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ORIGINAL RESEARCH

Web-Based Educational Resources for Patients with Sickle Cell Disease: Availability and Reliability

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Purpose: Arabic is the primary language used in the Middle East, where sickle cell disease (SCD) is prevalent. This study aims to quantify Arabic web educational materials for patients with SCD and provide a descriptive standardized assessment.

Methods and Materials: This retrospective, descriptive study aimed to analyze Arabic websites on SCD through the Discern instrument and JAMA benchmark.

Results: We evaluated the quality and reliability of 27 Arabic SCD-related websites. Regarding website content, all 27 (100%) defined sickle cell disease, whereas 25 (96.30%) and 24 (92.59%) illustrated its manifestations and treatments, respectively. However, only 12 (44.44%) discussed the prevention of the disease through premarital genetic screening and counseling. According to the Discern score, 11 (40.74%) websites were of low quality, while 16 (59.26%) were of moderate quality. On the other hand, the JAMA score reveals that only 2 (7.41%) websites were high reliability, while the majority 25 (92.59%) were low reliability. Additionally, analysis revealed a weak positive correlation between the Discern and JAMA scores (correlation coefficient of 0.19). There were no statistically significant differences in the Discern and JAMA scores between websites on the first page of the search results and those on other pages ($p = 0.941$ and 0.359, respectively).

Conclusion: Empowering patients with comprehensive knowledge about various disease aspects is a pivotal component in the effective management of SCD and, consequently, improving its outcomes. Regrettably, there is a notable scarcity of credible and high-quality written web-based health resources available in Arabic despite significant advancements in other clinical aspects of SCD. Augmenting the existing online resources in Arabic patients' native language could yield substantial enhancements in patient care across various dimensions.

Keywords: sickle cell disease, education, Arabic language

Introduction

Sickle cell disease is the most common monogenic inherited disorder, with a large and growing global public health significance that has been attributed to its impact on morbidity and mortality. Over half a million babies were born with sickle cell disease in 2021, and almost eight million people were living with the disease globally.[1,2]

A painful crisis is the hallmark of the disease, though affected individuals might experience other acute and chronic complications such as acute chest syndrome, chronic hemolytic anemia, and multiple organ failure.[3,4] The presence of different genotypes, co-existence with other hemoglobinopathies, and patients' variable socioeconomic statuses results in a diversity of clinical presentations and disease severity.[1,5] Nevertheless, a better understanding of the disease and its pathophysiology have resulted in the substantial evolvement of treatment paradigms over the last decade, including several disease-modifying agents, hematopoietic cell transplantation, and gene therapy.[6,7] These evolvements have

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resulted in better outcomes and improved quality of life. However, enabling patients with the knowledge to become co-managers of their care processes is a key component in creating a high-performing and cost-efficient healthcare system.[8]

Today, the internet serves as the world's primary source of information.[9] The rapid expansion of resources, large databases, and easy accessibility to online material have made web searching a preferred method for patients to learn about their medical conditions. However, this is a double-edged sword.[10] Due to the vast and unregulated nature of online information, the accuracy, comprehensiveness, and relevance of health content found on the internet can be unreliable. This variability creates a challenge for patients seeking consistent and trustworthy health resources.[10,11]

Because of the significant effect of web-based health information on patients' decision-making and overall attitude toward their diseases, the quality of such content must be assessed.[11,12] Several studies have evaluated the reliability of online content intended for patient education covering the different medical aspects of sickle cell disease. Since English dominates much of the world's public health information, these studies were limited to English-language publications. Although the issue of the quality and reliability of online health-related material is not restricted to a specific language, it is less of a problem for English-speaking individuals, who have a wider range of resources in their language.[13,14] However, in a world of incredible linguistic diversity, language-concordant care optimizes health outcomes and advances health equity for diverse populations.[15]

Arabic is the sixth most spoken language worldwide and the main language used in the Middle East, which has a high prevalence of SCD.[2] However, the literature lacks an exploration of the qualitative characteristics of Arabic websites concerning SCD. Therefore, this study aims to fill this gap by providing a descriptive standardized assessment of these websites and quantification of Arabic web educational materials for patients with SCD.

Methods

This retrospective, descriptive study analyzed Arabic websites covering the topic of sickle cell anemia. According to the Search Engine Journal, Google is the most popular search engine worldwide.[16] Consequently, we used Google to search for three common Arabic terms for sickle cell anemia. The search was conducted in private mode, using a new account with no search history to avoid the influence of previous user data on the search results.

The first hundred results or websites for each term were examined for eligibility according to the inclusion and exclusion criteria. To be included, websites had to be in Arabic and exclusively comprised of educational materials about sickle cell disease for patients and the general public. On the other hand, websites in other languages or those targeting medical professionals were excluded. Moreover, websites that appeared multiple times during the search process were counted as one after excluding duplicates. The search strategy is demonstrated in Figure 1.

