

Web-Based Information on Oral Manifestations of Papillon-Lefevre Syndrome - Quality and Readability

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Abstract

Objective: To review and evaluate the level of information on the oral manifestations of Papillon-Lefevre syndrome (PLS) that is available online, as well as its quality, readability, and content.

Methods: An online search was conducted using three different search engines and three distinct search terms about the oral manifestations of Papillon-Lefevre syndrome. The first 100 websites for each search engine and term were analyzed in duplicate. We use the available websites if there are fewer than 100 websites in each engine. Three different tools were used to assess the quality of each website. First, the DISCERN tool, second, the *Journal of the American Medical Association (JAMA)* website analysis standards, and third, the Health on the Net (HON) Seal. Four different measures were used to evaluate readability: the Flesch Reading Ease Score (FRES), the Flesch Kincaid Grade Level (FKGL), the Simplified Measure of Gobbledygook (SMOG), and the Coleman-Liau Index (CLI).

Results: 15 websites out of 724 remained after applying the exclusion criteria for all the three keywords for three different search engines. overall DISCERN scores for all 15 websites were 1.7 ± 1.23 . The HON seal was presented only on one website. Only 5 (33.3%) out of 15 websites achieved all four *JAMA* criteria. The FRES measure revealed that only two out of 15 websites had a standard level of readability, while the remaining 13 had readability scores ranging from difficult to very difficult.

Conclusion: The Information about Papillon-Lefevre syndrome that is currently available online is typically of poor quality and contains little information about the oral manifestations of the syndrome. The readability of the information that was available online failed to meet the standards that would enable the public to easily understand and read it. The current study's shortcomings must be addressed to create a web-based resource for the oral manifestation of papillon Lefevre syndrome.

Keywords: Papillon-Lefevre Syndrome; Online Information; Quality; Readability

Abbreviations

PLS: Papillon-Lefevre Syndrome; *JAMA*: *Journal of the American Medical Association*; HON: Health on the Net; FRES: Flesch Reading Ease Score; FKGL: Flesch Kincaid Grade Level; SMOG: Simplified Measure of Gobbledygook; CLI: Coleman-Liau Index

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Introduction

Papillon-Lefevre syndrome (PLS) is a rare autosomal recessive disorder that results from mutations in the cathepsin C gene (CTSC) [1]. The prevalence of PLS in the general population ranges from 1/250,000 to 1/1,000,000, with no sex or racial predominance [2]. It is characterized by redness and hyperkeratosis of the skin, especially the palms and soles, and progressive periodontitis, which affects primary and permanent teeth [3]. Oral manifestations begin with the eruption of primary teeth, which are characterized by swelling and inflammation of the gingiva, bone loss, and deep periodontal pockets, resulting in premature loss of teeth [3]. Permanent teeth followed the same pattern [3]. A multidisciplinary approach is required to manage patients with PLS, including dermatologists, pediatricians, and dentists (pedodontists, periodontists, and prosthodontists) [1]. Patients commonly use the Internet to look for and gather health-related information (Dresser, *et al.* 2011; Dresser, *et al.* 2007). Although the reliability of online health information is often questionable, many patients continue to rely on it [4]. Studies have shown that patients consider online information about their medical condition as good or better than that provided by healthcare professionals [5]. A 2012 study by the Pew Research Center's Internet and American Life Project revealed that 81% of American adults used the Internet, and in the past year 72% of those individuals had searched for online health information. Among online health seekers, 77% started with search engines such as Google, Bing, and Yahoo, and 13% visited specific health websites such as WebMD. Consumers of online health information are 39% likely to search for themselves, 39% likely to search for others, and 15% likely to search for themselves and others [6]. The future growth of this phenomenon relies on factors such as the patient's ability to utilize the Internet effectively and comprehend the information provided by caregivers. The presentation of information, which encompasses availability, quality, and ease of use, also plays an important role [7]. Early detection of PLS is crucial for improving patients' overall quality of life and reducing distress [8]. The oral manifestations of PLS typically appear with the emergence of primary teeth [3], making online information a valuable tool for parents to detect PLS early. However, there is currently no data on the usefulness of the information available online about the oral symptoms of PLS for patients or parents.

