



Quality and Content of Online Patient Resources for Celiac Disease

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Abstract

Background and Aims Patient-directed information on celiac disease has been reported to be of variable quality. We assessed the quantity and quality of information on blogs and Web sites intended to inform the layperson of celiac disease information.

Methods We performed a cross-sectional study analyzing celiac disease blogs and Web sites intended for the layperson. We searched from 20 cities, resulting in 55 Web sites. These sites were analyzed for 38 criteria that considered relevant clinical information for people with celiac disease. Claims were classified as true, false, or not proven. The readability level of each Web site was determined.

Results The 55 Web sites were categorized as national organizations, personal blogs, recipe-based blogs, or commercial/marketing Web sites. Only 40% of Web sites contained more than 50% of criteria. Of 212 claims assessed, 97% were found to be accurate. National organizations included the most criteria, followed by recipe-based blogs, then personal blogs, and lastly commercial/marketing Web sites. Additionally, national organizations had the highest proportion of accurate claims, followed by personal blogs, then commercial/marketing Web sites, and recipe-based blogs with the most inaccurate information. The average readability level of overall was 9.7, above the recommended readability level for patient education materials.

Conclusions A significant number of online claims regarding celiac disease were true, but the majority of patient-facing Web sites are missing large amounts of relevant information. This warrants efforts to improve the quality of medical information published online.

Keywords Celiac disease · Blog · Comprehension

Introduction

Celiac disease is an autoimmune disorder that develops in individuals who are genetically predisposed [1]. It is triggered by the ingestion of gluten, the protein component of wheat, rye, and barely [1]. It occurs in about 1% of people in most populations, and its prevalence has risen in recent decades. This increase seems to be due to a rise in incidence rather than an increase in awareness and testing [1]. A diagnosis for celiac disease typically requires an intestinal biopsy and an elevated celiac-related antibody test [1]. The only treatment for celiac disease is a gluten-free (GF) diet, and the symptoms improve for the majority of people who maintain this diet [1]. Various drugs that aim to improve symptoms or eliminate the need for a gluten-free diet are in

developmental and testing stages [1]. Due to the broad list of celiac disease symptoms including diarrhea or constipation, vomiting, fatigue, abdominal pain, and others, people refer to online sources to self-diagnose and use these sources to determine a treatment plan [2]. This could complicate later medical diagnosis since one must be consuming gluten to be properly diagnosed with celiac disease [2]. Using online information to self-diagnose therefore has the potential to lead to a misdiagnosis.

Given the rise in incidence of celiac disease, it is important that online resources provide the public with accurate information. Blogs are “frequently modified Web pages in which dated texts are archived in reverse chronological order” [3]. A 2011 survey found that people turn to blogs because of their convenience and the ability to interact with others [4]. A 2009 study found that only 16% of health and medical blogs contained actual health or medical information [3] as opposed to commentary pertaining to medicine. The increase in blog production and use has led to the

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concern regarding the accuracy of the information provided on these sites [5].

Incomplete or inaccurate online information appears to be prevalent. One study from 2004 investigated Web sites providing information on celiac diseases [6]. The study found that fewer than one-third of Web sites analyzed scored over 50% for overall accuracy. 15.9% of Web sites contained information that was inaccurate and potentially harmful [6]. Another study done in 2012 found that 48% of assessed Web sites had information about celiac disease that was less than 95% accurate. Additionally, 52% of assessed Web sites contained less than half the information about celiac disease deemed important to be included on a Web site discussing general celiac disease information [5]. However, no previous study has focused solely on Web sites created by non-medical or academic personnel.

The purpose of this study was to assess the quality and quantity of information provided by 55 celiac disease blogs and Web sites intended for the layperson. We assessed sites for pertinent information, readability, and accuracy.

Methods

To identify celiac disease blogs for analysis, we selected the five most populated metropolitan areas, according to World Population Review [7], in each major region in the USA (Northeast, South, Midwest, and West) yielding a total of 20 cities. We then performed Google searches for the search term “Celiac Disease Blogs.” We used the Web tool “isearchfrom.com” in order to simulate searching from each respective city. This tool also disabled Google’s personalized results function. All searches were performed during the month of June 2019 on a cleared browser. We recorded the first 50 results for each city. Duplicate links to the same Web site were removed. Colleges, hospitals, and advertisements were excluded. Only Web sites directed for patients/consumers and intended primarily for celiac disease or those on the gluten-free diet were included. General Web sites that only contained a list of celiac disease blogs were excluded, but the blogs they listed were included if they met the inclusion criteria. If the link was dead or the Web site gave directions to get to a new site, it was excluded. Any blog that required inputting an email or any personal information in order to access the site was excluded. Fifty-two unique Web sites were found to fit the criteria (Fig. 1). We conducted these searches during June 2019.