Websites were categorized into six groups: hospitals and medical centers, health portals (websites that present health-related articles on diverse topics), commercial websites (websites that sell a product or service), foundations (non-profit organizations), governmental websites, and blogs. Similarly, we grouped the websites that appeared on the first page of the search results to be compared with those on other pages because users usually view the top-ranked websites on Google's first page, which typically has ten results.[17] The quality and reliability of these websites were assessed through two well-established and validated tools: the Discern instrument and the JAMA benchmark.[18,19]

The DISCERN tool offers a standardized approach for evaluating the quality of patient education materials. This 16-question instrument assesses how well the material meets specific criteria. Each question receives a rating between 1 and 5, with 1 indicating the information is completely absent and 5 signifying it adheres to the criteria perfectly. A total score ranging from 16 (lowest) to 80 (highest) is obtained by summing these individual ratings. Additionally, the overall score is further categorized into three categories: low quality (16–32), moderate quality (33–64), and high quality (65 or higher).[20]

Similarly, the JAMA benchmark tool evaluates the trustworthiness of online information based on four key principles: authorship (identifying the author and their credentials), attribution (citing sources and references), disclosure (revealing ownership and potential conflicts of interest), and currentness (indicating the date of publication and updates). Each criterion met earns the website 1 point, resulting in a score ranging between 0 and 4. This score serves as a reliability indicator: Websites with a score of 3 or higher are considered highly reliable, while those scoring 2 or lower raise concerns about trustworthiness.[18]

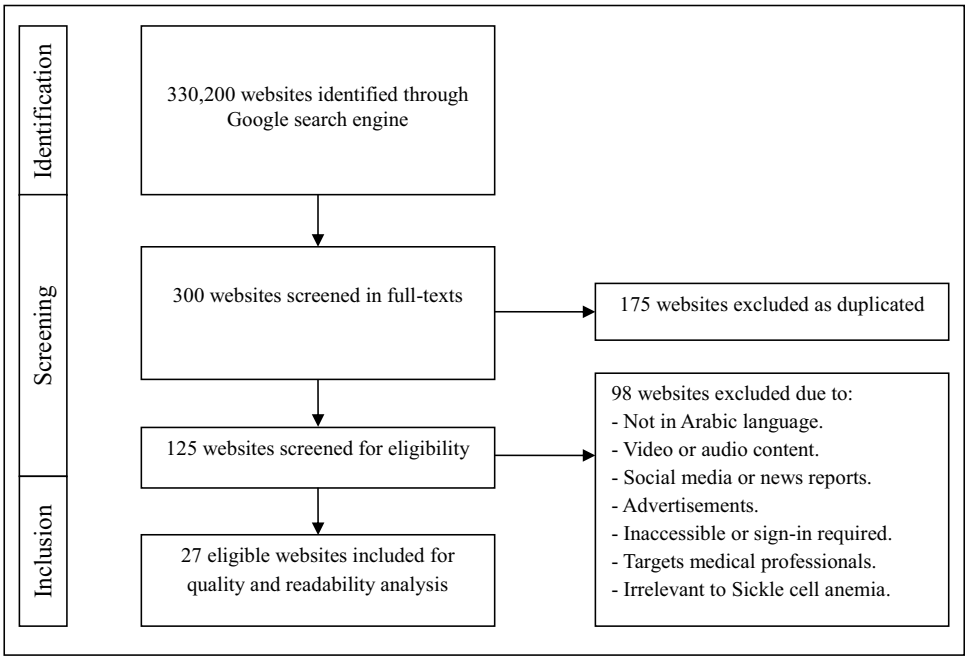

Figure 1 Flowchart of search results and steps of the procedure.

The rating was performed by two evaluators, raters A and B, independently at first, then followed by a shared evaluation to settle any disagreements. All evaluations were collected and analyzed using the International Business Machines (IBM) Statistical Package for the Social Sciences (SPSS) 27.

The descriptive analysis was done to show mean, median, and mode values with standard deviations (SD) for quantitative data. Frequencies and proportions were presented as tables. Normality tests were employed to determine if each data set was normally distributed, and appropriate statistical tests were chosen based on the results. P values less than 0.05 were considered to be statistically significant.

Results

We evaluated the quality and reliability of Arabic health-related material on 27 websites. Among these, 10 (37%) were owned by hospitals and medical centers, 9 (33.3%) were health portals, 3 (11.1%) were commercial websites, 2 (7.4%) were governmental websites, 2 (7.4%) were blogs, and 1 (3.7%) was owned by a foundation. Regarding the content of the websites, all 27 (100%) defined sickle cell disease, whereas 25 (96.30%) and 24 (92.59%) illustrated its manifestations and treatments, respectively. However, only 12 (44.44%) discussed the prevention of the disease through premarital genetic screening and counseling.