Aim of the Study

This study aimed to review and evaluate the level of information on the oral manifestations of PLS that is available online, as well as its quality, readability, and content.

Method

Search strategy

An online search was conducted using these three different search engines: Google, Bing, and Yahoo!. The searches were carried out in July 2023 using three distinct search terms: "Oral manifestations of Papillon Lefevre syndrome", "Oral Symptoms of Papillon Lefevre Syndrome", "Oral complications associated with Papillon Lefevre syndrome." The first 100 websites for each search engine and term were analyzed in duplicate. and we will use the available websites if there are fewer than 100 websites in each engine. The following exclusion criteria were applied: websites with only commercial content, forums, videos, online medical dictionaries, non-English links, websites with non-working links, non-related content, and websites containing links to scientific articles or book reviews [9]. The websites identified were categorized according to affiliation (nonprofit organizations, companies, academic centers, or professional associations) and specialization (entirely or partially related to the oral symptoms of Papillon-Lefevre syndrome). The content type (medical findings, clinical trials, human interest, and questions and answers) was also classified. And if the authors of the included websites provided information on their professions.

Quality assessment

Three different tools were used to assess the quality of each website. First, the DISCERN tool, second, the *Journal of the American Medical Association (JAMA)* website analysis standards, and third, the Health on the Net (HON) Seal. The DISCERN tool is reliable for evaluating the quality of health information that is available online [10]. It comprises 16 questions, each representing a distinct quality criterion that can be divided into three parts [10]. The first part (questions 1-8) assesses the credibility of the publication [10]. The second part

(questions 9 - 15) provides detailed information about treatment options [10]. The third part (Question 16) describes the overall quality based on the answers to parts one and two [10]. The answers to the questions were based on reviewer judgment, and two reviewers independently rated all sites. The *JAMA* benchmark is used to assess the quality of the websites [11]. It depends on four core standards to evaluate the websites: authorship (requires the authors and contributions), attribution (references for all contents and sources), disclosure (potential conflict of interest, website ownership), and currency (when the content was posted and updated) [11]. The Health On the Net (HON) is a code of ethics for medical websites. The sites that met the necessary standards were allowed to display the HON code.

Readability assessment

Readability is defined as the measure of reading comprehension required to understand a written text [12]. Four different measures were used to evaluate readability: the Flesch Reading Ease Score (FRES), the Flesch Kincaid Grade Level (FKGL), the Simplified Measure of Gobbledygook (SMOG), and the Coleman-Liau Index (CLI). Both FRES and FKGL were calculated by dividing the total number of words by sentences, which also determined the average number of syllables in each word [13]. The SMOG index calculates the number of polysyllabic words in three samples of ten sentences: 10 in the beginning, 10 in the middle, and 10 at the end of the text [14]. The Coleman-Liau Index (CLI) was calculated using the average number of letters per 100 words and the average length of the sentences [15].

Statistical analyses

All statistical analysis was performed using Microsoft Excel Version 2023 (MS Excel 2023) and tabulated as mean ± standard deviation of the mean.

Results

Search strategy

For each term, the first 100 websites from the Google search engine were included. Each keyword in the Bing and Yahoo search engines has less than 100 web pages available. A total of 300 websites were retrieved using Google, 223 using Bing, and 201 using Yahoo. Forty websites out of 724 remained after applying the exclusion criteria for all the three keywords for three different search engines (Figure 1). 625 websites out of 724 were scientific articles, 20 websites had non-related content, and 13 websites with non-working links. 8 websites required a subscription. 3 websites with non-English language. and 1 advertising website and 1 only video website. However, only 15 websites remained for final evaluation after excluding duplicated websites. Google shows the highest content for all the search terms with fewer duplicated and nonworking links compared to Bing and Yahoo. Regarding the search terms “oral symptoms of papillon LeFevre syndrome” “shows the most relevant websites to the patient with all search engines (n = 17) followed by “oral complications related to papillon LeFevre syndrome” (n = 13) and “oral manifestations of papillon LeFevre syndrome” (n = 10). Figure 1 shows a summary of the search results.

