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ORIGINAL ARTICLE

Worldwide public policies for celiac disease: are patients well assisted?

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Abstract

Objectives To evaluate public policies (PP) to celiac disease (CD) patients and classify countries regarding the level of assistance provided by the Public Policies for Celiac Disease Score.

Methods Countries were scored from 0 to 6 according to the existence of PP regarding industrial food and meal regulations, health service support, food allowance/financial incentive, gluten-free (GF) food certification, and CD associations. Subsequently, countries were allocated to continents.

In total, 192 countries are registered as members of the World Health Organization.

Results The European continent (score 3.63) is the most advanced in CD patient care, followed by South America (2.86), North America (1.05), Asia (0.53), Oceania (0.5), and Africa (0.27). Industrial food regulations were the most frequent PP (40.6%). 15.6% of the countries display regulations for meals; 13.5% have health service support; 13.5% have policies of food allowance/financial incentive; 19.3% have GF certification; and 34.4% have celiac associations.

Conclusions Policies regarding GF meals and food safety certification, health service support, and financial incentives need improvement to ensure correct treatment and reduce the diseases' financial burden for celiac patients and governments.

Keywords Public health · Celiac disease · Legislation · Regulation

Introduction

Celiac disease (CD) is an immune-mediated enteropathy triggered by gluten ingestion in genetically predisposed individuals (Sapone et al. 2012), and the gluten-free diet (GFD) is the only available safe treatment. Following a GFD is hard due to several factors such as lack of information and guidance to healthy gluten-free meal preparation, high food cost, and need for health support and information. The adjustment of long-rooted habits of consuming food prepared with wheat flour to a new diet style, combined with lack of cooking skills, favors treatment transgression impairing the health and quality of life of celiacs and their family (Häuser et al. 2007).

Since food and nutrition are elements included in the Human Right to Adequate Food, the support of public policies (PP) is primordial to help increase celiacs diet adherence, promoting the reduction in symptoms and secondary outcomes (Nadal et al. 2013). Around the world, there are some PP targeted at celiacs; among them, there are regulations concerning industrial food products and meals, health service support, food allowance, financial incentive, and CD associations.

However, no study evaluated and compared the existing PP around the world. Therefore, the study aimed to evaluate PP directed to celiacs worldwide and to classify countries regarding the level of assistance provided to these individuals, agglomerating them in their continents to visualize global celiac assistance better. Potentially, this study could also help health professionals and governmental institutions to develop effective strategies to improve the health and the quality of life of celiacs.

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Methods

Information sources and search strategy

All the 192 countries registered by the World Health Organization (World Health Organization (WHO) 2019) until June 1, 2019, were included in the study. To conduct the PP search, we used the Google Platform and the official websites of the countries, and celiac associations. The final data search and collection occurred on July 15, 2019.

To determine which aspects regarding PP for CD patients would be investigated, we conducted an extensive literature review in the Scopus, Science Direct, PubMed, Web of Science databases, and Google Scholar. We used combinations of truncation and words concerning studies that explored CD diagnosis and monitoring, the GFD, and challenges for diet adherence and food acquisition, especially for low-income populations. Studies of CD welfare were also considered since the quality of life contemplates the gastroenterological, emotional, worries, and social dimensions.

After critically examining studies and identifying the key topics that represent distress for CD patients, the following items composed the first score for evaluating the PP: regulations concerning industrial food products and meals, health service support, food allowance, financial incentive, and CD associations. Subsequently, we conducted a discussion with experts in the area to argue and deliberate the criteria established to evaluate the PP for celiac individuals across countries. The discussion was led by one mediator (researcher) and composed of five Brazilian professors from the University of Brasilia and the Federal University of Goiás, who are all involved in researches regarding CD. The professors suggested separating the item of regulations of food into two, being the first about food products and the second about meals. They also pointed out that the financial incentive category should also be included as food allowance polices. We used the commentaries of the discussion to achieve the final items to construct the instrument.

To evaluate the level of assistance for celiac patients, we developed an instrument with the following questions:

1. Does the country have any regulations concerning industrial packaged food products for people with CD?
2. Does the country have any regulations concerning meals and non-packaged food for people with CD?
3. Is there a specialized health service support for celiac patients?
4. Is there a governmental food allowance and/or financial incentive for CD patients?
5. Is there a GF certification program for manufactured products destined for people with CD?
6. Is there a national CD association?

Once established the final items to compose the score, the following keywords were used in the Google search strategy for PP in combination with each country's name to find its policies: gluten-free products ppm; gluten-free meal ppm, gluten-free regulation; gluten-free food certification; gluten-free labeling; CD regulation; health service support CD; healthcare CD; government support CD; CD association; and CD society. The data collected through the Google search were dichotomously classified and registered as "Yes" or "No," using a standardized table containing the questions mentioned above.

For countries with official languages other than English, the search was also performed in the country's language with the help of the Google Translator tool. Also, in cases in which the online translator was not able to translate the archives, we also contacted countries embassies asking for assistance to understand the data.

