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Evaluating the Information Content, Readability, and Reliability of Turkish Websites about Fibromyalgia

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Abstract

Aim: Although fibromyalgia patients frequently use the internet to get information about their diseases, there is no comprehensive and strong study investigating the quality and reliability of websites offering online information in Turkish. The aim of this study was to examine the content, readability, and reliability levels of the information published on Turkish websites about fibromyalgia.

Methods: In May 2022, the words "fibromyalgia" and "muscle rheumatism" were scanned on a Google search, and the websites in the first 20 pages were investigated. The websites were divided into three groups according to the creator: Group 1= hospitals, associations, and official institutions; group 2= health professionals; and group 3= others (news sites, blogs, etc.). The readability level was evaluated according to the Ateşman and Bezirci-Yılmaz formula; the reliability was evaluated according to the Journal of the American Medical Association (JAMA) score; and the information content was evaluated by referring to the subject headings in the patient information booklet prepared by the Turkish Physical Medicine and Rehabilitation Association. The grouping of the websites and evaluation of the JAMA score were rated by two independent researchers.

Results: One hundred and seven websites were included in the study; 48 (44.8%) were in group 1, 28 (26.2%) were in group 2, and 31 (29.0%) were in group 3. The median Ateşman value of all websites was 47.3 [minimum (min.)=21.6, maximum (max.)=80.2]; the median Bezirci-Yılmaz value was 13.1 (min.=4.8, max.=22.7). The JAMA median score was 2.0 (min.=0, max.=4), and 102 (95.2%) websites were classified as low-reliable (JAMA score≤2). The information content of 12 (11.2%) websites was complete. There was no difference between the groups in terms of the JAMA score, Ateşman, and Bezirci-Yılmaz values (p=0.705, 0.801, and 0.697, respectively). Websites on the first two pages (n=16) had a slightly lower JAMA score than the next pages (p=0.011). Inter-rater consistency was excellent (Cohen's=0.89 and 0.823, respectively; p<0.001).

Conclusion: Turkish websites are far from providing sufficient and quality information on fibromyalgia. Physicians and patients should be aware of this situation; relevant institutions should develop the necessary health policies to solve the problem.

Keywords: Comprehension, fibromyalgia, information quality, search engine

Introduction

Fibromyalgia is a polysymptomatic disease characterized by increased mechanical hyperalgesia and allodynia, accompanied by many symptoms such as chronic widespread pain, fatigue, morning stiffness, sleep disturbance, cognitive dysfunction, and depressed mood (1). The prevalence of fibromyalgia in the general population is 3%, and it is the third most common musculoskeletal disease (2). In cross-sectional studies conducted in Turkey, its prevalence was found to be between 3.6 and 8.8% (3). Fibromyalgia is a difficult disease whose etiopathogenesis is not yet known, which has no effective treatment and adversely affects the quality of life. Although there are different treatment options, the basis of high-evidence treatment is the combination of pharmacological (such as amitriptyline,

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duloxetine, and pregabalin) and non-pharmacological treatments (such as aerobics and relaxation exercises, patient education, cognitive behavioral therapy, and other alternative therapies) (4).

Due to developing technological opportunities, the use of the internet has become very common worldwide recently. Especially with the effect of the coronavirus disease-2019 (COVID-19) pandemic, people have started to spend more time at home and use the internet more. The Turkish Statistical Institute (TurkStat) reported that the rate of households with internet access in Turkey reach 92% in 2021, and the rate of those using the internet to seek health-related information reached 70% (5). This traumatic pandemic process, which developed quite suddenly, has revealed that health literacy is an important issue (6,7). In particular, fibromyalgia patients use the internet extensively to access information about their health status (8,9). However, in order for online information to be useful for a sensitive and exclusive population like those with fibromyalgia, it must contain enough information, be reliable, and be readable. Otherwise, this information will do more harm than good to the patient; it will cause additional difficulties in doctor-patient relations (10).