The average Discern score was 34.96 ± 9.53, with the highest being 58 and the lowest 20. Regarding quality classifications, 11 (40.74%) websites were of low quality, while 16 (59.26%) were of moderate quality. The highest average score, 3.89 out of 5, was for the question "Is it balanced and unbiased?" while the lowest average scores, 1.15 and 1.22, were for the questions "Does it describe what would happen if no treatment is used?" and "Does it describe how the treatment choices affect the overall quality of life?", respectively (Figure 2).

The average JAMA score was 1 ± 1.04, with the highest score being 4 and the lowest 0. Regarding reliability classifications, only 2 (7.41%) websites were considered to have high reliability, while 25 (92.59%) were of low reliability. The most frequently fulfilled principle was currency, which was achieved by 9 websites. However, disclosure of ownership and conflict of interest were only met by 1 (3.7%) website (Figure 3).

Regarding the mean assessment tools' scores across the different types of websites, the highest average Discern score of 36.50 was for hospital and medical center websites, while the highest average JAMA score of 1.50 was for blogs and webpages. However, there were no statistically significant differences in the Discern and JAMA scores across the

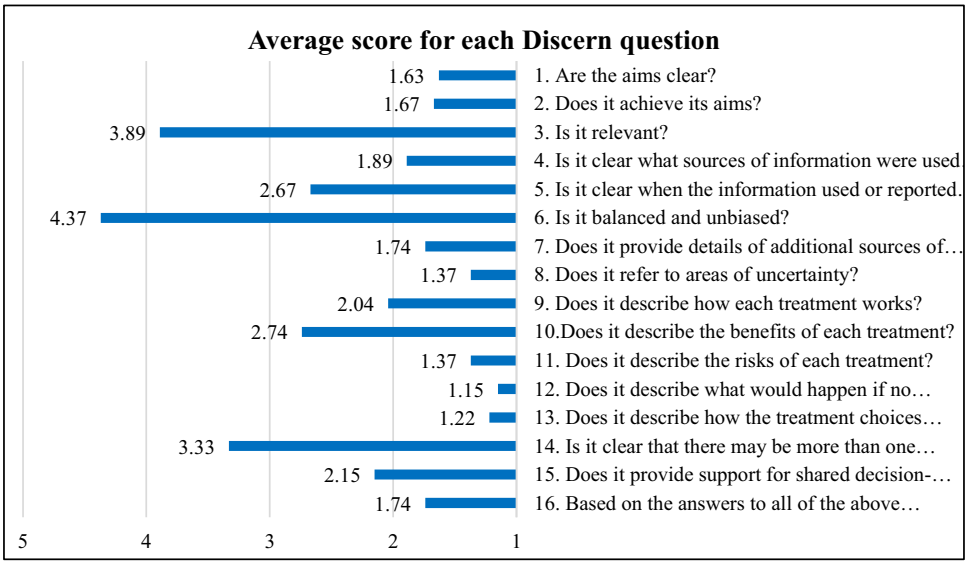

Figure 2 Average score for each Discern question.

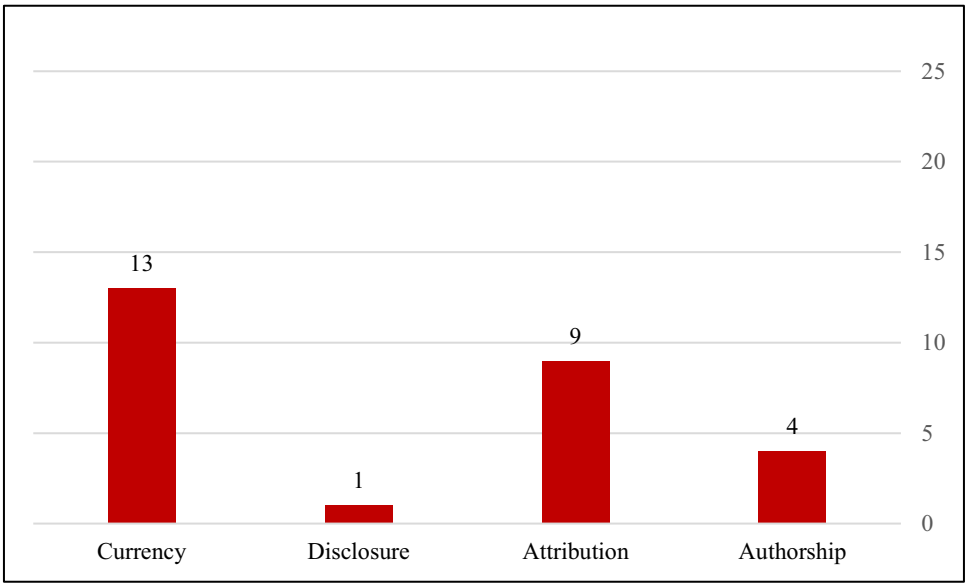

Figure 3 Number of websites that fulfilled each JAMA criteria.

different website types (p = 0.422 and 0.368, respectively). Additionally, analysis revealed a weak positive correlation between the Discern and JAMA scores (correlation coefficient of 0.19). There were no statistically significant differences in the Discern and JAMA scores between websites on the first page of search results and those on other pages (p = 0.941 and 0.359, respectively).

