A Comprehensive Analysis of Online Patient Educational Materials for Lichen Sclerosus

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Abstract

Background: Lichen sclerosus is a vulvar skin condition with sincere effects on patient quality of life. Due to the sensitive nature of the disease, patients are more likely to search their health information online. However, little is known about the quality of online patient educational materials for lichen sclerosus.

Objective: To comprehensively assess online patient educational materials for lichen sclerosus

Methods: Keyword searches for “lichen sclerosus” and “vulvar lichen sclerosus” were conducted using Google. Relevant results were assessed for readability, understandability, actionability, and overall quality.

Results: Online patient educational materials were consistently written at a level higher than the recommended grade level and lacked understandability, actionability, and overall quality.

Conclusions: As patients increasingly turn to online information for their health decisions, it is noteworthy that the majority of materials lacked acceptable readability, understandability, actionability, or overall quality. ?To bridge this gap, healthcare providers can play an important role by identifying or creating resources with accurate information to recommend to their patients. ?Future efforts in the development of patient education materials should prioritize improving readability, understandability, and actionability for vulvar lichen sclerosus.

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Abstract

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Introduction

Patients increasingly rely on online patient educational materials (PEMs) to better understand their medical conditions. Studies suggest that over 50% of individuals turn to the internet for information about their health concerns.[1] Notably, conditions such as lichen sclerosus (LS) often drive patients to seek information online due to the sensitive nature of the symptoms and associated stigma.[2] Online PEMs improve health literacy, health outcomes, and may prompt patients to seek medical attention sooner.[3] This is particularly pertinent as LS requires early recognition and intervention to prevent scarring and malignancy, but currently has a 4-year diagnostic delay.[2] Although the American Medical Association recommends no higher than a sixth-grade reading level for resources, PEM readability has previously fallen short for key dermatologic patient populations.[4-6] However, the readability and quality of online PEMs pertaining to LS remain unknown. Our study aims to evaluate online LS PEMs, focusing on readability, understandability, actionability, and overall quality.

Methods

Keyword searches for “lichen sclerosus” and “vulvar lichen sclerosus” were conducted using Google on September 1st, 2023. Searchers were conducted in Incognito mode to reduce bias. The first 30 webpages of each term were reviewed for relevant, patient-oriented materials. Readability of materials was calculated using multiple formulas to gain a broad understanding of material difficulty, as recommended by the Centers for Medicare and Medicaid Services,[7] using Readability Studio version 2021. Specific formulas are outlined in Table 1. To decrease score inflation, polysyllabic words (medication names, etc.) were removed prior to assessment.

Two raters (JF and HC) assessed the understandability and actionability of the materials using the Patient Education Materials and Assessment Tool (PEMAT), with passing set as >= 70%. Interrater reliability analysis was performed using the intraclass coefficient (ICC).[8] The *Journal of the American Medical Association* (JAMA) Benchmark Score was applied to evaluate overall quality.[9]

The correlation between Flesch Kincaid readability level and PEMAT understandability score was assessed using the Pearson correlation coefficient, and a p-value ≤ .05 was considered statistically significant.

Results

Of the 60 webpages reviewed, 26 met inclusion criteria. Nineteen percent (5/26) met the recommended 6th-grade reading level by any formula. Eighty-five percent (22/26) required a high school reading level and 19.2% (5/26) required a college grade reading level. Nineteen percent (5/26) of materials were deemed understandable and only one material (3.8%) was actionable. Interrater reliability analysis for PEMAT scoring demonstrated excellent agreement among raters with ICC values of 0.951 and 0.961 for understandability and actionability, respectively. Only one material (3.8%) met all JAMA benchmark criteria. There was a statistically significant negative correlation between readability and PEMAT understandability score (r = -0.682; p = 0.0001).

Conclusions

Our findings highlight significant gaps in the quality of PEMs about LS. Given the associated stigma with LS,[2] patients may be more inclined to seek information online rather than engaging in discussions with healthcare professionals. As such, it is important that online resources are presented in a manner that is easy to comprehend and navigate. Limitations of our study include the cross-sectional nature of online content selection and the restriction to English-language articles. To bridge this gap, healthcare providers can play an important role by identifying or creating resources with accurate information to recommend to their patients. Our study brings awareness to the inadequacies in online LS PEMs, underscoring the need for improved resources to support individuals affected by this condition. Future efforts in the development of patient education materials should prioritize improving readability, understandability, and actionability for vulvar lichen sclerosus.

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Table 1. Most searched vulvar lichen sclerosus educational website characteristics (n=26)

Website characteristics	**n (%)**
Author name provided	7 (26.9)
Author degree (n = 7): MD/other/unknown	4 (57.1) / 1(14.3) / 2(28.6)
Author is a dermatologist (n = 7)	4 (57.1)
Year written/modified was noted	15 (57.7)
Material updated within the last year (n = 15)	7 (46.7)
Ads on website	5 (19.2)
Commercial bias in material*	3 (11.5)
Overall website readability and quality scores†	**Mean ± standard deviation (range)**
Flesch Kincaid reading ease	58.5 ± 10.3 (40 - 76)
Flesch Kincaid grade level	8.58 ± 2.14 (5.1 - 12.6)
FORCAST	10.9 ± 0.62 (9.7 - 12.2)
Gunning Fog score	10.5 ± 2.12 (7.4 - 15.0)
Simple Measure of Gobbledygook (SMOG) index	11.2 ± 1.70 (8.8 - 14.7)
Coleman–Liau index	10.1 ± 1.75 (7.2 - 13.4)
Automated Readability index	8.36 ± 2.28 (4.4 - 13.0)
Average Understandability‡	52.2 ± 15.0 (17.3 - 76.0)
Average Actionability‡	39.2 ± 23.7 (0.0 - 80.0)
JAMA benchmark total criteria score§	1.88 ± 0.397 (0 - 4)

JAMA, Journal of the American Medical Association

*Materials were considered commercially biased if they were advertising for a particular product or service within the main text of the educational material.

† Reading ease was graded on a scale of 0 to 100, with scores closer to 100 indicating easier to read materials. Flesch Kincaid grade level, FORCAST, Gunning Fog score, SMOG index, Coleman-Liau index, and the Automated Readability index provide an estimated grade level.

‡The Patient Education Materials Assessment Tool (PEMAT) was used to determine the understandability and actionability of a material. The PEMAT grades materials on a scale of 0 to 100, with scores closer to 100 indicating higher understandability or actionability.

§ The JAMA Benchmark Test uses four criteria (authorship, attribution, currency, and disclosure) to grade the overall quality of the material. Materials that meet all four criteria are rated as a four, while those that meet none of the criteria are rated as a zero.

Figure Legends

Figure 1. Online health resources were assessed for readability using a variety of formulas. To minimize score inflation, unavoidable, polysyllabic terms (e.g. dermatologist, clobetasol) were removed to assess readability. This figure depicts the estimated average readability scores before and after word omission.

Supplementary Files

Figures

Online health resources were assessed for readability using a variety of formulas. To minimize score inflation, unavoidable, polysyllabic terms (e.g. dermatologist, clobetasol) were removed to assess readability. This figure depicts the estimated average readability scores before and after word omission.