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A review of content, quality and readability of websites addressing fibromyalgia.

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The first author, Dr. Daraz was in charge of all aspects of the research including choosing the topic, formulating research questions, reviewing literature, designing study, searching on Google, collecting data, evaluating websites and writing the manuscripts. Dr. MacDermid was involved in designing study, evaluating websites and reviewing manuscript. Dr. Wilkins and Ms. Gibson were involved in evaluating websites and reviewing manuscript. Dr. Shaw was involved in reviewing the manuscript.

Abstract

Background

People living with fibromyalgia strongly prefer to access health information from the Web. However, the majority of the people in previous studies strongly expressed their concerns about the quality of online information resources.

Objectives

The purpose of this review was to evaluate existing online fibromyalgia information resources for content, quality and readability.

Methods

The first 25 websites were identified using 'Google' and search keyword 'fibromyalgia'. Pairs of raters made independent evaluations of website quality using two structured tools (DISCERN, and a Quality Checklist). Readability was assessed using the Flesch Reading Ease score maps.

Results

Ranking of the websites' quality varied by the tools used, although there was general agreement about the "top" three websites (Fibromyalgia Information, Fibromyalgia Information Foundation and National Institute of Arthritis and Musculoskeletal and Skin Diseases). Content analysis indicated that 72% websites provided information on treatment options, 68% on symptoms, 60% on diagnosis and 40% on coping and resources. DISCERN ratings classified 32% websites as 'very good', 32% as 'good and 36% as 'marginal'. The mean overall DISCERN score was 36.88 (good). Only 16 % of websites met the recommended grade of 6 to 8 literacy level (Range 7 – 15).

Conclusion

Higher quality websites tended to be less readable. Online fibromyalgia information resources do not provide comprehensive information about fibromyalgia; have low quality and poor readability. While information is critical to living with fibromyalgia, current resources are unlikely to provide necessary or accurate information; and may not be usable for people.

Article Summary

Article focus

- The purpose of the study was to gain a better understanding of the online information resources that are available for people living with fibromyalgia and to evaluate those information resources for content, quality and readability.

- What are the content, website quality and readability of the most readily retrieved information available on the web when searching for fibromyalgia information?

Key messages

- Majority of the existing websites do not provide comprehensive information on fibromyalgia
- Websites are highly variable in terms of quality
- Higher quality websites do not present information in language/reading levels appropriate for the general population

Strengths and limitations of this study

- The search for online fibromyalgia information sources was not comprehensive due to the use of 'Google' and one keyword exclusively.
- There is no gold standard for comparison or ways to evaluate the quality of websites.
- The quality issue was discussed using the lens of critical appraisal tools designed for the lay public.
- Readability score may vary for some websites as it may be related to the use of words such as fibromyalgia; this seems to be a word that might rank high in the readability calculation.

INTRODUCTION

There are more than 70,000 web sites that offer health information for consumers and the number is growing everyday.[1] Many of these websites are accessed by people with fibromyalgia to self-manage their health. However, it is unknown if websites are consistent with the literacy and health needs of users such as persons with fibromyalgia. What we currently know is that web-based information has the potential to educate and empower consumers by providing information on the nature of their health problems and by helping to make informed decisions about their health. [2,3,4,5]

The extent of interest in web based health information is indicated by high and increasing usage.[6, 7] In Canada about 8.7 million Canadians use the Internet to search for medical and health-related information. Among these people, women are more likely to search for health information about specific diseases than men.[6] In addition, 54% - 79% of those seeking information expressed concerns about the quality of online health information.[6] Similarly, in the USA, the number of adults who go online for health information has increased from 46% in 2000 to 61% in 2009.[7] Many (66%) of these online health information seekers discuss their concern about the lack of quality of online health information sources with their healthcare providers.[7] Thus, researchers at the Pew Internet and American Life Project anticipate that the more people access the Internet for health information, their concern for the quality will also continue to grow.[7]

The Internet is now an important resource for people living with fibromyalgia.[8, 9, 10] Fibromyalgia, is described as an invisible chronic condition that has severe impacts on health and quality of life for people who are living with the illness.[11, 12, 13] This disease manifests itself as chronic widespread musculoskeletal pain in different areas of the body.[14,15,16] The need for information is greater due to the controversy surrounding the condition which includes a lack of specific diagnostics tests and evidence-based treatment guidelines. It has been suggested that people are often left on their own to manage their illness.[17, 16]

Daraz and others studied the information needs and preferences of people living with fibromyalgia.[8, 9] The majority of the people in those studies expressed their preference of the web as a major source for accessing fibromyalgia-related information. However, they also strongly expressed their concerns about the lack of availability of types of information about fibromyalgia (content), need for evidence-based information (quality) and difficulty in understanding medical or technical terminologies (literacy/readability). A similar study by Crooks demonstrated that people living with fibromyalgia like to go online to access information about fibromyalgia to inform themselves about the illness and to assist with shared decision making with their healthcare providers.[10] However, the perceived lack of quality of online information was a major factor that was also discussed in the study findings. Others have also suggested that web-based health information can increase people's perception of control, improve their ability to cope with the illness, enhance their self-care abilities, and improve their quality of life by decreasing anxiety, fear and distress while increasing hope.[18,19]A number of studies have evaluated the quality of online health information designed for specific populations and found it to be of variable quality.[20, 21, 22, 23, 24, 25, 2, 26] It is imperative that people living with fibromyalgia have access to quality evidence-based information to help them live with their illness since it is a

chronic disease. Therefore, it is important to evaluate if the information on websites can meet the needs of persons with fibromyalgia for accessible, high quality, useful information.

The purpose of this study was to gain a better understanding of the online information resources that are available for people living with fibromyalgia and to evaluate those information resources for content, quality and readability.

METHODS

This study was comprised of a keyword search, selecting websites and structured appraisal of the websites using quality and readability tools. Similar methods were used by others who evaluated the quality of websites for specific conditions. [20, 21, 24]

Search strategies to find online fibromyalgia information resources

In a previous study, the authors identified search terms and engines that women commonly used when looking for information on fibromyalgia.[8] Based on those findings we performed a keyword search on 'Google' (www.google.com) with a keyword 'Fibromyalgia' on December 11, 2009 to identify online resources about fibromyalgia that are most likely to be accessed by people. It has been suggested that lay people seldom search for information beyond the first 20 links retrieved by a search engine so we used this to dictate our website sample.[27]

Criteria for selecting online fibromyalgia information resources

Our inclusion criteria for selecting websites were: 1) provide information on fibromyalgia, 2) provide information for consumers/patients and for their caregivers, and 3) provide information in English. We excluded duplicate websites or sites with dead links.

Quality appraisal tools

DISCERN is a reliable and valid instrument that is used to assess the quality of written consumer health information which people can use without content expertise.[28] The instrument was developed and evaluated by an expert panel and a group of health information providers and self-help members. DISCERN consists of 15 questions (first 8 questions are for publication reliability and last 7 questions are for the quality of information on treatment choices) where each question is rated on a 1 to 5 point scale. We assigned scores using the score specified by DISCERN (Topic Addressed = 5, Partially addressed = 3, Not addressed = 1). This instrument has been evaluated for reliability and validity and is being used by many researchers to assess the quality of online health information for specific kinds of diseases.[20, 23, 24] However, DISCERN does not include many of the criteria that are important for assessing the content of specific information and for the development and dissemination process to distribute the information, for example, *accuracy*, *completeness*, *disclosure and readability*.[27]

As a result, we used a Quality Checklist developed by Daraz and others[29] to assess the quality of web health information (see Appendix C). This tool was developed based on a

structured review and appraisal of existing web health evaluation tools that were developed to assess the quality of web health information. Based on their review, the authors determined that the existing web health evaluation tools did not meet the criteria for readability and ease of use for general consumers. As a result, they recommended a customized tool / quality checklist designed for general consumers' use.The Quality Checklist consists of 7 categories: 1) Authorship, 2) Content, 3) Currency, 4) Usefulness, 5) Disclosure, 6) User Support and Feedback, and 7) Privacy and Confidentiality. A total of 10 questions are included in the checklist with a 'yes' or 'no' option.

