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QUALITY AND READABILITY OF WEBSITES ON FIBROMYALGIA IN SPANISH

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TITLE PAGE**QUALITY AND READABILITY OF WEBSITES ON FIBROMYALGIA IN SPANISH**

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ABSTRACT**Objective:**

To assess the content, quality, and readability of websites with information on fibromyalgia in Spanish.

Methods: Websites were retrieved entering the keyword “fibromyalgia” in Google, Yahoo!, and Bing, and by searching records of patients associations in Spain and Latin America. The Bermúdez-Tamayo and DISCERN questionnaires were employed for evaluating quality and content, and INFLESZ for readability. Statistical analysis was conducted using IBM SPSS®v24.

Results: Three hundred and five websites were found. After applying the exclusion criteria, 73 websites were analyzed. Websites retrieved by search engines obtained average scores of 28.44 [CI95%: 30.90–25.98] with DISCERN, 36.08 [CI95%: 38.25–33.90] with Bermúdez-Tamayo, and 52.39 [CI95%: 54.64–50.13] with INFLESZ, whereas those from patients associations scored 22.90 [CI95%: 24.05–21.76], 27.62 [CI95%: 28.95–26.29], and 47.70 [CI95%: 50.25–45.14], respectively. In general, content was not up-to-date.

Conclusions: Overall quality was medium-low, content quality was very low, and readability was poor. Further effort is needed to guarantee meeting quality criteria and accessing updated, relevant, and legible information.

This study exposes the quality and readability of websites on fibromyalgia in Spanish, which can help healthcare workers to better appraise this resource and its potential influence on the development of the pathology.

Keywords: Fibromyalgia, Education, Internet, Patient Portals, Spanish.

Strengths and limitations of this study:

- This study is the first to examine the quality of online Spanish fibromyalgia resources.
- The online resources analyzed also included all Fibromyalgia patient associations registered in Spain and Latin America.
- Standardised quality and readability tools were used to assess quality and readability.
- There is no gold standard to evaluate the quality of websites.
- The outcome validity of this study is temporary, and its quality analysis can vary in the future.

1. INTRODUCTION

Fibromyalgia (FM) is a “syndrome of widespread pain, decreased pain threshold, and characteristics symptoms, including non-restorative sleep, fatigue, stiffness, mood disturbance, irritable bowel syndrome, headache, paresthesias, and other less common features” [sic][1].

A systematic review in 2017 estimated that FM affects 2.10% of the population worldwide and 2.3% in Europe. In Spain, it has a prevalence of 2.4%, with an estimated yearly cost of 12,993€ million[2]. FM prevalence in Latin America is 1.12%, ranging from 0.7% in Mexico to 0.2% in Cuba or Venezuela, a variability that can result from diverse diagnosis criteria[2,3].

Since one of the main symptoms is generalized chronic pain[4], education plays an important role in the therapeutic approach to FM [5]. Research on the effect of diverse educational methods, such as cognitive behavioral therapy[6,7] and neuroscience education[7,8], has increased in the last years. Strong evidence exists about the effectiveness of combining education, exercising, and active coping strategies on pain, quality of life, and functionality [9]. Guides like the *European League Against Rheumatism* (EULAR) recommend including education among non-pharmacological treatments for FM[10].

The evolution of the Internet and its interactive features has favored the emergence of virtual health communities, such as patients associations, where users can share experiences and opinions and receive social support. Also, they provide a wide variety of information that affects and empowers users in their health-related decision-making[11].

In addition, the Internet has largely grown in the last decades. According to the *Observatorio Nacional de las Telecomunicaciones y de la Sociedad de la Información* (ONTSI), 60.5% of the Spanish population searches the web for health information[12]. With 572 million speakers worldwide, 477 million of which are native speakers, Spanish is the third most used language in the web, and 8.1% of the almost 3,885 million Internet users in December 2017 employed it[13].

Daraz *et al.* exposed the preferences and needs of FM patients when seeking information: 91% searched the web for it, specifically for treatments (87%), resources (85%), symptoms (81%), implications (79%), and coping (79%). Of them, 93% expressed a concern about information reliability and highlighted the need for reputable or medical-staff sources[14].

The only study found assessing the quality of online FM information in English concluded that sites of greater quality are generally less readable and that FM information is incomplete and of low quality[15]. The authors have not found any study on the quality and contents of websites on FM in Spanish.

The aim of this study was to identify information resources for FM patients, available online and in Spanish, and to evaluate their quality, content, and readability.

2. METHODS

2.1. Design and search strategy

A descriptive study was conducted where websites providing information on FM were analyzed for quality, content, and readability using standardized, validated tools[16-19].

“Fibromyalgia” was chosen as keyword for the web search given its popularity in “Google Trends” and a filter was applied for “Last 12 months” and “Worldwide”. Google, Yahoo!, and Bing were the employed search engines based on their popularity in “Statcounter”, both in Spain and Latin America.

Two researchers conducted an online search independently after emptying the cache and history and deactivating location in the computer, with no further filters being applied. Since users do not appear to seek information past the first 20 retrieved websites, each researcher selected the first 20 hits from each engine. Additionally, the researchers independently looked for websites of FM associations in Spain and Latin America among their relevant national records.

2.2. Selection criteria

All websites in Spanish containing FM information were included.

The following sites were excluded: broken links, duplicates, exclusively offering advertisements; mainly offering information in PDF, images, or videos; news or entries from a journal requiring subscription or payment to access information, without a main page explaining FM, and whose content consisted of links to other sites or documents; not allowing a readability analysis.

2.3. Tools for quality and readability analyses

The researches independently evaluated the content of the included websites using the DISCERN and Bermudez-Tamayo questionnaires and the INFLESZ scale.

The DISCERN questionnaire is a valid, reliable tool initially developed for assessing the quality of written information on health-treatment options, which was subsequently applied to websites[17,18]. It comprises three sections with 16 items: the first 8 assess general reliability of the content, the following 7 evaluate quality of treatment options, and the third section assigns an overall score to the publication. Each question receives a score ranging from 1=No to 5=Yes, allowing intermediate scores (2, 3, and 4). Since the questionnaire poses no interpretation about its score, the researchers agreed on these values for items concerning: content relevance, information sources, date of content, additional support resources, description of how the treatment works and its relevant risks and benefits, treatment options, and shared decision-making. The overall score range is 16–80, with higher scores having better content quality, defined as follows: 16–29=very low; 30–42=low; 43–55=moderate; 56–68=good, and 69–80=excellent.

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3 The Bermúdez-Tamayo questionnaire[16] evaluates the quality of health websites in Latin America following the
4 recommendations by the main ethical codes and law in Spain and Europe[20,21]. This validated tool shows
5 adequate reliability ($\kappa \geq 0.60$) for 12 of its 18 items and comprises six sections: transparency and absence of
6 conflicts (5 items), authorship (2 items), personal data protection (1 item), updating of information (1 item),
7 responsibility (4 items), and accessibility (5 items). Each item receives a score of 0–3 (0=Does not apply; 1=No;
8 2= Partially; 3= Yes), so that the overall score ranges from 17 to 54, with higher scores reflecting better quality,
9 defined as follows: 17–25=very low, 26–33=low, 34–40=moderate, 41–47=good, and 48–54=excellent. The
10 researchers agreed on items concerning: purpose and objective of the website; information sources; publication
11 date; and ease of content searching.
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17 INFLESZ is a readability scale, available online and validated in Spanish. Readability is “the ensemble of
18 typographic and linguistic features of written texts that allow for their easy reading and understanding” [sic][22].
19 This tool allows entering the text or its URL online and provides a score ranging from 0 to 100, with ease of text
20 readability defined as: very difficult <40, slightly difficult=40–55, normal=55–65, fairly easy=65–80, and very
21 easy >80. According to this scale, health texts are more likely to be understood if they score >55[19].
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25 Since none of the above-mentioned tools takes into consideration certain issues that are considered important by
26 FM subjects[14] or that have been reported to be of relevance in prior studies[5,10], the following data were also
27 recorded: terminology, relevance of information on diagnosis and treatment, illness acknowledgement, symptoms,
28 and both pharmacological and non-pharmacological treatments (with a focus on therapeutic exercise and
29 physiotherapy).
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34 **2.4. Data collection and analysis**

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36 Data were collected independently by two researchers who discussed and agreed on each item or website when
37 there was no consensus.
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40 IBM SPSS® version 24 software was used for the statistical analysis. Quantitative variables were described by
41 their mean and standard deviation, and confidence intervals were set at 95% after assuming the data fit a normal
42 distribution, which was verified using the Shapiro-Wilk test. Categorical variables were described by their
43 absolute frequencies and percentages.
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49 **3. RESULTS**

50 **3.1. Characteristics of analyzed websites**

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52 A total of 305 websites were found using search engines and from patient associations in Spain and Latin America.
53 After applying the exclusion criteria, 73 sites were included (Figure 1): 53 (72.6%) nonprofit, 7 (9.5%)
54 commercial, 6 (8.2%) institutional, 4 (5.4%) providing free-of-charge information, and 3 (4.1%) from media
55 owners. Of them, 7 (9.5%) and 4 (5.4%) were websites translated from English and Catalan, respectively.
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3 Among websites from patient associations, 43 were from Spain and 3 from Latin America (Argentina, Chile, and
4 Venezuela).
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8 **3.2. Type of information**

9 *3.2.1. Websites retrieved by search engines (Figure 2)*

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11 In terms of illness conceptualization, 6 websites (24%) mentioned that FM is acknowledged as an illness by the
12 WHO. Barely any mentioned central sensitization or central sensitization syndrome, and none named other terms
13 like dysfunctional pain.
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17 The least cited symptoms were paresthesia (11 websites; 44%) together with morning stiffness and anxiety (15
18 websites; 60%).
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21 The most cited pharmacological treatments were antidepressants (22 websites; 88%), followed by painkillers (17
22 websites; 68%) and antiepileptic drugs (15 websites; 64%). Muscle relaxants and non-steroid anti-inflammatory
23 drugs were named in 8 websites (32%). In terms of non-pharmacological treatments, the most highlighted
24 physiotherapy techniques were massage (10 websites; 40%), stretching (4 websites; 16%), and locally applied
25 heat (3 websites; 12%). The most frequently mentioned alternative therapies were yoga (10 websites; 40%),
26 acupuncture (9 websites; 36%), and Tai Chi (5 websites; 20%).
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30 In terms of advice, sleep strategies were the most recommended, specifically implementing sleep habits (7
31 websites; 28%), and moderating activity and daily-life pace, as well as mentality changes. Stress (7 websites;
32 28%), weather changes (cold, humidity) with anxiety/stress (6 websites; 24%), and excessive physical activity (3
33 websites; 12%) were highlighted as aggravating factors.
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36 *3.2.2. Websites from patients associations (Figure 3)*

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39 Among websites mentioning that FM is a disease, 10 (20.83%) included acknowledgment by the WHO, 1 (2.08%)
40 specifically cited that FM is in the International Classification of Illnesses, and 10 (20.83%) mentioned both facts.
41 In terms of symptoms, the least mentioned were hypersensitivity (15 websites; 31.25%) paresthesia (28 websites;
42 58.33%), and depression (29 websites; 60.41%). In terms of pharmacological treatment, antidepressants (19
43 websites; 39.58%), painkillers (15 websites; 31.25%), and muscle relaxants (9 websites; 18.75%) were the most
44 mentioned, and 9 (18.75%) of the websites including pharmacological treatment did not mention any in particular.
45 The most frequently cited physiotherapy techniques were massage (8 websites; 16.66%), stretching (5 websites;
46 10.41%), and locally applied heat (4 websites; 8.33%). Finally, the most cited alternative therapies were yoga and
47 acupuncture (8 websites; 16.66%) and Tai Chi (7 websites; 14.58%).
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51 In terms of recommendations, the most common advice was avoiding aggravating factors, like stress (9 websites;
52 18.75%), and improving sleep habits (6 websites; 12.5%). The most commonly mentioned aggravating factors
53 were weather changes (cold, humidity) (9 websites; 18.75%), stress/anxiety (7 websites; 14.58%), and excessive
54 physical activity (5 websites; 10.41%).
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3.3. Quality of health information

3.3.1. Websites retrieved by search engines

The overall quality as measured by the DISCERN obtained a mean score of 28.44 [CI95%: 30.90–25.98]: 18 (72%) scored 16–29 points (very low), 6 (24%) obtained 30–42 points (low), and only 1 (4%) website reached 43–55 points (moderate). All categories scored <2 (Table 1).

Table 1. Mean score of quality of health information by category according to the DISCERN questionnaire

	Category	Mean(SD)	CI95%
Websites retrieved by search engines	Reliability of the publication	1.78(0.48)	1.97–1.59
	Quality of information on treatment options	1.71(0.42)	1.87–1.54
	Overall score	1.48(0.62)	1.72–1.23
Websites of patients associations	Reliability of the publication	1.37(0.29)	1.48–1.25
	Quality of information on treatment options	1.37(0.34)	1.50–1.24
	Overall score	1.58(0.50)	1.78–1.39

SD: Standard deviation; CI: Confidence interval.

3.3.2. Websites from patients associations

According to the DISCERN, the overall quality was very low, with a mean score of 22.90 [CI95%: 24.05–21.76]: 44 websites (91.66%) scored 16–29 (very low) and other 4 websites (8.33%) scored 30–42 (low). All the categories scored <2 (Table 1).

3.4. Quality of websites

3.4.1. Websites retrieved by search engines

Using the Bermúdez-Tamayo questionnaire, the overall quality was moderate, with a mean score of 36.08 [CI95%: 38.25–33.90]: 9 websites (36%) obtained a score of 26–33 (low), 10 (40%) scored 34–40 (moderate), 5 (20%) obtained 41–47 points (good), and only 1 achieved a score of 48–54 (excellent). The category achieving the lowest score was updating of information (Table 2).

Table 2. Mean score of quality of websites by category according to the Bermúdez-Tamayo questionnaire

	Category	Mean(SD)	CI95%
Websites retrieved by search engines	Transparence and absence of conflict of interests	2.92(0.41)	3.10–2.74
	Authorship	1.52(0.65)	1.77–1.26
	Protection of personal data	2.92(0.4)	3.08–2.76
	Information updating	1.32(0.69)	1.59–1.05
	Responsibility	1.60(0.39)	1.75–1.44
	Accessibility	2.12(0.43)	2.29–1.95
Websites of patients associations	Transparence and absence of conflict of interests	1.67(0.55)	1.88–1.45
	Authorship	1.12(0.33)	1.25–0.99
	Protection of personal data	1.58(0.91)	1.94–1.22
	Information updating	1 (0)	-----
	Responsibility	1.34(0.14)	1.40–1.28
	Accessibility	1.98(0.23)	2.07–1.89

SD: Standard deviation; CI Confidence interval

3.4.2. Websites from patients associations

According to the Bermúdez-Tamayo questionnaire, the general quality was also low, with an average score of 27.62 [CI95%: 28.95–26.29]: 24 sites (50%) obtained a score of 17–25 (very low), 20 (41.66%) scored 26–33 (low), 3 (6.25%) obtained 34–40 points (moderate), and only 1 (2.08%) achieved 41–47 points (good). Scores were low for all the categories, among which updating of information scored the lowest (Table 2).

3.5. Readability

3.5.1. Websites retrieved by search engines

With a mean score of 52.39 [CI95%: 54.64–50.13], readability was found to be “slightly difficult”: 15 websites (60%) were categorized as “slightly difficult” (40–55 points) and 10 (40%) as “normal” in terms of readability (55–65 points).

3.5.2. Websites from patients associations

Overall readability was also “slightly difficult” with a mean score of 47.70 [CI95%: 50.25–45.14]: 4 websites (8.33) were considered “very difficult” (<40), 32 (66.66%) “slightly difficult” (40–55), 11 (22.91%) were “normal” (55–65), and 1 (2.08%) was “fairly easy” (65–80) to read.

4. DISCUSSION

These outcomes suggest that quality of FM websites in Spanish, as retrieved by the main search engines, tend to be of medium-low quality, whereas those from both Spanish and international patients associations tend to be of very low quality. Overall, content quality was very low, and readability was “slightly difficult”.

Website quality, readability, and content varied among websites, similarly to previous research for other chronic conditions[23,24]. As far as the authors know, this study is the first to assess quality of websites on FM in Spanish and the only one including an analysis of websites from FM patients associations, having not found any study in another language[15] or about other illnesses including FM[25,26].

4.1. Methodology

This study employed validated, widely used questionnaires for analyzing website quality. LIDA and DISCERN are the tools most frequently used for this purpose, which is the Bermúdez-Tamayo questionnaire for websites in Spanish.

LIDA is a tool that assesses healthcare websites for content and information design[27], with accessibility, usability, and reliability of information being the three main categories. The Bermúdez-Tamayo questionnaire was originally validated in Spanish[16] and also includes these categories but, as it mainly contemplates aspects of the website as such and not its contents, the DISCERN questionnaire was employed, a tool that has been broadly used in research, both in English and Spanish[15,23–25,28]. None of the employed questionnaires interprets the results or qualifies the score into quality levels. This leads researchers to propose their own levels and, although these tend to be very similar, they can be interpreted in different ways hindering comparison between outcomes. This trial created five quality levels for all the items.

Another important aspect of websites is readability. Studies assessing English websites tend to use *Flesch Reading Ease score maps*[15,24] and *Flesch-Kincaid*[24,28,29]. Both[30,31] provide a score from 0 to 100, where higher scores indicate texts that are easier to read. For the general public, 60 is considered an acceptable value. *Flesch-Kincaid*[31] also indicates the necessary education level to understand a text. Studies evaluating Spanish websites use the INFLESZ scale[19,23,26], which was created after the *Flesch* scale was reviewed[30] and is considered one of the Spanish-adapted versions of the former and *Flesch-Szigrist*[32] scales.

4.2. Websites characteristics and type of information

There were differences in the outcomes between websites found by search engines and those from patients associations. The greatest differences were observed using the Bermúdez-Tamayo questionnaire, where websites retrieved by search engines obtained higher scores. This could be due to the nonprofit character of websites of patients associations and because most seem to have been created by FM patients, likely using a non-paid website development tool, such as webnode[33]; in contrast, websites found by search engines belong to different

categories, like commercial or institutional, which can involve some sort of funding for their development and management. However, this is a hypothesis, since most websites do not state their funding body.

4.3. Type of information

Symptoms, treatment, and diagnosis were the most commonly tackled information in the assessed sites. Other issues of importance for FM patients, such as support[14, 34], are dealt with superficially and briefly, chiefly naming the importance of the doctor for determining pharmacological treatment.

