

Article

Unauthentic information about celiac disease on social networking pages: is it a matter of concern in celiac disease management?

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Abstract: Facebook (FB) is the most popular online networking platform. There are several FB pages dedicated to spreading awareness about the Celiac disease (CD). To get the latest information, a huge number of CD patients follow Celiac disease Facebook (CD-FB) pages. Such pages frequently post beneficial information. However, very less is known if they provide appropriate information to CD patients. We conducted this study to know if CD-FB pages spread misleading information to CD patients. CD-FB pages from three celiac-influenced countries were explored using the FB platform and Google search engine. From October 2021 to April 2022, a total of 147 CD-FB, Italy (n=63), the USA (n=46), and India (n=38), were found eligible. Of them, 13% of pages (followers Mean±SD; Italy 2478±2011; USA 12635±12486; India 667±313) shared misleading information, particularly about gluten-free ingredients, and treatment of CD. In total, 16% of CD-FB pages discussed alternative treatments option. Surprisingly, 7% of pages (followers Mean±SD; USA 23800±10465; India 628±333) supported alternative treatments for CD. CD-FB pages are useful for disseminating celiac-related information. While most of such pages provide useful information, a few pages sometimes contain misleading information. CD patients must consult their treating unit before following any uncertain information posted on CD-FB pages.

Keywords: celiac disease; gluten-free diet; Facebook; gluten-free ingredients; misleading information, alternative treatment

1. Introduction

In recent times, social networking platforms (Facebook, YouTube, Instagram, Twitter, WhatsApp, etc.) have become the most popular and fastest medium for spreading and exchanging information [1,2]. Additionally, because of their popularity and potential of influencing health and prevention of diseases, such social networking platforms are utilized to spread awareness about diseases amongst people all across the globe [2–4]. Among various social networking platforms, Facebook (FB) is the largest and most popular online networking platform with more than two billion users worldwide [5]. India has the largest number of FB users worldwide (416 million) followed by the USA (240

million) [6]. There are several FB pages dedicated to spreading awareness about the Celiac disease (CD). A large number of CD patients follow celiac disease Facebook (CD-FB) pages to get the latest information and various other celiac-related supports [7].

CD is a small intestine inflammatory condition caused by an immune-mediated response to gluten, a storage protein found in wheat and related grains (rye and barley), in genetically predisposed individuals. At least 1% of the world population is affected by CD [8]. The only accepted treatment for CD is life-long adherence to a strict gluten-free diet (GFD) [9,10]. According to the 'Standard for foods for special dietary use for persons intolerant to gluten CXS 118-1979' revised in 2008, a GFD is a special diet that completely lacks gluten and includes naturally gluten-free food products (e.g. fruits, legumes, meat, fish, and dairy products) or substitute of wheat-based grains (rice, maize, amaranth). Commercial food that does not contain gluten or contains less than 20 mg/kg (ppm) of gluten is labeled as gluten-free [11–13]. Adherence to a strict GFD prevents celiac-specific complications [14].

CD patients are highly sensitive to gluten traces, since a little exposure to gluten (>10 mg/daily) may prevent desirable mucosal healing [15]. Therefore, it is exceptionally important to provide correct information regarding the adherence to a GFD to CD patients. Incorrect information on social networking platforms such as CD-FB pages may mislead CD patients, and thus may adversely impact CD treatment and management.

To follow a strict GFD, celiac-specific dietary counseling is provided by a dietician experienced in celiac disease diet counseling. However, due to the wide use of gluten by the food processing industries [16], complete elimination of gluten from the diet is extremely difficult for CD patients. Poor adherence to a GFD often compromises the quality of life of CD patients [17,18]. Multiple factors including compromised taste, high cost, insufficient nutritional quality, and limited availability have been identified as a barrier to maintaining an excellent adherence to GFD [19]. To be updated about the latest CD news and to get affordable commercial or homemade gluten-free food options, CD patients keep exploring alternative methods of safe dining. To get instant updates, FB is one of the most convenient ways. On FB, a large number of CD-FB pages/communities are available, and such platforms frequently post numerous information related to GFD. There are chances of incorrect posts on CD-FB pages that can mislead CD patients [20,21]. We, therefore, explored the CD-FB pages from three celiac-influenced countries (Italy, USA, and India) to know if they provide appropriate information to CD patients.