Screening process

In the first phase, three investigators independently searched for the instrument's items for each country registered as a WHO member. The investigators used the Google Translator platform to read documents and information in languages other than English and Portuguese (research group native language). In the second phase, a fourth researcher read the data collected, repeated the screening process in cases of registration disagreement between investigators or not founded data, and made a final decision concerning each criteria's positive or negative answer. In the end, the 5th examiner critically proofread the final version of the data collected.

The construction process of the score to evaluate the countries regarding PP for celiac patients and the countries' evaluation is described in Fig. 1.

Score construction and quantitative analysis

We used the positive responses for the six questions of the instrument to construct the Public Policies for Celiac Disease Score (PPCDS). For each "Yes" registered as an answer, 1 point was allocated to the country; therefore, the final result ranged on a scale from 0 to 6 points. The score recognizes the instrument criteria as equally important for complete patient assistance.

The PPCDS was categorized as "High" when the country reached 5 points or more; "Moderate," when the country reached 3 or 4 points; "Low," when the country reached 1 or 2 points, and "Zero," when the country did not score any points.

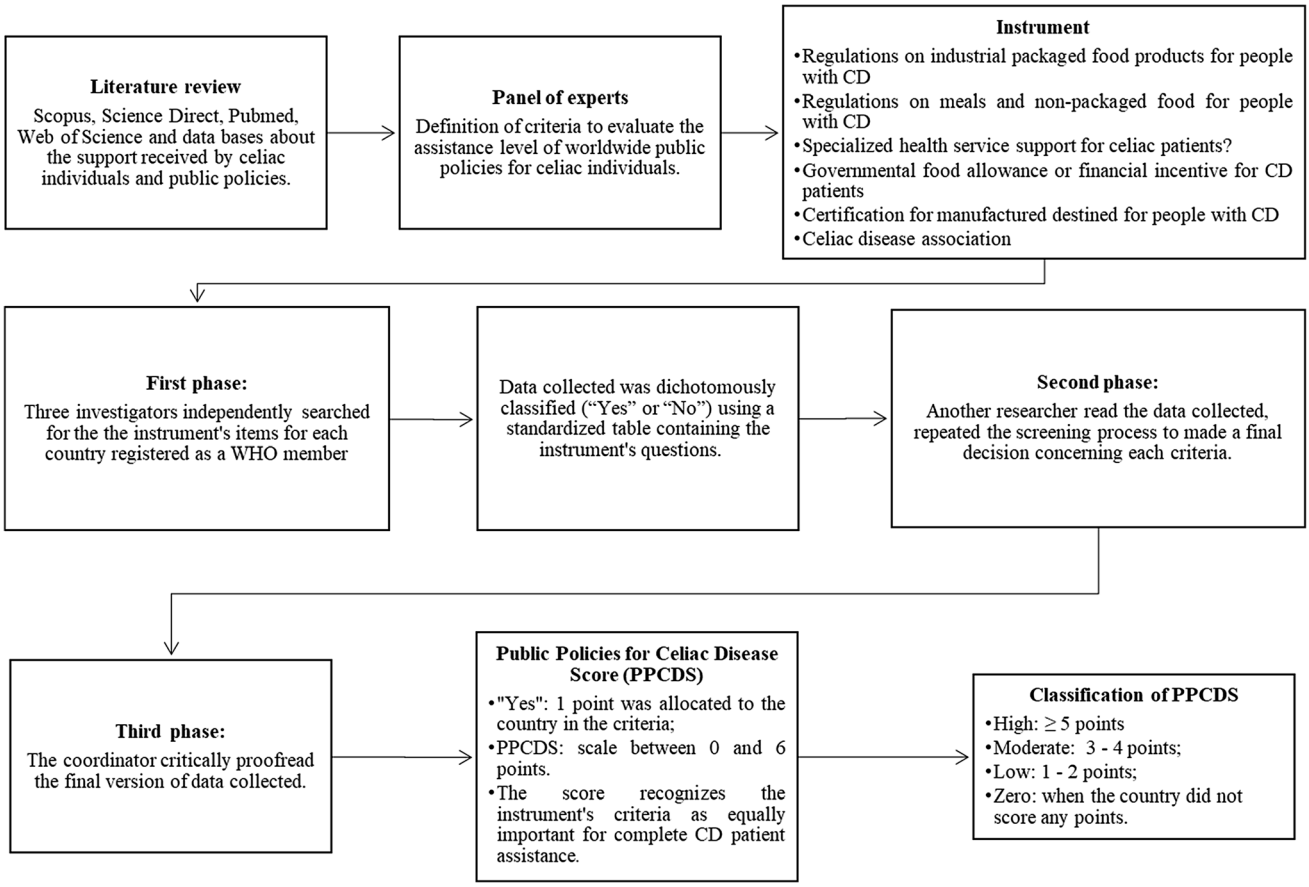

Fig. 1 Process stages of the development of the Public Policies for Celiac Disease Score (PPCDS), 2020

The Statistical Package for the Social Sciences (SPSS) (IBM Corp 2016) and R (R Core Team 2019) software were used to perform descriptive analysis. No inferential statistics analysis was conducted since a country census was performed and not an individual sample analysis.