A very mechanistic, vague vision of FM, with little scientific evidence, was generally observed. In terms of conceptualization of FM, no website was found that mentioned dysfunctional pain, no difference was made between clinical diagnosis or diagnosis criteria for research, and diagnostic points were those of 1990 even if Wolfe *et al.* warned about the risk this implied when used for clinical practice already in 2003[35]. Provided treatment alternatives can cause nothing but confusion due to the high variability found, little correlation with scientific literature (neither massage nor stretching are backed by scientific evidence[36,37] and, in certain cases, they can be counterproductive), and the superficial manner in which they are covered. For instance, education is one of the least mentioned treatments despite being one of the most recommended ones[5,10], and neuroscience education is not found in any of the websites citing it even if its effectiveness for treating pain has been proven[7–9]. The type or frequency of recommended physical exercise was not specified in any case despite being one of the most mentioned treatments in the Internet[10, 37, 38]. In terms of psychological therapies, cognitive behavioral therapy was mentioned in some websites but in a very vague way and without mentioning existing evidence for it[6].

4.4. Quality of health information

Information quality and reliability were assessed via the DISCERN questionnaire. The outcome showed that FM contents in websites in Spanish were of very low quality. In the study by Daraz *et al.*[15], which also employed this tool, 36% of the 25 included websites were qualified as “marginal” (14–27 points), 32% as “good” (28–42 points), and 32% as “very good” (43–57). Of the websites found by search engines in this study, 72% were classified as “very low quality” (14–27), 24% as “low quality” (27–39), and 4% as “moderate quality” (40–52). Similarly, 91.66% of the websites from patients associations obtained scores classified as “very low quality” (14–27) and 8.33% as “low quality” (27–39). In this regard, the quality of websites analyzed in this study seemed to be lower than that in the work by Daraz *et al.* It is necessary to acknowledge that the maximum score in the study by Daraz *et al.* was 75 points, since the last item was excluded; had this study proceeded similarly and followed the categories as Daraz *et al.*, 84% of websites found by search engines would be categorized as “marginal” and 16% as “good”, while there would not be changes in quality for patients associations websites. The mean score obtained by Daraz *et al.* (33.35) using the DISCERN questionnaire was considerably higher than that obtained in this study for websites found by search engines (26.41) and from patients associations (20.90). Daraz *et al.* also reported a mean score of 2.49 for the 15 items, whereas none of the three categories in the DISCERN questionnaire scored >2 in this trial. This could be due to the fact that our two independent researchers agreed on the score of

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3 some items and the necessary minimums for intermediate scores (2, 3, and 4), thus minimizing potential variability,
4 an aspect not mentioned by Daraz *et al.*
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7 On the other hand, the study by Kaicker *et al.*[28] employed the DISCERN questionnaire for assessing the quality
8 of contents of 161 websites in English found using GOOGLE, YAHOO!, and MSN, by entering “pain”, “chronic
9 pain”, “back pain”, “arthritis”, and “fibromyalgia” as search keywords. The mean score was 55.9 (moderate
10 quality). The higher score they obtained compared to this study could result from the fact that Kaicker *et al.* did
11 not analyze specific websites for FM.
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14 Washington *et al.*[29] designed their own questionnaire to assess the content of 240 websites in English found
15 using GOOGLE, YAHOO!, and MSN and entering “pain”, “chronic pain”, “back pain”, “arthritis”, and
16 “fibromyalgia” as keywords. They concluded that the overall quality was quite low, which is in agreement with
17 the outcome of this study despite using a different methodology.
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23 **4.5. Quality of websites**

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25 Website quality and how to assess it is a controversial issue, partly because there is a subjective component to
26 quality that is difficult to quantify[16]. This study employed the Bermúdez-Tamayo[16] questionnaire, the most
27 used tool in Spanish to evaluate quality-related criteria for websites. Using this questionnaire, updating of
28 information was the category that obtained the lowest score, both for websites found by search engines and those
29 from patients associations. This is in agreement with other trials using this tool[26,39,40] and results from the fact
30 that only three of the included websites found by search engines specified the last date of information update and
31 only two made a partial statement in this regard, whereas none of the sites of patients associations complied with
32 this item. Several ethical codes request that the latest update is clearly stated for each website and each of its
33 components. Additionally, e-Europe and the American Medical Association require that a revision be conducted
34 on the pertinence of the provided information based on the latest evidence[16].
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42 **4.6. Readability**

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44 Reducing text comprehensibility to a mathematic equation is difficult[41]. However, readability indexes are a well-
45 accepted approach for improving text readability and comprehension[42]. Also, the importance of this aspect must
46 be emphasized, since requiring high reading skills can reduce information accessibility and potentially exclude
47 users with low literacy[43].
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51 In this study, websites found both by search engines and from patients associations were categorized as “slightly
52 difficult to read”, with scores of 52.39 and 47.70, respectively. The recommended minimum score for health
53 information is 55[19], which is probably the reason why the general public has difficulties understanding the
54 information provided in the included websites. Other studies using the INFLESZ scale to analyze readability
55 obtained similar outcomes[23,26]. Readability can vary among websites due to the use of technical terms, such as
56 fibromyalgia, which appears to have low readability[15]. The readability degree of most of the websites assessed
57 by Daraz *et al.* corresponded with a 10th–12th school grade level, whereas the recommended level is that of 6th
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3 grade[45]. Kaicker *et al.*[28] obtained similar results, as is the case of our study with a score on the INFLESZ
4 scale of 40–55 (slightly difficult), which corresponds with high-school reading level[19].
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8 **4.7. Limitations**

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10 There are limitations to this study. Content updates in the Internet must be taken into consideration. Since newly
11 created websites can be incorporated, or the assessed sites can undergo revisions and modifications, the outcome
12 validity of this study is temporary, and its quality analysis can vary in the future.
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15 Additionally, using different search engines, in different dates, or entering other terms can modify the
16 results[44,45]. Since “fibromyalgia” was the only term entered as keyword, it is possible that websites consulted
17 by FM subjects were omitted in this trial, such as those on chronic pain. Additionally, by including only the first
18 20 links displayed by three search engines, some resources of interest could have been missed. This is a usual
19 limitation in any Internet search. However, this study tried to reproduce the most common pattern a Spanish-
20 speaker would follow: over 95% of searches in Spain are done via Google[46,47] by entering the name of the
21 disease or one of its symptoms[12]. Therefore, assessing 20 websites of those retrieved by Google/Yahoo!/Bing
22 appears to be sufficiently exhaustive, especially considering that the general population do not consult any site
23 further than the second one[48].
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31 **4.8. Clinical practice implications**

32 Since FM patients often consult the Internet to better understand their illness and how to manage it[14], which can
33 be an aid or a barrier for treating it[49], knowing about information available online can be useful for health
34 workers. The paucity of information on the diagnosis, treatment options, and conceptualization of FM this work
35 found must be compensated with correct information by health workers, especially considering that education is
36 an essential part of its treatment[10].
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44 **5. CONCLUSIONS**

45 The quality of websites on FM in Spanish is moderate-low, very low in terms of content, and their readability is
46 slightly difficult. Additionally, the provided contents are very diverse, often lack scientific evidence, and are not
47 up-to-date. Greater efforts are required to guarantee that FM websites comply with quality criteria and offer
48 updated information, relevant, of quality, and readable.
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Contributions:

Arturo Alioshkin Cheneguín: Conceptualization; Methodology; Investigation; Writing - Original Draft.

María Torres Lacomba: Conceptualization; Methodology; Software; Validation; Investigation; Formal analysis; Resources; Data Curation; Writing - Original Draft; Visualization; Supervision; Writing - Review & Editing.

Isabel Salvat Salvat: Validation; Writing - Original Draft.

Helena Romay Barrero: Writing - Original Draft; Visualization; Writing - Review & Editing.

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LEGENDS

Fig. 1 Flowchart of websites included in the study

Fig. 2 Type of information in websites retrieved by search engines

Fig. 3 Type of information in websites from patients associations

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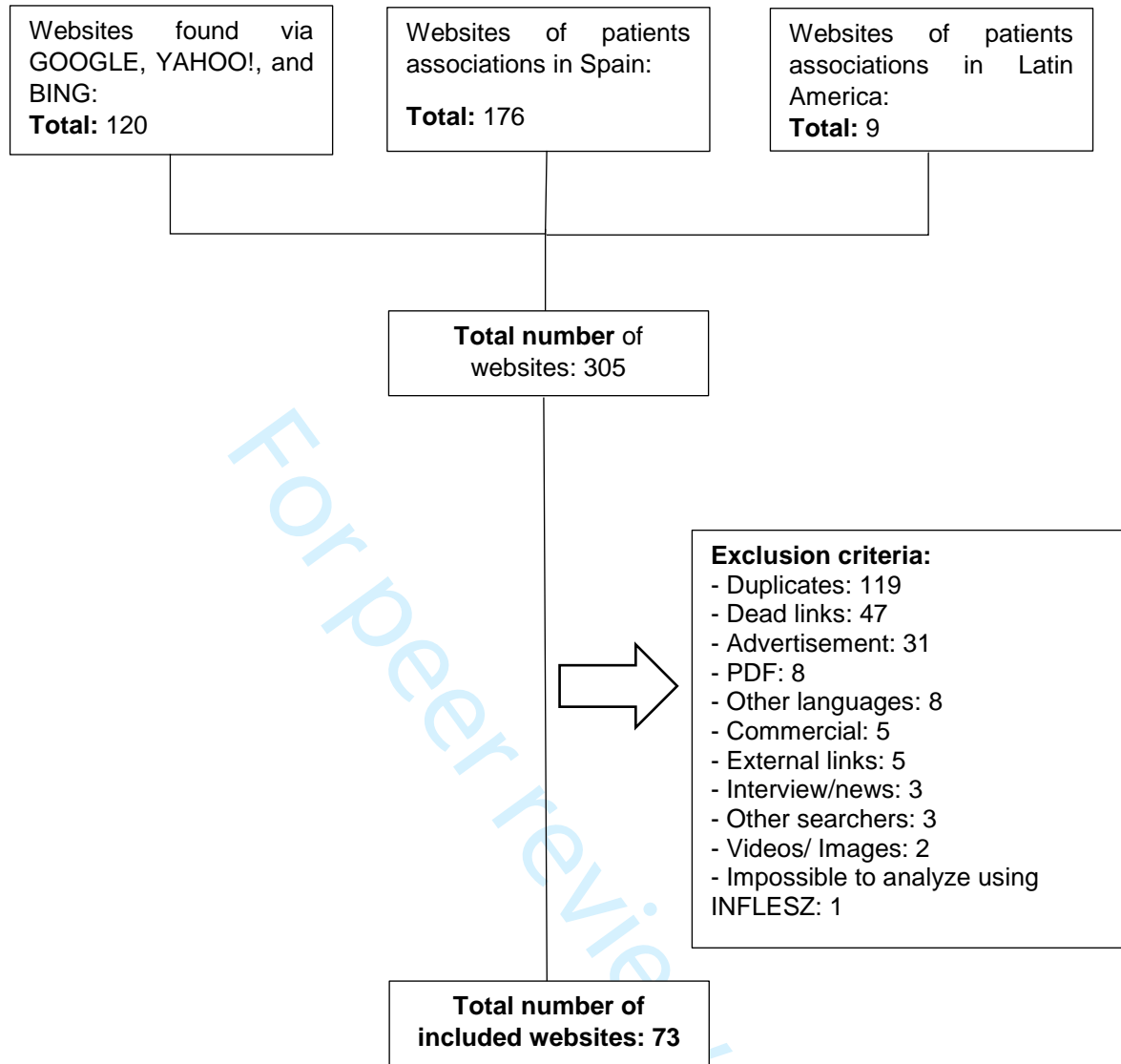
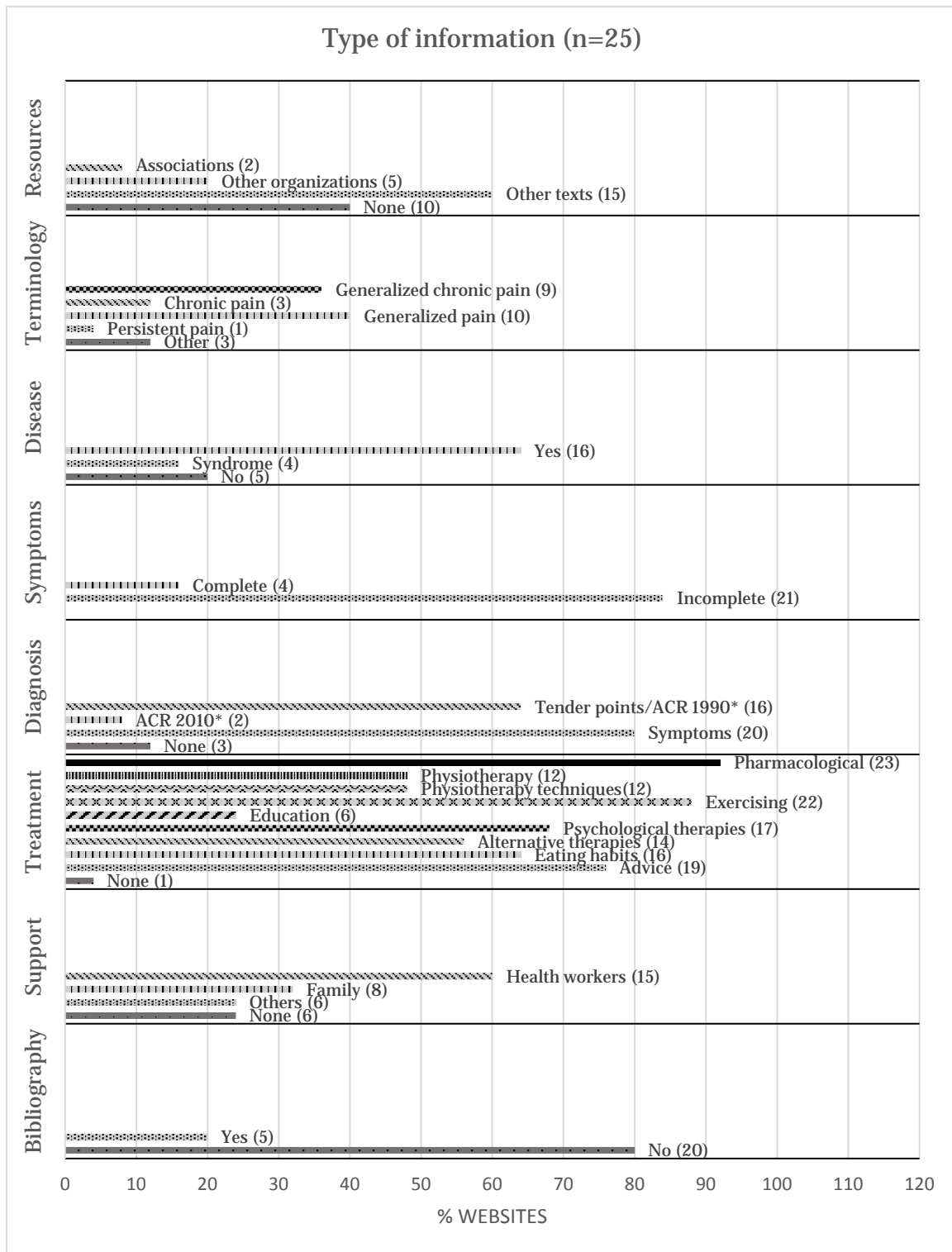


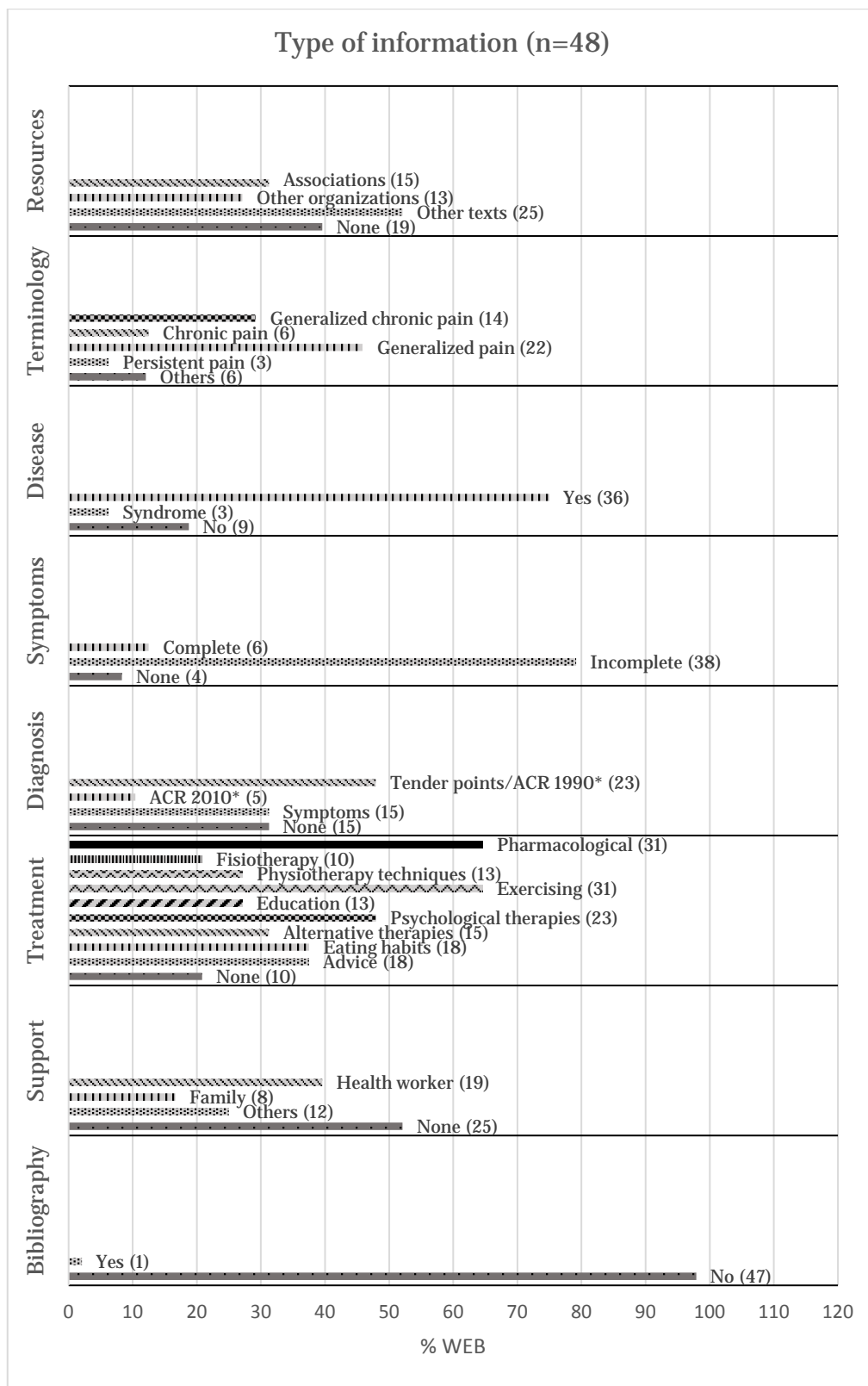
Fig. 1 Flowchart of websites included in the study



*Diagnostic criteria for fibromyalgia by the *American College of Rheumatology*.

