

Hidradenitis Suppurativa: An Analysis of Online Resources for Patient Use

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Hidradenitis Suppurativa: An Analysis of Online Resources for Patient Use

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Abstract

Background: Diagnosis of Hidradenitis Suppurativa (HS) can take seven to ten years and has a long and complicated disease course. Many individuals may turn to online resources to gather information about their condition. While online resources can promote greater shared decision making and improve communication between patients and physicians, poor quality and low readability of websites can mislead patients with incorrect information.

Objective: This study's aim was to evaluate the quality and readability of HS websites found on Google and Bing in order to identify reliable, well-written resources that could help patients better understand their condition.

Methods: The DISCERN Instrument and Flesch-Kincaid Readability metrics were used to evaluate the quality and readability of HS websites.

Results: Google and Bing had average DISCERN scores of 54.05 and 59.83, respectively. Ten of the websites were either written or reviewed by a physician. Websites written or reviewed by physicians had statistically significant higher DISCERN scores ($p = .018$). The average reading grade level for Google was 10.78 ± 2.40 , while the average for Bing was 10.48 ± 1.87 . The NIH recommends that medical information be written at a 6th to 7th grade reading level. Of the ten articles written or reviewed by physicians, half of those articles met this criterion (Table 5).

Conclusions: This study highlights the variable quality and readability of HS websites available on Google and Bing. Additionally, it provides websites that meet both high-quality standards and the NIH-recommended reading grade level.

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Original Manuscript

Title: Hidradenitis Suppurativa: An Analysis of Online Resources for Patient Use - Short Paper**ABSTRACT**

Introduction: Diagnosis of Hidradenitis Suppurativa (HS) can take seven to ten years and has a long and complicated disease course. Many individuals may turn to online resources to gather information about their condition. While online resources can promote greater shared decision making and improve communication between patients and physicians, poor quality and low readability of websites can mislead patients with incorrect information.

Objective: This study's aim was to evaluate the quality and readability of HS websites found on Google and Bing in order to identify reliable, well-written resources that could help patients better understand their condition.

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Conclusion: This study highlights the variable quality and readability of HS websites available on Google and Bing. Additionally, it provides websites that meet both high-quality standards and the NIH-recommended reading grade level.

INTRODUCTION

The Internet plays an integral role in the access and expansion of user knowledge about their

condition, including disease pathogenesis and treatment options. Patients who use internet resources to learn about their health condition experience greater shared decision-making, enhanced confidence in communication with physicians, and a better understanding of the diagnosis.¹

In this study, our aim was to assess the quality and readability of online information about Hidradenitis Suppurativa to determine if these resources provide reliable and comprehensive information for patients. For this assessment, we utilized the DISCERN instrument and Flesch-Kincaid Readability metrics.

Hidradenitis Suppurativa (HS) was first described in 1839 by a French surgeon.² In 2009, the HS Foundation described the condition as ‘a chronic, inflammatory, recurrent, debilitating, skin follicular disease that usually presents after puberty with painful deep-seated, inflamed lesions in the apocrine gland bearing areas of the body.’²

The prevalence of HS is unknown; however, some sources report rates of up to 4.10%.² This condition is more common in African Americans and biracial individuals.² Unfortunately, diagnosis can take around 7-10 years.³ With such a long and complicated diagnosis course, many patients turn to online resources to aid them in diagnosis comprehension and management.

By assessing the quality and reading ease of HS online resources, we hope to identify reliable resources that can bridge knowledge gaps and support informed discussions on management and treatment options.

METHODS

The term “Hidradenitis Suppurativa” was searched for on Google and Bing. To prevent search results

based on user history and location, each search was conducted in an incognito browser. Additionally, all location services were turned off. The top 20 results from each search engine were included in our analysis, even though over 97% of website clicks occur on the first page⁴, which typically displays 10 results. Websites were not included if they were sponsored advertisements, required payment (4), were duplicate websites (8), or incomplete articles (1). Twenty websites were included in the final analysis (8 Google, 4 Bing, 8 Google and Bing).

Two medical student researchers independently screened each website. Each researcher utilized the DISCERN Instrument to rate the quality of the website. The averages of the scores were calculated. Texts from each website were inserted into a word counter tool to obtain total words, syllables, and sentences, which were then used to calculate Flesch-Kincaid Readability.

DISCERN INSTRUMENT

The DISCERN Instrument is the first standardized index of quality of consumer health information.⁵ It was created to better help health professionals and consumers to work together to find the best treatment option for an individual.⁵ Having access to good quality information is an important part of consumer involvement when making decisions about their diagnosis. Even with a clear treatment course, quality information allows for individuals to understand and know what to expect.

The questions on DISCERN are categorized into three sections (Table 1).