2. Materials and Methods

CD-FB pages created from three countries (Italy, USA, and India) were explored using the Facebook social networking platform and Google search engine with different combinations of keywords such as 'Facebook pages on celiac disease <Country name>', 'Celiac disease Facebook page <country name>' and on Facebook using 'Search Facebook' window with keyword, 'Celiac disease page <country name>.' Type of Facebook page (commercial, public, non-profit organization, non-government organization, etc.), country of origin (Italy, USA, India), the purpose of the page (awareness, education, treatment, support, gluten-free recipes, etc.), page web link, number of followers/members, addi-

tional information about CD (if given) (e.g. definition, diagnosis, treatment, and alternative treatment options), were explored and documented in an excel sheet-

All CD-FB pages dedicated to CD in these three countries were included. A huge number of posts were screened from selected CD-FB pages by our celiac research team at the Celiac Disease Research laboratory, Polytechnic University of Marche, Ancona, Italy. If any uncertain post was found, it was discussed among the team member before considering it a misleading post. Pages with <100 members/followers, FB pages with the main purpose to crack jokes on CD (CD fun pages), pages that were not updated in the last three years, and pages only aimed to advertise or promote businesses to sell certified packed gluten-free products were not included. However, pages promoting restaurants vending self-prepared gluten-free food items were included.

2.1 Definitions of specific page type/page purpose

2.1.1 Celiac societies: Celiac societies are volunteer organizations that aim to help CD individuals. Celiac societies generally raise public awareness of CD and try to solve celiac-related legal and political issues. Some celiac societies often support academic research [22].

2.1.2 Awareness and support page: Spreads awareness about CD, its diagnosis, and management. Provides psychological support to CD patients and their families.

2.1.3 Clinical Support page: Helps to understand the clinical cases related to CD, provides useful tips for a correct diagnosis and follow-up through experts, and publication of insights on the latest scientific discoveries. Give answers to doubts related to CD.

2.1.4 Gluten-free recipe (GFR) page: Provides information about preparing gluten-free food (GFF) at home with well-balanced nutrition.

2.1.5 Commercial page: Promotes the local business, gluten-free brand, or homemade gluten-free products.

2.1.6 Public page: Promotes businesses, individuals, and organizations related to CD. Provide the latest information related to CD and spread awareness.

2.2 Statistical analysis

Statistical analysis was performed using Statistical Package for Social Sciences (SPSS) software version 22 (Chicago, USA). 'Chi-square test' or 'Fisher's exact test' (when 'chi-square test' assumptions don't hold due to low expected cell counts) was used to compare these proportions among different groups. The continuous variables (number of followers) were investigated using visual (histogram, probability plots) and analytical methods (Kolmogorov-Smirnov/Shapiro-Wilk's test) to determine if the number of followers was normally distributed. As the number of followers was not normally distributed, 'Kruskal-Wallis test' was conducted to compare these parameters among countries. Later, the 'Mann Whitney U' Test was performed to test the significance of pairwise differences using 'Bonferroni correction' to adjust for multiple comparisons. $p < 0,05$ was used to infer statistical differences. All quantitative variables were summarized as the mean \pm SD in the content.

3. Results

3.1 Number of celiac disease Facebook (CD-FB) pages

From October 2021 to June 2022, a total of 192 CD-FB pages were found potentially eligible (Italy 82, USA 59, and India 51). Following our selection criteria, 45 out of 192 pages (Italy 19, USA 13, and India 13) were excluded from the study. Ultimately, 147 of 192 pages (Italy 63, USA 46, and India 38) were found suitable and included in the study.