To determine the overall rating of the websites, we also used the total DISCERN score to categorize the websites as excellent (61-75), very good (60-46), good (45-31), marginal (30-16) and poor (15-1). It was not possible to assign similar categories to assess the overall rating of the websites using the Quality Checklist as the tool does not have a numerical scoring scheme like DISCERN.

For the readability evaluation, the information from each websites was evaluated for i) reading ease and ii) grade level calculation using the actual content from the websites. For the reading ease calculation we used "The Flesch Reading Ease (RE)" [30, 31]score maps that were designed to measure the readability of texts. The RE index is 0 to 100. An RE of around 60 to 70 is equivalent to a grade level of 6 to 8. The closer to 100 the text scores, the easier it is to read.[30, 31]

90 -100	Very easy	50 - 59	Fairly difficult
80 - 89	Easy	30 - 49	Difficult
70 - 79	Fairly easy	0 – 29	Very confusing
60 - 69	Standard		

For grade level calculation we used "The Flesch-Kincaid Grade Level" formula. It is recommended that anyone who aims to provide health information should try to achieve a grade level of 6 to 8. The scores using the 'Flesch Reading Ease' formula can be interpreted in the following format.[30, 31]

DATA EXTRACTION AND ANALYSIS

High quality information exists when the information on websites is consistent with the best research; high quality websites are those which have certain standards for how they are produced.[33, 20, 34] By 'content' we refer to specific information about fibromyalgia addressed: for example, treatment, diet, finding specialists etc; and by 'readability' we refer to reading ease and grade level. By 'quality' we refer to overall website quality, not the analysis of specific pieces of information on the website. Rather, website quality looks at the extent to which efforts were made to insure the information on the website is current and accurate based on current evidence/knowledge.

A data extraction tool was devised to allow reviewers to categorize the content contained on fibromyalgia websites. Categories were developed using concepts derived from both

qualitative and quantitative research [8, 9]; open-ended categories were later classified if concepts were reported that were not preconceived by the structured items. The data extraction table included: *country of origin*, *target audience*, *category of websites* and *types of content*. Websites were categorized as not-for-profit (e.g., societies, association, charitable, support group), commercial (e.g., private medical site, sponsored site), media (e.g., newspapers), and institutional (e.g., university or government).

To assess reliability of evaluation, each site was independently rated by the authors. Although kappa scores were not tabulated, the reviewers extensively discussed each question where scoring was different and they continued until the scoring conflicts were resolved. We used simple descriptive statistics to analyze the data. SPSS version 18[1] was used in our analysis for calculating frequencies and cross-tabulations.

RESULTS

Google retrieved 6,720,000 results for the keyword search. Among these, the first 25 websites were selected for analysis (Table 1). The country of origin for thirteen (52%) of the websites was USA, eight (32%) were from Canada, one from UK and the rest had no country specified (Table 1). The category of websites varied. Ten (40%) were not-for-profit organizations, six (24%) were commercial, five (20%) were media, and four (16%) were institutional. Only five (20%) websites were dedicated to women.

Figure 1 shows the types of information provided by selected websites. In addition to these kinds there were other types of information available on the selected websites, such as complications (8%), controversies (8%), exercise (8%), lifestyle guide (8%), education (4%), employment (4%), psychological issues (4%), quality of life (4%) and self-help (4%)

Figure 1. Types of information available on selected websites

[1] http://www.spss.com/

Table 1: 25 Selected sites and their overall scores

Website url	Developer Origin	DISCERN Score - 75	Quality Checklist % (Yes)	Readability (Grade level)
Fibromyalgia Treatment Center[35] http://www.fibromyalgiatreatment.com/	Fibromyalgia Treatment Center, Inc/USA	22	80	7
Fibromyalgia Network[36] http://www.fmnetnews.com/	Not specified/USA	38	60	8
Medline Plus[37] http://www.nlm.nih.gov/medlineplus	National Library of Medicine and National Institutes of Health /USA	40	80	8
Women's Health Matters[38] http://www.womenshealthmatters.ca	Women's College Hospital and the Women's College Research Institute /Canada	46	80	8
Body and Health[39] http://bodyandhealth.canada.com	MediResource /Canada	27	30	9
The Environmental Illness Resource[40] http://www.ei-resource.org/	Matthew Hogg /UK	32	70	9
Fibromyalgia Support[41] http://www.fibromyalgia-support.org	Global Healing Center /USA	28	90	9
FM-CFS Canada[42] http://fm-cfs.ca/fm.html	FM-CFS Canada /Canada	55	80	9
Wikipedia, the free encyclopedia http://en.wikipedia.org[43]	Wikimedia Foundation, Inc.,/USA	40	80	10
Canadian Women's Health Network[44] http://www.cwhn.ca	The Canadian Women's Health Network and the Centres of Excellence for Women's Health /Canada	34	60	10
MedicineNet.com[45] http://www.medicinenet.com	MedicineNet, Inc./USA	45	80	10
Fibromyalgia Symptoms[46] http://www.fibromyalgiasymptoms.org/	Not specified	46	40	10

About.com[47] http://chronicfatigue.about.com	The New York Times Company/USA	46	90	10
Women and Fibromyalgia[48] http://womenandfibromyalgia.com/	Book written by Barbara Keddy/Canada	23	60	10
National Fibromyalgia Partnership[49] http://www.fmpartnership.org/	The National Fibromyalgia Partnership, Inc/ not specified	50	60	10
Fibromyalgia Chronic Fatigue[50] http://www.chronicfatigue.org/	Clymer Healing Center /USA	21	50	10
Autoimmunity Research Foundation[51] http://bacteriality.com	Autoimmunity Research Foundation /USA	24	70	11
Fibromyalgia Information[52] http://fibromyalgia.ncf.ca/	Woman to Woman Computing/Canada	52	90	11
Ontario Fibromyalgia Association[53] http://www.hwcn.org/~aq226/ (no longer activated)	Not specified/Canada	23	40	11
NIAMSD[54] http://www.niams.nih.gov	National Institute of Arthritis and Musculoskeletal and Skin Diseases /USA	49	100	11
Fibromyalgia Information Foundation[55] http://www.myalgia.com/	Oregon Health & Science University/USA	51	90	11
Fibro Hugs[56] http://fibrohugs.com/	Ken Euteneier / not specified	16	40	12
Mayo Clinic[57] http://mayoclinic.com/	Mayo Foundation for Medical Education and Research/USA	45	90	13
BC fibromyalgia Society[58] http://www.mefm.bc.ca	MEFM Societies of BC /Canada	28	70	13
Neurology channel[59] http://www.neurologychannel.com	Healthcommunities.com, Inc. /USA	41	80	15

Note: List based on lower to highest readability scores

Figure 2 demonstrates websites reliability and quality of treatment information as measured by DISCERN. The mean score of all 15 questions combined was 2.49 out of 5. No question received a mean score of 4 or more. The questions that received the lowest score were related to sources of information, areas of uncertainty, side effects of treatments, effects of no treatment, effect on quality of life and shared decision-making. According to the DISCERN score, websites were also categorized as very good (32%), good (32%) and marginal (36%). The mean overall DISCERN score was 36.88 (good).

Figure 3 shows the combined Quality Checklist scores for the websites. The questions that received highest rating were contact information, confidentiality, ownership and useable /understandable.

Figure 2. Combined scores of the DISCERN reliability and quality of treatment information

Figure 3. Combined scores of the Quality Checklist questions (percentage of option 'yes')

The readability test showed that the reading level for fourteen (56%) websites was between grades 10 to 12, seven websites (28%) between grades 8 to 9, and one website (4%) between grades 6 to 7. Twelve percent were college level and none scored for grade 1 to 5 (Table 1).

Table 2 shows five highest ranked websites according to scores from DISCERN, Quality Checklist and Flesch Reading Ease.