Readability is a quantitative technical concept in linguistics that refers to the situation where texts are easy or difficult to understand by readers. In studies examining online information about fibromyalgia in different languages, it was emphasized that the content, reliability, and readability levels were insufficient and worrying (11-13). Considering that readability is a technical assessment specific to language and society, and online information on the internet, where there is no control mechanism, can vary considerably from country to country, the online information content and quality are specific to each country and should be examined separately. However, there is no comprehensive and methodologically strong study in the literature examining Turkish websites about fibromyalgia in terms of information content, readability, and reliability.

The aim of this study was to examine the information content, readability, and reliability levels of Turkish websites containing information about fibromyalgia.

Materials and Methods

Compliance with Ethical Standards

This study was a cross-sectional study in which data were scanned on the internet. The study approval was obtained from the University of Health Sciences Turkey, Hamidiye Scientific Research Ethics Committee (date: 06.04.2022, and approval number: 9/13).

Study Design and Data Collection

In May 2022, the keywords "fibromyalgia, muscle rheumatism" were written in Turkish on Google (https://www.google.com.tr), which is the most frequently used internet search engine in Turkey (85%) as it is worldwide (14). To prevent any possible impact on the study results, the browsing history and cookie settings in the computer's cache have been deleted, and the personal Google account has been logged out. In line with similar studies conducted on this subject, 200 websites in the first 20 pages were examined (15).

Websites that do not contain information about the disease, chat-forums, advertisements, magazines, for commercial purposes, contain only images or videos, have fewer than ten sentences, cannot reach the text in a maximum of three clicks and are repetitive were excluded from the study. According to the creator, the websites were divided into three categories: 1) prepared by a hospital, medical center, university, health-related associations, or other official institutions; 2) prepared by health professionals; 3) other (news sites, blogs, anonymous, unclassifiable). The grouping of websites was done by two independent researchers (RY and SK). In the event of an inconsistency among the researchers in the grouping, the third researcher (HHG) was also examined, and the final decision was made by consensus.

Information Content

The information content on the websites was reviewed with reference to the topics in the online accessible information booklet prepared by the Turkish Physical Medicine and Rehabilitation Association (TPMRA) for fibromyalgia patients (16). The seven main headings in this booklet are: the definition of the disease, its frequency, cause, symptoms, how the diagnosis was made, its differential diagnosis, and whether information was given about the treatment of the disease were examined. The information content was recorded as "yes" or "absent" by a single researcher (RY), regardless of the length of the text, level of academic evidence, and general medical accuracy, depending on whether the above topics were mentioned.

The Journal of the American Medical Association Benchmark Criteria

The Journal of the American Medical Association (JAMA) benchmark criteria is an international score used to evaluate the quality, reliability, reasonableness, and usefulness of medical information on the Internet (17). The evaluation examines four main elements: 1) Author information 2) attribution (reference, copyright information) 3) Transparency (advertising, sponsorship, and conflicts of interest) 4) currency. A score of 0 is given

for the absence of each criterion, and 1 for its presence. The total score can vary between 0 and 4. ≥3 points are considered "high reliability," and ≤2 points are considered "low reliability." The JAMA score was evaluated by two independent researchers (RY and SK). When there was inconsistency among the researchers in the scoring, it was also examined by a third independent researcher (HHG), and the final decision was made by consensus.

Readability

To evaluate the readability level of the texts on the websites, the Ateşman and Bezirci-Yılmaz formulas, which were specially developed to determine the readability level of Turkish texts, were used. Readability calculations were made by copying the analyzed texts and transferring them to a special computer program.

Ateşman Readability Formula

The Ateşman formula was developed by adapting the Flesch Ease of Reading formula, which evaluates English readability, into Turkish (18). It is a formula based on sentence length and the number of syllables in its words. The increase in sentence length and the number of syllables in words reduce the readability of the text. According to the Ateşman formula, if a text's score is between 90 and 100, it is "very easy," between 70 and 89, it is "easy," between 30 and 69, it is "medium," between 30 and 49, it is "difficult," and between 1 and 29 is considered "very difficult".