Discussion

Sickle cell disease is a complex inherited condition with an unpredictable and heterogeneous clinical course that could be challenging for patients and their families when making decisions about preventive measures and initiating treatment. Therefore, educating patients is crucial.[4,21] Several studies have shown that educating patients with SCD and empowering them with knowledge results in better clinical outcomes.[22] Conversely, misinformation has severe consequences for patients' quality of life and even mortality risk.[23]

The internet is considered a fundamental source for various health educational materials represented in different ways, including auditory, visual, and written.[9,24] Reading written material is considered an easy way to obtain and understand information though reliability is a major concern.[13,25] Previous studies have shown that despite the presence of English-language health resources for patients with SCD, these websites can be fairly difficult to read and lack a well-rounded view of the health information that patients need.[26] Our study found that Arabic web-based educational materials addressing different aspects of SCD are scarce, irrespective of their quality and reliability. Fundamentally, the majority of these websites include definitions of the disease, clinical presentations, and treatments. Nevertheless, more than one-third is of low quality, whereas the remaining are of moderate quality. Similarly, the majority of these websites are unreliable based on the JAMA scoring system. Interestingly, there were no differences in either reliability or quality between websites on the first page of search results and those on other pages.

Prevention plays a central role in the care of patients with sickle cell disease and can occur at different stages. One approach is the prevention of the disease itself through premarital counseling and in vitro fertilization (IVF) with preimplantation genetic (PGS) to ensure healthy offspring.[21,27] The other way is to prevent short- and long-term complications by optimizing non-curative approaches to improve patients' quality of life, decrease morbidity, and increase life expectancy.[28,29] However, less than half of the websites in our study address disease prevention in their educational material. Moreover, the quality and reliability of these websites did not reach the highest level.

This study shed light on the paucity of written Arabic web health resources for sickle cell disease patients and found that most of them are low quality and unreliable. These could be attributed to several factors including translation gap of educational medical material to Arabic language. Additionally, reliable resources or information usually provided through directed interview at the health centers or educational campaigns that are not necessarily posted in the websites. A lack of reliable resources compromises patient decisions and awareness about disease management options. For instance, results from a previous study revealed that many patients with SCD were unaware of hydroxyurea or preferred not to start using it despite this medication being approved for SCD treatment for more than two decades.[7] Conversely, a diversity of resources would allow patients to think and make thorough decisions about both preventative and treatment modalities. Furthermore, the scarcity and unreliability of health resources could delay patients from seeking medical services, which could translate into increased costs and burdens on health services or unwanted consequences and complications due to delayed recognition and presentation.

Several limitations might have influenced this study's results. Importantly, it might have underestimated the availability of educational material as several healthcare facilities do not have websites, preferring to offer patients printed rather than web-based material. Additionally, our study did not compare the availability and readability of written web-based resources with visual or auditory resources that could be abundant and more attractive to certain populations, particularly those with poor reading skills and language proficiency. Furthermore, readability is an important part of both tools though was not evaluated due to lack of Arabic platform for ideal assessment. Lastly, using single search engine might affect results' generalizability; nonetheless, Google is considered widely used search engine. Future studies are needed to evaluate the quality and reliability of visual and auditory Arabic health resources for patients with SCD and their efficacy compared to written web-based material. Moreover, website enrichment with reliable educational material about disease manifestations, available different treatments, and preventative measures in patient naive language would have a substantial impact on patient care. These goals could be achieved by controlling and monitoring of web-based health information through collaboration between national and international health organizations and scientific institute. Furthermore, Arabic abstracts incorporation to non-Arabic medical articles could enhance and enrich Arabic medical resources. Lastly, providing patients with reliable web-based health resources is crucial.

Conclusion

Empowering patients with comprehensive knowledge of sickle cell disease is pivotal for enhancing its management and overall outcomes. However, there is a notable scarcity of high-quality and reliable written web-based health resources in Arabic, in contrast to the considerable advancements observed in other clinical aspects, such as treatment modalities and preventive measures. The translation of these advanced measures into the native language of patients, through the

enrichment of online written resources, holds the potential to significantly impact patient care across various domains and alleviate the burden on healthcare services.

Abbreviations

SCD, Sickle cell disease; IBM, International Business Machines; SPSS, Statistical Package for the Social Sciences; SD, standard deviation.

Disclosure

The authors declare that they have no conflict of interest to disclose.

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