Table 2. Five top ranked websites based on DISCERN, Quality Checklist and The Flesch Reading Ease scores

Tool	Website
DISCERN	1. FM-CFS Canada 2. Fibromyalgia Information 3. Fibromyalgia Information Foundation 4. National Fibromyalgia Partnership 5. National Institute of Arthritis and Musculoskeletal and Skin Diseases
Quality Checklist	1. National Institute of Arthritis and Musculoskeletal and Skin Diseases 2. Fibromyalgia Support 3. About.com 4. Fibromyalgia Information 5. Fibromyalgia Information Foundation
Flesch Reading Ease	1. Fibromyalgia Treatment Center 2. Fibromyalgia Network 3. Medline Plus 4.Women's Health Matters 5. Body and Health

DISCUSSION

The results of this study suggest that fibromyalgia websites vary with respect to content, quality and readability. There is considerable variability between the average scores from DISCERN, the Quality Checklist and the Flesch Reading Ease. In cases where the quality of websites was good readability was often poor. There are only three websites: Fibromyalgia Information[52], Fibromyalgia Information Foundation[55] and National Institute of Arthritis and Musculoskeletal and Skin Diseases[54] that consistently rated with higher levels of quality (Table 1). Unfortunately, since these had high reading levels (Grade 11), they are not likely to be accessible by people with lower literacy.

Most commonly the content of websites addressed symptoms, treatment, and diagnosis. Many websites lacked information about important topics that patients have identified as significant such as causes of fibromyalgia, research, supports, alternative therapies, impact, and specialists that might help them understand and manage an illness.[8, 9, 60] As a result, people looking for these types of information on the web will find little on these aspects of information on fibromyalgia. More efforts are needed to include comprehensive information on the websites that provide customized information for people with fibromyalgia.

Websites quality scoring between the two quality appraisal tools resulted in different rankings. This can be attributed to having different items and scoring. Others have shown that there is considerable variability in the critical appraisal tools used for evaluating research[33]and it appears that a similar trend is evolving with respect to websites. While DISCERN seems to be most commonly used currently in the literature, it is important for those conducting reviews to evaluate whether the critical appraisal tool is most appropriate for their individual study.

This study focused on assessing the quality of a website from the perspective of a lay person.[26, 23] Lay 'quality' assessments assumes practices that indicate more rigorous development and authorship will lead to more timely and accurate information. That is because the general public cannot be assigned the task of verifying the accuracy of specific medical or scientific information on the website. This study indicates websites do not adequately identify the sources of information that are provided on the websites nor the timeliness of posted information. It has been suggested that providing a date does not necessarily mean that the information is correct or up-to-date.[2] However, when asking the lay public to assess information currency, this is a reasonable proxy. The true assessment of website currency would be to track down whether recent evidence was incorporated. This is not a reasonable expectation for the lay public. Similarly, providing contact information is thought to be associated with authors who take responsibility for information provided on their website, but a variety of motivations may be behind what specific elements are added to websites. This study focused on assessment of website quality from the perspective of the consumer. We also observed that two different tools (DISCERN and the Quality Checklist) designed for the lay public provided different scores and rankings. We have no way of knowing whether one tool provided a more valid assessment than the other. However, both scales agreed on 3 (Fibromyalgia Information[52], Fibromyalgia Information Foundation[55] and National Institute of Arthritis and Musculoskeletal and Skin Diseases[54]) out of 5 websites that placed in the top 5 websites list (Table 2) suggesting a level of concurrent validity. Studies that assess the extent to which different lay indicators of quality are

associated with actual quality and accuracy of information are needed to assess the criterion validity of these scales.

This review demonstrates that a substantial proportion of the most accessible websites that are fibromyalgia information resources do not meet the criteria established for website quality undermining the confidence that users can place in the accuracy of the information contained within these resources. More attention is needed from healthcare providers and websites developers so that they can work together to provide more consistent information for people living with fibromyalgia. There is also a need to determine which criterion can be most useful and accurate for lay individuals to assess website quality.

Another major finding of this review is that people need a high level of education to understand online information on fibromyalgia particularly on high quality websites. For example, the National Institute of Arthritis and Musculoskeletal and Skin Diseases website provides good quality information about fibromyalgia; however, a person with fibromyalgia needs a grade level of II to understand and to use that information. Only four (Fibromyalgia Treatment Center[35], Fibromyalgia Network[36], Medline Plus[37, Women's] Health Matters[38]) of the websites meet the literacy level for the general population. "High readability requirements decrease information accessibility and potentially exclude users with low literacy skills".[61] Using the web to provide useable quality information remains elusive. A common concern among people living with chronic illnesses including people with fibromyalgia is that difficult medical terminology is a major barrier for them to access and use online health information efficiently.[8, 9, 20, 61] Online information on fibromyalgia needs to be written at or below a grade 8 level so that all people are able to read the information and use it to participate in their own health decision-making. This suggests that people with health literacy expertise should be involved in website development.

Overall, there is evidence that there are inconsistencies across websites for providing information on content, overall quality and readability which are consistent with others who evaluated websites for other chronic conditions.[2, 26] People living with fibromyalgia have expressed a strong need for information and a dependency on web-based information as a primary source. This indicates that more effort is needed to ensure that the information provided on fibromyalgia websites meets the information needs, quality and suggested readability criteria.

LIMITATIONS OF THE STUDY

A number of limitations should be considered when interpreting our results. First, our search was not comprehensive as we only used 'Google' and one keyword to search for online fibromyalgia resources. We selected Google and "fibromyalgia" as these were most commonly used by our target audience[8], but recognized that other search engines and combination of multiple key words may have produced different results.

Some limitations are noted by the way that items on the Quality Checklist are formatted. Since some items have multiple questions that required a single yes/ no answer, reviewers sometimes had difficulty selecting an option when partial credit was assigned. In addition, there is lack of evidence available to validate the Quality Checklist. Thus some of the differences

between DISCERN and the Quality Checklist relate to scoring methods. Finally, we have no gold standard for whether these websites were quality websites. We addressed the quality issue using the lens of two critical appraisal tools designed for the lay public. A review that perform a detailed analysis of recommendations on the website and determine whether they are consistent with the highest quality evidence would have determined if the information itself was high quality. Finally, the readability score may vary for some websites as it may be related to the use of words such as fibromyalgia, since this seems to be a word that might rank low in the readability calculation.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

The Internet is changing the way that people gather information about dealing with chronic conditions like fibromyalgia and has the potential to facilitate disease 'self-management'. This study has determined that the majorities of the existing online fibromyalgia resources do not provide adequate information that are needed to fulfill people's need, lack quality and do not meet literacy standards for lay public information. This suggests that there is potential for misinformation when people with fibromyalgia access web-based health information. Healthcare and social service providers need to be aware of this state of online fibromyalgia resources so that they are able to provide better services to people with fibromyalgia. Healthcare providers will need to help their patients navigate and interpret appropriate web-based information.