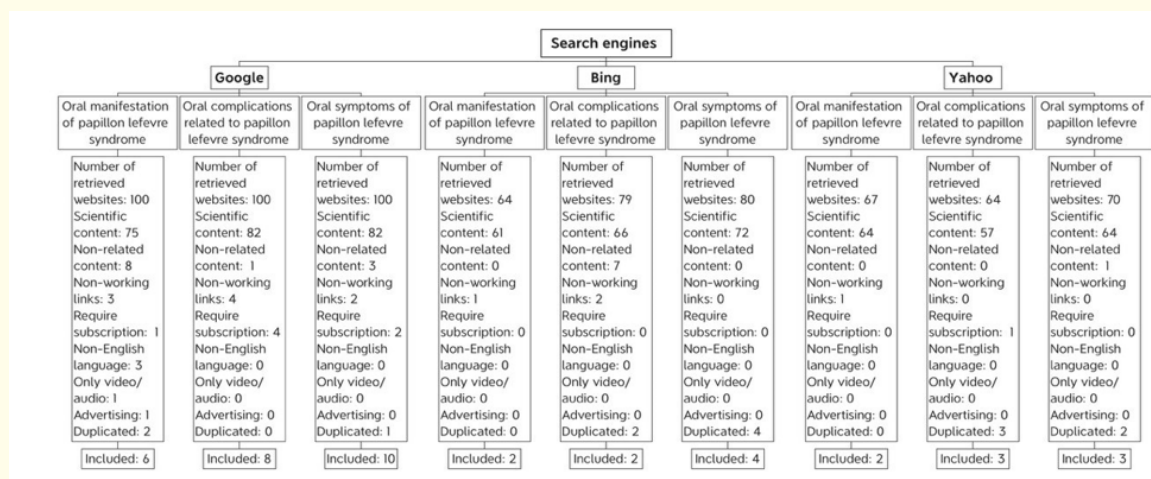


Figure 1: Summary of the search result.

For the websites category, first the affiliation: 11 websites (73.3%) were non-profit websites, 3 (20%) were commercial, and only 1 (6.7%) were either universities or hospitals. Medical facts were included on most websites. However, 4 of the sites included clinical trials, and only 2 websites were questions and answers. Regarding the content presentation, there are no videos or audio on any of the websites, and only 8 websites include images. A summary of website categorization is shown in table 1.

Category	Criteria	Number of websites (%)
Affiliation	Commercial	3 (20%)
	Non-profit organization	11 (73.3%)
	Governmental	0
	University/medical Center	1 (6.7%)
Specialization	Exclusively related	0
	Partly related	15 (100%)
Content type	Medical facts	15 (100%)
	Clinical trials	4 (26.7%)
	Human interest stories	0
	Question and answer	2 (13.3%)
Content presentation	Image	8 (53.3%)
	Video	0
	Audio	0

Table 1: Summary of the websites' categorization.

Quality assessment

The mean and standard deviation (SD) overall DISCERN scores for all 15 websites were 1.7 ± 1.23 (Table 2). Only one website obtained a 5 overall score, but most of the websites (73.3%) obtained a 1 overall score, and 20% of the websites achieved a 3 score. In the reliability section, the Poorest response was related to question one ("Are the aims clear?"), and in the treatment options section, it was ("Does it provide support for shared decision-making?") 80% and 73.3% of the websites achieved 1 score in these two questions, respectively. The HON seal was presented only on one out of the 15 websites. Only 5 (33.3%) out of 15 websites achieved all four JAMA criteria, 3 (20%) websites achieved three of the JAMA criteria, and 7 (46.7%) websites achieved two of the JAMA criteria. Most of the websites (93.3%) achieved the attribution and disclosure benchmark (Figure 2).