Questions	Readability	Details
1-8	Reliability	Can this article be a trusted source of information?
9-15	Treatment choices	Does this article provide

		specific details about treatment choices?
16	Overall quality	This rating is based on the individual's judgment of the quality of the publication

Table 1: DISCERN Question Categories⁵

Each question is rated on a 5-point scale. A score of 5 indicates that the quality criterion has been completely fulfilled. Scores ranging from 2-4 indicates that the criterion is partially fulfilled. A score of 1 indicates that the answer to the question is no.⁵ If a student researcher is unsure about how to respond to a question, the DISCERN Instrument provides a thorough example for each question.⁵

FLESCH-KINCAID READABILITY

The Flesch-Kincaid Readability scores were created by Rudolf Flesch and J. Peter Kincaid.⁶ It consists of two calculations which incorporate total words, syllables, and sentences of articles (Table 2). The Flesch-Kincaid reading ease is based on a scale of 0-100. The higher the score, the easier the text is to understand. The Flesch-Kincaid grade level calculates the American school grade level one would need to be in to understand the written material (Table 3).⁶

Flesch-Kincaid Reading Ease Formula:	$206.835 - 1.015 \times (\text{words/sentences}) - 84.6 \times (\text{syllables/words})$
Flesch-Kincaid Grade Level Formula:	$0.39 \times (\text{words/sentences}) + 11.8 \times (\text{syllables/words}) - 15.59$

Table 2: Flesch-Kincaid Readability Calculations⁶

90-100	5th grade	Very easy to read
--------	-----------	-------------------

80-90	6th grade	Easy to read
70-80	7th grade	Fairly easy to read
60-70	8th-9th grade	Plain English
50-60	10th-12th grade	Fairly difficult to read
30-50	College	Difficult to read
0-30	College Graduate	Very difficult to read

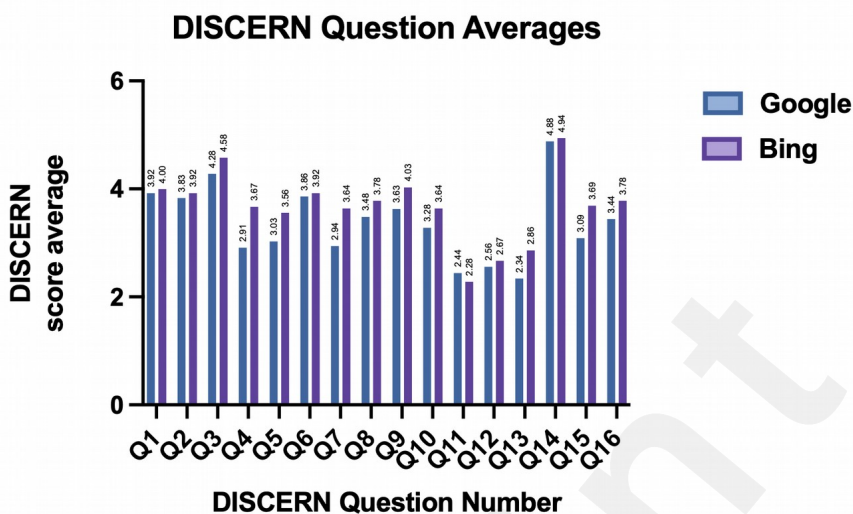
Table 3: Summary of Reading Ease and Grade Level⁷

STATISTICAL ANALYSIS

Data analysis was conducted by a statistician through the Medical Student Research Society at Eastern Virginia Medical School. Descriptive statistics include means and standard deviations. A two tailed independent t-test was calculated to compare the results between each search engine.

RESULTS

Twenty articles were included in the data. Eight articles were identified on Google, four on Bing, and eight on Google and Bing. Overall, Google had an average DISCERN score of 54.05, while Bing had an average DISCERN score of 59.83, indicating good quality.⁸ The averages for each DISCERN question were calculated (Figure 1). For each individual question, Google websites received an average score of 3.37 ± 1.34 , while Bing had an average score of 3.68 ± 1.17 . Bing had a higher statistical significance for question number 7, which asks ‘Does it provide details of additional sources of support and information?’ ($p=.03$). Additionally, there was near statistical significance for questions 10. Question 10 asks, ‘Does it describe the benefits of each treatment?’ ($p=.06$).

**Figure 1:**

Question

DISCERN

Averages

between Google and Bing

Ten out of the twenty websites were either written or reviewed by a physician. The remaining articles were written by an academic institution (5), National Health Services or Departments (2), non-profit organization (1), charity (1), hospital (1), or free online encyclopedia (1). Websites written or reviewed by physicians had statistically significant higher DISCERN scores ($p = .018$) (Table 4).

Written/Reviewed by Physician	Average DISCERN Score	P-Value
Yes (n=10)	62.1	.018
No (n=10)	49.7	

Table 4: Average DISCERN score between different authorships of articles

When assessing the Flesch-Kincaid Readability tests, the average grade level for Google was 10.78 ± 2.40 , while the average grade level for Bing was 10.48 ± 1.87 . Higher reading grade levels can lead

to misunderstanding of information which has the potential to affect decision making in individuals with basic reading skills. The National Institutes of Health (NIH) recommends that medical information be written at a 6th to 7th grade reading level.⁹ Of the ten articles written or reviewed by physicians, half of those articles were written at a 5th to 7th reading grade level (Table 5). These websites provide comprehensible and reliable information for patients diagnosed with Hidradenitis Suppurativa.