***Complete symptoms when including generalized pain, hypersensitivity (allodynia, hyperalgesia, and/or exacerbated sensitivity to stimuli in addition to pain), fatigue, sleep disorders, cognitive disorders, anxiety, paresthesia, morning stiffness, and depression*.

Fig. 2 Type of information in websites retrieved by search engines



* Diagnostic criteria for fibromyalgia by the *American College of Rheumatology*

Fig. 3 Type of information in websites from patients associations

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QUALITY AND READABILITY OF WEBSITES ON FIBROMYALGIA IN SPANISH

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TITLE PAGE

QUALITY AND READABILITY OF WEBSITES ON FIBROMYALGIA IN SPANISH

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ABSTRACT**Objective:**

To assess the content, quality, and readability of websites with information on fibromyalgia in Spanish.

Methods: Websites were retrieved entering the keyword “fibromyalgia” in Google, Yahoo!, and Bing, and by searching records of patients associations in Spain and Latin America. The Bermúdez-Tamayo and DISCERN questionnaires were employed for evaluating quality and content, and INFLESZ for readability. Statistical analysis was conducted using IBM SPSS®v24 (Chicago, USA).

Results: Three hundred and five websites were found. After applying the exclusion criteria, 73 websites were analyzed. Websites retrieved by search engines obtained median scores of 27.0 [(interquartile interval (IQI): 24.5–32.0)] with DISCERN, 35.0 [IQI: 31.0–40.5] with Bermúdez-Tamayo, and 53.7 [IQI: 47.4–56.2] with INFLESZ, whereas those from patients associations scored 21.0 [IQI: 19.2–23.8], 26.0 [IQI: 25.0–31.0], and 51.7 [IQI: 47.9–55.1], respectively. In general, content was not up-to-date.

Conclusions: Overall quality was medium-low, content quality was very low, and readability was poor. Further effort is needed to guarantee meeting quality criteria and accessing updated, relevant, and legible information.

This study exposes the quality and readability of websites on fibromyalgia in Spanish, which can help healthcare workers to better appraise this resource and its potential influence on the development of the pathology.

Keywords: Fibromyalgia, Education, Internet, Patient Portals, Spanish.

Strengths and limitations of this study:

- This study is the first to examine the quality of online Spanish fibromyalgia resources.
- The online resources analyzed also included all Fibromyalgia patients associations registered in Spain and Latin America.
- Standardized quality and readability tools were used to assess quality and readability.
- There is no gold standard to evaluate the quality of websites.
- The outcome validity of this study is temporary, and its quality analysis can vary in the future.

1. INTRODUCTION

Fibromyalgia (FM) is a “syndrome of widespread pain, decreased pain threshold, and characteristics symptoms, including non-restorative sleep, fatigue, stiffness, mood disturbance, irritable bowel syndrome, headache, paresthesias, and other less common features” [sic].¹

A systematic review in 2017 estimated that FM affects 2.10% of the population worldwide and 2.3% in Europe. In Spain, it has a prevalence of 2.4%, with an estimated yearly cost of 12,993€ million.² FM prevalence in Latin America is 1.12%, ranging from 0.7% in Mexico to 0.2% in Cuba or Venezuela, a variability that can result from diverse diagnosis criteria.^{2 3}

Since one of the main symptoms is generalized chronic pain,⁴ education plays an important role in the therapeutic approach to FM.⁵ Research on the effect of diverse educational methods, such as cognitive behavioral therapy^{6 7} and neuroscience education,^{7 8} has increased in the last years. Strong evidence exists about the effectiveness of combining education, exercising, and active coping strategies on pain, quality of life, and functionality.⁹ Guides like the *European League Against Rheumatism* (EULAR) recommend including education among non-pharmacological treatments for FM.¹⁰

The evolution of the Internet and its interactive features has favored the emergence of virtual health communities, such as patients associations, where users can share experiences and opinions and receive social support. Also, they provide a wide variety of information that affects and empowers users in their health-related decision-making.¹¹

In addition, the Internet has largely grown in the last decades. According to the *Observatorio Nacional de las Telecomunicaciones y de la Sociedad de la Información* (ONTSI), 60.5% of the Spanish population searches the web for health information.¹² With 572 million speakers worldwide, 477 million of which are native speakers, Spanish is the third most used language in the web, and 8.1% of the almost 3,885 million Internet users in December 2017 employed it.¹³

Daraz *et al.* exposed the preferences and needs of FM patients when seeking information: 91% searched the web for it, specifically for treatments (87%), resources (85%), symptoms (81%), implications (79%), and coping (79%). Of them, 93% expressed concern about information reliability and highlighted the need for reputable or medical-staff sources.¹⁴

The studies found assessing the quality of online FM information in English concluded that sites of greater quality are generally less readable and that FM information is incomplete and of low quality.^{15 16} The authors have not found any study on the quality and contents of websites on FM in Spanish.

The aim of this study was to identify information resources for FM patients, available online and in Spanish, and to evaluate their quality, content, and readability.

2. METHODS

2.1. Design and search strategy

A descriptive study was conducted where websites providing information on FM were analyzed for quality, content, and readability using standardized, validated tools.¹⁷⁻²⁰ Figure 1 shows a flowchart describing the stages of the search process.

“Fibromyalgia” was chosen as keyword for the web search given its popularity in “Google Trends”²¹ (trends.google.es) and a filter was applied for “Last 12 months” and “Worldwide”. Google (google.es), Yahoo! (es.yahoo.com), and Bing (bing.com) were the employed search engines based on their popularity in “Statcounter”, both in Spain and Latin America. All the above-mentioned searches were carried out in April of 2019.

Two researchers conducted an online search independently after emptying the cache and history and deactivating location in the computer, with no further filters being applied. GPS was deactivated to prevent the engines from displaying only websites close to the location of the researchers. Since users do not appear to seek information past the first 20 retrieved websites, each researcher selected the first 20 hits from each engine. Additionally, the researchers independently looked for websites of FM associations in Spain and Latin America among their relevant national Public Registry of Associations as of May 2019.

2.2. Selection criteria

All websites in Spanish containing FM information were included.

The following sites were excluded: broken links, duplicates, exclusively offering advertisements; mainly offering information in PDF, images, or videos; news or entries from a journal requiring subscription or payment to access information, without a main page explaining FM, and whose content consisted of links to other sites or documents; not allowing a readability analysis.

2.3. Tools for quality and readability analyses

The researches independently evaluated the content of the included websites using the DISCERN and Bermudez-Tamayo questionnaires and the INFLESZ scale.

The DISCERN questionnaire is a valid, reliable tool initially developed for assessing the quality of written information on health-treatment options, which was subsequently applied to websites.^{19 20} It comprises three sections with 16 items: the first 8 assess general reliability of the content, the following 7 evaluate quality of treatment options, and the third section assigns an overall score to the publication. Each question receives a score ranging from 1=No to 5=Yes, allowing intermediate scores (2, 3, and 4). Since the questionnaire poses no interpretation about its score, the researchers agreed on these values for items concerning: content relevance, information sources, date of content, additional support resources, description of how the treatment works and its relevant risks and benefits, treatment options, and shared decision-making. The overall score range is 16–80, with

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3 higher scores having better content quality, defined as follows: 16–29=very low; 30–42=low; 43–55=moderate; 56–
4 68=good, and 69–80=excellent.
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6 The Bermúdez-Tamayo questionnaire¹⁸ evaluates the quality of health websites in Spanish following the
7 recommendations by the main ethical codes and law in Spain and Europe.^{22 23} This validated tool shows adequate
8 reliability ($\kappa \geq 0.60$) for 12 of its 18 items and comprises six sections: transparency and absence of conflicts
9 (5 items), authorship (2 items), personal data protection (that is, the website must describe how the information on
10 an identified or identifiable individual is protected and how data is processed) (1 item), updating of information (1
11 item), responsibility (meaning the possibility of contacting someone responsible for the website to send comments
12 and/or suggestions, whether they offer on-line consultations, and if the team responsible for addressing
13 consultations can be identified) (4 items), and accessibility (5 items). Each item receives a score of 0–3 (0=Does
14 not apply; 1=No; 2= Partially; 3= Yes), so that the overall score ranges from 17 to 54, with higher scores reflecting
15 better quality, defined as follows: 17–25=very low, 26–33=low, 34–40=moderate, 41–47=good, and 48–
16 54=excellent. The researchers agreed on items concerning: purpose and objective of the website; information
17 sources; publication date; and ease of content searching.
18

19 INFLESZ is a readability scale, available online and validated in Spanish. Readability is “the ensemble of
20 typographic and linguistic features of written texts that allow for their easy reading and understanding” [sic].²⁴
21 INFLESZ is considered to be more the most suitable scale for the Spanish-speaking population. This tool allows
22 entering the text or its URL online and provides a score ranging from 0 to 100, with ease of text readability defined
23 as: very difficult<40, slightly difficult=40–55, normal=55–65, fairly easy=65–80, and very easy >80. According
24 to this scale, health texts are more likely to be understood if they score >55.¹⁷
25

26 Since none of the above-mentioned tools takes into consideration certain issues that are considered important by
27 FM subjects¹⁴ or that have been reported to be of relevance in prior studies,^{5 10} the following data were also
28 recorded: terminology (FM conceptualization, meaning whether FM is designated as a disease or not, and the terms
29 used to define FM, such as generalized pain syndrome, chronic pain, or central sensitization syndrome);
30 relevance of information on diagnosis (type of diagnosis, whether based on tender points as per the criteria by
31 Wolfe in 1990²⁵ or in 2010,²⁶ or based on symptomatology) and treatment (that is, if they mention the treatments
32 that are most supported by scientific evidence, such as therapeutic education of the patient and therapeutic
33 exercising); support (social, family, etc.); symptoms (FM-related symptoms)²⁶; and both pharmacological and non-
34 pharmacological treatments (type of treatment).
35

36 **2.4. Data collection and analysis**

37 Data were collected independently by two researchers who discussed and agreed on each item or website when
38 there was no consensus.
39

40 IBM SPSS® v24 (Chicago, USA) software was used for the statistical analysis. Quantitative variables were
41 described by their median and interquartile interval (IQI) assuming the data did not fit a normal distribution, which
42 was verified using the Shaphiro-Wilk test. Categorical variables were described by their absolute frequencies and
43 percentages. Quantitative variables from both categories of websites (retrieved by search engines or from patients
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associations) were compared using the nonparametric Mann-Whitney *U*-test. Additionally, Fisher's exact test was used to compare the typology of the ten first hits by search engines. All comparisons were two-tailed and statistical significance was set at $P < 0.05$.

2.5 Patient and public involvement

Patients were not involved in this study.

3. RESULTS

3.1. Characteristics of analyzed websites

A total of 305 websites were found using search engines and from patient associations in Spain and Latin America. After applying the exclusion criteria, 73 sites were included (Figure 1, see Appendix 1) and classified as follows: 53 (72.6%) nonprofit (*e.g.*: fundacion-canna.es), 7 (9.5%) commercial (websites selling products or services, *e.g.*: hhp.es, kernpharma.com, sanitas.es), 6 (8.2%) institutional [(government (*e.g.*: niams.nih.gov/es) and professional (*e.g.*: portal.hospitalclinic.org)], 4 (5.4%) providing free-of-charge information (*e.g.*: www.fisterra.com), and 3 (4.1%) from media owners (*e.g.*: www.infosalus.com). Of them, 7 (9.5%) and 4 (5.4%) were websites translated from English and Catalan, respectively. In terms of typology of websites found by search engines, no statistically significant differences in frequency were found between the top-ten and the totality of the included ones (see Table 1).

Table 1. Typology of the top-ten websites retrieved by search engines

Typology of website	Google	Yahoo	Bing!	<i>P</i> -value*	Google	Yahoo	Bing!	<i>P</i> -value*
	N in overall search (%) n = 25	N in overall search (%) n = 25	N in overall search (%) n = 25		N in top-ten (%) n = 10	N in top-ten (%) n = 10	N in top-ten (%) n = 10	
Commercial	8(32%)	3(12%)	5(20%)	0.261	3(30%)	1(10%)	2(20%)	0.847
Nonprofit	5(20%)	2(8%)	5(20%)	0.460	2(20%)	0(0%)	2(20%)	0.507
Institutional	5(20%)	8(32%)	4(16%)	0.477	3(30%)	3(30%)	1(10%)	0.642
Media	2(8%)	7(28%)	6(24%)	0.187	1(10%)	3(30%)	2(20%)	0.847
Free of charge information	5(20%)	5(20%)	5(20%)	1.000	1(10%)	3(30%)	3(30%)	0.642

*Fisher's Exact Test

Among websites from patient associations, 44 were from Spain and 3 from Latin America (Argentina, Chile, and Venezuela) (see Appendix 1).

3.2. Type of information

3.2.1. Websites retrieved by search engines

Figure 2 shows the type of information in the websites retrieved by search engines.

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3 In terms of illness conceptualization, 6 websites (24%) mentioned that FM is acknowledged as an illness by the
4 WHO. Barely any mentioned central sensitization or central sensitization syndrome, and none named other terms
5 like dysfunctional pain.
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8 The least cited symptoms were paresthesia (11 websites; 44%) together with morning stiffness and anxiety (15
9 websites; 60%). The most cited symptoms were pain (25 websites; 100%) followed by sleep disorders (23
10 websites; 92%) and fatigue (21 websites, 84%).
11

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13 The most cited pharmacological treatments were antidepressants (22 websites; 88%), followed by painkillers (17
14 websites; 68%) and antiepileptic drugs (15 websites; 64%). Muscle relaxants and non-steroid anti-inflammatory
15 drugs were named in 8 websites (32%). In terms of non-pharmacological treatments, the most highlighted
16 physiotherapy techniques were massage (10 websites; 40%), stretching (4 websites; 16%), and locally applied heat
17 (3 websites; 12%). The most frequently mentioned alternative therapies were yoga (10 websites; 40%), acupuncture
18 (9 websites; 36%), and Tai Chi (5 websites; 20%).
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21 In terms of advice, sleep strategies were the most recommended, specifically implementing sleep habits (7
22 websites; 28%), and moderating activity and daily-life pace, as well as mentality changes. Stress (7 websites;
23 28%), weather changes (cold, humidity) with anxiety/stress (6 websites; 24%), and excessive physical activity (3
24 websites; 12%) were highlighted as aggravating factors.
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27 28 29 *3.2.2. Websites from patients associations*

30
31 Figure 3 shows the type of information in the websites retrieved from patients associations websites.

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33 Among websites mentioning that FM is a disease, 10 (20.8%) included acknowledgment by the WHO, 1 (2.1%)
34 specifically cited that FM is in the International Classification of Illnesses, and 10 (20.8%) mentioned both facts.
35 In terms of symptoms, the least mentioned were hypersensitivity (15 websites; 31.2%) paresthesia (28 websites;
36 58.3%), and depression (29 websites; 60.4%). The most cited symptoms were pain (44 websites; 91.7%), followed
37 by sleep disorders (40 websites; 83.3%) and fatigue (37 websites ; 77.1%). In terms of pharmacological treatment,
38 antidepressants (19 websites; 39.6%), painkillers (15 websites; 31.2%), and muscle relaxants (9 websites; 18.7%)
39 were the most mentioned, and 9 (18.7%) of the websites including pharmacological treatment did not mention any
40 in particular. The most frequently cited physiotherapy techniques were massage (8 websites; 16.7%), stretching (5
41 websites; 10.4%), and locally applied heat (4 websites; 8.3%). Finally, the most cited alternative therapies were
42 yoga and acupuncture (8 websites; 16.7%) and Tai Chi (7 websites; 14.6%).
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48 In terms of recommendations, the most common advice was avoiding aggravating factors, like stress (9 websites;
49 18.7%), and improving sleep habits (6 websites; 12.5%). The most commonly mentioned aggravating factors were
50 weather changes (cold, humidity) (9 websites; 18.7%), stress/anxiety (7 websites; 14.6%), and excessive physical
51 activity (5 websites; 10.4%).
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53

54 55 **3.3. Quality of health information**

56 57 *3.3.1. Websites retrieved by search engines*

The overall quality as measured by the DISCERN²⁰ obtained a median score of 27.0 [IQI: 24.5–32.0]: 18 (72.0%) scored 16–29 points (very low), 6 (24.0%) obtained 30–42 points (low), and only 1 (4.0%) website reached 43–55 points (moderate). All categories scored <2 (Table 2). Regarding the quality of information on treatment choices, only one of the websites retrieved by search engines (4.0%) and ten websites from patient associations (20.8%) did not offer any information on treatment choices.

3.3.2. Websites from patients associations

According to the DISCERN,²⁰ the overall quality was very low, with a median score of 21.0 [IQI: 19.2–23.8]: 44 websites (91.7%) scored 16–29 (very low) and other 4 websites (8.3%) scored 30–42 (low). All the categories scored <2 (Table 2). Statistically significant differences were found in all categories between websites found by search engines and from patients associations (Table 2). The overall DISCERN score was lower for those from patients associations websites, $P < 0.001$ (Figure 4).

Table 2. Score for the quality of health information by category according to the DISCERN questionnaire

Category	Websites retrieved by search engines		Websites of patients associations		P-value*
	Median	IQI	Median	IQI	
Reliability of the publication	1.6	1.5–1.8	1.3	1.2–1.5	<0.001
Quality of information on treatment options	1.7	1.4–2.0	1.3	1.0–1.4	<0.001
Overall score	2.0	2.0–3.0	2.0	1.0–2.0	<0.001

IQI: Interquartile interval; * Mann-Whitney *U*-test

3.4. Quality of websites

3.4.1. Websites retrieved by search engines

Using the Bermúdez-Tamayo questionnaire,¹⁸ the overall quality was moderate, with a median score of 35.0 [IQI: 31.0–40.5]: 9 websites (36%) obtained a score of 26–33 (low), 10 (40%) scored 34–40 (moderate), 5 (20%) obtained 41–47 points (good), and only 1 achieved a score of 48–54 (excellent). The category achieving the lowest score was updating of information (Table 3). Statistically significant differences were observed in all the categories between the websites retrieved by search engines and those from patients associations, with the exception of accessibility (Table 3, $P = 0.342$).