Bezirci-Yılmaz Readability Formula

The Bezirci-Yılmaz formula was developed in 2010 based on the previously developed international readability scales and specific features of Turkish (19). Similar to the Ateşman formula, it considers the length of sentences and the number of syllables in words. This formula estimates how many years of training are needed to understand a text, similar to the Simple Measure of Gobbledygook score, which is commonly used to evaluate the readability of English texts. The numerical value obtained because of the calculation shows which class level it corresponds to according to the education system in Turkey. Accordingly, 1-8 refers to primary education, 9-12 refers to secondary (high school) education, 12-16 refers to university (undergraduate), and 16 refers to the academic level (19).

Statistical Analysis

Statistical analyses were performed using IBM® SPSS Statistics 21 software (Armonk, NY, USA). The frequency and percentage [n (%)] of categorical data are given; numerical data are given as the median (min.-max.) or mean ± standard deviation (SD). Cohen's kappa coefficient (κ) was used to determine the inter-rater consistency of categorical and ordinal data. The Shapiro-Wilks test was used to determine whether the data were normally distributed or not. Mann-Whitney U test was used in the comparison of numerical (non-parametric) data between two independent groups that did not show a normal distribution, and the chi-square test was used in the comparison of categorical (dichotomous) variables. A student's t-test was used to compare two parametric and independent groups. The Kruskal-Wallis non-parametric test or the one-way ANOVA parametric test was used to compare more than two independent groups. The Spearman's rho test was used for correlating non-parametric data that did not have a normal distribution. All statistical analyses were performed in two directions: at the 5% significance limit and the 95% confidence interval.

Results

Of the 200 websites examined, 107 were included in the study, as they were found to be suitable for the inclusion criteria. Of these sites, 48 (44.8%) were in group 1, 28 (26.2%) were in group 2, and 31 (29%) were in group 3 (Figure 1). The consistency among website-grouping raters was nearly perfect (Cohen's κ= 0.898, p<0.001).

We observed that the websites included an average of 5.0±1.23 (median=5, 1-7) of the seven main headings in the fibromyalgia information booklet of TPMRA. 104 (97.2%) of the web sites include the definition of the disease, 79 (73.8%) frequency, 87 (81.3%) causes, 105 (98.1%) symptoms, 38 (35.5%) how the diagnosis is made, 19 (17.8%) included information about differential diagnosis, and 103 (96.3%) information about treatment. The most common content was symptoms, and the least common content was differential diagnosis. Only 12 (11.2%) websites were complete in terms of content headlines. There was no difference between the groups in terms of the completeness of the topic information content (p=0.877) (Table 1).

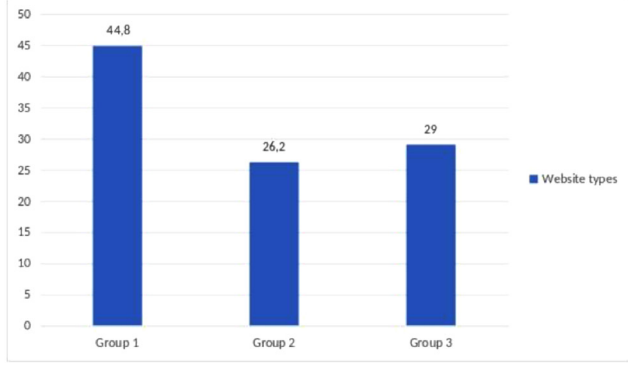

Figure 1. Frequency of website groups by creator (%)
Group 1; prepared by a hospital, medical center, university, health-related associations, or other official institutions
Group 2; prepared by health professionals
Group 3; other (news sites, blogs, anonymous, unclassifiable)

The overall JAMA benchmark median scores of websites were 2.0 (min=0, max=4) (1.46±0.768). Hundred and two (95.2%) of these sites were classified as low-reliable (JAMA score ≤2), and 5 (4.7%) of them were classified as high-reliable (JAMA score ≥3). The inter-rater reliability for determining the JAMA score of the websites was almost perfect agreement (Cohen's κ=0.823, p=0.000). There was no significant difference between the groups (typology of the websites) in terms of the JAMA scores (p=0.705) (Table 1).

