

THE COMPLETENESS AND ACCURACY OF INFORMATION ABOUT COELIAC DISEASE ON THE ROMANIAN WEBSITES

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Abstract

The internet has become an important source of health related information and a number of studies have shown that the quality thereof is, at best, problematic. Nevertheless, there are very few studies investigating the Romanian medical cyberspace. The goal of this study was to assess the completeness and accuracy of information about the coeliac disease on the Romanian websites directed to the general population. We evaluated a sample of 100 websites selected from the Google's first search results pages. The coverage of the topic was extremely deficient (the mean completeness score was 3.8 on a scale of 10), especially on sensitive issues such as the causes, treatment, and complications of the coeliac disease. On the other hand, the accuracy of the information was relatively good (mean accuracy score 7.2 on a scale of 10). With one exception, we found no statistically significant differences between the quality scores of the websites by their general characteristics.

Keywords: *coeliac disease; gluten intolerance; consumer health; information quality; Internet*

Introduction

The Internet has become a major source of health-related information available for most of the general population in the developed and developing countries (Eysenbach, 2000; Boyer, 2010). The latest surveys conducted in North America and Europe have shown that a proportion of 50 to 80% of the population have searched health-related information on the Internet (Wang et al, 2012; Seybert, 2011). A Romanian public survey reported that 96% of the Romanians were using the Internet to seek information and 15% of the respondents were looking for health-related information during their online searches (IRES, 2011). The poor quality online health information is an emerging public health concern as it exposes the unaware consumers to notable health risks by delaying imperative interventions, experimenting with ineffective or dangerous treatments, followed by aggravating of the disease or death (Weaver et al, 2009; Eng & Gustafson, 1999).

Although nutrition and nutritional diseases are listed among the most searched for topics among people of all ages, (Wang et al, 2012; Ettel et al, 2012), and coeliac disease and gluten intolerance seem to draw the attention of a wide group of population and the mass-media, the quality of information about these conditions on the Romanian Internet is virtually unknown.

The aim of the study was to answer the following research questions:

1. What are the general characteristics of the Romanian coeliac disease websites?
2. What is the quality of the information about coeliac disease, as far as completeness and accuracy are concerned?
3. Are there any significant differences regarding the quality of the information about the coeliac disease between the websites with different general characteristics?

2. Material and methods

The study was designed as an observational cross-sectional study. The sample included the first 100 websites listed on the Google search engine's results pages. The search was conducted during March-April 2016 using "boala celiacă" ("coeliac disease") as a query term. We limited the search to the Romanian websites by using the language specific search page (www.google.ro).

We included only those sites that covered the topic under investigation in at least 250 words in Romanian language and which were targeted to the general population. Sponsored links, discussion forums, video- or audio-only content, infected or unavailable sites and also sites that required registration were all excluded. When multiple pages or subdomains belonging to the same top level domain were listed as separate links on the search engine's results page, we treated them as one website.

We classified the websites by their general characteristics: type of ownership (private individual, foundation/association, educational or research institution, public or private health service provider, commercial society), main purpose (educational, commercial, networking), genre (thematic, online newspaper or journal, corporate website, online store, blog or personal website, other) and medical paradigm (conventional, alternative, mixed). The definition of each website category and the description of the assessment procedure were included in an assessment form that was made available to the person performing the evaluation.

The quality of the information about the coeliac disease was measured using two generally accepted quality criteria: completeness and accuracy. The content of each website was checked against a list of expected items that we developed from the evidence-based medical literature. This standard content list was also included in an assessment form along with comprehensive instructions for the evaluators. (The assessment forms are available upon request from the corresponding author.) Each website was rated for completeness and accuracy. The raw scores were eventually converted to a relative completeness score (rCS) and a relative accuracy score (rAS) ranging from 0 to 10, to facilitate comparison within the sample. The website content grading procedure and quality score calculations are described in detail in a previous work (Nădășan et al, 2011).

We checked for statistical differences between the quality scores of the websites classified by their general characteristics with the nonparametric Kruskal-Wallis test. The

level of statistical significance was set at 0.05. All statistical analyses were carried out using GraphPad InStat Demo 3.06.

Results

Descriptive data about the general characteristics of the coeliac disease websites included in the studied sample are presented in table 1.