Table 3. Score for the quality of websites by category according to the Bermúdez-Tamayo questionnaire

Category	Websites retrieved by search engines		Websites of patients associations		P-value*
	Median	IQI	Median	IQI	
Transparence and absence of conflict of interests	2.6	1.8–2.6	1.0	1.0–1.8	<0.001
Authorship	1.0	1.0–2.0	1.0	1.0–1.0	0.002
Protection of personal data	3.0	3.0–3.0	1.0	1.0–3.0	0.001
Information updating	1.0	1.0–1.0	1.0	1.0–1.0	<0.001
Responsibility	1.3	1.3–2.0	1.3	1.3–1.3	<0.001
Accessibility	2.0	1.8–2.3	2.0	1.8–2.0	0.342

IQI: Interquartile interval; * Mann-Whitney *U*-test

3.4.2. Websites from patients associations

According to the Bermúdez-Tamayo questionnaire,¹⁸ the general quality was also low, with a median score of 26.0 [IQI: 25.0–31.0]: 24 sites (50.0%) obtained a score of 17–25 (very low), 20 (41.7%) scored 26–33 (low), 3 (6.2%) obtained 34–40 points (moderate), and only 1 (2.1%) achieved 41–47 points (good). Scores were low for all the categories, among which updating of information scored the lowest (Table 3).

Statistically significant differences were noted in the total score of the Bermúdez-Tamayo questionnaire between the websites found by search engines and those from patients associations ($P < 0.001$, Figure 4).

3.5. Readability

3.5.1. Websites retrieved by search engines

With a median score of 53.7 [IQI: 47.4–56.2], readability was found to be “slightly difficult”: 15 websites (60.0%) were categorized as “slightly difficult” (40–55 points) and 10 (40.0%) as “normal” in terms of readability (55–65 points).

3.5.2. Websites from patients associations

Overall readability was also “slightly difficult” with a median score of 51.7 [IQI: 47.9–55.1]: 4 websites (8.3) were considered “very difficult” (<40), 32 (66.7%) “slightly difficult” (40–55), 11 (22.9%) were “normal” (55–65), and 1 (2.1%) was “fairly easy” (65–80) to read.

No statistically significant differences in readability were observed between websites found by search engines and from patients associations ($P < 0.396$) (see Figure 5).

DISCUSSION

The outcomes obtained with the tools this study employed suggest that quality of FM websites in Spanish, as retrieved by the main search engines, tend to be of medium-low quality, whereas those from both Spanish and international patients associations tend to be of very low quality. Overall, content quality was very low, and readability was “slightly difficult”.

Website quality, readability, and content varied among websites, similarly to previous research on FM^{15 16} and other chronic conditions.^{27 28} As far as the authors know, this study is the first to assess quality of websites on FM in Spanish and the only one including an analysis of websites from FM patients associations. The remainder of the articles that were found while analyzing websites quality^{29 30} do not specifically mention FM.

4.1. Methodology

This study employed validated, widely used questionnaires for analyzing website quality. LIDA and DISCERN are the tools most frequently used for this purpose,^{20 31} which is the Bermúdez-Tamayo questionnaire for websites in Spanish.¹⁸

LIDA is a tool that assesses healthcare websites for content and information design,³¹ with accessibility, usability, and reliability of information being the three main categories. The Bermúdez-Tamayo questionnaire was originally validated in Spanish¹⁸ and also includes these categories but, as it mainly contemplates aspects of the website as such and not its contents, the DISCERN questionnaire was employed, a tool that has been broadly used in research, both in English and Spanish.^{16 27-29 32} None of the employed questionnaires interprets the results or qualifies the score into quality levels. This leads researchers to propose their own levels and, although these tend to be very similar, they can be interpreted in different ways hindering comparison between outcomes. This trial created five quality levels for all the items.

Another important aspect of websites is readability. Studies assessing English websites tend to use *Flesch Reading Ease score maps*^{16 28} and *Flesch-Kincaid*.^{28 32 33} Both^{34 35} provide a score from 0 to 100, where higher scores indicate texts that are easier to read. For the general public, 60 is considered an acceptable value. *Flesch-Kincaid*³⁴ also indicates the necessary education level to understand a text. Studies evaluating Spanish websites use the INFLESZ scale,^{17 27 30} which was created after the *Flesch* scale was reviewed³⁵ and is considered one of the Spanish-adapted versions of the former and *Flesch-Szigrist*³⁶ scales. Comparisons between INFELSZ and FLESH scores can be found in Appendix 2.

4.2. Websites characteristics and type of information

There were differences in the outcomes between websites found by search engines and those from patients associations. The greatest differences were observed using the Bermúdez-Tamayo questionnaire,¹⁸ where websites retrieved by search engines obtained higher scores. This could be due to the nonprofit character of websites of patients associations and because most seem to have been created by FM patients with no mention about whether the contents have been selected by a professional expert in FM or a scientific board, and also the websites do not

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3 seem to be created by webpage developers but more likely using a non-paid website development tool, such as
4 webnode.³⁷ In contrast, websites found by search engines belong to different categories, like commercial or
5 institutional, which can involve some sort of funding for their development and management. However, this is a
6 hypothesis, since most websites do not state their funding body. This outcome differs from that by Basavakumar
7 *et al.*¹⁵ that found websites from not-for-profit organizations to be the most complete ones. This could be due to
8 the different tools and methods employed in the different studies to analyze the quality and type of included
9 websites. Additionally, the non-for-profit websites in the above-mentioned study only accounted for 9% of the
10 total, and it does not specify if it included websites from patients associations. The websites from patients
11 associations included in this study (64% of assessed websites) are all non-for-profit and show the worst quality.
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19 **4.3. Type of information**

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21 Symptoms, treatment, and diagnosis were the most commonly tackled information in the assessed sites. Other
22 issues of importance for FM patients, such as support,^{14,38} are dealt with superficially and briefly, chiefly naming
23 the importance of the doctor for determining pharmacological treatment.
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26 A very mechanistic, vague vision of FM, with little scientific evidence, was generally observed. In terms of
27 conceptualization of FM, no website was found that mentioned dysfunctional pain, no difference was made
28 between clinical diagnosis or diagnosis criteria for research, and diagnostic points were those of 1990 even if
29 Wolfe *et al.* warned about the risk this implied when used for clinical practice already in 2003.³⁹ Provided treatment
30 alternatives can cause nothing but confusion due to the high variability found, little correlation with scientific
31 literature (neither massage nor stretching are backed by scientific evidence^{40,41} and, in certain cases, they can be
32 counterproductive), and the superficial manner in which they are covered. For instance, education is one of the
33 least mentioned treatments despite being one of the most recommended ones,^{5,10} and neuroscience education is not
34 found in any of the websites citing it even if its effectiveness for treating pain has been proven.^{7,9} The type or
35 frequency of recommended physical exercise was not specified in any case despite being one of the most
36 mentioned treatments in the Internet.^{10,41,42} In terms of psychological therapies, cognitive behavioral therapy was
37 mentioned in some websites but in a very vague way and without mentioning exiting evidence for it.⁶
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46 **4.4. Quality of health information**

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48 Information quality and reliability were assessed via the DISCERN questionnaire.²⁰ The outcome showed that FM
49 contents in websites in Spanish were of very low quality. In the study by Daraz *et al.*,¹⁶ which also employed this
50 tool, 36% of the 25 included websites were qualified as “marginal”, 32% as “good”, and 32% as “very good”. Of
51 the websites found by search engines in this study, 72% were classified as “very low quality”, 24% as “low
52 quality”, and 4% as “moderate quality”. Similarly, 91.6% of the websites from patients associations obtained
53 scores classified as “very low quality” and 8.3% as “low quality”. In this regard, the quality of websites analyzed
54 in this study seemed to be lower than that in the work by Daraz *et al.*¹⁶ It is necessary to acknowledge that the
55 maximum score in the study by Daraz *et al.*¹⁶ was 75 points, since the last item was excluded; had this study
56 proceeded similarly and followed the categories as Daraz *et al.*,¹⁶ 84.0% of websites found by search engines
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3 would be categorized as “marginal” and 16.0% as “good”, while there would not be changes in quality for patients
4 associations websites. The mean score obtained by Daraz *et al.*¹⁶ (33.3) using the DISCERN questionnaire²⁰ was
5 considerably higher than that obtained in this study for websites found by search engines (26.4) and from patients
6 associations (20.9). Daraz *et al.*¹⁶ also reported a mean score of 2.5 for the 15 items, whereas none of the three
7 categories in the DISCERN questionnaire²⁰ scored >2 in this trial. This could be due to the fact that our two
8 independent researchers agreed on the score of some items and the necessary minimums for intermediate scores
9 (2, 3, and 4), thus minimizing potential variability, an aspect not mentioned by Daraz *et al.*¹⁶

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14 On the other hand, the study by Kaicker *et al.*³² employed the DISCERN questionnaire²⁰ for assessing the quality
15 of contents of 161 websites in English found using GOOGLE, YAHOO!, and MSN, by entering “pain”, “chronic
16 pain”, “back pain”, “arthritis”, and “fibromyalgia” as search keywords. The mean score was 55.9 (moderate
17 quality). The higher score they obtained compared to this study could result from the fact that Kaicker *et al.* did
18 not analyze specific websites for FM.
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22 Washington *et al.*³³ designed their own questionnaire to assess the content of 240 websites in English found using
23 GOOGLE, YAHOO!, and MSN and entering “pain”, “chronic pain”, “back pain”, “arthritis”, and “fibromyalgia”
24 as keywords. They concluded that the overall quality was quite low, which is in agreement with the outcome of
25 this study despite using a different methodology.
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30 **4.5. Quality of websites**

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32 Website quality and how to assess it is a controversial issue, partly because there is a subjective component to
33 quality that is difficult to quantify.¹⁸ This study employed the Bermúdez-Tamayo questionnaire,¹⁸ the most used
34 tool in Spanish to evaluate quality-related criteria for websites. Using this questionnaire, updating of information
35 was the category that obtained the lowest score, both for websites found by search engines and those from patients
36 associations. This is in agreement with other trials using this tool^{30 43 44} and results from the fact that only three of
37 the included websites found by search engines specified the last date of information update and only two made a
38 partial statement in this regard, whereas none of the sites of patients associations complied with this item. Several
39 ethical codes request that the latest update is clearly stated for each website and each of its components.
40 Additionally, e-Europe and the American Medical Association require that a revision be conducted on the
41 pertinence of the provided information based on the latest evidence¹⁸. Basavakumar *et al.*¹⁵ analyzed 148
42 webpages, using the JAMA score (ranged between 0 and 4) and found that only 63 webpages (43%) met the quality
43 threshold of ≥ 3 .
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52 **4.6. Readability**

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54 Reducing text comprehensibility to a mathematic equation is difficult.⁴⁵ However, readability indexes are a well-
55 accepted approach for improving text readability and comprehension.⁴⁶ Also, the importance of this aspect must
56 be emphasized, since requiring high reading skills can reduce information accessibility and potentially exclude
57 users with low literacy.⁴⁷
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3 In this study, websites found both by search engines and from patients associations were categorized as “slightly
4 difficult to read”, with scores of 52.39 and 47.70, respectively. The recommended minimum score for health
5 information is 55,¹⁷ which is probably the reason why the general public has difficulties understanding the
6 information provided in the included websites. Other studies using the INFLESZ scale¹⁷ to analyze readability
7 obtained similar outcomes.^{27 30} Readability can vary among websites due to the use of technical terms, such as
8 fibromyalgia, which appears to have low readability.¹⁶ The readability degree of most of the websites assessed by
9 Daraz *et al.*¹⁶ corresponded with a 10th–12th school grade level, whereas the recommended level is that of 6th
10 grade.⁴⁸ Kaicker *et al.*³² obtained similar results, as is the case of our study with a score on the INFLESZ scale¹⁷
11 of 40–55 (slightly difficult), which corresponds with high-school reading level.¹⁷ Using a standardized online tool
12 (<https://www.webfx.com/tools/read-able/>), Basavakumar *et al.*¹⁵ found that only 92% of websites met the
13 recommended readability.
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22 **4.7. Limitations**

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24 There are limitations to this study. Content updates in the Internet must be taken into consideration. Since newly
25 created websites can be incorporated, or the assessed sites can undergo revisions and modifications, the outcome
26 validity of this study is temporary, and its quality analysis can vary in the future.
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29 Additionally, using different search engines, on different dates, or entering other terms can modify the results.⁴⁸
30 ⁴⁹ Since “fibromyalgia” was the only term entered as keyword, it is possible that websites consulted by FM subjects
31 were omitted in this trial, such as those on chronic pain. Additionally, by including only the first 20 links displayed
32 by three search engines, some resources of interest could have been missed. This is a usual limitation in any
33 Internet search. However, this study tried to reproduce the most common pattern a Spanish-speaker would follow:
34 over 95% of searches in Spain are done via Google ^{50 51} by entering the name of the disease or one of its
35 symptoms.¹² Therefore, assessing 20 websites of those retrieved by Google/Yahoo!/Bing appears to be sufficiently
36 exhaustive, especially considering that the general population do not consult any site further than the second one.⁵²
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43 **4.8. Clinical practice implications**

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45 Since FM patients often consult the Internet to better understand their illness and how to manage it,^{14 21} which can
46 be an aid or a barrier for treating it,⁵³ knowing about information available online can be useful for health workers.
47 The paucity of information on the diagnosis, treatment options, and conceptualization of FM this work found must
48 be compensated with correct information by health workers, especially considering that education is an essential
49 part of its treatment.¹⁰
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56 **4. CONCLUSIONS**

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58 The quality of websites on FM in Spanish is moderate-low, very low in terms of content, and their readability is
59 slightly difficult. Additionally, the provided contents are very diverse, often lack scientific evidence, and are not
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up-to-date. Greater efforts are required to guarantee that FM websites comply with quality criteria and offer updated information, relevant, of quality, and readable.

For peer review only

Contributions:

Arturo Alioshkin Cheneguín: Conceptualization; Methodology; Investigation; Writing - Original Draft.

María Torres Lacomba: Conceptualization; Methodology; Software; Validation; Investigation; Formal analysis; Resources; Data Curation; Writing - Original Draft; Visualization; Supervision; Writing - Review & Editing.

Isabel Salvat Salvat: Validation; Writing - Original Draft.

Helena Romay Barrero: Writing - Original Draft; Visualization; Writing - Review & Editing.

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LEGENDS

Fig. 1 Flowchart showing the selection process of websites.

Fig. 2 Type of information in websites retrieved by search engines.

Fig. 3 Type of information in websites from patients associations.

Fig. 4: Comparison of the quality of websites according to the DISCERN and Bermúdez-Tamayo questionnaires between websites retrieved by engines and from patients associations.

Fig. 5: Comparison of readability between websites retrieved by engines and from patients associations.

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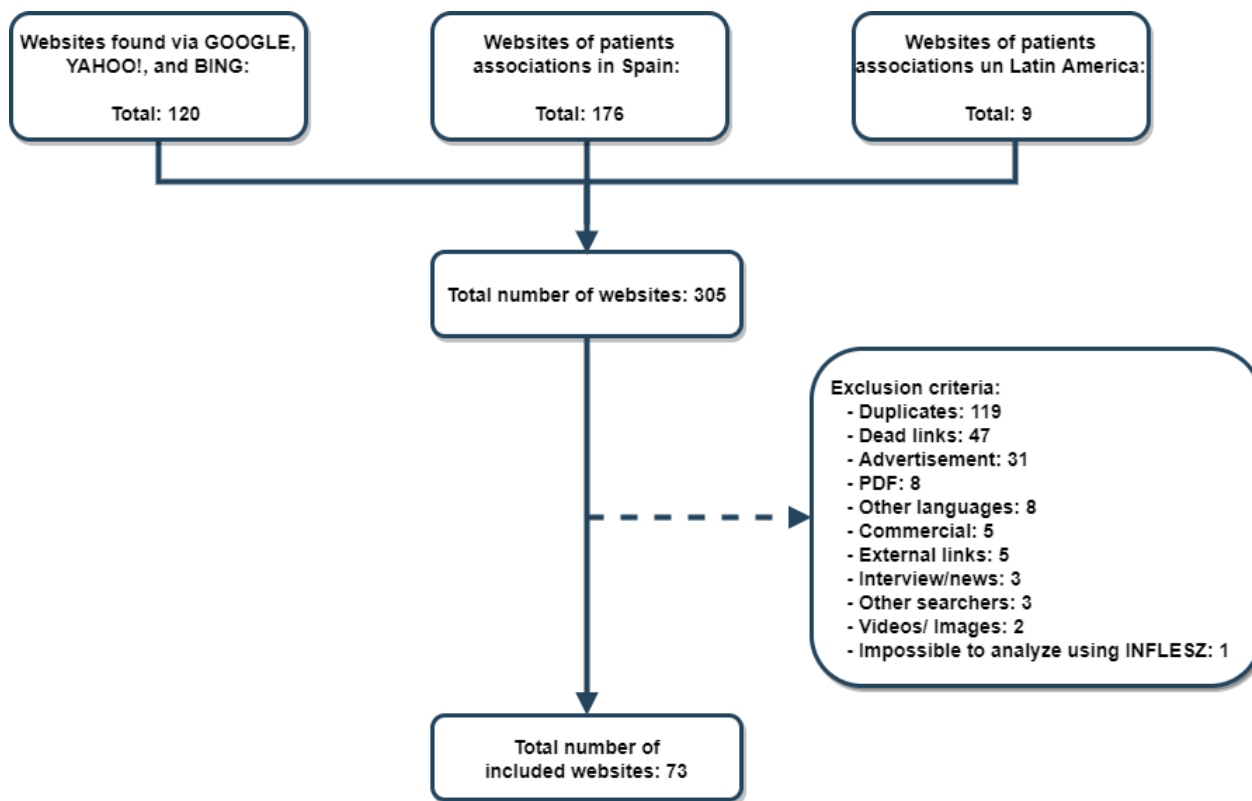
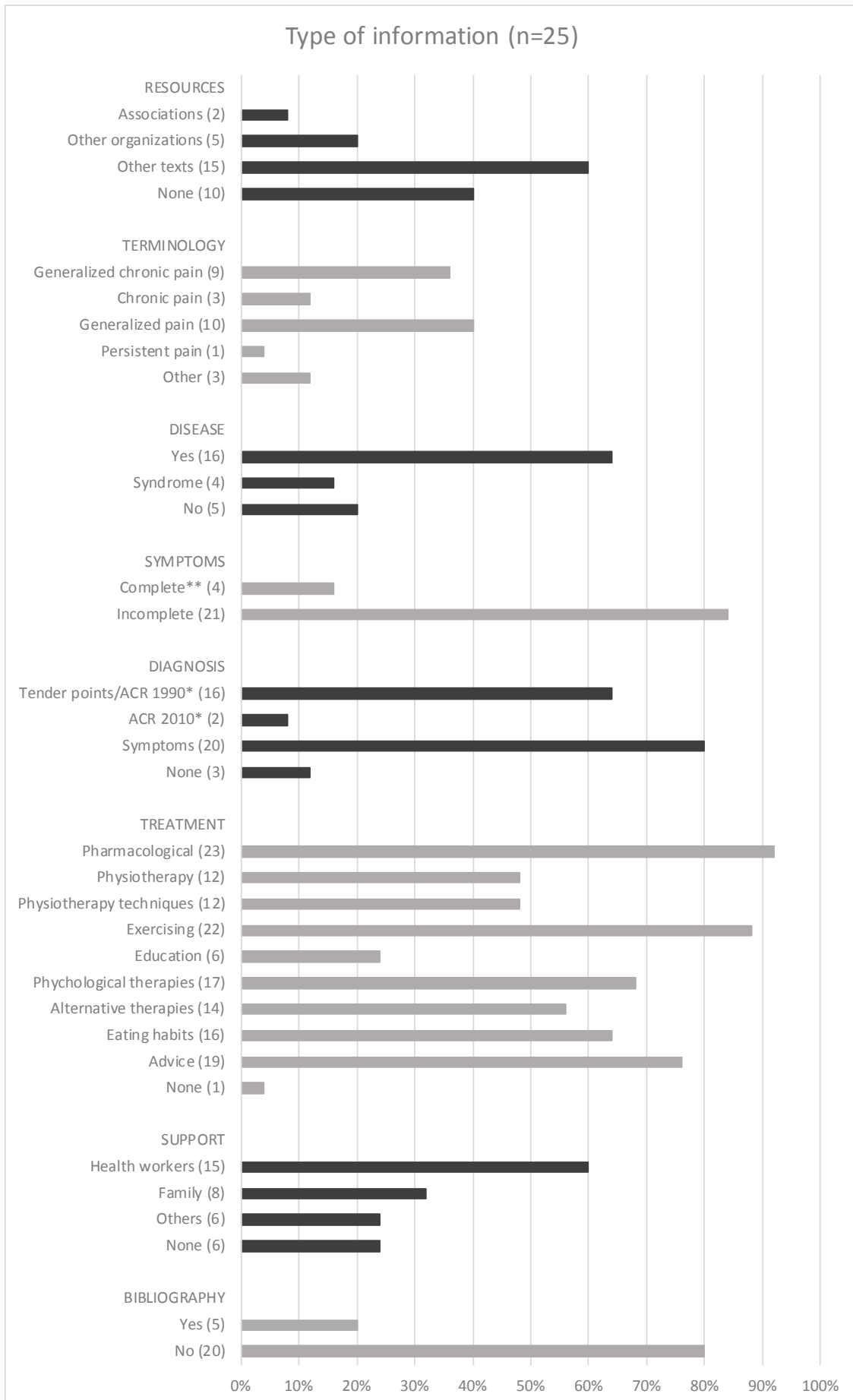