The mean Ateşman readability value of all websites included in the study was 46.74±9.15 (median=47.3, min=21.6, max=80.2), and the mean Bezirci-Yılmaz readability value was 13.30±3.17 (median=13.1, min=4.8, max=22.7). The mean Ateşman readability value of all websites included in the study was found to be "difficult". The Bezirci-Yılmaz readability value of the websites included in the study corresponds to the 13th grade (undergraduate) in the Turkish education system. No statistically significant differences were detected between the Ateşman readability values of the study groups (p=0.754) and the Bezirci-Yılmaz readability values (p=0.650) (Table 1).

When the readability ranges are examined according to the Ateşman formula, 73 (68.2%) websites are found to be "very difficult" or "difficult" to read. No statistically significant differences were detected between the readability ranges (very difficult + difficult vs. medium + easy + very easy) of the types of websites (p=0.558) (Table 2).

Most (75%) of the websites on the first two pages (n=16) were in group 1, whereas the websites on the last 18 pages had a more homogeneous distribution (p=0.006). Contrary to expectations, it was observed that the JAMA score of the websites on the first two pages was slightly lower than the following pages (p=0.011) (Table 3). There was no significant difference between these groups in terms of information content and readability values for the Ateşman and Bezirci-Yılmaz (p=0.56, p=0.82, and p=0.78, respectively) (Table 3). Furthermore, there was no significant correlation between the JAMA scores of the websites and Ateşman and Bezirci-Yılmaz's readability values (r=0.04, p=0.97; and r=-0.02; p=0.87, respectively).

Discussion

This study aimed to evaluate the information coverage, readability, and reliability levels of Turkish websites containing information about fibromyalgia. Almost all (95%) of the 107 websites examined were found to have a low level of reliability according to the JAMA score. In terms of readability, it is difficult to understand according to the Ateşman formula, and according to the Bezirci-Yılmaz formula, it is at an understandable level with 13 years of undergraduate education according to the Turkish education system. It was also observed that there was insufficient information in terms of content.

With the rapid increase in the use of the Internet, especially in the last decade, people are trying to get access to a lot of health-related information from the Internet. Most of the time, in this process, which is

Table 1. Information content, readability and reliability levels of websites by groups

Website type	Group 1 (n=48, 45%) mean ± SD median (min.-max.)	Group 2 (n=28, 26%) mean ± SD median (min.-max.)	Group 3 (n=31, 29%) mean ± SD median (min.-max.)	p-value
Information content*	5.02±1.37 5.0 (1-7)	5.04±0.92 5.0 (3-6)	4.94±1.31 5.0 (2-7)	0.877[a]
JAMA score	1.38±0.84 1 (0-3)	1.54±0.51 2 (1-2)	1.52±0.85 2 (0-4)	0.705[a]
Ateşman value	46.7±7.67 47.46 (23.6-63.4)	47.8±10.4 47.53 (23.7-80.2)	46.0±10.42 47.08 (21.6-63.4)	0.754[b]
Bezirci-Yılmaz value	13.3±2.84 13.4 (7.8-21.9)	12.9±3.52 12.2 (4.8-22.5)	13.6±3.40 12.7 (8.5-22.7)	0.650[b]

*According to the information booklet prepared by the Turkish Physical Medicine and Rehabilitation Association for fibromyalgia patients.
[a]Kruskal-Wallis test; [b]one-way ANOVA test, p<0.05 is significant
JAMA: Journal of the American Medical Association, min.-max.: Minimum-maximum, SD: Standard deviation

Table 2. Evaluation of the readability ranges of the groups according to the Ateşman value

Website type	Group 1 48 (45%)	Group 2 28 (26%)	Group 3 31 (29%)	p-value*
Very difficult + difficult	35 (73%)	19 (68%)	19 (61%)	0.558[a]
Very easy + easy + medium	13 (27%)	9 (32%)	12 (39%)	