DISCUSSION

Hidradenitis Suppurativa can have a difficult and complex disease course. Ensuring patients have access to reliable and clear resources is important for management and understanding of diagnosis and treatment options.

While the average DISCERN scores were comparable across search engines, Bing exhibited a statistically significant difference for question 7 ($p = .03$) and near statistical significance for question 10 ($p = .06$). This suggests that websites found on Bing may provide higher-quality information related to treatment options and additional resources.

Despite these differences, both Google and Bing failed to meet the National Institutes of Health (NIH) recommendation for medical information to be written at a 6th to 7th grade reading level. Google's average reading level was 10.78 ± 2.40 , while Bing's was 10.48 ± 1.87 . These higher reading grade levels can lead to misunderstanding of information, which has the potential to affect decision making in individuals with low health literacy.

Moreover, articles written or reviewed by physicians achieved significantly higher DISCERN scores ($p = .018$), affirming the importance of expert oversight in patient education. While high-quality information is crucial for accurate findings and treatment options, it is equally important that this information is comprehensible to all patients. To address this need, Table 5 showcases five online

resources that were written or reviewed by a physician and had a reading grade level between 6th and 7th grade.

<u>Website</u>	<u>Search Engine Website Was Found On</u>	<u>Reading Grade Level</u>
WebMD	Google	5.7
American Academy of Dermatology	Google and Bing	6.3
Cedars Sinai	Google	6.4
Family Doctor	Bing	7.5
Healthline	Bing	7.6

Table 5: Hidradenitis Suppurative Websites Written or Reviewed by a Physician with an NIH

Recommended Reading Grade Level

LIMITATIONS

Despite these findings, several limitations must be considered. First, the study focused on the top search results for Google and Bing at a specific time point, which may not reflect dynamic changes in search algorithms. Additionally, the readability analysis relied on established formulas, which primarily assess sentence length and word complexity. These tools do not account for contextual factors such as formatting choices or the presence of visual aids that could impact comprehension.

CONCLUSION

It is important for patients with Hidradenitis Suppurativa to have access to informative and accurate articles that are easy to understand. Accessible information empowers patients to take an active role in their healthcare, enhancing their ability to manage their condition effectively. Given the complexities of HS, such as its symptoms, potential treatment options, and the emotional toll it can

take, patients can benefit greatly from resources that are of high quality and easy to read.

CONFLICTS OF INTEREST: None

REFERENCES

1. Laugesen J, Hassanein K, Yuan Y. The Impact of Internet Health Information on Patient Compliance: A Research Model and an Empirical Study. *J Med Internet Res*. 2015 Jun 11;17(6):e143. doi: 10.2196/jmir.4333. PMID: 26068214; PMCID: PMC4526934.
2. Goldburg SR, Strober BE, Payette MJ. Hidradenitis suppurativa: Epidemiology, clinical presentation, and pathogenesis. *J Am Acad Dermatol*. 2020 May;82(5):1045-1058. doi: 10.1016/j.jaad.2019.08.090. Epub 2019 Oct 9. PMID: 31604104.
3. Martins IA, Vilela BF, Cabete J. Diagnostic delay in hidradenitis suppurativa: still an unsolved problem. *Skin Appendage Disord*. 2024;10(2):129-132. doi:10.1159/000534845
4. Urman, A., Makhortykh, M. You are how (and where) you search? Comparative analysis of web search behavior using web tracking data. *J Comput Soc Sc* **6**, 741–756 (2023). <https://doi.org/10.1007/s42001-023-00208-9>
5. *Background*. DISCERN. (n.d.). http://www.discern.org.uk/background_to_discern.php Accessed August, 6, 2024.
6. *What is Flesch-Kincaid Readability?*. WebFX. Updated July 12, 2023. <https://www.webfx.com/tools/read-able/flesch-kincaid/>
7. Spadaro, Daniel & Robinson, Lawrence & Smith, L.. (1980). Assessing Readability of Patient Information Materials. *American journal of hospital pharmacy*. 37. 215-21. 10.1093/ajhp/37.2.215..
8. *Discern*. Lippincott. (n.d.). https://cdn-links.lww.com/permalink/jbjs/a/jbjs_2017_02_14_cassidy_325_sdc4.pdf
9. Hutchinson N, Baird GL, Garg M. Examining the Reading Level of Internet Medical

Information for Common Internal Medicine Diagnoses. Am J Med. 2016 Jun;129(6):637-9. doi: 10.1016/j.amjmed.2016.01.008. Epub 2016 Jan 30. PMID: 26829438.



Supplementary Files

Multimedia Appendixes

Discern Questionnaire.

URL: <http://asset.jmir.pub/assets/97719481b6ef4954a3dacd16711b0707.docx>