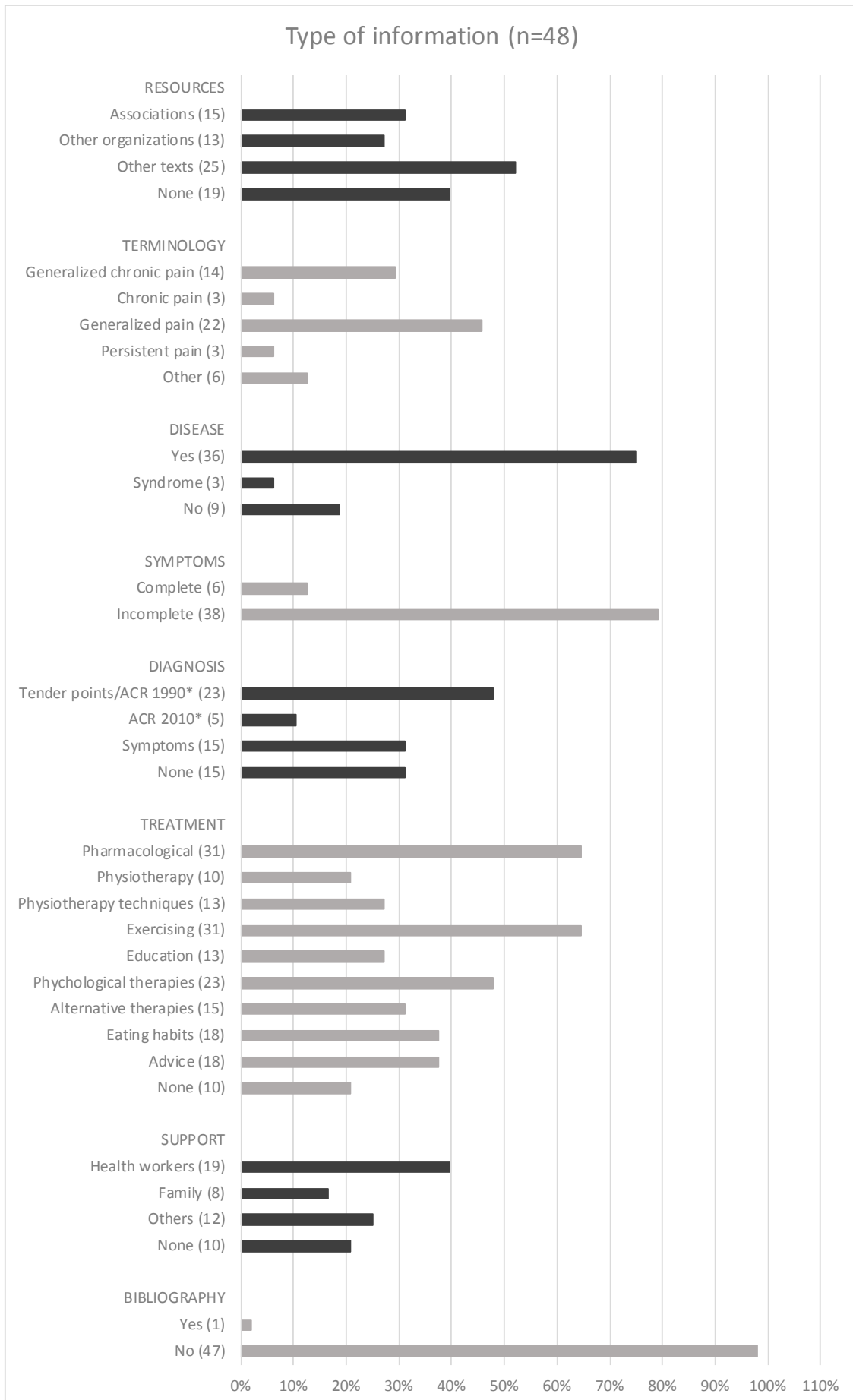
Figure 1 Flowchart showing the selection process of websites.



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3 **Figure 2** Type of information in websites retrieved by search engines

4 *Diagnostic criteria for fibromyalgia by the *American College of Rheumatology*.

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7 ***Complete symptoms when including* generalized pain, hypersensitivity (allodynia, hyperalgesia, and/or
8 exacerbated sensitivity to stimuli in addition to pain), fatigue, sleep disorders, cognitive disorders, anxiety,
9 paresthesia, morning stiffness, and depression).
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3 **Figure 3** Type of information in websites from patients associations

4 * Diagnostic criteria for fibromyalgia by the American College of Rheumatology

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For peer review only

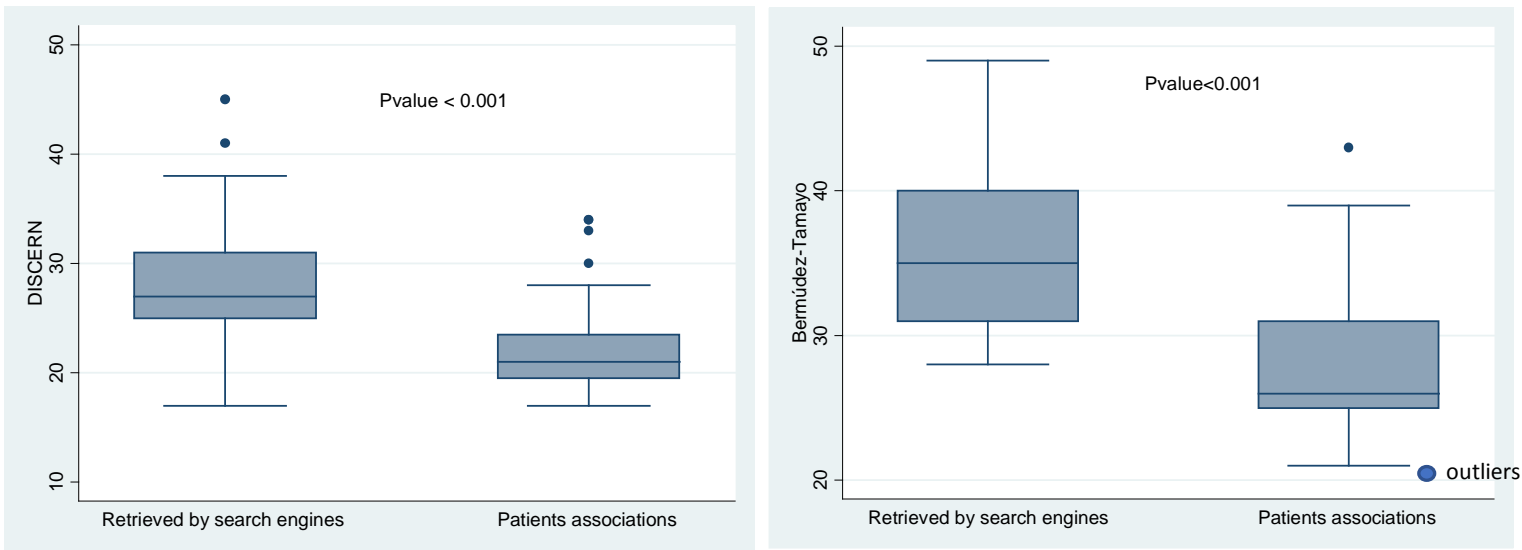


Figure 4 Comparison of the quality of websites according to the DISCERN and Bermúdez-Tamayo questionnaires between websites retrieved by engines and from patients associations.

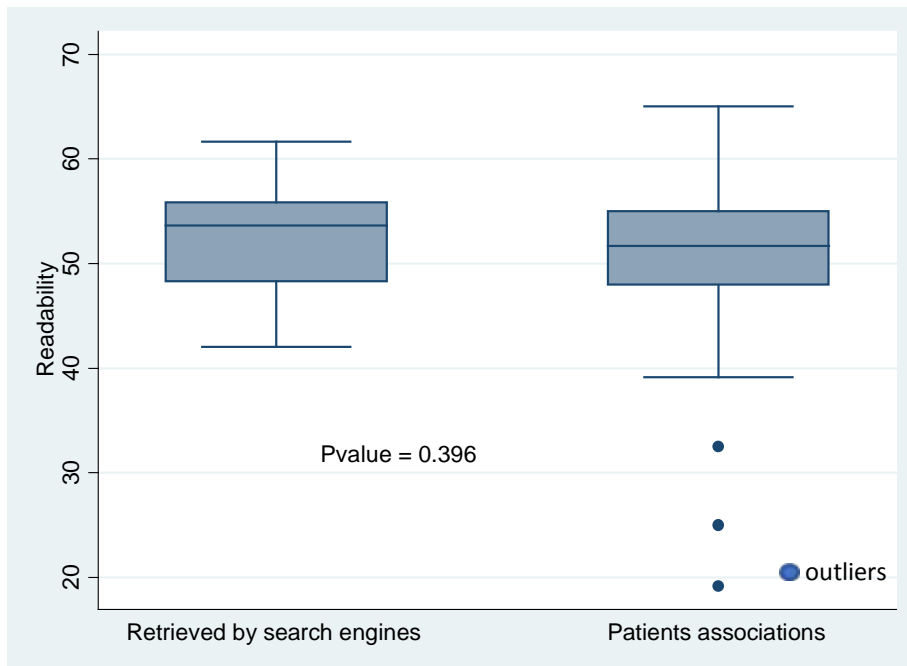


Figure 5 Comparison of readability between websites retrieved by engines and from patients associations

Appendix 1. Raw data from the Websites

Raw data from the Websites retrieved by search engines

URL	Bermúdez-Tamayo	DISGERN	INFLESZ
1. https://infoeuma.com/enfermedades-reumaticas/fibromialgia/	34		48,61
2. https://www.cun.es/enfermedades-tratamientos/enfermedades/fibromialgia	28		51,67
3. https://www.mayoclinic.org/es-es/diseases-conditions/fibromyalgia/symptoms-causes/syc-20354780	49		50,95
4. https://cuidateplus.marca.com/enfermedades/musculos-y-huesos/fibromialgia.html	36		48,35
5. https://es.wikipedia.org/wiki/Fibromialgia	35		56,63
6. https://medlineplus.gov/spanish/ency/article/000427.htm	45		55,84
7. http://espanol.arthritis.org/espanol/disease-center/fibromialgia/	34		53,67
8. https://portal.hospitalclinic.org/enfermedades/fibromialgia	42		48,33
9. https://www.kernpharma.com/es/blog/todo-lo-que-debes-saber-sobre-la-fibromialgia	33		58,72
10. http://muysaludable.sanitas.es/salud/la-fibromialgia-causas-sintomas-tratamientos/	29		46,54
11. https://espanol.womenshealth.gov/a-z-topics/fibromyalgia	44		59,32
12. https://www.niams.nih.gov/es/informacion-de-salud/fibromialgia	40		59,83
13. https://www.fisterra.com/Salud/1infoConse/fibromialgia.asp	37		46,36
14. https://kidshealth.org/es/parents/fibromyalgia-esp.html	42		55,44
15. https://www.webconsultas.com/categoria/salud-al-dia/fibromialgia	37		54,46
16. https://www.hhp.es/patologias/fibromialgia/	31		42,05
17. https://www.segundomedico.com/fibromialgia-causas-sintomas-diagnostico-y-tratamiento/	32		53,21
18. https://es.familydoctor.org/condicion/fibromialgia/	39		61,02
19. https://www.sabervivirtv.com/medicina-general/fibromialgia-detectar-enfermedad_434	31		61,65
20. https://www.fundacion-alborada.org/enfermedades-ambientales/fibromialgia/	31		43,55
21. https://mejorconsalud.com/5-sintomas-tempranos-la-fibromialgia/	41		55,16
22. https://cuideo.com/blog-cuideo/ayuda-fibromialgia-todo-lo-que-debes-saber/	31		53,85
23. https://www.fesemi.org/informacion-pacientes/hemeroteca-salud/enfermedades/fibromialgia-y-fatiga-cronica	35		55,16
24. https://www.infosalus.com/enfermedades/aparato-locomotor/fibromialgia/que-es-fibromialgia-31.html	37		45,25
25. https://www.fundacion-canna.es/fibromialgia	29		44,02

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<i>Raw data from the Websites of Spanish patients associations</i>				
	URL	Bermúdez-Tamayo	DISCERN	INFLESZ
1.	http://www.fibromialgiautrera.com/quienes_somos.php	23	33	19,12
2.	http://www.asociacionapaffer.org/1029--que-es-la-fibromialgia-.html	23	33	56,54
3.	http://www.apafima.org/que-es-la-fibromialgia.html	33	33	49,49
4.	http://afibrose.org/index.php?option=com_content&view=article&id=50&Itemid=41	25	33	32,48
5.	https://afipo.webnode.es/	27	33	56,83
6.	https://agrafim.weebly.com/fibromialgia-fm.html	24	33	43,88
7.	http://www.alaguas.net/afico/	25	33	53,53
8.	https://afimreb.wordpress.com/fibromialgia-2/	27	33	48,74
9.	http://www.asociacionafcas.es/	29	33	50,05
10.	https://fibromialgiamarinaalta.es.tl/QUE-ES-LA-FIBROMIALGIA.htm	25	33	58,24
11.	http://avafi.es/?page_id=88	43	33	50,38
12.	https://adafir.wordpress.com/fibromialgia/	25	33	55,71
13.	http://afa.asofiben.es/?page_id=241	23	33	49,94
14.	http://www.asfiel.org/fibromialgia/	27	33	54,38
15.	https://fibromialgianovelda.es.tl/%BFQue-es-la-Fibromialgia-f-.htm	33	33	44,25
16.	http://fibromialgiasantapola.blogspot.com/p/que-es-la-fibromialgia.html	25	33	48,01
17.	http://s619678501.web-inicial.es/qui%C3%A9nes-somos/la-enfermedad/	31	33	50,07
18.	https://punto19.org/fibromialgia	31	33	47,9
19.	http://afibroalba.blogspot.com/	27	33	50,92
20.	http://afibrotar.es/la-fibromialgia/	29	33	42,03
21.	http://www.ffclm.es/fibromialgia.php	25	33	39,14
22.	https://aficrovall.jimdo.com/que-es-la-fibromialgia/	35	33	45,22
23.	https://www.avuntamientoarevalo.es/03c_la_villa/08_asociaciones/c08aso_afemar_07.htm	23	33	54,31
24.	https://afibrosal.org/enfermedades/fibromialgia	33	33	52,19
25.	https://afibroal.webnode.es/laenfermedad/	25	33	25,01
26.	https://fexaf.wordpress.com/fibromialgia-fm/	27	33	42,95
27.	http://www.afifasen.es/fibromialgia/	27	33	54,4
28.	https://www.asafa.es/	31	33	54,89
29.	https://www.fibroparla.es/	27	33	54,17
30.	https://www.afifuen.com/acerca-de/fm/	25	33	65,05
31.	http://www.fibromialgia.cat/cast/frames.htm	39	33	59,59
32.	http://afibrocat.barcelona.ppe.entitats.diba.cat/sobre-la-fibromialgia/	29	33	53,62

Raw data from the Websites of Spanish patients associations (continuation)

URL	Bermúdez-Tamayo	DISGERN	INFLESZ
33. https://ashofi.org/es/etiologia-2/	35	28	49,76
34. https://fibromialgiabadalona.wordpress.com/la-enfermedad/	25	21	55,19
35. http://fibrofels.castelldefels.ppe.entitats.diba.cat/es/la-fibromialgia-2/	25	21	50,98
36. http://www.afibrocar.com/fibromialgia.php	25	20	57,03
37. http://fibrofamur.blogspot.com/p/diagnostico.html	25	20	54,36
38. https://fibrorioja.org/quienes-somos/fibromialgia/	25	20	50,86
39. https://cafpontevedra.es.tl/%BFQUE-ES-LA-FIBROMIALGIA-f-.htm	25	20	56,66
40. https://afibropo.webnode.es/fibromialgia/	29	20	59,82
41. http://www.asafima.org/	31	20	59
42. http://www.bizi-bide.com/	31	20	43,15
43. http://www.afibrolan.org/sobre-la-fibromialgia/	23	20	54,19
44. https://fibromialgiasafor.es.tl/%BFQu-e2--es-la-fibromialgia-f--.htm	21	20	58,4
45. http://redespanolafibromialgia.com/que-es-la-fibromialgia/	33	20	52,68

Raw data from the Websites of Latin America patients associations

URL	Bermúdez-Tamayo	DISGERN	INFLESZ
46. http://www.asociacionfibroamerica.org/	25	20	44,91
47. http://www.fibromialgiachile.cl/index.php/tratamientos	25	24	53,33
48. https://fibromialgia.softwaredigitals.com.ve/index.php/%C2%BFqu%C3%A9-es-la-fibromialgia	25	24	51,15

Appendix 2. Comparisons of the INFELSZ with the FLESH ranges.