[a]Kruskal-Wallis test, p<0.05 is significant

Table 3. Comparison of the websites on the first two pages and the websites on the remaining pages			
	First two page (n=16) mean ± SD median (min.-max.)	**Other 18 page (n=91) mean ± SD median (min.-max.)**	**p-value**
Information content	5.19±1.28 5 (3-7)	4.97±1.23 5 (1-7)	0.560[a]
JAMA score	1.0±0.73 1 (0-2)	1.54±0.75 2 (0-4)	0.011[a]
Ateşman value	46.3±6.9 47.3 (33.2-60.6)	46.8±9.5 47.3 (21.6-80.2)	0.820[b]
Bezirci-Yılmaz value	13.1±2.38 13.5 (8.8-18.3)	13.3±3.3 12.9 (4.8-22.7)	0.779[b]

[a]Mann-Whitney U test; [b]Student's t-test; p<0.05 is significant
JAMA: Journal of the American Medical Association, min.-max.: Minimum-maximum, SD: Standard deviation

conducted through search engines, individuals try to obtain information about the characteristics of the diseases, diagnostic methods, treatment options, or which disease their current symptoms may indicate (20). Although it has been reported that online health information can improve people's ability to cope with diseases and increase their quality of life by reducing their anxiety and fears, it seems very difficult to obtain reliable and readable information with sufficient and correct content (11-12,21). General medical information with low information content, low quality, and non-individual is deceptive and confusing because it cannot be correctly interpreted, ultimately leading to maladaptive behaviors and concerns (22).

Increased anxiety and social isolation during the COVID-19 pandemic adversely affected fibromyalgia symptoms (23). In this process, it has been reported that the incidence of chronic widespread pain, including fibromyalgia, increases (24,25). The chronic, difficult, and wearisome nature of fibromyalgia, the cause of which is unknown without objective diagnostic criteria and effective treatment, increases the search for a cure in these patients. Indeed, fibromyalgia patients report a preference for engaging with online health information (26). Additionally, considering that patient education for treating fibromyalgia is recommended with a strong level of evidence (level 1A), it is critical to access reliable and quality information on the internet (27).

Daraz et al. (11) examined the first 25 English-language websites on Google that provide online information about fibromyalgia in terms of information content, quality, and readability. The DISCERN tool was used for information quality and reliability, but they also used the Quality Checklist, which consists of seven items such as authorship, content, currency, and disclosure, considering that this DISCERN scale would not be an adequate assessment on its own. Because of the research, they reported that the websites did not contain comprehensive information, were of low quality, and were difficult to read. It has been observed that only 16% of the websites can provide the 6-8 year education level recommended for ideal readability.

In another recent study, the top 200 websites on Google offering fibromyalgia information online in English in the United States were examined for information completeness and trustworthiness (28). It was determined that the information content did not meet the inquiry needs of the patients, and the median value of the JAMA score was 2.0. It has been reported that 43% of websites could achieve the sufficient quality threshold of ≥3 JAMA scores, and only 8% were at the recommended readability grade of 6.

In a study conducted on Spanish-language websites, the third most frequently used language on the internet in the world in 2020, the content, quality, and readability of online information about fibromyalgia were evaluated (13). This study, which included 73 sites, found that the information content was very limited, the quality was medium-low, and the readability was poor. There is no quality, readable, reliable, and sufficient content online information presentation that can benefit a population with a high tendency and need to access online information, such as fibromyalgia patients.

The results obtained in this study are similar to those obtained from research conducted in other countries and languages. In the information content review, the patient information booklet of a very active association on fibromyalgia in Turkey was taken as a reference, and it was observed that only 11% of the websites had complete subject integrity. The fact that online resources have not specifically addressed how the diagnosis is made and the issue of differential diagnosis is far from meeting the needs of a patient group with a high tendency to cyberchondria, such as fibromyalgia.

According to the 2020 Human Development Report, the average education period in Turkey is 8.1 years (29). According to the Bezirci-Yılmaz formula, the online resources examined in our study were 5 years above the national education average. This result, which shows that it is very difficult for individuals with average education to understand the texts, agrees with studies on different

subjects who evaluated the readability of both fibromyalgia-related websites in other languages and Turkish websites (11,13,15,28).