Results

Score distribution per continents

After the data collection and scoring process, countries were agglomerated in six continents: Europe, South America, North/Central America, Asia, Oceania, and Africa. Table 1 details the countries' score distribution according to their corresponding continent.

The European continent had the highest overall score among the continents (3.63) and 79% ($n = 34$) of its countries classified as moderate and high (Table 1). South America had the second-best overall score (2.86), with 35.7% of its countries concentrated in the moderate classification. The third highest score was achieved by North America, where 50% ($n = 10$) of the countries were classified as low. In total, North America had 90% ($n = 18$) of countries scoring under 3 points. All the other continents obtained a total score lower than 1 point.

Asia presented 95.3% ($n = 41$) of its countries under average classification, with 65.1% ($n = 28$) of Asia's score composed of zero PPCDS. Africa had the lowest total score (0.52), with an unquestionably worrying 100% ($n = 56$) of its countries classified with low and zero scores. Examining Oceania's internal classification distribution, two countries reached moderate scores, and all the others did not score any points, demonstrating a significant discrepancy of CD awareness among Oceania.

Score distribution per countries

Observing the score distribution (Fig. 2 and Table S1), the highest scores are concentrated in the European continent. Only the following six achieved the maximum score: France, Italy, the Netherlands, Slovenia, Sweden, and the UK, offering the best assistance to CD patients. In contrast, 101 countries that correspond to an alarming 52.6% of the WHO members did not score any points.

Table 1 Public Policies for Celiac Disease Score averages and countries' score distribution according to the corresponding continent (Worldwide, 2020)

Continent	Classification				Mean score per continent and standard deviation
	Zero	Low (1–2)	Moderate (3–4)	High (5–6)	
Europe	7 (16.3%)	2 (4.7%)	17 (39.5%)	17 (39.5%)	3.63 (1.98)
South America	1 (7.1%)	5 (35.7%)	5 (35.7%)	2 (21.4%)	2.86 (1.70)
Central/North America	8 (40%)	10 (50%)	2 (10%)	0 (0%)	1.05 (1.15)
Asia	28 (65.1%)	13 (30.2%)	1 (2.3%)	1 (2.3%)	0.53 (0.98)
Oceania	14 (87.5%)	0 (0%)	2 (12.5%)	0 (0%)	0.50 (1.37)
Africa	43 (76.8%)	13 (23.2%)	0 (0%)	0 (0%)	0.27 (0.52)
Total	101 (52.6%)	43 (22.4%)	27 (14.1%)	21 (10.9%)	1.37 (1.88)