IFSZ	INFLEZ	FLESch	School level
0	Very difficult	Very difficult	College graduate
15			
30			
35	Slightly difficult	Difficult	College
40			
45			
50	Fairly difficult	Fairly difficult	10th-12th grade
55			
60			
65	Normal	Normal	8th-9th grade
70			
75			
80	Fairly Easy	Fairly easy	7th grade
85			
90			
95	Very easy	Easy	6th grade
100			
		Very easy	5th grade

IFSZ: Flesch-Szigriszt index; FLESch: Flesch Reading Ease Score

BMJ Open

HOW GOOD IS ONLINE INFORMATION ON FIBROMYALGIA? AN ANALYSIS OF QUALITY AND READABILITY OF WEBSITES ON FIBROMYALGIA IN SPANISH

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TITLE PAGE

HOW GOOD IS ONLINE INFORMATION ON FIBROMYALGIA? AN ANALYSIS OF QUALITY AND READABILITY OF WEBSITES ON FIBROMYALGIA IN SPANISH

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ABSTRACT**Objective:**

To assess the content, quality, and readability of websites with information on fibromyalgia in Spanish.

Methods: Websites were retrieved entering the keyword “fibromyalgia” in Google, Yahoo!, and Bing, and by searching records of patients associations in Spain and Latin America. The Bermúdez-Tamayo and DISCERN questionnaires were employed for evaluating quality and content, and INFLESZ for readability. Statistical analysis was conducted using IBM SPSS®v24 (Chicago, USA).

Results: Three hundred and five websites were found. After applying the exclusion criteria, 73 websites were analyzed. Websites retrieved by search engines obtained median scores of 27.0 [(interquartile interval (IQI): 24.5–32.0)] with DISCERN, 35.0 [IQI: 31.0–40.5] with Bermúdez-Tamayo, and 53.7 [IQI: 47.4–56.2] with INFLESZ, whereas those from patients associations scored 21.0 [IQI: 19.2–23.8], 26.0 [IQI: 25.0–31.0], and 51.7 [IQI: 47.9–55.1], respectively. In general, content was not up-to-date.

Conclusions: Overall quality was medium-low, content quality was very low, and readability was poor. Further effort is needed to guarantee meeting quality criteria and accessing updated, relevant, and legible information.

This study exposes the quality and readability of websites on fibromyalgia in Spanish, which can help healthcare workers to better appraise this resource and its potential influence on the development of the pathology.

Keywords: Fibromyalgia, Education, Internet, Patient Portals, Spanish.

Strengths and limitations of this study:

- This study is the first to examine the quality of online Spanish fibromyalgia resources.
- The online resources analyzed also included all Fibromyalgia patients associations registered in Spain and Latin America.
- Standardized quality and readability tools were used to assess quality and readability.
- There is no gold standard to evaluate the quality of websites.
- The outcome validity of this study is temporary, and its quality analysis can vary in the future.

1. INTRODUCTION

Fibromyalgia (FM) is a “syndrome of widespread pain, decreased pain threshold, and characteristics symptoms, including non-restorative sleep, fatigue, stiffness, mood disturbance, irritable bowel syndrome, headache, paresthesias, and other less common features” [sic].¹

A systematic review in 2017 estimated that FM affects 2.10% of the population worldwide and 2.3% in Europe. In Spain, it has a prevalence of 2.4%, with an estimated yearly cost of 12,993€ million.² FM prevalence in Latin America is 1.12%, ranging from 0.7% in Mexico to 0.2% in Cuba or Venezuela, a variability that can result from diverse diagnosis criteria.^{2 3}

Since one of the main symptoms is generalized chronic pain,⁴ education plays an important role in the therapeutic approach to FM.⁵ Research on the effect of diverse educational methods, such as cognitive behavioral therapy^{6 7} and neuroscience education,^{7 8} has increased in the last years. Strong evidence exists about the effectiveness of combining education, exercising, and active coping strategies on pain, quality of life, and functionality.⁹ Guides like the *European League Against Rheumatism* (EULAR) recommend including education among non-pharmacological treatments for FM.¹⁰

The evolution of the Internet and its interactive features has favored the emergence of virtual health communities, such as patients associations, where users can share experiences and opinions and receive social support. Also, they provide a wide variety of information that affects and empowers users in their health-related decision-making.¹¹

In addition, the Internet has largely grown in the last decades. According to the *Observatorio Nacional de las Telecomunicaciones y de la Sociedad de la Información* (ONTSI), 60.5% of the Spanish population searches the web for health information.¹² With 572 million speakers worldwide, 477 million of which are native speakers, Spanish is the third most used language in the web, and 8.1% of the almost 3,885 million Internet users in December 2017 employed it.¹³

Daraz *et al.* exposed the preferences and needs of FM patients when seeking information: 91% searched the web for it, specifically for treatments (87%), resources (85%), symptoms (81%), implications (79%), and coping (79%). Of them, 93% expressed concern about information reliability and highlighted the need for reputable or medical-staff sources.¹⁴

The studies found assessing the quality of online FM information in English concluded that sites of greater quality are generally less readable and that FM information is incomplete and of low quality.^{15 16} The authors have not found any study on the quality and contents of websites on FM in Spanish.

The aim of this study was to identify information resources for FM patients, available online and in Spanish, and to evaluate their quality, content, and readability.

2. METHODS

2.1. Design and search strategy

A descriptive study was conducted where websites providing information on FM were analyzed for quality, content, and readability using standardized, validated tools.¹⁷⁻²⁰ Figure 1 shows a flowchart describing the stages of the search process.

“Fibromyalgia” was chosen as keyword for the web search given its popularity in “Google Trends”²¹ (trends.google.es) and a filter was applied for “Last 12 months” and “Worldwide”. Google (google.es), Yahoo! (es.yahoo.com), and Bing (bing.com) were the employed search engines based on their popularity in “Statcounter”, both in Spain and Latin America. All the above-mentioned searches were carried out in April of 2019.

Two researchers conducted an online search independently after emptying the cache and history and deactivating location in the computer, with no further filters being applied. GPS was deactivated to prevent the engines from displaying only websites close to the location of the researchers. Since users do not appear to seek information past the first 20 retrieved websites, each researcher selected the first 20 hits from each engine. Additionally, the researchers independently looked for websites of FM associations in Spain and Latin America among their relevant national Public Registry of Associations as of May 2019.

2.2. Selection criteria

All websites in Spanish containing FM information were included.

The following sites were excluded: broken links, duplicates, exclusively offering advertisements; mainly offering information in PDF, images, or videos; news or entries from a journal requiring subscription or payment to access information, without a main page explaining FM, and whose content consisted of links to other sites or documents; not allowing a readability analysis. The included webpages were classified according to the typology of the website. The following typologies were established: nonprofit; commercial (websites selling products or services); institutional [government and professional (organizations with professional medical qualification)]; free-of-charge information; and media owners.

2.3. Tools for quality and readability analyses

The researches independently evaluated the content of the included websites using the DISCERN and Bérnudez-Tamayo questionnaires and the INFLESZ scale.

The DISCERN questionnaire is a valid, reliable tool initially developed for assessing the quality of written information on health-treatment options, which was subsequently applied to websites.^{19 20} It comprises three sections with 16 items: the first 8 assess general reliability of the content, the following 7 evaluate quality of treatment options, and the third section assigns an overall score to the publication. Each question receives a score ranging from 1=No to 5=Yes, allowing intermediate scores (2, 3, and 4). Since the questionnaire poses no

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3 interpretation about its score, the researchers agreed on these values for items concerning: content relevance,
4 information sources, date of content, additional support resources, description of how the treatment works and its
5 relevant risks and benefits, treatment options, and shared decision-making. The overall score range is 16–80, with
6 higher scores having better content quality, defined as follows: 16–29=very low; 30–42=low; 43–55=moderate; 56–
7 68=good, and 69–80=excellent.
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11 The Bermúdez-Tamayo questionnaire¹⁸ evaluates the quality of health websites in Spanish following the
12 recommendations by the main ethical codes and law in Spain and Europe.^{22 23} This validated tool shows adequate
13 reliability ($\kappa \geq 0.60$) for 12 of its 18 items and comprises six sections: transparency and absence of conflicts
14 (5 items), authorship (2 items), personal data protection (that is, the website must describe how the information on
15 an identified or identifiable individual is protected and how data is processed) (1 item), updating of information (1
16 item), responsibility (meaning the possibility of contacting someone responsible for the website to send comments
17 and/or suggestions, whether they offer on-line consultations, and if the team responsible for addressing
18 consultations can be identified) (4 items), and accessibility (5 items). Each item receives a score of 0–3 (0=Does
19 not apply; 1=No; 2=Partially; 3=Yes), so that the overall score ranges from 17 to 54, with higher scores reflecting
20 better quality, defined as follows: 17–25=very low, 26–33=low, 34–40=moderate, 41–47=good, and 48–
21 54=excellent. The researchers agreed on items concerning: purpose and objective of the website; information
22 sources; publication date; and ease of content searching.
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29 INFLESZ is a readability scale, available online and validated in Spanish. Readability is “the ensemble of
30 typographic and linguistic features of written texts that allow for their easy reading and understanding” [sic].²⁴
31 INFLESZ is considered to be more the most suitable scale for the Spanish-speaking population. This tool allows
32 entering the text or its URL online and provides a score ranging from 0 to 100, with ease of text readability defined
33 as: very difficult<40, slightly difficult=40–55, normal=55–65, fairly easy=65–80, and very easy >80. According
34 to this scale, health texts are more likely to be understood if they score >55.¹⁷
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38 Since none of the above-mentioned tools takes into consideration certain issues that are considered important by
39 FM subjects¹⁴ or that have been reported to be of relevance in prior studies,^{5 10} the following data were also
40 recorded: terminology (FM conceptualization, meaning whether FM is designated as a disease or not, and the terms
41 used to define FM, such as generalized pain syndrome, chronic pain, or central sensitization syndrome);
42 relevance of information on diagnosis (type of diagnosis, whether based on tender points as per the criteria by
43 Wolfe in 1990²⁵ or in 2010,²⁶ or based on symptomatology) and treatment (that is, if they mention the treatments
44 that are most supported by scientific evidence, such as therapeutic education of the patient and therapeutic
45 exercising); support (social, family, etc.); symptoms (FM-related symptoms)²⁶; and both pharmacological and non-
46 pharmacological treatments (type of treatment).
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55 **2.4. Data collection and analysis**

56 Data were collected independently by two researchers who discussed and agreed on each item or website when
57 there was no consensus.
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IBM SPSS® v24 (Chicago, USA) software was used for the statistical analysis. Quantitative variables were described by their median and interquartile interval (IQI) assuming the data did not fit a normal distribution, which was verified using the Shapiro-Wilk test. Categorical variables were described by their absolute frequencies and percentages. Quantitative variables from both categories of websites (retrieved by search engines or from patients associations) were compared using the nonparametric Mann-Whitney *U*-test. Additionally, Fisher's exact test was used to compare the typology of the ten first hits by search engines. All comparisons were two-tailed and statistical significance was set at $P < 0.05$.

2.5 Patient and public involvement

This research was done without patient involvement. Patients were not invited to comment on the study design and were not consulted to develop patient relevant outcomes or interpret the results. Patients were not invited to contribute to the writing or editing of this document for readability or accuracy.

3. RESULTS

3.1. Characteristics of analyzed websites

A total of 305 websites were found using search engines and from patient associations in Spain and Latin America. After applying the exclusion criteria, 73 sites were included (Figure 1, see Appendix 1) and classified as follows: 53 (72.6%) nonprofit (*e.g.*: fundacion-canna.es), 7 (9.5%) commercial (*e.g.*: hhp.es, kernpharma.com, sanitas.es), 6 (8.2%) institutional [(government (*e.g.*: niams.nih.gov/es) and professional (*e.g.*: portal.hospitalclinic.org)], 4 (5.4%) providing free-of-charge information (*e.g.*: www.fisterra.com), and 3 (4.1%) from media owners (*e.g.*: www.infosalus.com). Of them, 7 (9.5%) and 4 (5.4%) were websites translated from English and Catalan, respectively. In terms of typology of websites found by search engines, no statistically significant differences in frequency were found between the top-ten and the totality of the included ones (see Table 1).

Table 1. Typology of the top-ten websites retrieved by search engines

Typology of website	Google	Yahoo	Bing!	<i>P</i> -value*	Google	Yahoo	Bing!	<i>P</i> -value*
	N in overall search (%) n = 25	N in overall search (%) n = 25	N in overall search (%) n = 25		N in top-ten (%) n = 10	N in top-ten (%) n = 10	N in top-ten (%) n = 10	
Commercial	8(32%)	3(12%)	5(20%)	0.261	3(30%)	1(10%)	2(20%)	0.847
Nonprofit	5(20%)	2(8%)	5(20%)	0.460	2(20%)	0(0%)	2(20%)	0.507
Institutional	5(20%)	8(32%)	4(16%)	0.477	3(30%)	3(30%)	1(10%)	0.642
Media	2(8%)	7(28%)	6(24%)	0.187	1(10%)	3(30%)	2(20%)	0.847
Free of charge information	5(20%)	5(20%)	5(20%)	1.000	1(10%)	3(30%)	3(30%)	0.642

*Fisher's Exact Test

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3 Among websites from patient associations, 44 were from Spain and 3 from Latin America (Argentina, Chile, and
4 Venezuela) (see Appendix 1).
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6 **3.2. Type of information**

7 *3.2.1. Websites retrieved by search engines*

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10 Figure 2 shows the type of information in the websites retrieved by search engines.

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12 In terms of illness conceptualization, 6 websites (24%) mentioned that FM is acknowledged as an illness by the
13 WHO. Barely any mentioned central sensitization or central sensitization syndrome, and none named other terms
14 like dysfunctional pain.
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17 The least cited symptoms were paresthesia (11 websites; 44%) together with morning stiffness and anxiety (15
18 websites; 60%). The most cited symptoms were pain (25 websites; 100%) followed by sleep disorders (23
19 websites; 92%) and fatigue (21 websites, 84%).
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22 The most cited pharmacological treatments were antidepressants (22 websites; 88%), followed by painkillers (17
23 websites; 68%) and antiepileptic drugs (15 websites; 64%). Muscle relaxants and non-steroid anti-inflammatory
24 drugs were named in 8 websites (32%). In terms of non-pharmacological treatments, the most highlighted
25 physiotherapy techniques were massage (10 websites; 40%), stretching (4 websites; 16%), and locally applied heat
26 (3 websites; 12%). The most frequently mentioned alternative therapies were yoga (10 websites; 40%), acupuncture
27 (9 websites; 36%), and Tai Chi (5 websites; 20%).
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30 In terms of advice, sleep strategies were the most recommended, specifically implementing sleep habits (7
31 websites; 28%), and moderating activity and daily-life pace, as well as mentality changes. Stress (7 websites;
32 28%), weather changes (cold, humidity) with anxiety/stress (6 websites; 24%), and excessive physical activity (3
33 websites; 12%) were highlighted as aggravating factors.
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37 *3.2.2. Websites from patients associations*

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40 Figure 3 shows the type of information in the websites retrieved from patients associations websites.

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42 Among websites mentioning that FM is a disease, 10 (20.8%) included acknowledgment by the WHO, 1 (2.1%)
43 specifically cited that FM is in the International Classification of Illnesses, and 10 (20.8%) mentioned both facts.
44 In terms of symptoms, the least mentioned were hypersensitivity (15 websites; 31.2%) paresthesia (28 websites;
45 58.3%), and depression (29 websites; 60.4%). The most cited symptoms were pain (44 websites; 91.7%), followed
46 by sleep disorders (40 websites; 83.3%) and fatigue (37 websites ; 77.1%). In terms of pharmacological treatment,
47 antidepressants (19 websites; 39.6%), painkillers (15 websites; 31.2%), and muscle relaxants (9 websites; 18.7%)
48 were the most mentioned, and 9 (18.7%) of the websites including pharmacological treatment did not mention any
49 in particular. The most frequently cited physiotherapy techniques were massage (8 websites; 16.7%), stretching (5
50 websites; 10.4%), and locally applied heat (4 websites; 8.3%). Finally, the most cited alternative therapies were
51 yoga and acupuncture (8 websites; 16.7%) and Tai Chi (7 websites; 14.6%).
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57 In terms of recommendations, the most common advice was avoiding aggravating factors, like stress (9 websites;
58 18.7%), and improving sleep habits (6 websites; 12.5%). The most commonly mentioned aggravating factors were
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weather changes (cold, humidity) (9 websites; 18.7%), stress/anxiety (7 websites; 14.6%), and excessive physical activity (5 websites; 10.4%).

3.3. Quality of health information

3.3.1. Websites retrieved by search engines

The overall quality as measured by the DISCERN²⁰ obtained a median score of 27.0 [IQI: 24.5–32.0]: 18 (72.0%) scored 16–29 points (very low), 6 (24.0%) obtained 30–42 points (low), and only 1 (4.0%) website reached 43–55 points (moderate). All categories scored <2 (Table 2). Regarding the quality of information on treatment choices, only one of the websites retrieved by search engines (4.0%) and ten websites from patient associations (20.8%) did not offer any information on treatment choices.

3.3.2. Websites from patients associations

According to the DISCERN,²⁰ the overall quality was very low, with a median score of 21.0 [IQI: 19.2–23.8]: 44 websites (91.7%) scored 16–29 (very low) and other 4 websites (8.3%) scored 30–42 (low). All the categories scored <2 (Table 2). Statistically significant differences were found in all categories between websites found by search engines and from patients associations (Table 2). The overall DISCERN score was lower for those from patients associations websites, $P<0.001$ (Figure 4).