The top 20 results on the first two pages are generally clicked on in searches made via search engines on the Internet (30). Considering this behavior pattern in our study, the websites on the first two pages were compared with those on the other pages, and we observed that the majority of the first two pages (75%) were in group 1. We think that this heterogeneous distribution is due to the recognition of hospitals and the belief that they can be a more reliable source of information. However, contrary to expectations, the JAMA score of the websites on the first two pages was slightly lower. Whereas, Basavakumar et al. (28) found the JAMA score and information coverage of the top 10 websites to be slightly higher and the readability level to be easier to understand. In a study examining information about osteoporosis on English-language websites, similar to the results obtained, no difference was observed between the first 10 websites and the remaining 141 websites in terms of the JAMA score and readability (31).

It is surprising that the websites prepared by health professionals in our study were indistinguishable from those of other groups in terms of the parameters examined, but this is not consistent with the literature (31). Failure to pay attention to academic writing principles such as date, reference, and disclosure to these sites caused the JAMA score to lower. The fact that the texts were prepared by copying from previously written on online sources may have led to similar results in different website types.

In a fairly recent study, 80 websites in four different search engines (Google, Yandex, Bing, and Yahoo) providing online information about fibromyalgia in Turkey were examined (32). Similar to the results of our study, it was emphasized that the information content was weak, the least loss of libido (2.5%) was mentioned among the symptoms of the disease, and only 3.8% of the websites had references. The websites were found to be of low quality (median=30) according to the DISCERN score, and "moderately difficult" (median=55.5) according to the Ateşman formula. The JAMA score and the education level corresponding to the Bezirci-Yılmaz formula have not been examined in this study. Similar to our study, no difference was observed between the website types in terms of quality and readability. Search engines other than Google (1-15%) are used at a negligible level in Turkey (14,33). The DISCERN score is a tool that primarily assesses the quality of treatment, not the overall quality. In our study, the JAMA score, which is a more objective reliability and quality scale, was used, and the evaluations were made by two independent researchers. Considering all of these, we think that the results obtained in this study are more comprehensive and powerful.

Study Limitations

The most important limitation of this study is that the analyzed online information belongs to a certain period. With a cross-sectional assessment, it cannot be ruled out that changing trends on the internet or search engines may offer different best results to different users. As in all similar studies, the formulas used for readability were calculated by considering the technical aspect of grammar. Therefore, the fact that the words in the texts are simple, close to the average folk language, or consist of technical and medical terms does not affect the calculated readability value. In other words, it is a difficult text to understand because of the heavy use of medical terms. If the number of words and syllables in the sentences is low, it can be calculated at an easily readable level according to the readability formulas. Another limitation is that although critical parameters in terms of reliability have been examined with the JAMA score, this and similar studies are methodologically far from being able to definitively reveal the academic accuracy and currency of online information content. Despite these limitations, we believe that our study presented a current and comprehensive review with an original and robust methodology by a team of authors experienced in fibromyalgia and health literacy.

Conclusion

Turkish websites are far from properly illuminating fibromyalgia.The inadequacy of the information content, especially on diagnosis and differential diagnosis, makes it difficult to understand the subject. Considering that patient education is an important element for treating fibromyalgia and that these patients have a high tendency to access online information, the results obtained reveal a deficiency in this regard. Misinformation with insufficient content can cause confusion, anxiety, and maladaptive behavior. Official institutions related to health policies and sources providing online information should make the necessary improvements within the framework of this data. Patients should also be made aware of the fact that the existing websites are far too inadequate and unreliable to be useful to them.

Ethics

Ethics Committee Approval: The study approval was obtained from the University of Health Sciences Turkey, Hamidiye Scientific Research Ethics Committee (date: 06.04.2022, and approval number: 9/13).

Informed Consent: Not necessary.

Peer-review: Externally peer-reviewed

Authorship Contributions

Concept: R.Y., S.K., H.H.G., H.Y., Design: R.Y., S.K., Data Collection and/or Processing: R.Y., S.K., H.H.G., Analysis and/or Interpretation: R.Y., S.K., H.H.G., H.Y., Literature Research: R.Y., S.K., H.H.G., Writing: R.Y., S.K.

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