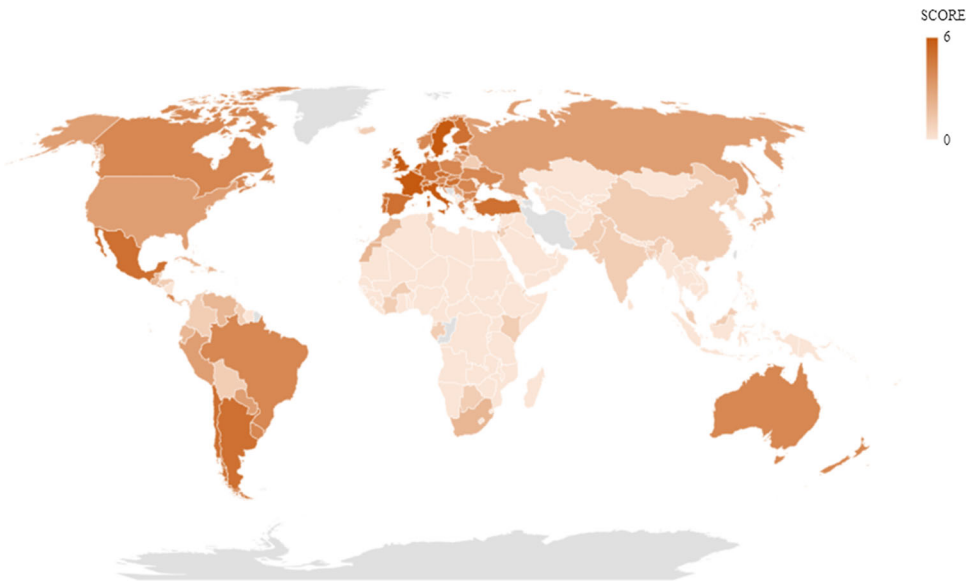

Fig. 2 Worldwide Public Policies for Celiac Disease Score (PPCDS) distribution (Worldwide, 2020). The gray area corresponds to countries that are not members of the WHO. Evaluated countries: Afghanistan, Albania, Algeria, Andorra, Angola, Antigua and Barbuda, Argentina, Armenia, Australia, Austria, Azerbaijan, Bahamas, Bahrain, Bangladesh, Barbados, Belarus, Belgium, Belize, Benin, Bhutan, Bolivia, Botswana, Brazil, Brunei Darussalam, Bulgaria, Burkina Faso, Burundi, Cabo Verde, Cambodia, Cameroon, Canada, Central African Republic, Chad, Chile, China, Colombia, Comoros, Congo, Cook Islands, Costa Rica, Côte d'Ivoire, Croatia, Cuba, Cyprus, Czechia, Democratic People's Republic of Korea, Democratic Republic of the Congo, Denmark, Dijibouti, Dominica, Dominican Republic, Ecuador, Egypt, El Salvador, Equatorial Guinea, Eritrea, Estonia, Eswatini, Ethiopia, Fiji, Finland, France, Gabon, Gambia, Georgia, Germany, Ghana, Greece, Grenada, Guatemala, Guinea, Guinea-Bissau, Guyana, Haiti, Honduras, Hungary, Iceland, India, Indonesia, Iran, Iraq, Ireland, Israel, Italy, Jamaica, Japan, Jordan, Kazakhstan, Kenya, Kiribati, Kuwait, Kyrgyzstan, Lao People's Democratic Republic, Latvia, Lebanon, Lesotho, Liberia, Libya, Lithuania, Luxembourg, Madagascar, Malawi, Malaysia, Maldives, Mali, Marshall Islands, Mauritania, Maurithius, Mexico, Micronesia, Monaco, Mongolia, Montenegro, Morocco, Mozambique, Myanmar, Namibia, Nauru, Nepal, the Netherlands, New Zealand, Nicaragua, Niger, Nigeria, Niue, North Macedonia, Norway, Oman, Pakistan, Palau, Panama, Papua New Guinea, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Republic of Korea, Republic of Moldova, Romania, Russian Federation, Rwanda, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Samoa, San Marino, São Tome And Principe, Saudi Arabia, Senegal, Serbia, Seychelles, Sierra Leone, Singapore, Slovakia, Slovenia, Solomon Islands, Somalia, South Africa, South Sudan, Spain, Sri Lanka, Sudan, Suriname, Sweden, Switzerland, Syrian Arab Republic, Tajikistan, Thailand, Timor-Leste, Togo, Tonga, Trinidad and Tobago, Tunisia, Turkey, Turkmenistan, Tuvalu, Uganda, Ukraine, United Arab Emirates, the UK, United Republic of Tanzania, the USA, Uruguay, Uzbekistan, Vanuatu, Venezuela, Vietnam, Yemen, Zambia, Zimbabue

Score constitution by items responses

For further understanding of which aspects of CD assistance need improvement, Table 2 presents the frequencies and percentages of "positive" answers to each item of the instrument per country.

The most frequent item implemented toward CD patient care is the existence of regulation concerning industrial food products, present in 40.6% of countries and all the countries classified with a high score.

The existence of a celiac association is found in all the high scoring countries and 96.3% of countries with moderate scores. Considering all the countries analyzed, the presence of CD associations was observed only in 34.4% of them, highlighting the relevance of this particular item in offering patient assistance above average. Table 2 shows that 15.6% of countries have regulations concerning GF meals. Among high and moderate scoring countries, a total of 81% and 48.1% presented this CD assistance item, respectively.

GF certification for manufactured meals exists in 19.3% of countries of low, moderate, and high scores. The specialized health service support and food allowance and/or financial incentive items exist in 13.5% of countries (only in moderate and high scoring areas).

The European continent stood out, punctuating the overall most significant percentages in 4 out of 6 items (Table 3). Analyzing its internal rating, Europe achieved its highest positive responses in GF regulation for industrial food products and the presence of CD associations. Items 3 and 4 (specialized health service support and food allowance and/or financial incentive) were present in less than half of its countries, 37.2%, and 46.5%, respectively, indicating that need improvement regarding patient's assistance in the continent.

South America had item 1 (regulations concerning industrial food products) as its most punctuated element, followed by item 6 (existence of CD associations). Since items 2–5 did not reach 50% of "positive" answers and item 2 obtained the lowest continents percentage (14.3%), all those elements need improvement, especially the development and implementation of regulations concerning GF meals.

The other continents did not achieve over 50% of positive responses to the PPCDS items. Among those, North America obtained 45% of item 1 and 40% of item 6. It also did not punctuate the food allowance and/or financial incentive criteria. Even though all the items need measures for amelioration, items 2–5 require special attention, since they are only present in $\leq 10\%$ of North America's countries, which corresponds to 2 countries or less in the whole continent.

Asia's highest scored items were also items 1 (23.3%) and 6 (20.9%). Despite being the most punctuated items, those percentages are low and correspond to less than one-fourth of the continents' countries. All items require intervention, especially items 2–5.

Only two countries from Oceania punctuated in the PPCDS, Australia, and New Zealand (Tables 3 and S1). Those two countries scored all items except the ones regarding GF meal regulations and food allowance and/or financial support. Therefore, these countries need to improve items 2 and 4, and all the other countries require urgent measures to develop CD assistance nationally.

In the African continent, the most frequent item was the presence of GF regulation for industrial products (with a low percentage of 17.9%). Items 5 and 6 were only punctuated by 2 and 3 out of 56 countries, respectively, and the other items were not scored by any country.

Overall, 17.19% ($n = 33$) out of the 192 countries included in this study presented at least one of the policies analyzed, and in 52.6% ($n = 101$), no PP information was found. Data of the countries that did not score points may not exist or may have been lost due to linguistic barriers or no response to the attempted contact with the countries' instances.