3.2 Number of followers on celiac disease Facebook (CD-FB) pages

We found that overall, the USA has the highest number of followers ($n=146485$, Mean \pm SD: 14810 ± 27952) followed by Italy ($n=78411$, Mean \pm SD: 7292 ± 12385) and India ($n=10980$, Mean \pm SD: 125 ± 1827). A significant difference in the followers among the countries was found by Kruskal-Wallis test ($p < 0.001$). Of 147 pages, 54 (37%) had the primary purpose of spreading CD awareness (Italy 22, USA 20, India 12) as well as sharing and learning GF recipes (Italy 29, USA 14, India 11). However, pages with the primary purpose of CD awareness were found to have a higher number of followers ($n=146485$, Mean \pm SD: 10719 ± 24419) in comparison to pages with the primary purpose of gluten-free recipes ($n=38613$, Mean \pm SD: 5551 ± 8203) followed by gluten-free products pages ($n=30466$; Mean \pm SD: 5124 ± 8523). Kruskal-Wallis test showed a non-significant difference among all groups according to the purpose of the FB page ($p=0,89$).

3.3 Type of information on celiac disease Facebook (CD-FB) pages

We looked for information about the definition of CD, GF food, treatment of CD, and alternative (non-dietary) treatment of CD provided by the CD-FB pages and/or discussed in the post comments. We found that 86 (56%) FB pages discussed and gave a satisfactory explanation about CD. Similarly, 97 (66%) and 98 (66%) pages gave a reasonable explanation of CD etiology and treatment, respectively. A total of 135 (92%) pages discussed GF food, most of them sharing GF recipes. Many of the pages were owned by dietitians, and they took care of gluten-free ingredients while explaining GF food.

The purpose and details of every page were carefully screened, and we found that all pages delivered support to CD patients by circulating awareness about CD, encouraging patients by providing information on several naturally prepared or labeled and/or certified gluten-free products, or by organizing financial assistance to underprivileged CD patients. Several FB pages organized seminars, meetings, food festivals, and gluten-free recipe sharing. Pages disseminate information regarding gluten content to food manufacturers, food handlers, restaurants, and food facilities, as well as provide appropriate options. Most pages allow members to share their doubts regarding CD, members often share a picture of any doubtful products to take advice from other group members and the page administrator. While the spread of such information through FB pages is beneficial, we however also found many FB pages spread misleading information about CD and its treatment. We also observed that FB pages owned by non-profit organizations do not post any doubtful information. Moreover, they screen public posts before displaying them on their respective CD-FB page. They also keep an eye on the discussion among the members and provide a scientific justification for their queries. Although other categories of CD-FB pages screen public posts, however, several such pages do not frequently screen posts and sometimes allow suspicious posts to be displayed on their pages.

3.4 Misleading information on celiac disease Facebook (CD-FB) pages

Of 147 CD-FB pages, 19 (13%) pages (Italy 3; USA 5; India 11) (followers Mean \pm SD; Italy 2478 \pm 2011, USA 12635 \pm 12486, India 667 \pm 313) shared misleading information, particularly about gluten-free ingredients, and the CD treatment of (**Table 1, Fig. 1**). In total, 24 (16%) pages discussed alternative treatment (Italy 3, USA 11, India 10) either by their post or by questions asked by the respective FB page members. Nevertheless, most of such posts or comments were defended by the administrator/s or by the follower/s of the respective page using counter-comments. Woefully, 11 (7%) pages (Italy 0, USA 2, India 9) (followers Mean \pm SD; USA 23800 \pm 10465, India 628 \pm 333) surprisingly supported alternative treatments for CD (**Fig. 1**). Unfortunately, the administrator/s did not react/defend such misleading posts/comments.

Apart from this, there was multiple misleading information circulating on CD-FB pages about the scarcity of knowledge. We made a list of some common untrustworthy information that is being dispersed on such CD-FB pages. We tried our best to compile their scientific justification. (**Table 2**)

Table 1: Detail of Celiac Facebook pages with misleading information.