In addition to the 52 sites identified via the methodology above, we included a priori three Web sites that sell products that test the gluten content of food or sell other diagnostic tests directly to consumers to aid people on a gluten-free diet. We included these sites given the rising popularity of

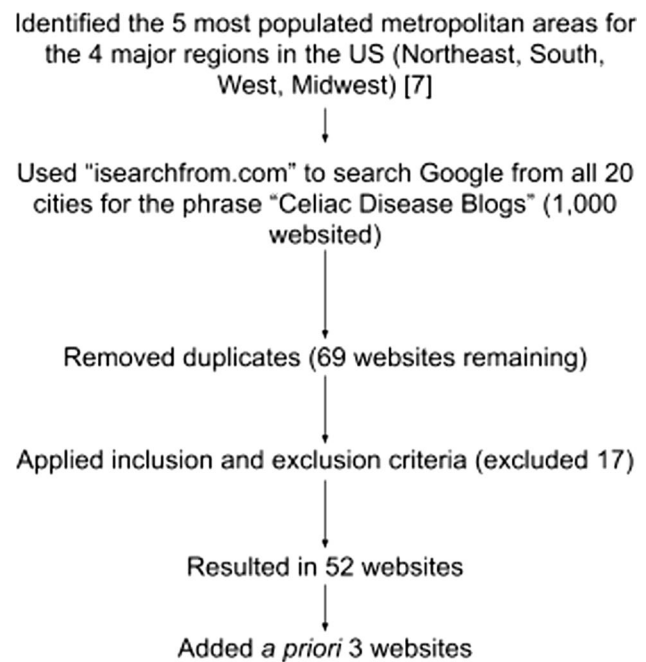


Fig. 1 Flowchart depicting the selection of Web sites for analysis

this technology, to compare the information on these sites with the blogs found in our search.

The Web sites were classified as one of four categories: national organizations, personal blogs, recipe-based blogs, or commercial/marketing Web sites. Recipe-based blogs for the most part were personal blogs, but specifically focused on gluten-free recipes. The three Web sites we included a priori were placed in the commercial/marketing category.

Each Web site was then searched manually for 38 criteria that the authors determined to be pertinent information relating to the diagnosis and management of celiac disease (Table 1). If the criterion was not found on a first-pass manual review, the Web site was searched for the individual criteria using Google domain search (e.g., “site:https://[site name here] symptoms”).

We also assessed the readability of each site using the Flesch–Kincaid readability test [8] to determine the grade level of education an individual in the USA would need to easily read the information provided [5]. The recommended readability level for patient education materials should not exceed a sixth-grade reading level [9]. The first blog post from each Web site was used to generalize the readability of the entire site.

We assessed accuracy by identifying the first five claims about celiac disease or gluten-free living on each Web site, and having two authors (BL and PHRG) adjudicating the claim independently. We excluded Web sites that did not have readily accessible claims in one of their first few blog posts.

Table 1 Percentage of each celiac disease-related point of information mentioned by each site type