Table 1. The general characteristics of the Romanian websites presenting information about the coeliac disease

Characteristics	Subcategories	N (%)
Ownership	Individual	10 (10)
	Foundation, association	17 (17)
	Educational institution	2 (2)
	Health service provider	10 (10)
	Commercial society	31 (31)
	Unidentifiable	30 (30)
Purpose	Educational	83 (83)
	Commercial	15 (15)
	Networking	2 (2)
Genre	Thematic	27 (27)
	Online newspaper, journal	12 (12)
	Corporate website	24 (24)
	Online store	9 (9)
	Blog, personal website	18 (18)
	Other genre	10 (10)
Medical paradigm	Conventional	33 (33)
	Alternative	7 (7)
	Mixed	20 (20)
	Unidentifiable	40 (40)

The mean rCS for the whole sample was 3.8 points and the rAS was 7.2 points (on a scale ranging from 0 to 10). The mean rCS and rAS of the websites categorized by their general characteristics are shown in table 2.

Table 2. Mean rCS and rAS of the Romanian websites presenting information about the celiac disease by subcategory

Characteristic	Subcategory	Mean RCS (SD)	Kruskal-Wallis H (p-value)	Mean RAS (SD)	Kruskal-Wallis H (p-value)
Ownership	Individual	3.9 (2.1)	745 (0.3402)	7.9 (1.3)	5.297 (0.3807)
	Foundation, association	3.8 (2.0)		7.6 (1.2)	
	Educational	5.5 (0.7)		07.06.16	

Characteristic	Subcategory	Mean (SD) RCS	Kruskal-Wallis (p-value) H	Mean (SD) RAS	Kruskal-Wallis (p-value) H
	institution				
	Health service provider	3.4 (1.9)		7.0 (1.1)	
	Commercial society	3.7 (1.8)		7.3 (1.2)	
	Unidentifiable	4.5 (2.0)		7.4 (1.0)	
Purpose	Educational	3.9 (2.0)	0.8542 (0.6524)	7.4 (1.1)	0.9570 (0.6197)
	Commercial	4.1 (2.0)		7.3 (1.1)	
	Networking	5.0 (1.4)		7.0 (0.1)	
Genre	Thematic	4.9 (1.9)	5.269 (0.0988)	7.5 (1.1)	2.178 (0.8240)
	Online newspaper	3.7 (1.8)		7.6 (0.9)	
	Corporate website	3.7 (1.6)		7.3 (1.1)	
	Online store	3.5 (1.7)		7.5 (1.4)	
	Blog, personal website	3.8 (2.4)		7.5 (1.2)	
	Other genre	3.2 (1.8)		7.0 (1.1)	
Medical paradigm	Conventional	4.4 (1.9)	9.384 (0.0246)	7.7 (0.9)	3.896 (0.2729)
	Alternative	5.4 (1.5)		6.8 (1.2)	
	Mixed	3.7 (1.9)		7.3 (1.1)	
	Unidentifiable	3.5 (1.9)		7.4 (1.2)	

The mean rCSs and mean rASs of information calculated separately for the main subsections of the coeliac disease are represented in figure 1.

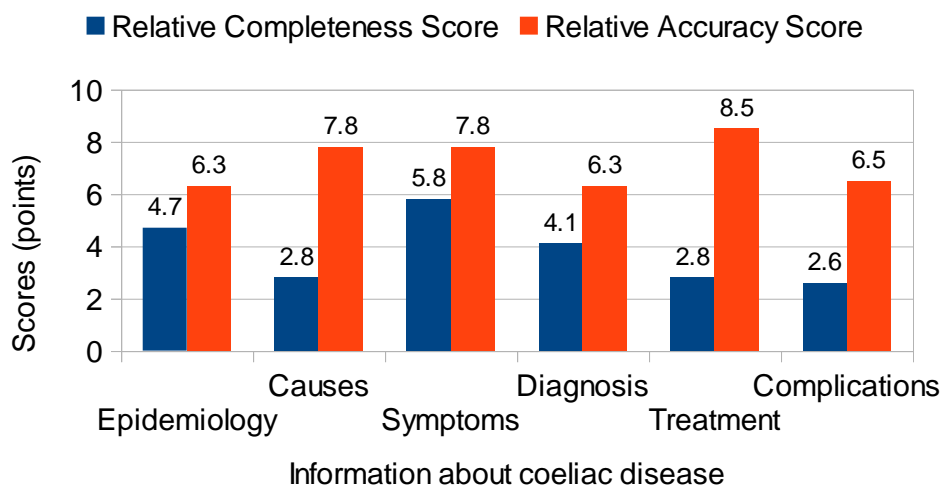


Figure 1. The mean relative completeness score and relative accuracy score of the information about coeliac disease on the Romanian websites by subsections

Discussions

To the best of our knowledge, this is the first study to assess the quality of the coeliac disease-related information on the Romanian websites.