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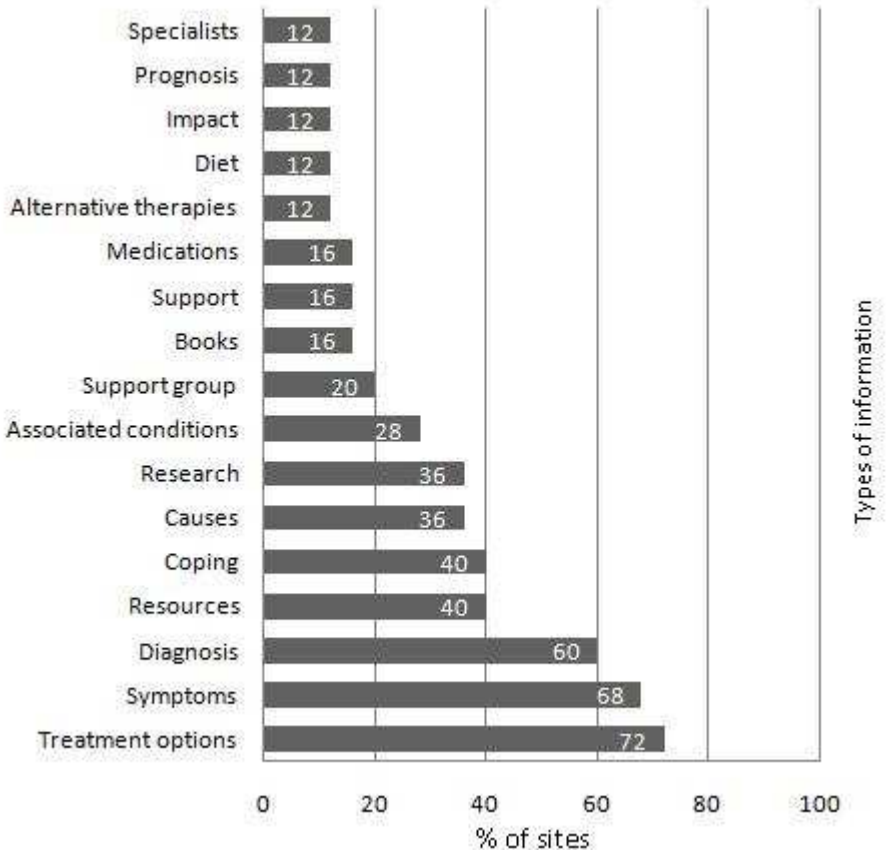
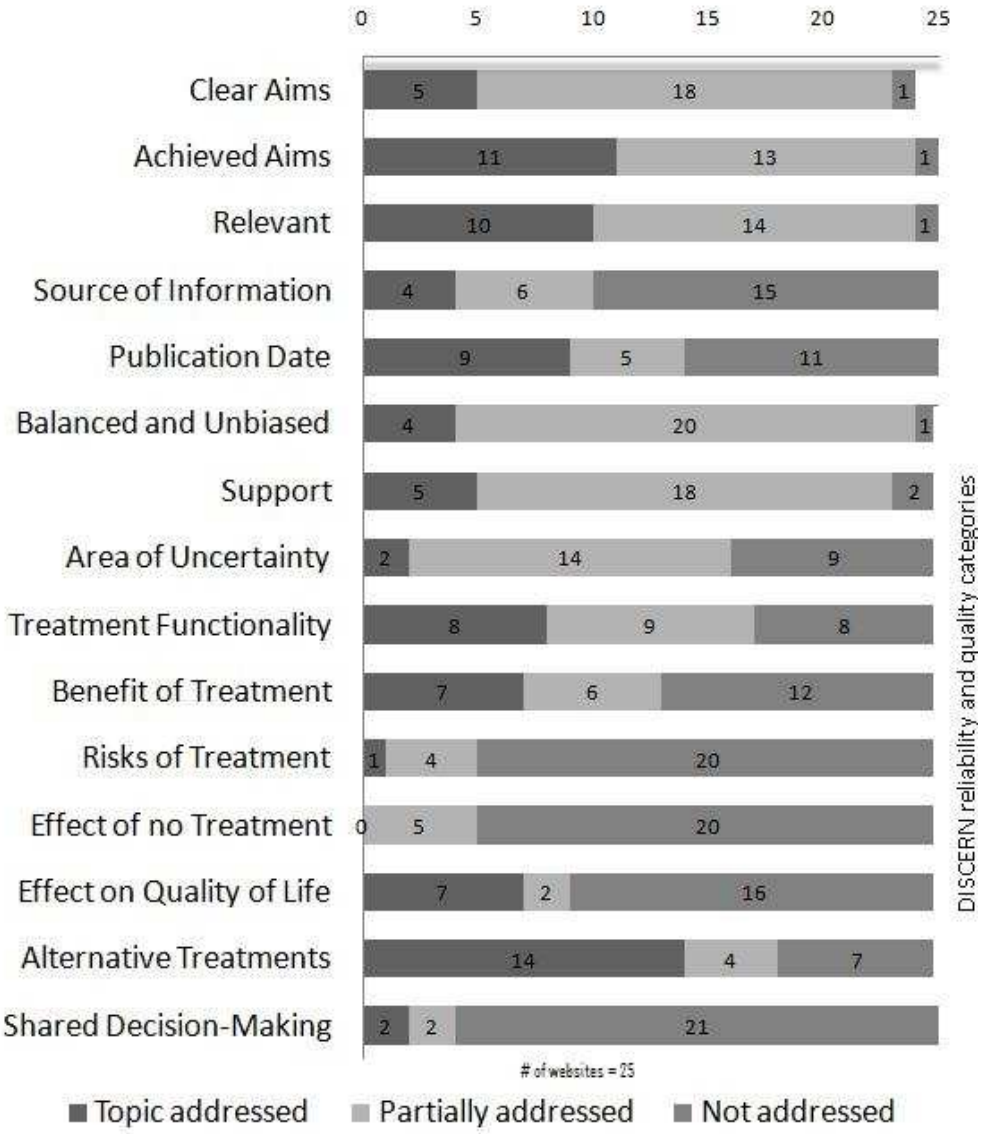
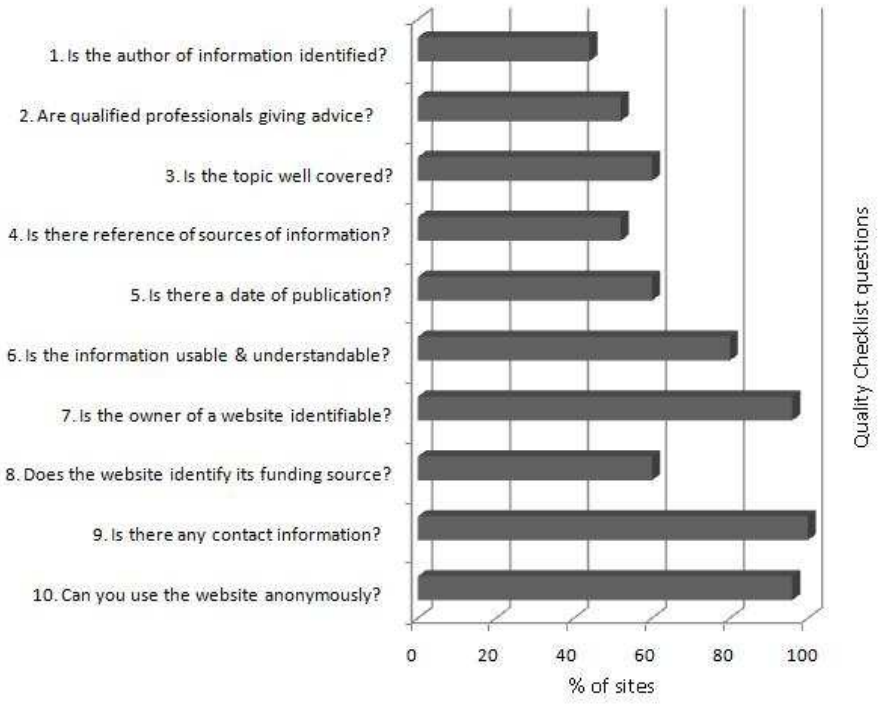


128x115mm (96 x 96 DPI)



Combined scores of the DISCERN reliability and quality of treatment information
148x174mm (96 x 96 DPI)



Combined scores of the Quality Checklist questions (percentage of option 'yes')
175x129mm (96 x 96 DPI)

The quality of websites addressing fibromyalgia – an assessment of quality and readability using standardized tools.

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The first author, Dr. Daraz was in charge of all aspects of the research including choosing the topic, formulating research questions, reviewing literature, designing study, searching on Google, collecting data, evaluating websites, drafting and revising manuscript critically for important intellectual content and provided final approval of the version to be published. Dr. MacDermid was involved in substantial contributions to conception and design, evaluating websites, revising manuscript critically for important intellectual content and provided final approval of the version to be published. Dr. Wilkins and Ms. Gibson were involved in substantial contributions to conception and design, evaluating websites and revising manuscript critically for important intellectual content and provided final approval of the version to be published. Dr. Shaw was involved in substantial contributions to conception and design, revising manuscript critically for important intellectual content and provided final approval of the version to be published.