Table 2 Number of countries (n) and percentages of positive response to items of the Public Policies Celiac Disease Score instrument according to countries' classification (Worldwide, 2020)

Items	Classification				Total ($n = 192$)
	Zero ($n = 101$)	Low (1–2) ($n = 43$)	Moderate (3–4) ($n = 27$)	High (5–6) ($n = 21$)	
Item 1	0 (0%)	32 (74.4%)	25 (92.6%)	21 (100%)	78 (40.6%)
Item 2	0 (0%)	0 (0%)	13 (48.1%)	17 (81.0%)	30 (15.6%)
Item 3	0 (0%)	0 (0%)	11 (40.7%)	15 (71.4%)	26 (13.5%)
Item 4	0 (0%)	0 (0%)	8 (29.6%)	18 (85.7%)	26 (13.5%)
Item 5	0 (0%)	2 (4.7%)	16 (59.3%)	19 (90.5%)	37 (19.3%)
Item 6	0 (0%)	19 (44.2%)	26 (96.3%)	21 (100%)	66 (34.4%)

Item 1, regulations concerning industrial food products; Item 2, regulations relating to meals; Item 3, specialized health service support; Item 4, food allowance and/or financial incentive; Item 5, gluten-free certification for manufactured meals; Item 6, celiac disease associations

Table 3 Number of countries (*n*) and percentages of positive responsive to items of the Public Policies Celiac Disease Score instrument, according to continents (Worldwide, 2020)

Items	Continent						Total (*n* = 192)
	Africa (*n* = 56)	North America (*n* = 20)	South America (*n* = 14)	Europe (*n* = 43)	Asia (*n* = 43)	Oceania (*n* = 16)	
Item 1	10 (17.9%)	9 (45.0%)	13 (92.9%)	34 (79.1%)	10 (23.3%)	2 (12.5%)	78 (40.6%)
Item 2	0 (0%)	1 (5.0%)	2 (14.3%)	27 (62.8%)	0 (0%)	0 (0%)	30 (15.6%)
Item 3	0 (0%)	1 (5%)	6 (42.9%)	16 (37.2%)	1 (2.3%)	2 (12.5%)	26 (13.5%)
Item 4	0 (0%)	0 (0%)	4 (28.6%)	20 (46.5%)	2 (4.7%)	0 (0%)	26 (13.5%)
Item 5	2 (3.6%)	2 (10.0%)	5 (35.7%)	25 (58.1%)	1 (2.3%)	2 (12.5%)	37 (19.3%)
Item 6	3 (5.4%)	8 (40.0%)	10 (71.4%)	34 (79.1%)	9 (20.9%)	2 (12.5%)	66 (34.4%)

Item 1, regulations concerning industrial food products; Item 2, regulations relating to meals; Item 3, specialized health service support; Item 4, food allowance and/or financial incentive; Item 5, gluten-free certification for manufactured meals; Item 6, celiac disease associations

Discussion

CD is considered a public health problem; therefore, countries started to search for strategies to assist their celiac population (Barada et al. 2012; Bacigalupe and Plocha 2015). Since the CD treatment consists of the GFD (Itzlinger et al. 2018), it is essential to ensure that the food sold or distributed to the consumer has less than 20 ppm (mg/kg) (Codex Alimentarius Comission 2008). Gluten cross-contamination (GCC) may happen along the food production chain (Falcomer et al. 2018). A systematic review identified the occurrence of 13.2% GCC in industrial food products and 41.5% in non-industrial, demonstrating that industrial products labeled as GF presents the lower percentage of contamination than non-industrialized (Falcomer et al. 2018). Therefore, regulations concerning all GF food and GF certification for manufactured food are important to minimize GCC, contributing to food safety and celiacs' health (Farage et al. 2017; Falcomer et al. 2018).

In addition, to ensure of GF food safety, the promotion of food accessibility is also crucial to help increase adherence to the GFD (Bacigalupe and Plocha 2015). GF food has a higher cost compared to gluten-containing food (Mogul et al. 2017), representing a hazard for celiacs' access to adequate food (Zarkadas et al. 2013; MacCulloch and Rashid 2014). Nadal et al. (2013) claim it as a condition that violates the principle of the human right to adequate food since it puts celiacs into permanent food insecurity. Not been able to afford proper food because of its higher cost is a factor that may cause loss of quality of life, non-adherence to treatment, and socialization difficulties (Troncone et al. 2008; Pouchot et al. 2014; Pratesi et al. 2018). Studies have been conducted to determine which aspects can negatively impact celiac life and how. Hauser et al. (2006) developed an instrument to measure celiacs' perception of the quality of life with four domains (emotions, social, worries, and gastrointestinal) showing that CD may impact in multidimensions of life and needs to be closely watched by health professionals. Even though the treatment is based on food restriction, symptoms and social well-being of celiacs can be improved with GFD adherence (Häuser et al. 2006; Casellas et al. 2013; Marchese et al. 2013; Pouchot et al. 2014; Aksan et al. 2015; Pratesi et al. 2018). Therefore, PP for these individuals are essential to support the treatment and their quality of life.