Readability

Regarding the readability assessment, FRES showed a range of scores from 1 to 61.9 with a mean of $30.66 (\pm 18.02)$. FKGL ranged from 7.8 to 23.5 with a mean score of $13.78 (\pm 3.36)$, SMOG ranged from 6 to 18.2 with a mean score of $12 (\pm 3.35)$ and CLI ranged from 9 to 18 with a mean score of $13.6 (\pm 2.64)$. The FRES measure revealed that only two out of 15 websites had a standard level of readability, while the remaining 13 had readability scores ranging from difficult to very difficult (Figure 3).

Discussion

Different studies show that the Internet is considered the primary resource for health information [6,16-19]. Providing high-quality medical information is very important because inaccurate information can lead to serious health consequences for the patient [20].

Domain	DISCERN question	Mean (SD)
Reliability	Q1. Explicit aims	1.27 (± 0.594)
	Q2. Aims achieved	1.2 (± 0.414)
	Q3. Relevance	3.53 (± 0.990)
	Q4. Explicit sources	3.266667 (± 1.335)
	Q5. Explicit date	3.47 (± 1.356)
	Q6. Balanced and unbiased	4 (± 1.195)
	Q7. Additional sources	1.8 (± 1.373)
	Q8. Areas of uncertainty	2.13 (± 1.187)
Treatment options	Q9. How treatment works	2.4 (± 1.056)
	Q10. Benefits of treatment	2.07 (± 0.961)
	Q11. Risk of treatment	1.6 (± 0.986)
	Q12. Effects of no treatment	1.6 (± 0.986)
	Q13. Effects on quality of life	1.47 (± 0.6399)
	Q14. All alternatives described	2.73 (± 1.387)
	Q15. Shared decision	1.47 (± 0.915)
Overall rating		1.67 (± 1.234)

Table 2: Means and standard deviation (SD) scores for DISCERN.

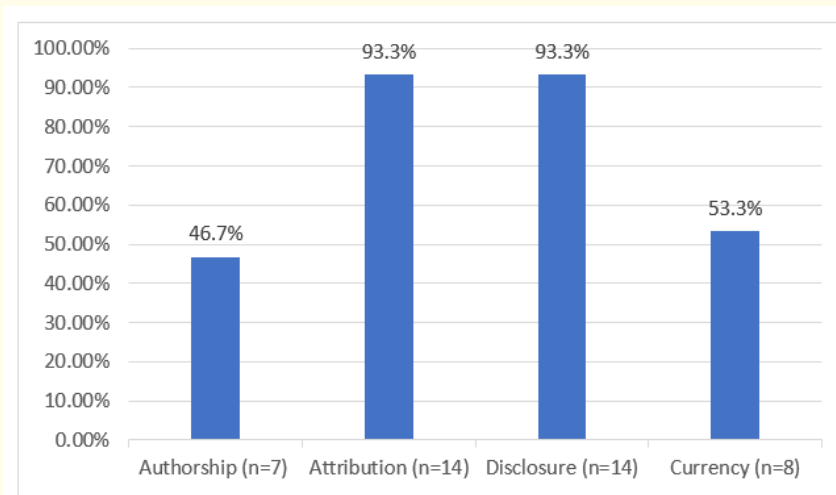


Figure 2: The JAMA benchmarks achieved by number and percentage of the 15 websites.

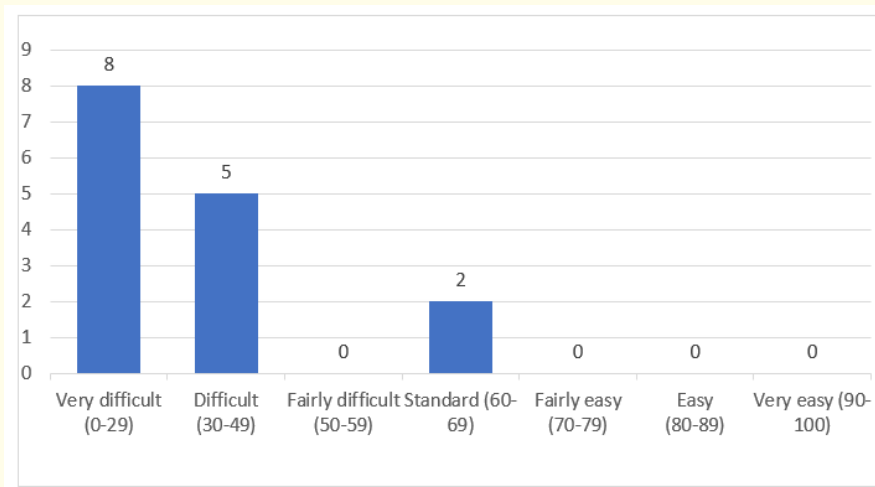


Figure 3: The number of websites per reading easiness grade based on Flesch Reading Ease Scores.