Table 2. Score for the quality of health information by category according to the DISCERN questionnaire

Category	Websites retrieved by search engines		Websites of patients associations		P-value*
	Median	IQI	Median	IQI	
Reliability of the publication	1.6	1.5–1.8	1.3	1.2–1.5	<0.001
Quality of information on treatment options	1.7	1.4–2.0	1.3	1.0–1.4	<0.001
Overall score	2.0	2.0–3.0	2.0	1.0–2.0	<0.001

IQI: Interquartile interval; * Mann-Whitney *U*-test

3.4. Quality of websites

3.4.1. Websites retrieved by search engines

Using the Bermúdez-Tamayo questionnaire,¹⁸ the overall quality was moderate, with a median score of 35.0 [IQI: 31.0–40.5]: 9 websites (36%) obtained a score of 26–33 (low), 10 (40%) scored 34–40 (moderate), 5 (20%) obtained 41–47 points (good), and only 1 achieved a score of 48–54 (excellent). The category achieving the lowest score was updating of information (Table 3). Statistically significant differences were observed in all the categories between the websites retrieved by search engines and those from patients associations, with the exception of accessibility (Table 3, $P=0.342$).

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Table 3. Score for the quality of websites by category according to the Bermúdez-Tamayo questionnaire

Category	Websites retrieved by search engines		Websites of patients associations		P-value*
	Median	IQI	Median	IQI	
Transparence and absence of conflict of interests	2.6	1.8–2.6	1.0	1.0–1.8	<0.001
Authorship	1.0	1.0–2.0	1.0	1.0–1.0	0.002
Protection of personal data	3.0	3.0–3.0	1.0	1.0–3.0	0.001
Information updating	1.0	1.0–1.0	1.0	1.0–1.0	<0.001
Responsibility	1.3	1.3–2.0	1.3	1.3–1.3	<0.001
Accessibility	2.0	1.8–2.3	2.0	1.8–2.0	0.342

IQI: Interquartile interval; * Mann-Whitney *U*-test

3.4.2. Websites from patients associations

According to the Bermúdez-Tamayo questionnaire,¹⁸ the general quality was also low, with a median score of 26.0 [IQI: 25.0–31.0]: 24 sites (50.0%) obtained a score of 17–25 (very low), 20 (41.7%) scored 26–33 (low), 3 (6.2%) obtained 34–40 points (moderate), and only 1 (2.1%) achieved 41–47 points (good). Scores were low for all the categories, among which updating of information scored the lowest (Table 3).

Statistically significant differences were noted in the total score of the Bermúdez-Tamayo questionnaire between the websites found by search engines and those from patients associations ($P < 0.001$, Figure 4).

3.5. Readability

3.5.1. Websites retrieved by search engines

With a median score of 53.7 [IQI: 47.4–56.2], readability was found to be “slightly difficult”: 15 websites (60.0%) were categorized as “slightly difficult” (40–55 points) and 10 (40.0%) as “normal” in terms of readability (55–65 points).

3.5.2. Websites from patients associations

Overall readability was also “slightly difficult” with a median score of 51.7 [IQI: 47.9–55.1]: 4 websites (8.3) were considered “very difficult” (<40), 32 (66.7%) “slightly difficult” (40–55), 11 (22.9%) were “normal” (55–65), and 1 (2.1%) was “fairly easy” (65–80) to read.

No statistically significant differences in readability were observed between websites found by search engines and from patients associations ($P < 0.396$) (see Figure 5).

DISCUSSION

The outcomes obtained with the tools this study employed suggest that quality of FM websites in Spanish, as retrieved by the main search engines, tend to be of medium-low quality, whereas those from both Spanish and international patients associations tend to be of very low quality. Overall, content quality was very low, and readability was “slightly difficult”.

Website quality, readability, and content varied among websites, similarly to previous research on FM^{15 16} and other chronic conditions.^{27 28} As far as the authors know, this study is the first to assess quality of websites on FM in Spanish and the only one including an analysis of websites from FM patients associations. The remainder of the articles that were found while analyzing websites quality^{29 30} do not specifically mention FM.

4.1. Methodology

This study employed validated, widely used questionnaires for analyzing website quality. LIDA and DISCERN are the tools most frequently used for this purpose,^{20 31} which is the Bermúdez-Tamayo questionnaire for websites in Spanish.¹⁸

LIDA is a tool that assesses healthcare websites for content and information design,³¹ with accessibility, usability, and reliability of information being the three main categories. The Bermúdez-Tamayo questionnaire was originally validated in Spanish¹⁸ and also includes these categories but, as it mainly contemplates aspects of the website as such and not its contents, the DISCERN questionnaire was employed, a tool that has been broadly used in research, both in English and Spanish.^{16 27-29 32} None of the employed questionnaires interprets the results or qualifies the score into quality levels. This leads researchers to propose their own levels and, although these tend to be very similar, they can be interpreted in different ways hindering comparison between outcomes. This trial created five quality levels for all the items.

Another important aspect of websites is readability. Studies assessing English websites tend to use *Flesch Reading Ease score maps*^{16 28} and *Flesch-Kincaid*.^{28 32 33} Both^{34 35} provide a score from 0 to 100, where higher scores indicate texts that are easier to read. For the general public, 60 is considered an acceptable value. *Flesch-Kincaid*³⁴ also indicates the necessary education level to understand a text. Studies evaluating Spanish websites use the INFLESZ scale,^{17 27 30} which was created after the *Flesch* scale was reviewed³⁵ and is considered one of the Spanish-adapted versions of the former and *Flesch-Szigrist*³⁶ scales. Comparisons between INFELSZ and FLESH scores can be found in Appendix 2.

4.2. Websites characteristics and type of information

There were differences in the outcomes between websites found by search engines and those from patients associations. The greatest differences were observed using the Bermúdez-Tamayo questionnaire,¹⁸ where websites retrieved by search engines obtained higher scores. This could be due to the nonprofit character of websites of patients associations and because most seem to have been created by FM patients with no mention about whether the contents have been selected by a professional expert in FM or a scientific board, and also the websites do not

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3 seem to be created by webpage developers but more likely using a non-paid website development tool, such as
4 webnode.³⁷ In contrast, websites found by search engines belong to different categories, like commercial or
5 institutional, which can involve some sort of funding for their development and management. However, this is a
6 hypothesis, since most websites do not state their funding body. This outcome differs from that by Basavakumar
7 *et al.*¹⁵ that found websites from not-for-profit organizations to be the most complete ones. This could be due to
8 the different tools and methods employed in the different studies to analyze the quality and type of included
9 websites. Additionally, the non-for-profit websites in the above-mentioned study only accounted for 9% of the
10 total, and it does not specify if it included websites from patients associations. The websites from patients
11 associations included in this study (64% of assessed websites) are all non-for-profit and show the worst quality.
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19 **4.3. Type of information**

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21 Symptoms, treatment, and diagnosis were the most commonly tackled information in the assessed sites. Other
22 issues of importance for FM patients, such as support,^{14,38} are dealt with superficially and briefly, chiefly naming
23 the importance of the doctor for determining pharmacological treatment.
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26 A very mechanistic, vague vision of FM, with little scientific evidence, was generally observed. In terms of
27 conceptualization of FM, no website was found that mentioned dysfunctional pain, no difference was made
28 between clinical diagnosis or diagnosis criteria for research, and diagnostic points were those of 1990 even if
29 Wolfe *et al.* warned about the risk this implied when used for clinical practice already in 2003.³⁹ Provided treatment
30 alternatives can cause nothing but confusion due to the high variability found, little correlation with scientific
31 literature (neither massage nor stretching are backed by scientific evidence^{40,41} and, in certain cases, they can be
32 counterproductive), and the superficial manner in which they are covered. For instance, education is one of the
33 least mentioned treatments despite being one of the most recommended ones,^{5,10} and neuroscience education is not
34 found in any of the websites citing it even if its effectiveness for treating pain has been proven.^{7,9} The type or
35 frequency of recommended physical exercise was not specified in any case despite being one of the most
36 mentioned treatments in the Internet.^{10,41,42} In terms of psychological therapies, cognitive behavioral therapy was
37 mentioned in some websites but in a very vague way and without mentioning exiting evidence for it.⁶
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46 **4.4. Quality of health information**

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48 Information quality and reliability were assessed via the DISCERN questionnaire.²⁰ The outcome showed that FM
49 contents in websites in Spanish were of very low quality. In the study by Daraz *et al.*,¹⁶ which also employed this
50 tool, 36% of the 25 included websites were qualified as “marginal”, 32% as “good”, and 32% as “very good”. Of
51 the websites found by search engines in this study, 72% were classified as “very low quality”, 24% as “low
52 quality”, and 4% as “moderate quality”. Similarly, 91.6% of the websites from patients associations obtained
53 scores classified as “very low quality” and 8.3% as “low quality”. In this regard, the quality of websites analyzed
54 in this study seemed to be lower than that in the work by Daraz *et al.*¹⁶ It is necessary to acknowledge that the
55 maximum score in the study by Daraz *et al.*¹⁶ was 75 points, since the last item was excluded; had this study
56 proceeded similarly and followed the categories as Daraz *et al.*,¹⁶ 84.0% of websites found by search engines
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3 would be categorized as “marginal” and 16.0% as “good”, while there would not be changes in quality for patients
4 associations websites. The mean score obtained by Daraz *et al.*¹⁶ (33.3) using the DISCERN questionnaire²⁰ was
5 considerably higher than that obtained in this study for websites found by search engines (26.4) and from patients
6 associations (20.9). Daraz *et al.*¹⁶ also reported a mean score of 2.5 for the 15 items, whereas none of the three
7 categories in the DISCERN questionnaire²⁰ scored >2 in this trial. This could be due to the fact that our two
8 independent researchers agreed on the score of some items and the necessary minimums for intermediate scores
9 (2, 3, and 4), thus minimizing potential variability, an aspect not mentioned by Daraz *et al.*¹⁶

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14 On the other hand, the study by Kaicker *et al.*³² employed the DISCERN questionnaire²⁰ for assessing the quality
15 of contents of 161 websites in English found using GOOGLE, YAHOO!, and MSN, by entering “pain”, “chronic
16 pain”, “back pain”, “arthritis”, and “fibromyalgia” as search keywords. The mean score was 55.9 (moderate
17 quality). The higher score they obtained compared to this study could result from the fact that Kaicker *et al.* did
18 not analyze specific websites for FM.

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21 Washington *et al.*³³ designed their own questionnaire to assess the content of 240 websites in English found using
22 GOOGLE, YAHOO!, and MSN and entering “pain”, “chronic pain”, “back pain”, “arthritis”, and “fibromyalgia”
23 as keywords. They concluded that the overall quality was quite low, which is in agreement with the outcome of
24 this study despite using a different methodology.

25 26 27 28 29 30 31 **4.5. Quality of websites**

32 Website quality and how to assess it is a controversial issue, partly because there is a subjective component to
33 quality that is difficult to quantify.¹⁸ This study employed the Bermúdez-Tamayo questionnaire,¹⁸ the most used
34 tool in Spanish to evaluate quality-related criteria for websites. Using this questionnaire, updating of information
35 was the category that obtained the lowest score, both for websites found by search engines and those from patients
36 associations. This is in agreement with other trials using this tool^{30 43 44} and results from the fact that only three of
37 the included websites found by search engines specified the last date of information update and only two made a
38 partial statement in this regard, whereas none of the sites of patients associations complied with this item. Several
39 ethical codes request that the latest update is clearly stated for each website and each of its components.
40 Additionally, e-Europe and the American Medical Association require that a revision be conducted on the
41 pertinence of the provided information based on the latest evidence¹⁸. Basavakumar *et al.*¹⁵ analyzed 148
42 webpages, using the JAMA score (ranged between 0 and 4) and found that only 63 webpages (43%) met the quality
43 threshold of ≥ 3 .

44 45 46 47 48 49 50 51 52 **4.6. Readability**

53 Reducing text comprehensibility to a mathematic equation is difficult.⁴⁵ However, readability indexes are a well-
54 accepted approach for improving text readability and comprehension.⁴⁶ Also, the importance of this aspect must
55 be emphasized, since requiring high reading skills can reduce information accessibility and potentially exclude
56 users with low literacy.⁴⁷

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3 In this study, websites found both by search engines and from patients associations were categorized as “slightly
4 difficult to read”, with scores of 52.39 and 47.70, respectively. The recommended minimum score for health
5 information is 55,¹⁷ which is probably the reason why the general public has difficulties understanding the
6 information provided in the included websites. Other studies using the INFLESZ scale¹⁷ to analyze readability
7 obtained similar outcomes.^{27 30} Readability can vary among websites due to the use of technical terms, such as
8 fibromyalgia, which appears to have low readability.¹⁶ The readability degree of most of the websites assessed by
9 Daraz *et al.*¹⁶ corresponded with a 10th–12th school grade level, whereas the recommended level is that of 6th
10 grade.⁴⁸ Kaicker *et al.*³² obtained similar results, as is the case of our study with a score on the INFLESZ scale¹⁷
11 of 40–55 (slightly difficult), which corresponds with high-school reading level.¹⁷ Using a standardized online tool
12 (<https://www.webfx.com/tools/read-able/>), Basavakumar *et al.*¹⁵ found that only 92% of websites met the
13 recommended readability.
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22 **4.7. Limitations**

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24 There are limitations to this study. Content updates in the Internet must be taken into consideration. Since newly
25 created websites can be incorporated, or the assessed sites can undergo revisions and modifications, the outcome
26 validity of this study is temporary, and its quality analysis can vary in the future.
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29 Additionally, using different search engines, on different dates, or entering other terms can modify the results.⁴⁸
30 ⁴⁹ Since “fibromyalgia” was the only term entered as keyword, it is possible that websites consulted by FM subjects
31 were omitted in this trial, such as those on chronic pain. Additionally, by including only the first 20 links displayed
32 by three search engines, some resources of interest could have been missed. This is a usual limitation in any
33 Internet search. However, this study tried to reproduce the most common pattern a Spanish-speaker would follow:
34 over 95% of searches in Spain are done via Google ^{50 51} by entering the name of the disease or one of its
35 symptoms.¹² Therefore, assessing 20 websites of those retrieved by Google/Yahoo!/Bing appears to be sufficiently
36 exhaustive, especially considering that the general population do not consult any site further than the second one.⁵²
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43 **4.8. Clinical practice implications**

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45 Since FM patients often consult the Internet to better understand their illness and how to manage it,^{14 21} which can
46 be an aid or a barrier for treating it,⁵³ knowing about information available online can be useful for health workers.
47 The paucity of information on the diagnosis, treatment options, and conceptualization of FM this work found must
48 be compensated with correct information by health workers, especially considering that education is an essential
49 part of its treatment.¹⁰
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56 **4. CONCLUSIONS**

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58 The quality of websites on FM in Spanish is moderate-low, very low in terms of content, and their readability is
59 slightly difficult. Additionally, the provided contents are very diverse, often lack scientific evidence, and are not
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3 up-to-date. Greater efforts are required to guarantee that FM websites comply with quality criteria and offer
4 updated information, relevant, of quality, and readable.
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Contributions:

Arturo Alioshkin Cheneguín: Conceptualization; Methodology; Investigation; Writing - Original Draft.

María Torres Lacomba: Conceptualization; Methodology; Software; Validation; Investigation; Formal analysis; Resources; Data Curation; Writing - Original Draft; Visualization; Supervision; Writing - Review & Editing.

Isabel Salvat Salvat: Validation; Writing - Original Draft.

Helena Romay Barrero: Writing - Original Draft; Visualization; Writing - Review & Editing.

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LEGENDS

Fig. 1 Flowchart showing the selection process of websites.

Fig. 2 Type of information in websites retrieved by search engines.

Fig. 3 Type of information in websites from patients associations.

Fig. 4: Comparison of the quality of websites according to the DISCERN and Bermúdez-Tamayo questionnaires between websites retrieved by engines and from patients associations.

Fig. 5: Comparison of readability between websites retrieved by engines and from patients associations.