An interesting strategy to encourage GFD adherence and reduce food inaccessibility is arranging a governmental food allowance or financial support to purchase GF food. Those arrangements constitute important PP that may facilitate individuals following the GFD and minimize one of the disease burdens (Cataldo and Montalto 2007; Mogul et al. 2017).

In addition to the dietary facet of CD, there is an economic facet. The government costs associated with the disease are being studied to determine its impact on the total direct medical costs care (Mogul et al. 2017). Poor recognition of CD symptoms and delayed diagnosis contribute to serological and histological features that may contribute to gut mucosal damage and, as a consequence, induce the development of other diseases linked to CD (Bertini et al. 2009; Shamir et al. 2014). As a result, a non-treated CD may indirectly generate a negative impact on the country's economy (Mogul et al. 2017).

On the other hand, early diagnoses may minimize the CD impact on health. A study suggested a 29% reduction in the patient costs in the year following diagnosis and a 39% overall reduction in the total medical cost of care (Long et al. 2010). This economic burden may be reduced with adequate health assistance, knowledge of the disease, and access to proper diagnostic methods, to facilitate early

detection and treatment, and to reduced risk to develop other disorders(Cataldo and Montalto 2007; Long et al. 2010).

Additionally, to attenuate social barriers (as the process of accepting the diagnosis, learning what food contains or does not contain gluten, feeling different because of the dietary pattern, alternating vacation plans, not participating in celebrations) and make a living with CD easier, participation in social groups of individuals with the disease may endorse the "belonging feeling" and propitiate sharing frustrations and successes, increasing treatment adherence and quality of life (Häuser et al. 2007; Nadal et al. 2013; Marchese et al. 2013; Bacigalupe and Plocha 2015; Pratesi et al. 2018).

After analyzing the CD scenario and the primordial aspects to guarantee its adequate dietary treatment and management, the evaluation of PP created specifically to this population was perceived as an essential process for identifying how to improve worldwide celiac assistance.

Worldwide current management of CD

The PPCDS analysis indicates that Europe displays a greater commitment with the CD cause (3.63), classified as moderate in the score. As CD was once believed to affect only the European population, it is possible that the awareness of the disease and its causes motivated early diagnoses and specified healthcare assistance (Mustalahti et al. 2010). Only six European countries reached the maximum score (France, Italy, the Netherlands, Slovenia, Sweden, and the UK).

Despite Europe's higher overall score, the average points still show that policies may be improved, particularly in the implementation and training of a specialized healthcare system for patients (Table 2).

South America presented the second-best scores for all the items in which Argentina stands out due to its important policies for celiacs, which include specific legislation for CD related to national medical care, clinical and epidemiological research, professional training in early detection, diagnosis and CD treatment; specific legislation for the food industry and food services; provision of gluten-free food or food subsidies; existence of a celiac association; and specific food labeling declaring the presence of gluten (limit of 10 ppm of gluten to be considered gluten-free) (Congreso de la nacion argentina 2009, 2015).

Brazil also displays interesting political approaches to support celiacs, such as the creation of the Intersectoral Technical Committee for Comprehensive Care for Celiacs; the Celiac Disease Assistance Program in the Rio de Janeiro; municipal laws on the provision of special food for celiac students from public schools; labeling legislation regarding the presence of gluten in industry products and some state laws applied to food services; among others. Besides those policies, the existence of the Health Unique System (SUS) in Brazil ensures free access to health care (Brasil 2020).

Even studies showing the CD incidence in Asia, the continent only reached 0.53 points in the PPCDS, and 65.1% of its countries did not score any points. Asia demonstrates a lack of engagement of the governments and associations toward celiacs' care (Fig. 2). It is important the creation and enhancement of PP for celiacs, and to highlight that recent studies conducted in developing countries in Asia have shown increasing numbers of CD prevalence, and some authors refer to it as a "new endemic disease" (Catassi et al. 1999; Cataldo and Montalto 2007).

The only Asian country that achieved a high score was Turkey, and this finding could be related to more significant CD awareness in the region, since it affects between 1:100 and 1:200 of Turkish individuals (Aksan et al. 2015). Turkey was also one of the countries where the CD-QoL was applied, demonstrating the country's efforts to improve CD assistance and quality of life (Aksan et al. 2015). Results from that research showed that although sociodemographic parameters of the Turkish sample were similar to the ones from celiac health surveys in Germany (Häuser et al. 2006) and Italy (Marchese et al. 2013), the scores in all subscales and overall were lower in the Turkish study population (Aksan et al. 2015). Although Turkey stands out positively from its continent, there is still work to make living with CD easier in the country.

Africa as a really fainted area in the worldwide PPCDS distribution (Fig. 2). The near-zero overall average of the continents' PPCDS stresses an enormous concern in patients' health care. Studies in Africa have argued that the lower prevalence in some regions of the continent and the complete absence of data in other regions are related to the lack of diagnostic facilities with technology to perform CD examinations (Fasano and Catassi 2001; Cataldo and Montalto 2007; Catassi et al. 2015). Also, in Africa, poor diseases are common, and their symptoms may present a bias for being similar to CD.