Abstract

Background

People living with fibromyalgia strongly prefer to access health information from the Web. However, the majority of the people in previous studies strongly expressed their concerns about the quality of online information resources.

Objectives

The purpose of this study was to evaluate existing online fibromyalgia information resources for content, quality and readability by using standardized quality and readability tools.

Methods

The first 25 websites were identified using 'Google' and search keyword 'fibromyalgia'. Pairs of raters made independent evaluations of website quality using two structured tools (DISCERN and a Quality Checklist). Readability was assessed using the Flesch Reading Ease score maps.

Results

Ranking of the websites' quality varied by the tools used, although there was general agreement about the "top" three websites (Fibromyalgia Information, Fibromyalgia Information Foundation and National Institute of Arthritis and Musculoskeletal and Skin Diseases). Content analysis indicated that 72% websites provided information on treatment options, 68% on symptoms, 60% on diagnosis and 40% on coping and resources. DISCERN ratings classified 32% websites as 'very good', 32% as 'good and 36% as 'marginal'. The mean overall DISCERN score was 36.88 (good). Only 16 % of websites met the recommended grade of 6 to 8 literacy level (Range 7 – 15).

Conclusion

Higher quality websites tended to be less readable. Online fibromyalgia information resources do not provide comprehensive information about fibromyalgia; have low quality and poor readability. While information is critical to living with fibromyalgia, current resources are unlikely to provide necessary or accurate information; and may not be usable for people.

Article Summary

Article focus

- The purpose of the study was to gain a better understanding of the online information resources that are available for people living with fibromyalgia and to evaluate those information resources for content, quality and readability.

- What are the content, website quality and readability of the most readily retrieved information available on the web when searching for fibromyalgia information?

Key messages

- Majority of the existing websites do not provide comprehensive information on fibromyalgia
- Websites are highly variable in terms of quality
- Higher quality websites do not present information in language/reading levels appropriate for the general population

Strengths and limitations of this study

- This study provides the evidence of the quality of the majority of existing online fibromyalgia resources
- Standardized quality and readability tools were used to assess quality and readability
- There is no gold standard for comparison or ways to evaluate the quality of websites.
- The quality issue was discussed using the lens of critical appraisal tools designed for the lay public.
- Readability score may vary for some websites as it may be related to the use of technical terms such as fibromyalgia.

INTRODUCTION

There are more than 70,000 web sites that offer health information for consumers and the number is growing everyday.[1] Many of these websites are accessed by people with fibromyalgia to self-manage their health. However, it is unknown if websites are consistent with the literacy and health needs of users such as persons with fibromyalgia. What we currently know is that web-based information has the potential to educate and empower consumers by providing information on the nature of their health problems and by helping to make informed decisions about their health. [2,3,4,5]

The extent of interest in web based health information is indicated by high and increasing usage.[6, 7] In Canada about 8.7 million Canadians use the Internet to search for medical and health-related information. Among these people, women are more likely to search for health information about specific diseases than men.[6] In addition, 54% - 79% of those seeking information expressed concerns about the quality of online health information.[6] Similarly, in the USA, the number of adults who go online for health information has increased from 46% in 2000 to 61% in 2009.[7] Many (66%) of these online health information seekers discuss their concern about the lack of quality of online health information sources with their healthcare providers.[7] Thus, researchers at the Pew Internet and American Life Project anticipate that the more people access the Internet for health information, their concern for the quality will also continue to grow.[7]

The Internet is now an important resource for people living with fibromyalgia.[8, 9, 10] Fibromyalgia, is described as an invisible chronic condition that has severe impacts on health and quality of life for people who are living with the illness.[11, 12, 13] This disease manifests itself as chronic widespread musculoskeletal pain in different areas of the body.[14,15,16] The need for information is greater due to the controversy surrounding the condition which includes a lack of specific diagnostics tests and evidence-based treatment guidelines. It has been suggested that people are often left on their own to manage their illness.[17, 16]

Daraz and others studied the information needs and preferences of people living with fibromyalgia.[8, 9] The majority of the people in those studies expressed their preference of the web as a major source for accessing fibromyalgia-related information. However, they also strongly expressed their concerns about the lack of availability of types of information about fibromyalgia (content), need for evidence-based information (quality) and difficulty in understanding medical or technical terminologies (literacy/readability). A similar study by Crooks demonstrated that people living with fibromyalgia like to go online to access information about fibromyalgia to inform themselves about the illness and to assist with shared decision making with their healthcare providers.[10] However, the perceived lack of quality of online information was a major factor that was also discussed in the study findings. Others have also suggested that web-based health information can increase people's perception of control, improve their ability to cope with the illness, enhance their self-care abilities, and improve their quality of life by decreasing anxiety, fear and distress while increasing hope.[18,19]A number of studies have evaluated the quality of online health information designed for specific populations and found it to be of variable quality.[20, 21, 22, 23, 24, 25, 2, 26] It is imperative that people living with fibromyalgia have

access to quality evidence-based information to help them live with their illness since it is a chronic disease. Therefore, it is important to evaluate if the information on websites can meet the needs of persons with fibromyalgia for accessible, high quality, useful information.

The purpose of this study was to gain a better understanding of the online information resources that are available for people living with fibromyalgia and to evaluate those information resources for content, quality and readability.

METHODS

This study was comprised of a keyword search, selecting websites and structured appraisal of the websites using standardized quality and readability tools. Similar methods were used by others who evaluated the quality of websites for specific conditions. [20, 21, 24]

Search strategies to find online fibromyalgia information resources

In a previous study, the authors identified search terms and engines that women commonly used when looking for information on fibromyalgia.[8] Based on those findings we performed a keyword search on 'Google' (www.google.com) with a keyword 'Fibromyalgia' on December 11, 2009 to identify online resources about fibromyalgia that are most likely to be accessed by people. It has been suggested that lay people seldom search for information beyond the first 20 links retrieved by a search engine so we used this to dictate our website sample.[27]

Criteria for selecting online fibromyalgia information resources

Our inclusion criteria for selecting websites were: 1) provide information on fibromyalgia, 2) provide information for consumers/patients and for their caregivers, and 3) provide information in English. We excluded duplicate websites or sites with dead links.

Quality appraisal tools

DISCERN is a reliable and valid instrument that is used to assess the quality of written consumer health information which people can use without content expertise.[28,29] The instrument was developed and evaluated by an expert panel and a group of health information providers and self-help members. DISCERN consists of 15 questions (first 8 questions are for publication reliability and last 7 questions are for the quality of information on treatment choices) where each question is rated on a 1 to 5 point scale. We assigned scores using the score specified by DISCERN (Topic Addressed = 5, Partially addressed = 3, Not addressed = 1). This instrument has been evaluated for reliability and validity and is being used by many researchers to assess the quality of online health information for specific kinds of diseases.[20, 23, 24] However, DISCERN does not include many of the criteria that are important for assessing the content of specific information and for the development and dissemination process to distribute the information, for example, *accuracy*, *completeness*, *disclosure and readability*.[27]

As a result, we used a Quality Checklist developed by Daraz and others[30] to assess the quality of web health information. This tool was developed based on a structured review and appraisal of existing web health evaluation tools that were developed to assess the quality of web health information. Based on their review, the authors determined that the existing web health evaluation tools did not meet the criteria for readability and ease of use for general consumers. As a result, they recommended a customized tool / quality checklist designed for general consumers' use.The Quality Checklist consists of 7 categories: 1) Authorship, 2) Content, 3) Currency, 4) Usefulness, 5) Disclosure, 6) User Support and Feedback, and 7) Privacy and Confidentiality. A total of 10 questions are included in the checklist with a 'yes' or 'no' option.