S.No.	CD-FB pagecode	Country	Misleading information**
1.	CD-FB page_9	Italy	Post that wrongly declared gluten-containing ingredients as gluten-free +
2.	CD-FB page_10	Italy	Post that wrongly declared gluten-containing ingredients as gluten-free +
3.	CD-FB page_41	Italy	Post that wrongly declared gluten-containing ingredients as gluten-free +
4.	CD-FB page_83	USA	Alternative treatment available for celiac disease +
5.	CD-FB page_84	USA	Post that wrongly declared gluten-containing ingredients as gluten-free +
6.	CD-FB page_90	USA	Post that wrongly declared gluten-containing ingredients as gluten-free +
7.	CD-FB page_127	USA	Post that wrongly declared gluten-containing ingredients as gluten-free +
8.	CD-FB page_129	USA	Alternative treatment available for celiac disease +
9.	CD-FB page_53	India	Alternative treatment available for celiac disease #
10.	CD-FB page_56	India	Alternative treatment available for celiac disease #
11.	CD-FB page_63	India	Alternative treatment available for celiac disease #
12.	CD-FB page_97	India	Post that wrongly declared gluten-containing ingredients as gluten-free +
13.	CD-FB page_138	India	Alternative treatment available for celiac disease #
14.	CD-FB page_141	India	Post that wrongly declared gluten-containing ingredients as gluten-free +
15.	CD-FB page_142	India	Alternative treatment available for celiac disease #
16.	CD-FB page_143	India	Alternative treatment available for celiac disease #
17.	CD-FB page_144	India	Alternative treatment available for celiac disease #
18.	CD-FB page_145	India	Alternative treatment available for celiac disease #
19.	CD-FB page_146	India	Alternative treatment available for celiac disease #

**Post that wrongly declared gluten-containing ingredients as gluten-free and/or the alternative/non-dietary treatments of celiac disease.

+No justification provided by the CD-FB page administrator; # Information posted by the administrator

Figure 1: Total number of celiac disease Facebook pages allowed posting misleading information related to celiac disease.

