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## Research Letter

## Quality and engagement of online hidradenitis suppurativa information



Dear Editors,

Hidradenitis suppurativa (HS) disproportionately affects women (female:male ratio 3:1) and Black Americans. With a median diagnostic delay of 7 years and women encountering a greater diagnostic delay than men, patients with HS often turn to online resources for information (Saunte et al., 2015; Shukla et al., 2020). We sought to characterize the source, medical comprehensiveness, quality, and readability of online HS information.

Between March 1, 2020 and August 1, 2020, we performed Google and YouTube searches using the term “hidradenitis suppurativa”. Google searches were performed in incognito mode to allow private, unidentified browsing not influenced by user data.

The top 50 Google and YouTube search results were reviewed by two independent investigators. Advertisements, non-English webpages, and non-HS videos were excluded. We collected data on medical comprehensiveness and source (dermatologist, nondermatologist physician, and nonphysician) for all media. For webpages, we also collected data on readability using the Flesch-Kincaid grade level (Stossel et al., 2012). For videos, we recorded length, number of comments, and number of likes and dislikes. Videos with high engagement had lower views/comment ratios. Online HS information was *comprehensive* if it contained informa-

tion from  $\geq 2$  UpToDate categories, including etiology, clinical characteristics, or treatments. Descriptive statistics were calculated using a *t* test for continuous variables and Fisher exact tests for proportions. All analyses were conducted using R studio, with significance determined by  $p < .05$ .

Of the top 50 webpages, 19 of 41 webpages (46.3%) containing HS information authored by physicians and 3 of 9 webpages (6.0%) authored by nonphysicians were comprehensive (Table 1). Dermatologist-authored webpages were more comprehensive ( $n = 18$  of 32; 56.3% vs.  $n = 1$  of 9; 11.1%;  $p = .02$ ) and had a higher mean Flesch-Kincaid grade level than non-dermatologist-authored webpages (12.7 vs. 9.68;  $p = .06$ ).

Of the 38 videos meeting the inclusion criteria, 4 of 16 videos (25%) created by physicians and 2 of 22 videos (9.1%) created by nonphysicians were comprehensive. The mean number of likes was greater for dermatologist-created videos versus nondermatologist physician-created videos (95.7 vs. 49.5;  $p = .049$ ). The view:-comment ratio was greater for physician-created videos than non-physician-created videos (1075.8 vs. 322.8;  $p = .0087$ ).

All 50 webpages included language at a grade level higher than the recommended fifth grade reading level for health information

Table 1

Characteristics of the top 50 webpages and YouTube videos for hidradenitis suppurativa authored by physicians and nonphysicians.

	All physicians			Total	Nonphysicians	p-value
	Dermatologist	Nondermatologist	p-value			
<b>Website count</b>	<b>32</b>	<b>9</b>		<b>41</b>	<b>9</b>	
Comprehensive, % (proportion)	56.3 (18/32)	11.1 (1/9)	<b>.02*</b>	46.3 (19/41)	33.3 (3/9)	.71
Flesch-Kincaid grade level (mean)	12.7 (6–23.1)	9.7 (5.9–15.9)	.06	12.1 (5.9–23.1)	12.5 (7.2–16)	.72
<b>Video count</b>	<b>14</b>	<b>2</b>		<b>16</b>	<b>22</b>	
Comprehensive, % (proportion)	21.4 (3/14)	50 (1/2)	.45	25 (4/16)	9.1 (2/22)	.22
Views	207,623.7	25,270.5	.18	183,309.9	93,504.2	.47
Length, min	12.3	6.53	.46	11.5	15.1	.48
Likes	985.7	49.5	<b>.049*</b>	868.7	500.6	.46
Dislikes	80.1	6.5	.07	70.9	68.9	.94
Total comments	196.1	13	<b>.01*</b>	173.3	266.6	.34
Positive comments	54.9	1.5	<b>.046*</b>	47.7	79.8	.22
Negative comments	7.7	1.5	.1	6.9	1.7	.18
Mixed comments	7.3	1	.066	6.5	4.4	.83
Views/comments	874.3	2183.5	<b>.032*</b>	1075.8	322.8	<b>.0087*</b>

Bold text represent significant data.

\* Significant at  $p < .05$  level.

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(Stossel et al., 2012), with dermatologist-authored webpages being more comprehensive but written at a higher reading level than nondermatologist physician webpages. Videos by nonphysicians had greater user engagement than those by physicians, of which dermatologist-authored videos were more engaging than non-dermatologist-authored videos. This study is limited by a review of a subset of online materials, namely the top 50 webpage and YouTube video search results. However, this is likely representative of what patients read, because the first page of search results captures 71% of search clicks (Shelton, 2017). Views, likes, dislikes, and comments on YouTube videos can constantly be added, removed, or changed; therefore, our study is limited by data evident at the time of collection.

Most patients access health information online, and patients with HS are likely seek information about their symptoms and disease through the Internet (Hessam et al., 2017; Saunte et al., 2015). However, inconsistent quality and limited engagement with dermatologist-authored information may compromise HS patient education. This study highlights a need for high-quality, readable, and engaging online HS information to improve patient education and patient-dermatologist communication.

### Conflicts of interest

Dr. Naik receives grant support from AbbVie and consulting fees from 23andme, advisory board fees from Boehringer Ingelheim and is a board member of the U.S. Hidradenitis Suppurativa Foundation. Dr Linos receives grant support from K24AR075060.

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### Study approval

The author(s) confirm that any aspect of the work covered in this manuscript that has involved human patients has been conducted with the ethical approval of all relevant bodies.

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