Criteria (<i>n</i> = 38)		Personal (<i>n</i> = 27) (%)	Recipes (<i>n</i> = 14) (%)	Commercial/ marketing (<i>n</i> = 6) (%)	National organi- zation (<i>n</i> = 8) (%)
Clinical	Lists symptoms of celiac disease (CD)	67	71	67	100
	Mentions that celiac disease may be asymptomatic	44	29	33	100
	Mentions that anemia and osteoporosis are common with CD	78	79	83	100
Diagnosis	Someone should be tested for CD before starting a gluten-free (GF) diet	59	21	67	100
	The diagnosis of CD should involve blood testing for antibodies	52	57	83	100
	After blood work, intestinal biopsy should be done for diagnosis	56	64	100	100
	Relatives of someone with CD should be screened	33	29	67	100
	Patients should be tested for associated autoimmune disorders	37	29	50	100
	A bone density test is recommended	30	21	33	100
	Coexistence of other food intolerances	26	29	33	100
Treatment	A GF diet should be advised/guided by a dietitian	19	14	33	100
	Lists sources of hidden gluten	67	71	100	100
	Gluten can be found in medications	44	50	67	100
	Gluten can be found in supplements	11	14	50	75
	Regular visits with a dietitian are advised	19	14	33	88
	A GF diet is not necessarily regarded as a healthy diet	30	14	17	63
	Mentions anything potentially deleterious in general about the diet	19	21	33	25
	Regular follow-up with physicians concerning medical care of CD is advised	26	0	50	100
	Adolescents with CD should transition to adult care	0	0	0	38
	All gluten should be avoided by people with celiac disease	67	86	83	100
	There are currently no available therapies for CD other than a GF diet	59	57	83	100
	There are currently no proven over the counter glutenases/digestive enzymes	11	14	33	63
	Has links to medical centers	7	0	17	50
	Has links to CD centers	22	14	0	63
	Provides dietary advice	44	86	67	100
	A patient may need vitamin supplements	48	29	50	88
	Research	Describes the current status of non-dietary therapies that are in trials	7	7	17
Suggests supporting research financially		15	0	0	50
Suggests supporting research by participating in research		22	14	0	63
Lists potential therapies being developed		26	29	17	100
Possible vaccinations being developed		30	21	17	100
Follow-up	Annual blood tests are advised	33	0	33	100
	There are possible psychiatric symptoms	56	50	50	100
	Has links to medical guidelines	89	43	33	100
	Has links to in-person support groups	44	36	50	100
	Lists ingredients to avoid	37	57	67	100
	Lists GF grains	33	71	67	100
	Describes the importance of dietary fiber	15	7	17	38

The six commercial/marketing sites include both three identified in our search and three sites we a priori identified

Results

We identified 55 Web sites after searching from 20 cities. Twenty-seven of these Web sites were personal blogs, fourteen were recipe-based blogs, six were Web sites marketing products to individuals on a gluten-free diet (commercial/marketing), and eight were considered national organizations. Twenty-two (40%) of these Web sites had over 50% of the criteria present on their site (Fig. 2). 5% had $\geq 90\%$ of the criteria. Overall, National Organizations had the most informational criteria met out of the four types of sites, ranging from 79 to 97% (Table 2). In contrast, the majority (79%) of recipe-based Web sites had below 50% of the criteria met, followed by personal Web sites with 70% below 50% of criteria, and 50% of commercial/marketing Web sites with below 50% of the criteria. Percentage of criteria present on personal sites ranged from 8 to 84%, recipe sites 8% to 64%, and commercial/marketing Web sites 11% to 74% (Table 2).

The criteria that were most frequently met by all categories were mentions of anemia or osteoporosis (85% of all Web sites), lists of the sources of gluten (80%), statements that all gluten should be avoided (82%), and lists of symptoms (73%). These criteria were present in at least 65% of the Web sites from every category.

Table 2 Percentage of total celiac disease-related points of information mentioned by each site type

Category	Min (%)	Median (%)	Max (%)
National Organizations (<i>n</i> = 8)	79	84	97
Personal (<i>n</i> = 27)	8	33	84
Recipes (<i>n</i> = 14)	8	33	63
Commercial/marketing (<i>n</i> = 6)	11	50	74

The criterion featured most commonly on personal sites was links to guidelines (89%). The need to avoid all gluten was the most commonly mentioned criterion on recipe sites (86%). On commercial/marketing Web sites (*n* = 6), stating that an intestinal biopsy is needed for diagnosis and a list of sources of gluten were present on 100% of sites.

Twenty-six of the 38 criteria (68%) were present on 100% of national organization sites. The criteria that were least frequently present on the national organization Web sites were anything deleterious about the diet (25% present), adolescent transition to adult care (38%), links to medical centers (50%), opportunities to support research financially (50%), and the importance of dietary fiber (38%) (Table 1).