To determine the overall rating of the websites, we also used the total DISCERN score to categorize the websites as excellent (61-75), very good (60-46), good (45-31), marginal (30-16) and poor (15-1). It was not possible to assign similar categories to assess the overall rating of the websites using the Quality Checklist as the tool does not have a numerical scoring scheme like DISCERN.

For the readability evaluation, the information from each websites was evaluated for i) reading ease and ii) grade level calculation using the actual content from the websites. For the reading ease calculation we used "The Flesch Reading Ease (RE)" [31, 32]score maps that were designed to measure the readability of texts. The RE index is 0 to 100. An RE of around 60 to 70 is equivalent to a grade level of 6 to 8. The closer to 100 the text scores, the easier it is to read.[31, 33]

90 -100	Very easy	50 - 59	Fairly difficult
80 - 89	Easy	30 - 49	Difficult
70 - 79	Fairly easy	0 – 29	Very confusing
60 - 69	Standard		

For grade level calculation we used "The Flesch-Kincaid Grade Level" formula. It is recommended that anyone who aims to provide health information should try to achieve a grade level of 6 to 8. The scores using the 'Flesch Reading Ease' formula can be interpreted in the following format.[31, 32]

DATA EXTRACTION AND ANALYSIS

High quality information exists when the information on websites is consistent with the best research; high quality websites are those which have certain standards for how they are produced.[34, 20, 35] By 'content' we refer to specific information about fibromyalgia addressed: for example, treatment, diet, finding specialists etc; and by 'readability' we refer to reading ease and grade level. By 'quality' we refer to overall website quality, not the analysis of specific pieces of information on the website. Rather, website quality looks at the extent to which efforts were made to insure the information on the website is current and accurate based on current evidence/knowledge.

A data extraction tool was devised to allow reviewers to categorize the content contained on fibromyalgia websites. Categories were developed using concepts derived from both qualitative and quantitative research [8, 9]; open-ended categories were later classified if concepts were reported that were not preconceived by the structured items. The data extraction table included: *country of origin*, *target audience*, *category of websites* and *types of content*. Websites were categorized as not-for-profit (e.g., societies, association, charitable, support group), commercial (e.g., private medical site, sponsored site), media (e.g., newspapers), and institutional (e.g., university or government).

To assess reliability of evaluation, each site was independently rated by the authors. Although kappa scores were not tabulated, the reviewers extensively discussed each question where scoring was different and they continued until the scoring conflicts were resolved. We used simple descriptive statistics to analyze the data. SPSS version 18[1] was used in our analysis for calculating frequencies and cross-tabulations. For example, frequency command was used to determine the percentiles of websites for country of origin or to determine the categories of websites.

RESULTS

Google retrieved 6,720,000 results for the keyword search. Among these, the first 25 websites were selected for analysis (Table 1). The country of origin for thirteen (52%) of the websites was USA, eight (32%) were from Canada, one from UK and the rest had no country specified (Table 1). The category of websites varied. Ten (40%) were not-for-profit organizations, six (24%) were commercial, five (20%) were media, and four (16%) were institutional. Only five (20%) websites were dedicated to women. Table 1 also demonstrates scores for DISCERN (column 3) and percentage for 'yes' option only for the Quality Checklist (column 4).

Figure 1 shows the types of information provided by selected websites. In addition to these kinds there were other types of information available on the selected websites, such as complications (8%), controversies (8%), exercise (8%), lifestyle guide (8%), education (4%), employment (4%), psychological issues (4%), quality of life (4%) and self-help (4%)

Figure 1. Types of information available on selected websites

[1] http://www.spss.com/

Table 1: 25 Selected sites and their overall scores

Website url	Developer Origin	DISCERN Score - 75	Quality Checklist % (Yes)	Readability (Grade level)
Fibromyalgia Treatment Center[36] http://www.fibromyalgiatreatment.com/	Fibromyalgia Treatment Center, Inc/USA	22	80	7
Fibromyalgia Network[37] http://www.fmnetnews.com/	Not specified/USA	38	60	8
Medline Plus[38] http://www.nlm.nih.gov/medlineplus	National Library of Medicine and National Institutes of Health /USA	40	80	8
Women's Health Matters[39] http://www.womenshealthmatters.ca	Women's College Hospital and the Women's College Research Institute /Canada	46	80	8
Body and Health[40] http://bodyandhealth.canada.com	MediResource /Canada	27	30	9
The Environmental Illness Resource[41] http://www.ei-resource.org/	Matthew Hogg /UK	32	70	9
Fibromyalgia Support[42] http://www.fibromyalgia-support.org	Global Healing Center /USA	28	90	9
FM-CFS Canada[43] http://fm-cfs.ca/fm.html	FM-CFS Canada /Canada	55	80	9
Wikipedia, the free encyclopedia http://en.wikipedia.org[44]	Wikimedia Foundation, Inc.,/USA	40	80	10
Canadian Women's Health Network[45] http://www.cwhn.ca	The Canadian Women's Health Network and the Centres of Excellence for Women's Health /Canada	34	60	10
MedicineNet.com[46] http://www.medicinenet.com	MedicineNet, Inc./USA	45	80	10
Fibromyalgia Symptoms[47] http://www.fibromyalgiasymptoms.org/	Not specified	46	40	10

About.com[48] http://chronicfatigue.about.com	The New York Times Company/USA	46	90	10
Women and Fibromyalgia[49] http://womenandfibromyalgia.com/	Book written by Barbara Keddy/Canada	23	60	10
National Fibromyalgia Partnership[50] http://www.fmpartnership.org/	The National Fibromyalgia Partnership, Inc/ not specified	50	60	10
Fibromyalgia Chronic Fatigue[51] http://www.chronicfatigue.org/	Clymer Healing Center /USA	21	50	10
Autoimmunity Research Foundation[52] http://bacteriality.com	Autoimmunity Research Foundation /USA	24	70	11
Fibromyalgia Information[53] http://fibromyalgia.ncf.ca/	Woman to Woman Computing/Canada	52	90	11
Ontario Fibromyalgia Association[54] http://www.hwcn.org/~aq226/ (no longer activated)	Not specified/Canada	23	40	11
NIAMSD[55] http://www.niams.nih.gov	National Institute of Arthritis and Musculoskeletal and Skin Diseases /USA	49	100	11
Fibromyalgia Information Foundation[56] http://www.myalgia.com/	Oregon Health & Science University/USA	51	90	11
Fibro Hugs[57] http://fibrohugs.com/	Ken Euteneier / not specified	16	40	12
Mayo Clinic[58] http://mayoclinic.com/	Mayo Foundation for Medical Education and Research/USA	45	90	13
BC fibromyalgia Society[59] http://www.mefm.bc.ca	MEFM Societies of BC /Canada	28	70	13
Neurology channel[60] http://www.neurologychannel.com	Healthcommunities.com, Inc. /USA	41	80	15

Note: List based on lower to highest readability scores

Figure 2 demonstrates websites reliability and quality of treatment information as measured by DISCERN. The mean score of all 15 questions combined was 2.49 out of 5. No question received a mean score of 4 or more. The questions that received the lowest score were related to sources of information, areas of uncertainty, side effects of treatments, effects of no treatment, effect on quality of life and shared decision-making. According to the DISCERN score, websites were also categorized as very good (32%), good (32%) and marginal (36%). The mean overall DISCERN score was 36.88 (good).

Figure 3 shows the combined Quality Checklist scores for the websites. The questions that received highest rating were contact information, confidentiality, ownership and useable /understandable.

Figure 2. Combined scores of the DISCERN reliability and quality of treatment information

Figure 3. Combined scores of the Quality Checklist questions (percentage of option 'yes')

The readability test showed that the reading level for fourteen (56%) websites was between grades 10 to 12, seven websites (28%) between grades 8 to 9, and one website (4%) between grades 6 to 7. Twelve percent were college level and none scored for grade 1 to 5 (Table 1).

Table 2 shows five highest ranked websites according to scores from DISCERN, Quality Checklist and Flesch Reading Ease.