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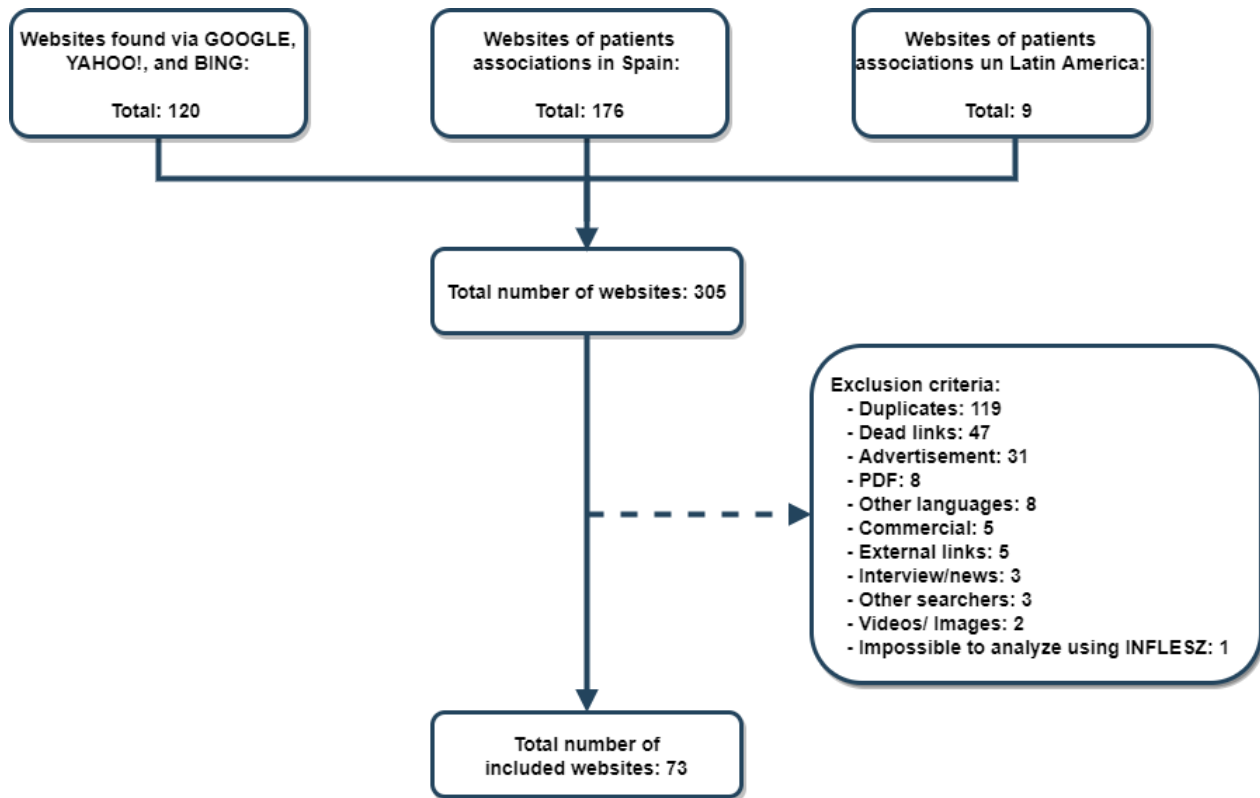
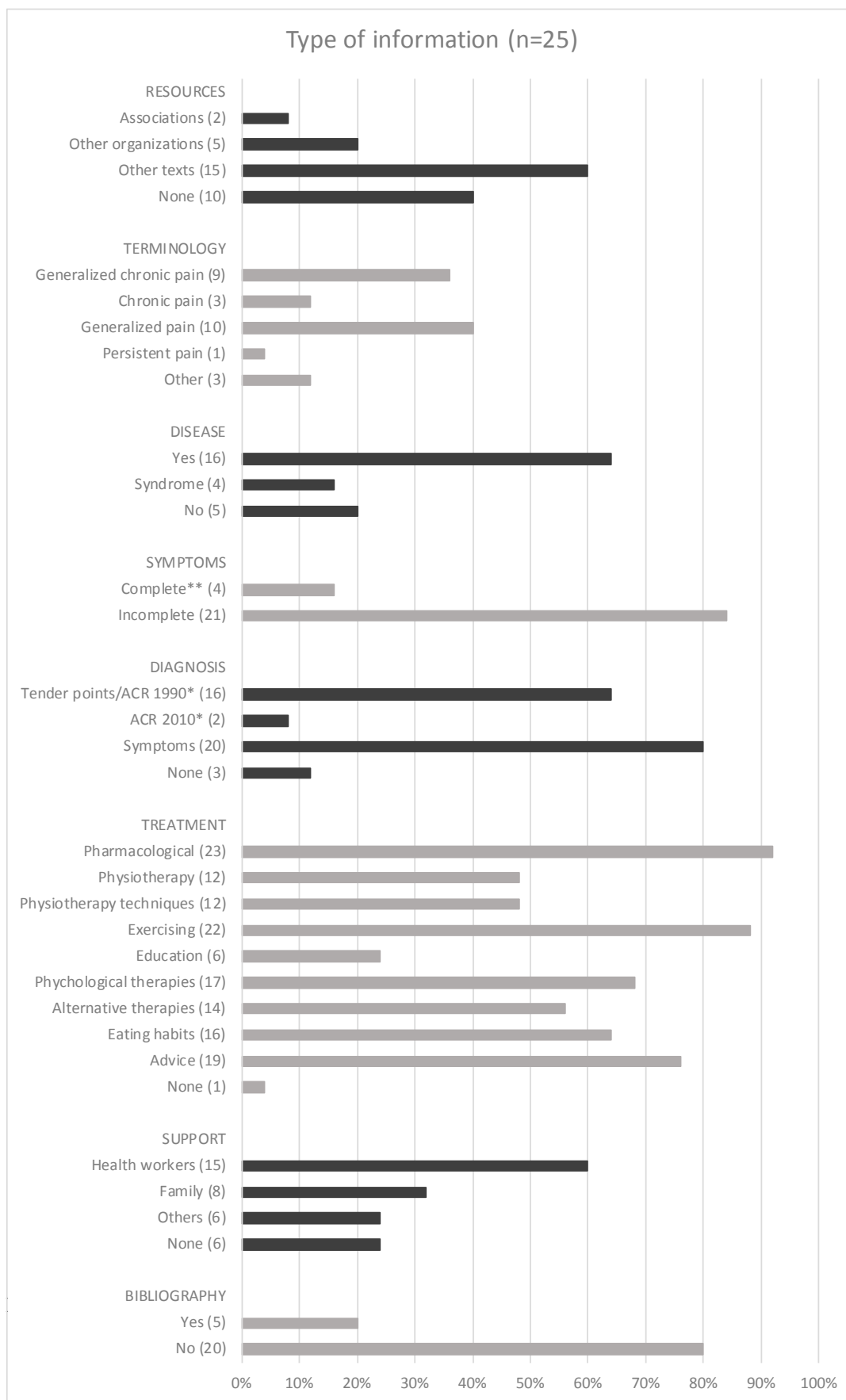


Figure 1 Flowchart showing the selection process of websites.



*Diagnostic criteria for fibromyalgia by the *American College of Rheumatology*.

***Complete symptoms when including generalized pain, hypersensitivity (allodynia, hyperalgesia, and/or exacerbated sensitivity to stimuli in addition to pain), fatigue, sleep disorders, cognitive disorders, anxiety, paresthesia, morning stiffness, and depression*

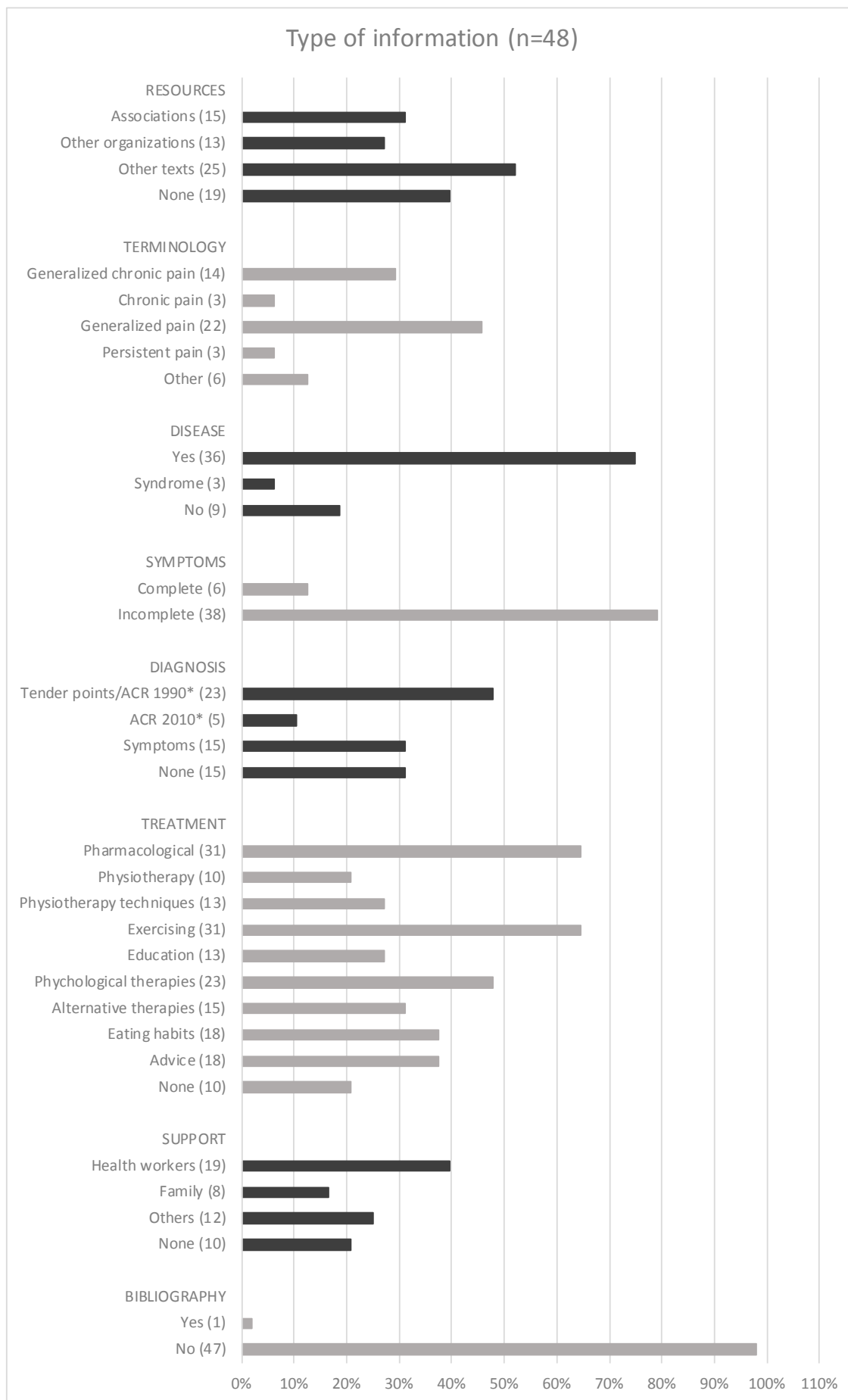


Figure 3 Type of information in websites from patients associations

* Diagnostic criteria for fibromyalgia by the American College of Rheumatology



Figure 4 Comparison of the quality of websites according to the DISCERN and Bermúdez-Tamayo questionnaires between websites retrieved by engines and from patients associations.

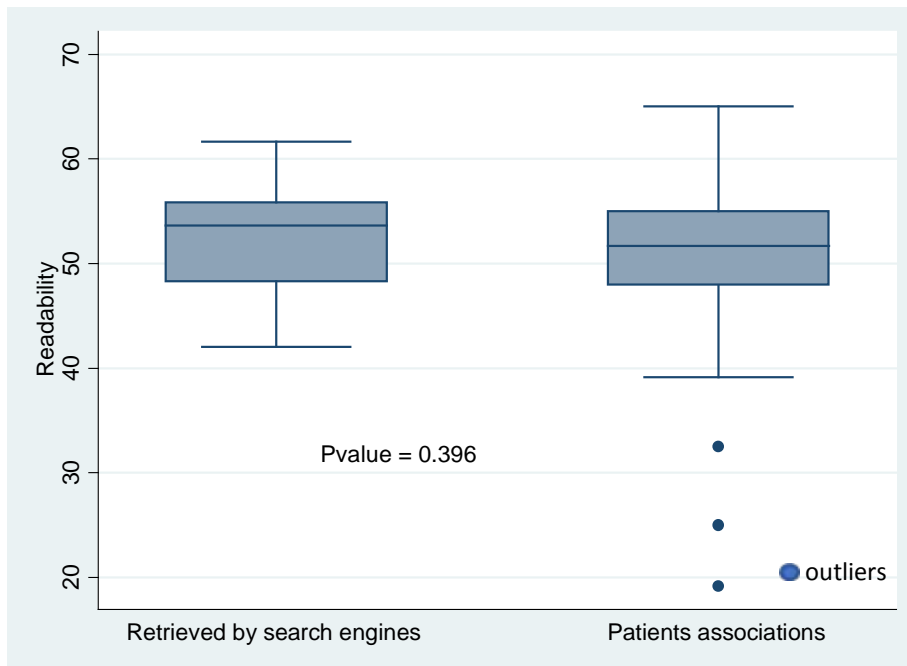


Figure 5 Comparison of readability between websites retrieved by engines and from patients associations

Appendix 1. Raw data from the websites

Raw data from the Websites retrieved by search engines according to order of retrieval				
URL	Bermúdez-Tamayo	DISCERN	INFLESZ	HONcode
1. https://infoeuma.com/enfermedades-reumaticas/fibromialgia/	34	NO	48,61	NO
2. https://www.cun.es/enfermedades-tratamientos/enfermedades/fibromialgia	28	NO	51,67	NO
3. https://www.mayoclinic.org/es-es/diseases-conditions/fibromyalgia/symptoms-causes/syc-20354780	49	NO	50,95	YES
4. https://cuidateplus.marca.com/enfermedades/musculos-y-huesos/fibromialgia.html	36	NO	48,35	NO
5. https://es.wikipedia.org/wiki/Fibromialgia	35	NO	56,63	NO
6. https://medlineplus.gov/spanish/ency/article/000427.htm	45	NO	55,84	NO
7. http://espanol.arthritis.org/espanol/disease-center/fibromialgia/	34	NO	53,67	NO
8. https://portal.hospitalclinic.org/enfermedades/fibromialgia	42	NO	48,33	NO
9. https://www.kernpharma.com/es/blog/todo-lo-que-debes-saber-sobre-la-fibromialgia	33	NO	58,72	NO
10. http://muysaludable.sanitas.es/salud/la-fibromialgia-causas-sintomas-tratamientos/	29	NO	46,54	NO
11. https://espanol.womenshealth.gov/a-z-topics/fibromyalgia	44	NO	59,32	NO
12. https://www.niams.nih.gov/es/informacion-de-salud/fibromialgia	40	NO	59,83	NO
13. https://www.fisterra.com/Salud/1infoConse/fibromialgia.asp	37	NO	46,36	YES
14. https://kidshealth.org/es/parents/fibromyalgia-esp.html	42	NO	55,44	NO
15. https://www.webconsultas.com/categoria/salud-al-dia/fibromialgia	37	NO	54,46	NO
16. https://www.hhp.es/patologias/fibromialgia/	31	NO	42,05	NO
17. https://www.segundomedico.com/fibromialgia-causas-sintomas-diagnostico-y-tratamiento/	32	NO	53,21	NO
18. https://es.familydoctor.org/condicion/fibromialgia/	39	NO	61,02	NO
19. https://www.sabervivirtv.com/medicina-general/fibromialgia-detectar-enfermedad_434	31	NO	61,65	NO
20. https://www.fundacion-alborada.org/enfermedades-ambientales/fibromialgia/	31	NO	43,55	NO
21. https://mejorconsalud.com/5-sintomas-tempranos-la-fibromialgia/	41	NO	55,16	YES
22. https://cuideo.com/blog-cuideo/ayuda-fibromialgia-todo-lo-que-debes-saber/	31	NO	53,85	NO
23. https://www.fesemi.org/informacion-pacientes/hemeroteca-salud/enfermedades/fibromialgia-y-fatiga-cronica	35	NO	55,16	YES
24. https://www.infosalus.com/enfermedades/aparato-locomotor/fibromialgia/que-es-fibromialgia-31.html	37	NO	45,25	NO
25. https://www.fundacion-canna.es/fibromialgia	29	NO	44,02	NO

Websites from Spanish patients associations ordered according to the National Public Registry of Associations

URL	Bermúdez-Tamayo	DISCERN	INFLESZ	HONcode
1. http://www.fibromialgiaotrera.com/quienes_somos.php	23		19,12	NO
2. http://www.asociacionapaffer.org/1029--que-es-la-fibromialgia-.html	23		56,54	NO
3. http://www.apafima.org/que-es-la-fibromialgia.html	33		49,49	NO
4. http://afibrose.org/index.php?option=com_content&view=article&id=50&Itemid=41	25		32,48	NO
5. https://afipo.webnode.es/	27		56,83	NO
6. https://agrafim.weebly.com/fibromialgia-fm.html	24		43,88	NO
7. http://www.alaguas.net/afico/	25		53,53	NO
8. https://afimreb.wordpress.com/fibromialgia-2/	27		48,74	NO
9. http://www.asociacionafcas.es/	29		50,05	NO
10. https://fibromialgiamarinaalta.es.tl/QUE-ES-LA-FIBROMIALGIA.htm	25		58,24	NO
11. http://avafi.es/?page_id=88	43		50,38	YES
12. https://adafir.wordpress.com/fibromialgia/	25		55,71	NO
13. http://afa.asofiben.es/?page_id=241	23		49,94	NO
14. http://www.asfiel.org/fibromialgia/	27		54,38	NO
15. https://fibromialgianovelda.es.tl/%BFQue-es-la-Fibromialgia-f-.htm	33		44,25	NO
16. http://fibromialgiasantapola.blogspot.com/p/que-es-la-fibromialgia.html	25		48,01	NO
17. http://s619678501.web-inicial.es/qui%C3%A9nes-somos/la-enfermedad/	31		50,07	NO
18. https://punto19.org/fibromialgia	31		47,9	NO
19. http://afibroalba.blogspot.com/	27		50,92	NO
20. http://afibrotar.es/la-fibromialgia/	29		42,03	NO
21. http://www.ffclm.es/fibromialgia.php	25		39,14	NO
22. https://aficrovall.iimdo.com/que-es-la-fibromialgia/	35		45,22	NO
23. https://www.ayuntamientoarevalo.es/03c_la_villa/08_asociaciones/c08aso_afemar_07.htm	23		54,31	NO
24. https://afibrosal.org/enfermedades/fibromialgia	33		52,19	NO
25. https://afibroal.webnode.es/laenfermedad/	25		25,01	NO
26. https://fexaf.wordpress.com/fibromialgia-fm/	27		42,95	NO
27. http://www.afifasen.es/fibromialgia/	27		54,4	NO
28. https://www.asafa.es/	31		54,89	NO
29. https://www.fibroparla.es/	27		54,17	NO
30. https://www.afifuen.com/acerca-de/fm/	25		65,05	NO
31. http://www.fibromialgia.cat/cast/frames.htm	39		59,59	YES
32. http://afibrocat.barcelona.ppe.entitats.diba.cat/sobre-la-fibromialgia/	29		53,62	NO

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<i>Raw data from the Websites of Spanish patients associations ordered according to the National Public Registry of Associations (continuation)</i>				
URL	Bermúdez-Tamayo	DISCERN	INFLESZ	HONcode
33. https://ashofi.org/es/etiologia-2/	35	25	49,76	NO
34. https://fibromialgiabadalona.wordpress.com/la-enfermedad/	25	25	55,19	NO
35. http://fibrofels.castelldefels.ppe.entitats.diba.cat/es/la-fibromialgia-2/	25	25	50,98	NO
36. http://www.afibrocar.com/fibromialgia.php	25	25	57,03	NO
37. http://fibrofamur.blogspot.com/p/diagnostico.html	25	25	54,36	NO
38. https://fibrorioja.org/quienes-somos/fibromialgia/	25	25	50,86	NO
39. https://cafpontevedra.es.tl/%BFQUE-ES-LA-FIBROMIALGIA-f-.htm	25	25	56,66	NO
40. https://afibropo.webnode.es/fibromialgia/	29	25	59,82	NO
41. http://www.asafima.org/	31	25	59	NO
42. http://www.bizi-bide.com/	31	25	43,15	NO
43. http://www.afibrolan.org/sobre-la-fibromialgia/	23	25	54,19	NO
44. https://fibromialgialasafor.es.tl/%BFQu-e2--es-la-fibromialgia-f--.htm	21	25	58,4	NO
45. http://redspanolafibromialgia.com/que-es-la-fibromialgia/	33	25	52,68	NO

Raw data from the Websites of Latin America patients associations ordered according to the National Public Registry of Associations

URL	Bermúdez-Tamayo	DISCERN	INFLESZ	HONcode
46. http://www.asociacionfibroamerica.org/	25		44,91	NO
47. http://www.fibromialgiachile.cl/index.php/tratamientos	25		53,33	NO
48. https://fibromialgia.softwaredigitals.com.ve/index.php/%C2%BFqu%C3%A9-es-la-fibromialgia	25		51,15	NO

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Appendix 2. Comparisons of the INFELSZ with the FLESH ranges.

IFSZ	INFLEZ	FLESH	School level
0	Very difficult	Very difficult	College graduate
15			
30			
35	Slightly difficult	Difficult	College
40			
45			
50	Fairly difficult	Fairly difficult	10th-12th grade
55			
60			
65	Normal	Normal	8th-9th grade
70			
75			
80	Fairly Easy	Fairly easy	7th grade
85			
90			
95	Very easy	Easy	6th grade
100			
		Very easy	5th grade

IFSZ: Flesch-Szigriszt index; FLESH: Flesch Reading Ease Score