The least commonly cited criteria for all categories except national organizations were recommendations for a bone density (28% of all Web sites from the three

Fig. 2 Percentage of criteria present on each Web site

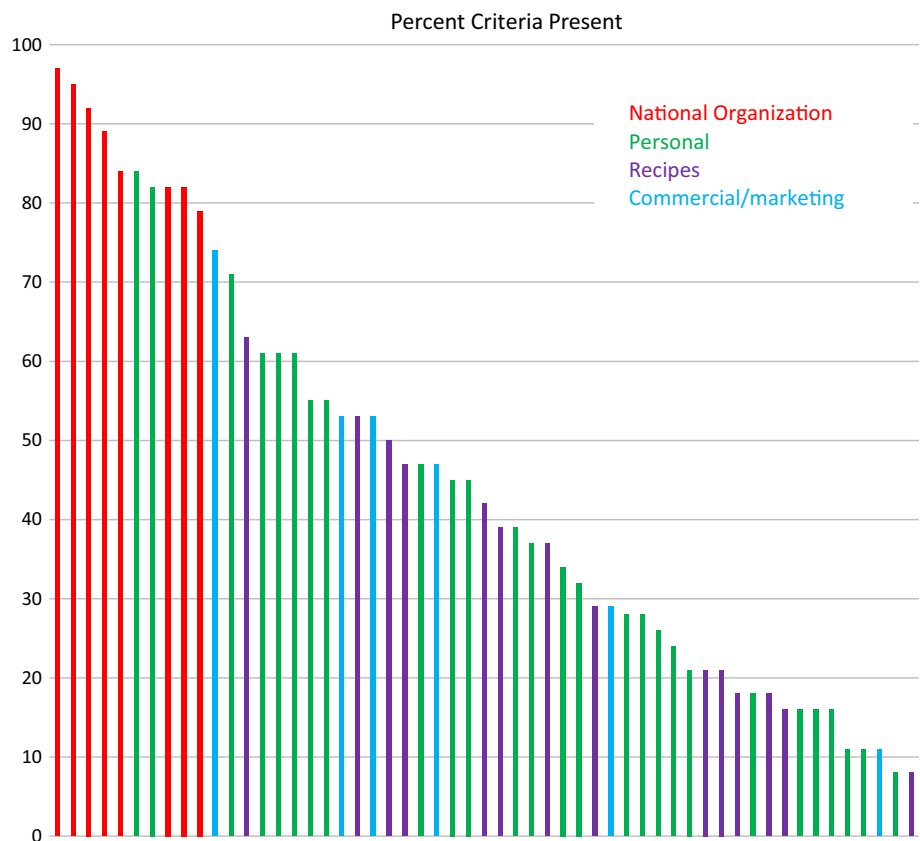


Table 3 False or unproven claims

False/unproven claims
“Gluten destroys all villi”
“After years of gluten injury, it can take 5–10 years for the intestines of celiac patients to recover”
“1 out of 200 people have non celiac gluten sensitivity”
“All it takes is just one microscopic piece of gluten to cause a reaction for a celiac”
“For those who are very sensitive to gluten, the tiny amount of avenin protein in oat can be a problem for them”
“Only about 17% of people with celiac disease in the US are diagnosed”
“In order to develop celiac disease, you at least need the following three things: you need the genes, you need to be eating gluten, you need an unhealthy gut and loss of intestinal barrier function”

Table 4 Percent unproven or false claims

Category	Percent unproven/false claims (%)
National organizations	0
Personal	3
Recipes	6
Commercial/marketing	5

Table 5 Readability level

Category	Average grade-level readability
National organizations	12.4
Personal	8.9
Recipes	8.8
Commercial/marketing	12.2
Overall	9.7

categories), coexistence of other food intolerances (28%), potential non-dietary therapies being developed (26%), information regarding the importance of vaccinations (26%), the need for annual blood tests (23%), anything deleterious about the diet (21%), a statement that a GF diet should be advised/guided by a dietitian (19%), the importance of regular visits with dietitian (19%), links to celiac disease centers (17%), the importance of participating in research (17%), a statement that there are no proven over-the-counter aids to digest gluten (15%), the importance of dietary fiber (13%), the current status of non-dietary therapies (9%), the importance of supporting research financially (9%), links to medical centers (6%), and the importance of transitioning care from adolescence to adulthood (0%). These criteria were present in fewer than 35% of Web sites from each category (Table 1).

We identified 212 health claims from 44 sites regarding gluten, the gluten-free diet, and celiac disease. The vast majority of these claims (205/212, 97%) were deemed accurate. There were seven (3%) false or unproven claims (Table 3), comprising 6% of the claims on recipe sites, 5% on sites selling a product, and 3% of claims on personal sites. No false or unproven claims were found on the sites of national organizations (Table 4).

