenitis suppurativa.

Table I. Differences between posts requesting information and posts providing information

Message category	Message subcategory	Requesting information, n (%) (n = 559)	Providing information, n (%) (n = 90)
Lifestyle		180 (32.2)	57 (63.3)
	Cleansers/deodorants/oils	107	42
	Dietary changes	40	8
	Hair removal	14	2
	Dressings/pads	9	2
	Other	13	3
Help with a specific symptom		113 (20.2)	3 (3.3)
	New location of disease	34	
	Pain	19	1
	Draining	11	
	Scarring	11	1
	Odor	11	1
	Wound care	9	
	Fistulas	6	
	Other	10	
Epidemiology		70 (12.5)	10 (11.1)
	Comorbid conditions (T2DM, psoriasis, joint pain, MRSA, obesity, IBD, etc)	34	2
	Hormonal etiology (relationship to menses, pregnancy, PCOS, hormonal imbalance, etc)	20	3
	Triggers and causes of disease	13	4
	Autoimmune etiology	8	
	Age/sex	3	
	Other	3	1
Medications		68 (12.2)	10 (11.1)
	Antibiotics	22	3
	Biologics	20	4
	Analgesics	7	
	Hormonal	4	
	Other (immunosuppressants, retinoids, radiation therapy, metformin, onabotulinumtoxinA, etc)	15	3
General advice		51 (9.1)	4 (4.4)
Surgery		33 (5.9)	2 (2.2)
Physician recommendations		20 (3.6)	0 (0)
Staging		18 (3.2)	1 (1.1)
Other		19 (3.4)	3 (3.3)

IBS, Irritable bowel syndrome; *MRSA*, methicillin-resistant *Staphylococcus aureus*; *PCOS*, polycystic ovary syndrome; *T2DM*, type 2 diabetes mellitus.

(4.7% of all posts), have limited evidence. Nevertheless, in contrast to patients with other diseases such as diabetes,[2] patients with HS request much more information than they provide one another, which demonstrates a gap in available informational resources for patients. Improving the number and quality of publicly available educational materials is essential to address knowledge gaps and dispel misinformation.[3,4] Additionally, dermatologists treating patients with HS who inquire about and discuss lifestyle measures as well as disease-related psychosocial concerns may better meet the needs of these patients.

Safe spaces and online communities, particularly for people who have chronic and debilitating diseases such as HS, are very important. Although we conducted this research according to current federal standards for the conduct of human research and the

intent was to highlight patient needs, educate providers, and advocate for people with HS, we regret that this publication has raised privacy concerns. When questions about the research were raised, we met with patients with HS and advocates and apologized to any members who indicated to us that they were made uncomfortable. We have made modifications to this letter in response to suggestions from the HS community and have learned a great deal from them about how research such as this could be approached in better ways. To that end, we are committed to developing and promulgating recommendations for research standards to better inform online community members, researchers, and institutional review boards about how to best conduct this type of research. In this spirit, we hope that we will be able to move research, patient care, and support for patient communities forward in a way that will benefit patients with HS, about whom we care deeply.

The authors would like to thank the patients with HS, advocates, Hope for HS (HopeforHS.org), and the Hidradenitis Suppurativa Foundation board members who contributed to the revision of this article.

Nicole M. Golbari, BA,[a] *Martina L. Porter, MD,*[b] *and Alexa B. Kimball, MD, MPH*[b]

From the Stony Brook University School of Medicine, Stony Brook, New York,[a] *and Harvard Medical School and Clinical Laboratory for Epidemiology and Applied Research in Skin, Department of Dermatology, Beth Israel Deaconess Medical Center, Boston, Massachusetts*[b]

Funding sources: None.

Disclosure: Dr Martina Porter has received fellowship funding from Abbvie. Dr Kimball serves as a consultant for Novartis, Abbvie, UCB, Janssen and Lilly; an investigator to Abbvie, UCB, Novartis, and Janssen; and receives fellowship funding from Janssen and Abbvie. Ms Golbari has no conflicts of interest to disclose.

Reprint requests: Alexa B. Kimball, MD, MPH, President and CEO, Harvard Medical Faculty Physicians, Beth Israel Deaconess Medical Center, 375 Longwood Ave, Boston, MA 02215

E-mail: clears@bidmc.harvard.edu

REFERENCES

1. Esmann S, Jemec GB. Psychosocial impact of hidradenitis suppurativa: a qualitative study. *Acta Derm Venereol*. 2011;91(3):328-332.
2. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *J Gen Intern Med*. 2011;26(3):287-292.
3. Golda N, Beeson S, Kohli N, Merrill B. Recommendations for improving the patient experience in specialty encounters. *J Am Acad Dermatol*. 2018;78(4):653-659.
4. Hessam S, Salem J, Bechara FG, et al. Hidradenitis suppurativa gains increasing interest on World Wide Web: a source for patient information? *Int J Dermatol*. 2017;56(7):726-732.

https://doi.org/10.1016/j.jaad.2018.08.031

Antibiotic exposure is associated with cutaneous adverse events in hairy cell leukemia patients treated with purine analogues

To the Editor: The purine analogues cladribine and pentostatin have been associated with cutaneous adverse events in the treatment of hairy cell leukemia (HCL).[1-3] Studies have shown that rash development may be associated with hypersensitivity to concomitant medications rather than to the purine analogue itself.[1-3] The objective of this study was to perform a case-control analysis of cutaneous eruptions in patients with HCL treated with purine analogues to determine which factors may be associated with development of the morbilliform rash described in a separate publication.

Patients with HCL at The Ohio State University who were treated with cladribine or pentostatin from 1994 to 2017 were studied. Eighty-eight patients were identified. Nine patients treated with both agents were considered separately for analysis, for a total of 97 cases treated with either chemotherapeutic agent. Medication exposures were evaluated in a binary fashion if the medication was used during the treatment course. Univariate logistic regression was performed to analyze potential predictors of morbilliform rash. A multivariate model of covariates with a P value less than .10 from the univariate model was then created. Separate models were created in similar fashion for antibiotic subclasses. P values less than .05 were considered statistically significant. Analyses were performed with JMP 13 and R software.

Of the 88 patients treated with purine analogues, 17 developed a morbilliform rash and 80 had no documented rash. Concomitant antibiotics, antivirals, dapsone, allopurinol, and use of pentostatin were associated with morbilliform rash on univariate analysis. The initial multivariate analysis with these variables revealed only antibiotic exposure as a significant independent predictor of morbilliform eruption (odds ratio [OR], 21.20; 95% confidence interval [CI], 3.08-201) (Table I). To further