Papillon-Lefevre syndrome is considered a rare disease that affects between 1 to 4 people per million worldwide [21]. Patients diagnosed with a rare disease and their relatives use different sources to gather information [22]. An important step in enhancing the overall situation of patients who are suffering from rare diseases is the distribution of information and knowledge about these diseases [20]. When it comes to spreading knowledge about rare diseases, the internet is critical [23]. The information helps the patient understand the causes, symptoms, and treatment of the disease, which plays an important role in helping them deal with the condition in their daily lives and may also improve their quality of life [22]. Several studies show that, for rare diseases, the available information on the internet is scarce and insufficient [24-26]. Also, correct information for rare diseases is difficult to find and assess [24-26].

Oral manifestations of PLS present early in life when deciduous teeth erupt [3]. The literature reports that oral manifestations could be different [27]. In general, Parents use the web widely to find out about the state of their child’s health issues and to know whether they need medical aid or not [28-30]. Parents depend on web information to make Health-related decisions, and this can have a critical effect on the child’s health status [31].

The early oral and dermatological symptoms that affect children with PLS may have a lifelong impact on different aspects (functional, psychological, aesthetic, and social) [32]. The Quality of life for the children could be improved by an early diagnosis of PLS and appropriate treatment to achieve good oral conditions [8,32]. Around 35% of people who search on the internet for health-related information use it to diagnose their condition [33]. Due to the importance of early diagnosis, the variety of oral manifestations of PLS, and the lack of content that talks about the quality of available online information about PLS, Evaluation of the readability and quality of online content relating to the oral symptoms of PLS is essential.

Regarding the websites evaluated in this study, none of them were entirely dedicated to the oral manifestations of Papillon-Lefevre syndrome, and all of them were thought to be at least partially related to the oral manifestations of Papillon-Lefevre syndrome. Additionally, all the websites found in this investigation had medical information. It is not unexpected that the reading level ranged from “difficult” to “very difficult” given that the whole content was considered as a medical fact.

Patients looking for information especially devoted to the oral manifestations of Papillon-Lefevre syndrome will need to try to understand the extensive medical content as well as find a website for information related to the oral cavity. It has been questioned in previous years whether patients can understand medical information accurately [34].

The quality and reliability of the assessed websites were low to moderate using the DISCERN rating and *JAMA* benchmarks, which are validated and commonly used tools to evaluate the quality of online content [35]. The websites that were analyzed had a mean DISCERN score of 1.7 (\pm 1.23), which indicates that the quality of the available websites was low to moderate [36]. Only 33.3% of the websites met the full *JAMA* benchmarks. Several studies addressing various diseases related to oral health have revealed similar findings [37]. Although one of the analyzed websites displayed the HON code seal.

The websites' content's readability was evaluated using FRES, FKGL, SMOG, and CLI. The majority of the websites have a readability rating as "difficult" to "very difficult".

Conclusion

The Information about Papillon-Lefevre syndrome that is currently available online is typically of poor quality and contains little information about the oral manifestations of the syndrome. According to the most recent findings, the readability of the information that was available online failed to meet the standards that would enable the public to easily understand and read it. As a result, individuals looking for information online regarding the oral manifestations of Papillon-Lefevre syndrome are likely to struggle to understand and find trustworthy information on the condition and its potential effects on their lives. The current study's shortcomings must be addressed to create a web-based resource for the oral manifestation of papillon Lefevre syndrome.

Conflicts of Interest

The authors declare no conflicts of interest with regards to this study.

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