Our findings show that most of the websites are owned by commercial entities and there is an obvious lack of involvement of the educational and research institutions. Considering that the coeliac disease represents an opportunity to merchandise gluten-free packaged foods, the prominent online presence of commercial companies among the websites disseminating information about this nutritional disease seems a natural consequence since a web page is one of the most cost-efficient promotional solution. While one would expect that educational or research institutions would produce and publish higher quality information, our study was not able to identify a significant difference between the quality of information related to coeliac disease available on the websites owned by commercial or non-commercial entities.

As far as the medical paradigm of the websites, the field seems to be about equally shared by those who embrace the conventional (33 websites) and the alternative or mixed approach (27 websites). The results of our assessment have shown a slightly higher mean completeness score for the alternative medicine websites but this observation needs to be taken with caution as the magnitude of the difference might be of rather statistical than practical significance. The explanation of the somewhat higher completeness scores observed among the alternative medicine websites in this study might be related to the fact that the primary therapy for coeliac disease at this time consists of a gluten-free diet, which is probably perceived, unwarrantedly, as an alternative method of treatment and so, this type of websites tend to provide more detailed information on the topic. However, it should be noticed that a previous more comprehensive research on the quality of health-related Romanian websites have not reported such a superiority of the alternative medicine websites compared to the conventional medicine websites (Nădășan, 2011).

The main findings of our study show that overall, the completeness of the information presented on the Romanian coeliac disease websites is extremely deficient (the mean rCS was 3.8 on a scale of 10) while the overall accuracy of the information is apparently good (the mean rAS was 7.2 on a scale of 10). A similar paper investigating the quality of information related to coeliac disease on English language websites reported that not more than 50% of the information provided at least half of the required information related to coeliac disease and 52% of the websites have reached a level of accuracy of 95% (McNally et al, 2012). The authors conclude that the lacking accuracy and transparency of the investigated English language websites about coeliac disease makes them unreliable for both medical professionals and general users.

Besides the quality assessment conducted on each website as a whole, we assessed also the quality of the information by each separate chapter of the coeliac disease. These additional analyses revealed that there are sensitive sections, especially the information regarding the treatment and complications of coeliac disease (rCS was 2.8 and 2.6 respectively) that are deficiently covered and thus represent a potential risk for the patients.

It should be underlined that the completeness and accuracy scores used in this study must not be interpreted independently because the completeness score measures exclusively the coverage of the topic while the accuracy score exclusively the correctness of the information without any reference to completeness. Therefore, websites with unacceptably

low coverage of the topic can receive a high or very high accuracy rating if the information they do provide, is free from errors.

At a closer examination, we found that only three of the websites in the Romanian sample had both completeness and accuracy scores in the acceptable range (>7.5 to 10 points). This observation might have practical implications since the probability of finding exhaustive and simultaneously correct information about the topic on a single website is extremely low. Thus, the likelihood of inexperienced users who do not spend sufficient time to cross-check the information on several websites, to be exposed to incomplete and/or inaccurate information seems to be very high.

The main limitation of the study is inherently related to the Internet research. Given the fluidity and volatility of the online content, the replication of the study seems virtually impossible. Using different search engines or query terms is likely to significantly alter the elements and hierarchy of the sample and thus an upward or downward shift in the quality scores as well.

We attempted to minimize the subjectivity of the assessment by developing a detailed description of the assessment methodology. However, the results of our evaluation might be affected by the subjective nature of certain aspects of the rating procedure.

Although the scope of this study was limited to a narrow field of the Romanian medical cyberspace, the reported observations bring new knowledge to the general picture of the quality of health-related information on the Romanian Internet.

Conclusions

1. The coverage of the coeliac disease as a health topic on the Romanian websites was extremely deficient (mean completeness score 3.8 on a scale of 10).
2. The extreme lack of information on sensitive issues such as the causes, treatment, and complications of the coeliac disease should be a real concern.
3. The accuracy of the information about the coeliac disease on the Romanian websites was relatively good (mean accuracy score 7.2 on a scale of 10).
4. With one, probably irrelevant exception, we found no statistically significant differences between the quality scores of the websites by their general characteristics.

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