In contempt for the CD diagnostic difficulties in the African continent, a study in the Sahara region (Catassi et al. 1999) revealed an alarming prevalence of 5.6% of anti-endomysium antibody positivity identified in 989 samples of unselected Saharawi children. This result is higher than the ones found in most European countries (Catassi et al. 1999, 2015), demonstrating that prevalence is increasing in developing countries. In the African continent, the highest scores were achieved by Morocco and South Africa, though their punctuation was still classified as low in the PPCDS. Those numbers emphasize the necessity of not only specialized health care but also

policies to assist those individuals in managing the disease (Cataldo and Montalto 2007; Barada et al. 2012).

The Oceanian continent has a considerable discrepancy between countries (Tables 1 and 3, Fig. 2, and Supplementary material - Table S1). Australia and New Zealand were the two countries that achieved a moderate score, and all the other countries did not punctuate at all. The difference between the countries could be related to economic aspects and also a lack of knowledge about CD in the smaller islands, in which PP could provide the means to correct information, proper CD diagnosis, and treatment.

Among the current PP around the globe, national regulation of GF products sold or distributed to the population attending the *Codex Alimentarius* standards for GF food is the most common policy adopted by countries. The creation and embodiment of CD associations is also a policy frequently adopted around the world.

Some countries have developed food allowance or financial incentive policies that have proved to be effective. The UK has a food allowance strategy in which patients with CD receive prescriptions for GF food, in order to incentive GFD adhesion and as an effort to minimize the financial burden with more expensive food. In other countries as Romania, Canada, and Portugal, celiacs are eligible to tax exemption or discounts to buy GF as a financial incentive.

Regarding GF meals and its certification, most countries that legislate non-packaged GF food and also present GF security certification performed by private companies. Among these countries are Costa Rica, Croatia, Cyprus, Czechia, Denmark, and Estonia.

The lack of control in the food production chain, whether in the industry or food services, may lead to gluten cross-contamination in supposedly gluten-free food and consequent transgression in the treatment of CD, which negatively impacts patients' health (Farage et al. 2019) and may overload the health system. Results from this study show that many countries still lack adequate health support for the treatment of CD, which can potentially increase the complications resulting from the disease and mortality.

In summary, the GFD and CD health assistance represent public health challenges, especially in developing countries (Cataldo and Montalto 2007; Nadal et al. 2013). Implementing policy changes may be a "quick win" for national health services and populations under extreme financial pressure (Linton et al. 2018). Understanding the difficulties faced by the patients may help improve their lives, reducing their burdens and the overall economic impact of CD.

There are methodological limitations since the study conducted a census of countries and information was collected through websites in various languages, despite the usage of a translator platform and attempting to reach countries embassies and government agencies, some data could have been missed due to language barriers.

Conclusions

The PPCDS was composed of six questions, and it was categorized as "High" ($\geq$ 5 points), "Moderate" (3–4 points), "Low" (1–2 points), and "Zero" when the country did not score any points. The European continent is more advanced in celiacs' care than the other continents. Regulations concerning GF industrial products were the most frequent policies identified on PPCDS. However, to ensure correct treatment adhesion, it is necessary to also regulate GF meals in food services. The overall low results in policies regarding GF meals, health service support, and financial incentives demonstrate the need for more policies. Since CD is a worldwide health concern that represents dietary, social, and economic challenges, it is primordial that countries improve their healthcare assistance for celiacs for preventing health complications that will also economically impact countries.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

References

Aksan A, Mercanligil SM, Häuser W, Karaismailo E (2015) Validation of the Turkish version of the Celiac Disease Questionnaire (CDQ). Health Qual Life Outcomes 13:1–7. https://doi.org/10.1186/s12955-015-0272-y

Bacigalupe G, Plocha A (2015) Celiac is a social disease: family challenges and strategies. Fam Syst Heal 33:46–54. https://doi.org/10.1037/fsh0000099

Barada K, Abu Daya H, Rostami K, Catassi C (2012) Celiac disease in the developing world. Gastrointest Endosc Clin. https://doi.org/10.1016/j.giec.2012.07.002

Bertini I, Calabrò A, De Carli V et al (2009) The metabonomic signature of celiac disease. J Proteome Res 8:170–177. https://doi.org/10.1021/pr800548z

Brasil (2020) Sistema Único de Saúde (SUS). In: Ministério da Saúde

Casellas F, Rodrigo L, Molina-Infante J et al (2013) Transcultural adaptation and validation of the Celiac Disease Quality of Life Transcultural adaptation and validation of the Celiac Disease Quality of Life (CD-QOL) survey, a specific questionnaire to measure quality of life in patients with celiac dis. Rev Espanõla Enfermedades Dig 105:585–593. https://doi.org/10.4321/S1130-01082013001000003

Cataldo F, Montalto G (2007) Celiac disease in the developing countries: a new and challenging public health problem. World J Gastroenterol 13:2153–2159

Catassi C, Ratsch I-M, Gandolfi L et al (1999) Why is coeliac disease endemic in the people of the Sahara? Lancet 354:647–648

Catassi C, Gatti S, Lionetti E (2015) World perspective and celiac disease epidemiology. Dig Dis 33:141–146. https://doi.org/10.1159/000369518