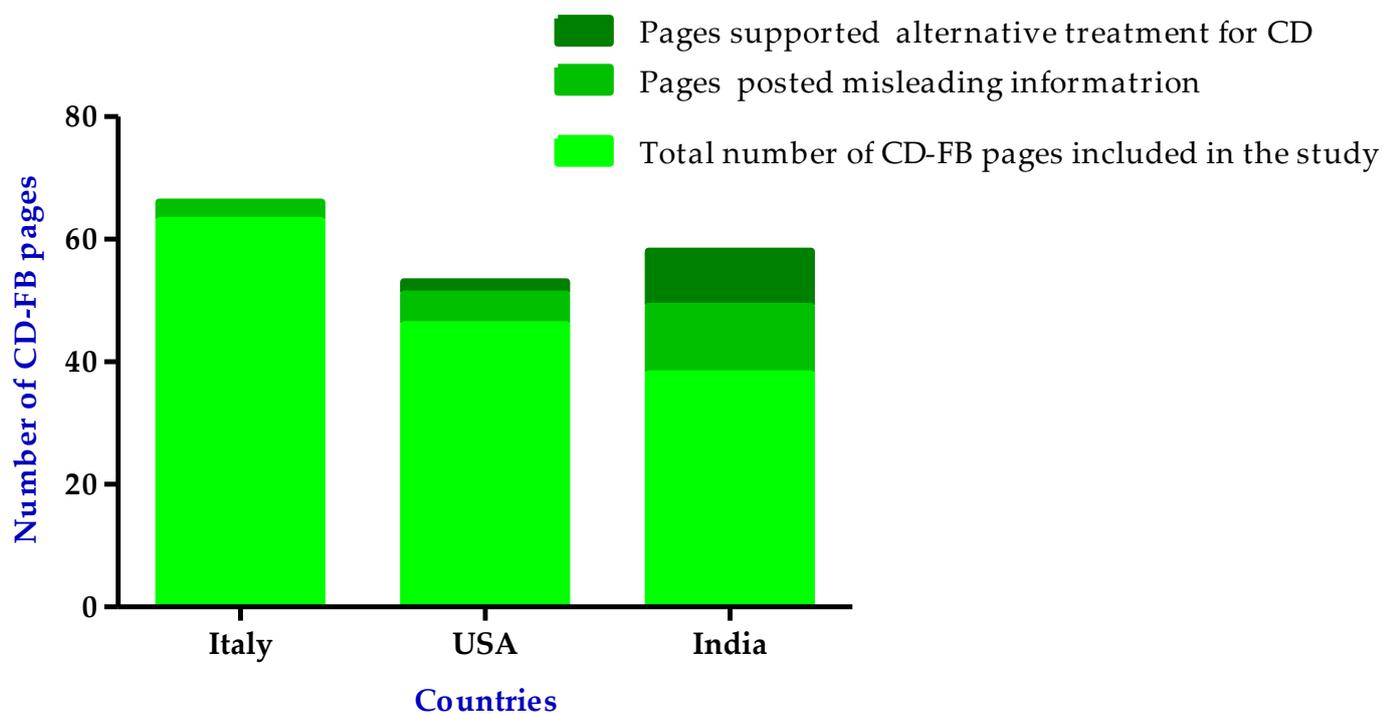


Table 2: Literature-based scientific justifications of some commonly misleading statements on celiac disease Facebook pages.

S.no.	Questions	Uncertain/wrong information among celiac patients	Possible scientific justifications
1.	Is there any dietary/non-dietary treatment available for celiac disease?	Commercially available drugs (Gluten Cutter, Gluten Defense, gluten digest, Glutenaid, etc) digest gluten. CD patients can take such enzyme supplements and can consume gluten.	Commercially available drugs broadly contain proteases with labels claiming that these drugs digest gluten for which they don't have any scientific justifications [23]. Multiple trials are going on to develop a non-dietary treatment for CD. Some possible agents are Latiglutenase, BL-7010, Bifidobacterium infantis, Larazotideacetate (AT-1001), TG2 Inhibitors, HLA-DQ2 or HLA-DQ8 Blockers, etc [24]. However, all these agents are under trial and have no data for their effectiveness on CD.
2.	Can celiac patients drink beer?	Barley-based 'gluten-removed' and/or beer with the label 'processed to remove gluten' is safe for CD patients.	Traditionally, beer is prepared by the fermentation of barley and sometimes from wheat, these grains contain gluten. Therefore, CD patients cannot drink conventionally brewed beer. Beer with the label 'Product fermented from grains containing gluten and processed to remove gluten' can contain gluten hence is not safe for CD patients. However, there is an option of 'gluten-free beer' that is prepared from either naturally gluten-free grains (e.g., rice, maize, etc.) or gluten-containing grains (wheat, barley). In case the beer has been produced from gluten-containing grains, the amount of gluten is reduced by a process called hydrolysis, or enzymes are used in the fermentation process that breaks down gluten. These processes maintain a gluten level of <20 mg/kg and hence can be labeled as gluten-free [25]. According to the EU regulation (Regulation No. 1169/2011 of 25 October 2011), such beers are allowed to label as gluten-free. However, according to the latest report from the Prolamins Working Group (PWG), Food Drug Administration (FDA) has not recognized any analytical method for determining gluten content