Table 2. Five top ranked websites based on DISCERN, Quality Checklist and The Flesch Reading Ease scores

Tool	Website
DISCERN	1. FM-CFS Canada 2. Fibromyalgia Information 3. Fibromyalgia Information Foundation 4. National Fibromyalgia Partnership 5. National Institute of Arthritis and Musculoskeletal and Skin Diseases
Quality Checklist	1. National Institute of Arthritis and Musculoskeletal and Skin Diseases 2. Fibromyalgia Support 3. About.com 4. Fibromyalgia Information 5. Fibromyalgia Information Foundation
Flesch Reading Ease	1. Fibromyalgia Treatment Center 2. Fibromyalgia Network 3. Medline Plus 4.Women's Health Matters 5. Body and Health

DISCUSSION

The results of this study suggest that fibromyalgia websites vary with respect to content, quality and readability. There is considerable variability between the average scores from DISCERN, the Quality Checklist and the Flesch Reading Ease. In cases where the quality of websites was good readability was often poor. There are only three websites: Fibromyalgia Information[53], Fibromyalgia Information Foundation[56] and National Institute of Arthritis and Musculoskeletal and Skin Diseases[55] that consistently rated with higher levels of quality (Table 1). Unfortunately, since these had high reading levels (Grade 11), they are not likely to be accessible by people with lower literacy.

Most commonly the content of websites addressed symptoms, treatment, and diagnosis. Many websites lacked information about important topics that patients have identified as significant such as causes of fibromyalgia, research, supports, alternative therapies, impact, and specialists that might help them understand and manage an illness.[8, 9, 61] As a result, people looking for these types of information on the web will find little on these aspects of information on fibromyalgia. More efforts are needed to include comprehensive information on the websites that provide customized information for people with fibromyalgia.

Websites quality scoring between the two quality appraisal tools resulted in different rankings. This can be attributed to having different items and scoring. Others have shown that there is considerable variability in the critical appraisal tools used for evaluating research[34]and it appears that a similar trend is evolving with respect to websites. While DISCERN seems to be most commonly used currently in the literature, it is important for those conducting reviews to evaluate whether the critical appraisal tool is most appropriate for their individual study.

This study focused on assessing the quality of a website from the perspective of a lay person.[26, 23] Lay 'quality' assessments assumes practices that indicate more rigorous development and authorship will lead to more timely and accurate information. That is because the general public cannot be assigned the task of verifying the accuracy of specific medical or scientific information on the website. This study indicates websites do not adequately identify the sources of information that are provided on the websites nor the timeliness of posted information. It has been suggested that providing a date does not necessarily mean that the information is correct or up-to-date.[2] However, when asking the lay public to assess information currency, this is a reasonable proxy. The true assessment of website currency would be to track down whether recent evidence was incorporated. This is not a reasonable expectation for the lay public. Similarly, providing contact information is thought to be associated with authors who take responsibility for information provided on their website, but a variety of motivations may be behind what specific elements are added to websites. This study focused on assessment of website quality from the perspective of the consumer. We also observed that two different tools (DISCERN and the Quality Checklist) designed for the lay public provided different scores and rankings. We have no way of knowing whether one tool provided a more valid assessment than the other. However, both scales agreed on 3 (Fibromyalgia Information[53], Fibromyalgia Information Foundation[56] and National Institute of Arthritis and Musculoskeletal and Skin Diseases[55]) out of 5 websites that placed in the top 5 websites list (Table 2) suggesting a level of concurrent validity. Studies that assess the extent to which different lay indicators of quality are

associated with actual quality and accuracy of information are needed to assess the criterion validity of these scales.

This review demonstrates that a substantial proportion of the most accessible websites that are fibromyalgia information resources do not meet the criteria established for website quality undermining the confidence that users can place in the accuracy of the information contained within these resources. More attention is needed from healthcare providers and websites developers so that they can work together to provide more consistent information for people living with fibromyalgia. There is also a need to determine which criterion can be most useful and accurate for lay individuals to assess website quality. For example, none of the tools used for this study are able to assess websites for accessibility, linking, peer to peer feedback or web standards.

Another major finding of this review is that people need a high level of education to understand online information on fibromyalgia particularly on high quality websites. For example, the National Institute of Arthritis and Musculoskeletal and Skin Diseases website provides good quality information about fibromyalgia; however, a person with fibromyalgia needs a grade level of II to understand and to use that information. Only four (Fibromyalgia Treatment Center[36], Fibromyalgia Network[37], Medline Plus[38, Women's] Health Matters[39]) of the websites meet the literacy level for the general population. "High readability requirements decrease information accessibility and potentially exclude users with low literacy skills".[62] Using the web to provide useable quality information remains elusive. A common concern among people living with chronic illnesses including people with fibromyalgia is that difficult medical terminology is a major barrier for them to access and use online health information efficiently.[8, 9, 20, 63] Online information on fibromyalgia needs to be written at or below a grade 8 level so that all people are able to read the information and use it to participate in their own health decision-making. This suggests that people with health literacy expertise should be involved in website development.

Overall, there is evidence that there are inconsistencies across websites for providing information on content, overall quality and readability which are consistent with others who evaluated websites for other chronic conditions.[2, 26] People living with fibromyalgia have expressed a strong need for information and a dependency on web-based information as a primary source. This indicates that more effort is needed to ensure that the information provided on fibromyalgia websites meets the information needs, quality and suggested readability criteria.

LIMITATIONS OF THE STUDY

A number of limitations should be considered when interpreting our results. First, our search was not comprehensive as we only used 'Google' and one keyword to search for online fibromyalgia resources. We selected Google and "fibromyalgia" as these were most commonly used by our target audience[8], but recognized that other search engines and combination of multiple key words may have produced different results.

Some limitations are noted by the way that items on the Quality Checklist are formatted. Since some items have multiple questions that required a single yes/ no answer, reviewers

sometimes had difficulty selecting an option when partial credit was assigned. In addition, there is lack of evidence available to validate the Quality Checklist. Thus some of the differences between DISCERN and the Quality Checklist relate to scoring methods. Finally, we have no gold standard for whether these websites were quality websites. We addressed the quality issue using the lens of two critical appraisal tools designed for the lay public. Some of the other important criteria such as accessibility, linking, web standards or peer to peer feedback are not included in the quality tools that we used. As a result, a review that perform a detailed analysis of recommendations on the website and determine whether they are consistent with the highest quality evidence would have determined if the information itself was high quality. Finally, the readability score may vary for some websites as it may be related to the use of technical terms such as fibromyalgia, since this seems to be a word that might rank low in the readability calculation.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

The Internet is changing the way that people gather information about dealing with chronic conditions like fibromyalgia and has the potential to facilitate disease 'self-management'. This study has demonstrated that the existing online fibromyalgia resources do not provide comprehensive information about fibromyalgia. The majority of the existing websites provide information on only a few content areas and websites are highly variable in terms of quality and readability. Ranking of the websites' quality varied by the tools used, although there was general agreement about the "top" three websites. Higher quality websites do not present information in language/reading levels appropriate for the general population. Thus, it is difficult for people living with fibromyalgia to distinguish between 'good' and 'poor' online resources. This suggests that there is potential for misinformation when people with fibromyalgia access web-based health information. Healthcare and social service providers need to be aware of this state of online fibromyalgia resources so that they are able to provide better services to people with fibromyalgia. Healthcare providers need to be more involved in the health decision-making for people with fibromyalgia by helping them access quality online health information.