Codex Alimentarius Comission (2008) Draft Revised Standard for Foods for Special Dietary Use for Persons Intolerant to Gluten, Joint FAO/WHO Food Standards Program

IBM Corp (2016) SPSS: statistical package for the social sciences. Version 24.0

Falcomer AL, Araújo LS, Farage P et al (2018) Gluten contamination in food services and industry: a systematic review. Crit Rev Food Sci Nutr. https://doi.org/10.1080/10408398.2018.1541864

Farage P, de Medeiros Nóbrega YK, Pratesi R et al (2017) Gluten contamination in gluten-free bakery products: a risk for coeliac disease patients. Public Health Nutr 20:413–416. https://doi.org/10.1017/S1368980016002433

Farage P, Zandonadi RP, Gandolfi L et al (2019) Accidental gluten contamination in traditional lunch meals from food services in Brasilia, Brazil. Nutrients 11:1–11

Fasano A, Catassi C (2001) Current approaches to diagnosis and treatment of celiac disease: an evolving spectrum. Gastroenterology 120:636–651. https://doi.org/10.1053/gast.2001.22123

Häuser W, Gold J, Stein J et al (2006) CDQ germany.pdf. Eur J Gastroenterol Hepatol 18:747–753

Häuser W, Stallmach A, Caspary WF, Stein J (2007) Predictors of reduced health-related quality of life in adults with coeliac disease. Aliment Pharmacol Ther 25:569–578. https://doi.org/10.1111/j.1365-2036.2006.03227.x

Honorable Congreso de la Nacion Argentina (2009) Ley 26588/2009. In: Ley 26588. https://www.argentina.gob.ar/normativa/nacional/ley-26588-162428/texto. Accessed 31 Jan 2020

Honorable Congreso de la Nacion Argentina (2015) Ley 27196/2015. In: Ley 27196. https://www.argentina.gob.ar/normativa/nacional/ley-27196-255225/texto. Accessed 1 Feb 2020

Itzlinger A, Branchi F, Elli L et al (2018) Gluten-free diet in celiac disease—forever and for All? Nutrients 10:1796. https://doi.org/10.3390/nu10111796

Linton MJ, Jones T, Owen-Smith A et al (2018) Breaking bread: examining the impact of policy changes in access to state-funded provisions of gluten-free foods in England. BMC Med. https://doi.org/10.1186/s12916-018-1106-7

Long KH, Wagie AE, Iii LJM et al (2010) The economics of coeliac disease: a population-based study. Aliment Pharmacol Ther 32:261–269. https://doi.org/10.1111/j.1365-2036.2010.04327.x

MacCulloch K, Rashid M (2014) Factors affecting adherence to a gluten—free diet in adults with coeliac disease. Paediatr Child Health 19:305–309

Marchese A, Klersy C, Biagi F et al (2013) Quality of life in coeliac patients: Italian validation of a coeliac questionnaire. Eur J Intern Med 24:87–91

Mogul D, Nakamura Y, Seo J et al (2017) The unknown burden and cost of celiac disease in the U.S. Expert Rev Pharmacoecon Outcomes Res 17:181–188. https://doi.org/10.1080/14737167.2017.1314785

Mustalahti K, Catassi C, Reunanen A et al (2010) The prevalence of celiac disease in Europe: results of a centralized, international mass screening project. Ann Med 42:587–595. https://doi.org/10.3109/07853890.2010.505931

Nadal J, Ferreira SMR, da Costa IB, Schmidt ST (2013) The principle of human right to adequate food and celiac disease: advancements and challenges. Demetra Food Nutr Heal 8:411–423

Pouchot J, Despujol C, Malamut G et al (2014) Validation of a French version of the quality of life "celiac disease questionnaire". PLoS ONE 9:1–9. https://doi.org/10.1371/journal.pone.0096346

Pratesi CB, Häuser W, Uenishi RH et al (2018) Quality of life of celiac patients in Brazil: questionnaire translation, cultural adaptation and validation. Nutrients 10:1–12. https://doi.org/10.3390/nu10091167

R Core Team (2019) R: a language and environment for statistical computing. R Foundation fro Statistical Computing, Vienna

Sapone A, Bai JC, Ciacci C et al (2012) Spectrum of gluten-related disorders: consensus on new nomenclature and classification. BMC Med 10:13. https://doi.org/10.1186/1741-7015-10-13

Shamir R, Heyman MB, Koning F et al (2014) Celiac disease. J Pediatr Gastroenterol Nutr 59:S1. https://doi.org/10.1097/MPG.0000000000000410

Troncone R, Ivarsson A, Szajewska H, Mearin ML (2008) Review article: Future research on coeliac disease—a position report from the European multistakeholder platform on coeliac disease (CDEUSSA). Aliment Pharmacol Ther 27:1030–1043. https://doi.org/10.1111/j.1365-2036.2008.03668.x

World Health Organization (WHO) (2019) Alphabetical list of WHO member states

Zarkadas M, Dubois S, MacIsaac K et al (2013) Living with coeliac disease and a gluten-free diet: a Canadian perspective. J Hum Nutr Diet 26:10–23. https://doi.org/10.1111/j.1365-277X.2012.01288.x