			in fermented and hydrolyzed food products. Hence, hydrolyzed items will be considered gluten-free if the used ingredients are gluten-free before the fermentation or hydrolysis process. Hence, gluten-containing grain-based beer (e.g. barley) in which the gluten is removed during the brewing process is not allowed to be labeled as gluten-free [26].
3.	Is turmeric helpful for fighting CD?	Tradition spices like turmeric potentially heal gluten-induced mucosal damage. Hence, it treats CD.	Turmeric is an ancient traditional medicine used to enhance overall immunity. Curcumin is one of the constituents of 'turmeric', which is known for its medicinal properties. Curcumin is considered an effective intestinal antiseptic agent helpful for increasing immunity and overall healing of the gut.[27] A recent study investigated the effect of curcumin but did not consider it as a potential treatment for CD [28].
4.	Can Camel milk cure CD?	Camels have robust immune systems, so their milk provides elements that heal mucosal damage hence useful to treat CD.	Milk is naturally gluten-free, so CD patients can consume milk unless a patient has lactose intolerance. Camel milk has similar benefits as other mammalian milk (cow, goat, etc.). Though a study suggested that camel milk could be a promising therapeutic intervention in autism spectrum disorders (ASD), Camel milk has not been proven as a treatment for CD so far [29,30].
5.	Can CD be treated by plant-derived medicines?	Plant-derived medicines such as chamomile, marshmallow, liquorice help digest gluten	All types of medicines must complete phase-3 clinical trials to be approved by FDA. However, the herbal supplement must get permission from Food and Agriculture Ministry as well before their availability on the market for human use. Therefore, if any type of drug beneficial for CD gets approval from government agencies. It will be fully recognized and will be prescribed by the medical practitioner. So far, there is no information if such plant-derived medicines that have been approved for CD. However, some specific plant-derived medicines such as chamomile, marshmallow, liquorice are controversially promoted as a treatment for CD. Such medicines have anti-inflammatory effects or facilitate digestion [31–33]. These medicines are not specific to CD and can be used for other intestinal disorders as well.
6.	Can a celiac patient be vaccinated with the COVID-19 vaccine?	COVID-19 vaccine may cause serious complications in CD patients	Immuno-compromised patients (e.g. cancer patients) are severely affected by coronavirus disease 2019 (COVID-19) [34]. CD patients (affected only with CD)

			<p>are not immunocompromised so they should take all the standard precautions recommended for healthy individuals. It has been indicated that COVID-19 is not increased in CD patients.[35] However, Our group recommended validating this fact with further longitudinal studies [36]. Nevertheless, COVID-19 vaccination should not cause any potential adverse effects to them. Therefore, CD patients (with defined age restrictions) can proceed with COVID-19 vaccination without any anticipated life-threatening risk [37–39].</p>
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4. Discussion

We reviewed Italian, USA, and Indian CD-FB pages to know the level of authenticity of celiac disease-related information circulated on such pages. According to our findings, 13% of CD-FB pages did not scrutinize potentially misleading posts i.e. any information that misleads celiac patients including alternative treatment options. We found that in comparison to Italy and the USA relatively a larger number of Indian CD-FB pages report misleading information including alternative treatment options ($p=0,04$). In total 7% of pages allowed sharing alternative treatment or non-dietary treatment options (Table 1, Fig. 1). Chi-square test showed a significant difference in the proportions of misleading information among India and other countries ($p=0,04$). On the other hand, we did not find alternative treatment information on Italian CD- FB pages.

We also found significant differences among countries in the total number of followers ($p<0.001$). Mann Whitney U test showed a significant difference in the total followers of The US and India ($p< 0.001$). Moreover, there were significant differences among countries in the followers following misleading pages ($p=0.02$). When all misleading information including alternative treatment pages was evaluated, although India has the highest proportion of misleading CD-FB pages, the number of followers was lesser than in the USA ($p=0.003$). Hence, if a CD-FB page from the USA spreads misleading information, it circulates among a huge number of followers.

Moreover, we believe that those 9 Indian CD-FB pages (commercial page category) that support alternative CD treatment options were created by one organization for different Indian cities. The alternative treatment option was posted by the page administrator claiming to have some medicines that completely heal CD as well as wheat allergy (WA) and allow patients to consume wheat. However, the detail of the therapy was not declared. In our search, we did not find any such information in the medical literature (e.g. PubMed website) or on the ClinicalTrial.gov website. Although, few alternative treatment options are under the clinical trial phase, so far there is no consensus on outcome measures of these trials [24,40]. Circulating such unscientific information could be a major breach in CD management. As all these 9 pages were created by one organization, if we virtually consider them as one page, India has a similar number of pages ($n=2+1$), in comparison to Italy ($n=3$) and the USA ($n=3$), which allows misleading information on their respective CD-FB pages.