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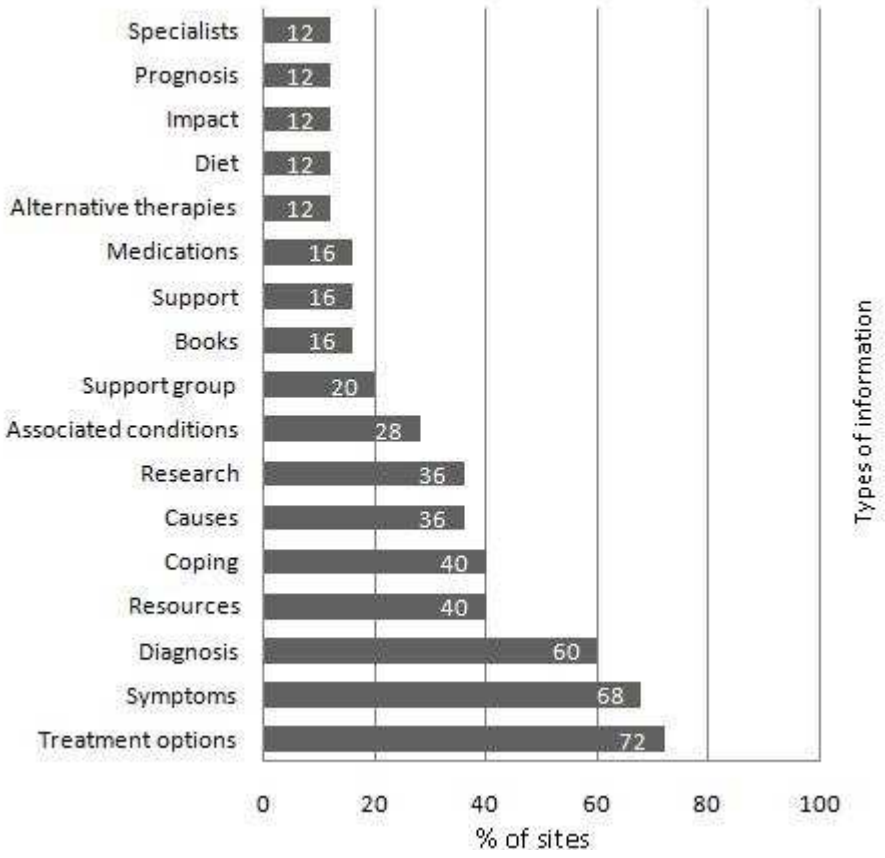

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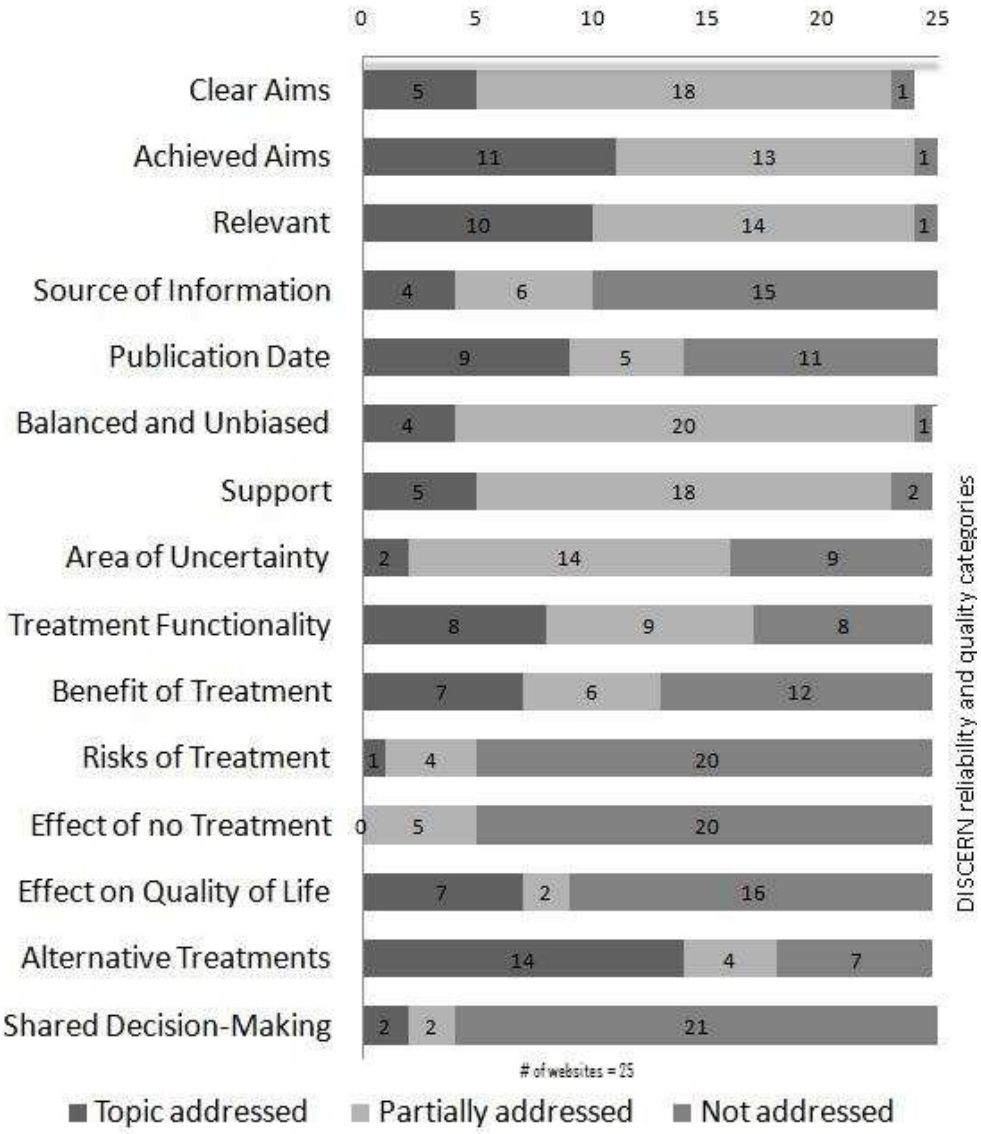
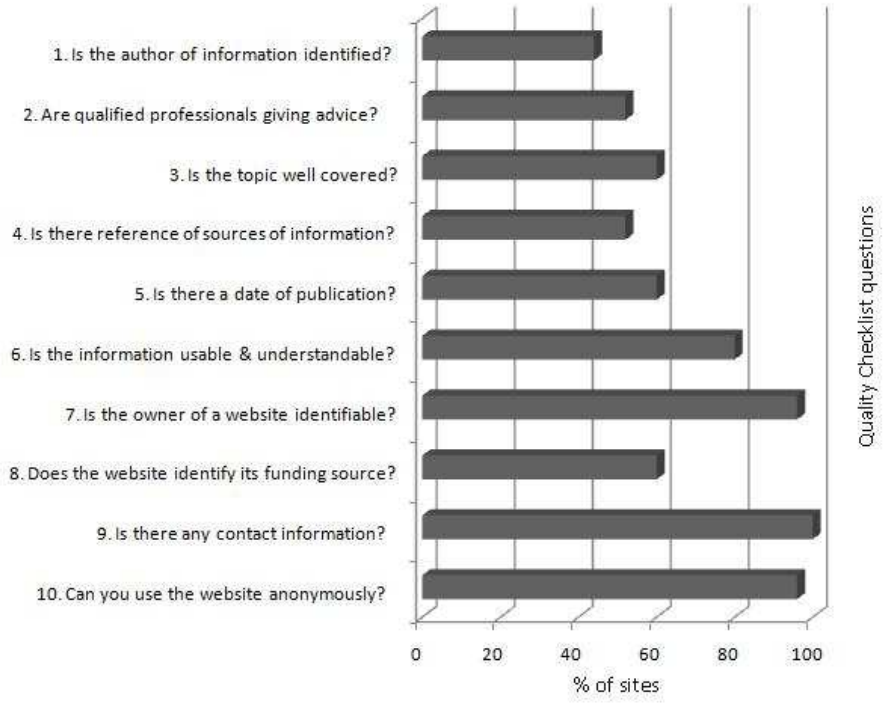


Combined scores of the DISCERN reliability and quality of treatment information
47x55mm (300 x 300 DPI)



Combined scores of the Quality Checklist questions (percentage of option 'yes')
56x41mm (300 x 300 DPI)