All categories had an average readability level of over grade 8. National organization had an average level of 12.4. Personal sites had an average level of 8.9. Recipe sites had an average level of 9. Commercial/marketing sites had an average level of 12.2 (Table 5).

All national organizations appeared within the first 30 search items. All other categories were equally distributed throughout the search.

Discussion

In this analysis of 55 Web sites, we found that only 3% of claims were false or unproven. This is reassuring because patients using these resources for the most part are not receiving false information. The false or unproven claims are mostly relating to statistics about the disease and would not cause harm to a patient. For example, the claim “1 out of 200 people have non celiac gluten sensitivity” is not proven, but it does not have the potential to cause a person harm if believed.

Though misinformation was reassuringly rare, it is concerning that many of these Web sites lack pertinent information regarding the diagnosis and management of celiac disease. Sixty percentage of the Web sites had fewer than 50% of the pertinent criteria we developed. National organizations had the most information but still lacked pertinent information. For example, only 25% of these national organization sites stated anything potentially deleterious about the diet such as the possibility of micronutrient deficiencies or weight gain. Additionally, only 38% of national organizations mentioned the need for adolescents with celiac disease to transition to adult care and only 38% of national organizations discussed the importance of fiber in the diet.

Even with these gaps in information, national organizations in general had significantly more information than Web sites of the other three categories. It is clear that there is room for improvement in all areas.

The scope of information provided on personal and/or recipe-based Web sites generally lacked comprehensive or detailed information for a patient. For example, 73% of Web sites listed the symptoms of celiac disease, but only 5% of Web sites suggested a transition of medical care from pediatric/adolescent to adult care. Additionally, the 5% of sites that did mention this criterion are national organizations. The lack of information on the large majority of Web sites analyzed suggests that not enough information is being provided to patients who turn to these sites for information.

The reading grade level is the grade level of education an individual in the USA would need to easily read the information provided [5]. According to the American Medical Association and the National Institutes of Health, the recommended readability level for patient education materials should not exceed a sixth-grade reading level [9]. The average reading skill of a US adult is eighth grade [9]. Only 12.7% of Web sites analyzed had a readability level of sixth grade or below. The average readability level of all categories was above this recommended reading level. If an individual has difficulty reading and understanding the information on a Web site, the greater the chance they will misinterpret the information or not apply it correctly to their life. The need for a patient to have an advanced education due to a high readability level of all Web site categories supports the notion that celiac disease sites are targeting, in effect if not in intent, an audience of high socioeconomic status. Typically, a gluten-free diet is more expensive and is difficult to follow. One study found that on average, gluten-free products are 242% more expensive than non-gluten-free products [10]. On the other hand, celiac disease presentation does appear to be influenced by socioeconomic status. Patients in lower socioeconomic status are less likely to be diagnosed with celiac disease if they present with non-classical symptoms, leading to under-recognized celiac disease in this population [11].

We did not assess medical centers because the goal of this study was to focus on information presented by the layperson for the layperson. Medical center information may be confusing for patients, so they turn to a Web site that is more casual and easier for them to understand. A previous study conducted in 2012 analyzed 98 Web sites, including those from academic or medical institutions. They found that the majority of information on these Web sites was not sufficient and comprehensive enough [5]. Additionally, they found that the readability level of these sites was higher than recommended [5], similar to the results of our analysis.

A study done in 2018, analyzing YouTube videos related to celiac disease, found that many videos were lacking

information determined to be necessary to provide to someone with celiac disease [12]. The accuracy of information presented in the videos was not assessed. Similar to that study, we found that there is a need for an increase in information presented through these mediums.

Our study has several limitations. The exclusion of all sites in a language other than English limits the ability to represent what all Americans are exposed to. Another limitation is the inability to assess all claims made by the Web sites, resulting in the possibility of missing false or unproven claims made in blog posts. Further analysis is necessary to assess the amount of usage of these Web sites and by whom as well as at what point in diagnosis and treatment a patient is accessing the site. This analysis was focused on celiac disease-related information, and the popularity of the gluten-free diet has increased substantially in recent years [14] in people without celiac disease partially due to the misconception that a gluten-free diet is inherently healthy. Additional analysis is needed to assess Web sites discussing a gluten-free diet without an emphasis on celiac disease to determine the validity of claims made on the gluten-free diet in this context.

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Compliance with Ethical Standards

Conflict of interest None of the authors have a conflict of interest in relationship to this topic.

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