We observed that in all three countries followers have a huge interest in GFD and GF food. In Italy, multiple pages recommended shops where celiac patients can find fresh baked GF products and commercial GF food items. Some are personal blogs linked to correspondent websites for certified GF products. In Italy, there is an official GF symbol (cross-ear) that guarantees the safety of GF products [41]. Most of such pages were found reliable. However, at least three pages reported misleading information, a little bit confusing for a person who is not well-informed about scientific topics.

In the USA, FB pages are a little more advanced, although celiac patients are interested in GF recipes, they frequently discuss GF non-food items like soap, shampoo, shower gel, cosmetics, etc. They want to be sure if such non-food items can indirectly expose them to the minute amount of wheat. In India, FB pages are owned by nutritionists/dieticians/specialized organizations, and/or celiac patients (personal blogs). Most of the given information was found correct and updated. Pages with GF recipes were found reliable. In Italy and the USA, people mostly select certified or labeled GF products, while

in India people mostly use traditional naturally gluten-free ingredients to prepare GF food. In India, certified GF food products are quite expensive and not easily available. Therefore, CD patients mostly use self-certified commercial labeled GF food products. However, such food products have a high chance of cross-contamination [41–45]. The cost and availability of GF food products are somewhere associated with GF dietary adherence [46]. To maintain GFD effectively, various CD support programs (monthly food allowance or financial aid) are available in some countries. For example, in Italy, the Italian Ministry of Health provides monthly financial support of up to €124/month to confirmed CD patients (based on gender and age) to buy gluten-free products [47]. In the UK, the Ministry of Health provides monthly gluten-free food aid to celiac patients. Commissions formed by experts in the field of health determined monthly amounts considering the average nutritional requirements of celiac patients, age, gender, gestation, and aging. These units generally cover the basic food groups for celiac patients (bread, flour and flour mixtures, breakfast cereals, crackers, oats, pasta, and pizza dough) [48]. These are very encouraging steps taken by the respective government bodies. However, multiple countries (e.g., India) do not have such policies, and due to this, CD patients who are not financially very sound, face problems.

According to our observation, numerous FB pages owned by non-profit organizations e.g., the Italian celiac association (AIC, Italy), and the National Celiac Association (USA), follow strict criteria to manage their FB pages. Such organizations screen their posts before approving them on their respective CD-FB pages. They also monitor the discussion among members and provide a scientific justification for their queries. However, several other pages do not frequently screen their posts and sometimes probably unintentionally approve suspicious posts.

In this study, we covered a large number of CD-FB pages and reviewed posts and comments over three years. We also tried to justify some frequently discussed doubts on the pages. However, we understand that we should have added some other countries to get more confident results. Nevertheless, the three countries included in this study were celiac-prevalent countries and multiple landmark CD studies have been conducted in these countries [49–51]. Another drawback of our study was the limited years of monitoring of FB posts (i.e., two years), there are chances that there would be some other dubious posts that we would have missed. However, we followed the latest European Society Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) guidelines to judge the celiac disease definitions, and treatment options provided by the CD-FB pages [52]. We took information about gluten-free food and gluten contamination from our previously published work [14,41]. Our study was purely conducted to understand the authenticity of the information being provided on CD-FB pages. We do not intend to defame CD-FB pages or to discourage CD patients from using social networking sites neither we assume that social networking platforms provide wrong information.

5. Conclusions

Celiac disease Facebook pages are useful for disseminating celiac-related latest information. While most of such pages provide useful information to CD patients, a few pages sometimes do not frequently screen the posts and approve unauthentic and misleading information. CD-FB page administrators should screen the posts before approving them on their pages. While following online CD-FB pages, CD patients should also be in contact with their treating units. If they find any unconvincing information, patients should contact their treating unit before following them. Patients should not post any information that they are not fully confident with. During general celiac counseling, clinicians

should inform the patients to protect themselves from fabricated information posted on CD-FB pages. Administrators of CD-FB pages should also collaborate with a health professional for verifying the validity of the information.

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