

The Brazilian State has assured the human right to adequate food for people with celiac disease?

O Estado brasileiro tem garantido o direito humano à alimentação adequada às pessoas com doença celíaca?

¿Ha garantizado el Estado brasileño el derecho humano a una alimentación adecuada para las personas celíacas?

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Abstract

Introduction: By assuming adequate food as a social right, the Brazilian State became the bearer of the duty to respect, provide, promote and protect the Human Right to Adequate Food (HRAF) for all Brazilians, including celiacs. Therefore, it is essential that the State institute a normative apparatus compatible with the needs of the celiac population, guaranteeing the fulfillment of their rights. **Objective:** to assess whether the legislation in force in Brazil meets the demands of people with celiac disease. **Methods:** document analysis was adopted according to the methodology proposed by Pimentel. The set of documents analyzed is composed of all publications found that express the demands of celiacs, including: articles, manuals and complaint letters from representative bodies. **Results:** The incipience of legal instruments was observed, aggravated by the fact that a significant portion of the demands of the celiac population has not yet been covered by the current set of regulations. The legislation in force expresses the existence of specific initiatives in some Brazilian states and municipalities, which do not cover the entire national territory. This situation does not comply with the principle of universality that governs the HRAF, compromising the demand for compliance and reparation by public bodies for the celiac population. **Conclusion:** due to the punctual and incipient nature of the Brazilian legal apparatus, it remains predominantly the responsibility of civil society, individually or through representative associations, initiatives that guarantee the realization of the Human Right to Adequate Food for celiacs.

Keywords: Celiac disease; Human Right to Adequate Food; Legislation.

Resumo

Introdução: Ao assumir a alimentação adequada como um direito social, o Estado brasileiro passou a ser portador do dever de respeitar, prover, promover e proteger o Direito Humano à Alimentação Adequada (DHA) para todos os brasileiros, inclusive os celíacos. Para tanto, é imprescindível que o Estado institua um aparato normativo compatível com as necessidades da população celíaca, garantindo o cumprimento de seus direitos. **Objetivo:** avaliar se a legislação em vigor no Brasil atende às demandas das pessoas com doença celíaca. **Métodos:** foi adotada a análise documental de acordo com a metodologia proposta por Pimentel. O conjunto de documentos analisados é composto por todas as publicações encontradas que expressam as demandas dos celíacos, incluindo: artigos, manuais e cartas de reclamação das instâncias representativas. **Resultados:** Observou-se a incipiência dos instrumentos legais, agravada pelo fato de uma parcela significativa das demandas da população celíaca ainda não ter sido contemplada pelo atual conjunto normativo. A legislação em vigor expressa a existência de iniciativas específicas de alguns estados e municípios brasileiros, não abrangendo todo o território nacional. Esta situação não obedece ao princípio da universalidade que rege o DHA, comprometendo a exigibilidade do seu cumprimento e reparação pelos órgãos públicos à população celíaca. **Conclusão:** devido ao caráter pontual e incipiente do aparato jurídico brasileiro, permanece, predominantemente, a carga da sociedade civil, individualmente ou por meio de associações representativas, iniciativas que garantam a realização do Direito Humano à Alimentação Adequada dos celíacos.

Palavras-chave: Doença celíaca; Direito Humano à Alimentação Adequada; Legislação.

Resumen

Introducción: Al asumir la alimentación adecuada como un derecho social, el Estado brasileño se convirtió en portador del deber de respetar, proveer, promover y proteger el Derecho Humano a la Alimentación Adecuada (HRAF) para todos los brasileños, incluidos los celíacos. Por tanto, es fundamental que el Estado instituya un aparato normativo compatible con las necesidades de la población celíaca, garantizando el cumplimiento de sus derechos. **Objetivo:** evaluar si la legislación vigente en Brasil responde a las demandas de las personas celíacas. **Métodos:** se adoptó el análisis de documentos según la metodología propuesta por Pimentel. El conjunto de documentos analizados está compuesto por todas las publicaciones encontradas que expresan las demandas de los celíacos, incluyendo: artículos, manuales y cartas de denuncia de órganos representativos. **Resultados:** Se constató la incipiencia de los instrumentos legales, agravada por el hecho de que una parte importante de las demandas de la población celíaca aún no ha sido cubierta por la normativa vigente. La legislación vigente expresa la existencia de iniciativas específicas en algunos estados y municipios brasileños, que no cubren todo el territorio nacional. Esta situación no cumple con el principio de universalidad que rige la HRAF, comprometiendo la exigencia de cumplimiento y reparación por parte de los organismos públicos para la población celíaca. **Conclusión:** debido al carácter puntual e incipiente del aparato legal brasileño, sigue siendo predominantemente responsabilidad de la sociedad civil, individualmente o a través de asociaciones representativas, iniciativas que garantizan la realización del Derecho Humano a la Alimentación Adecuada para celíacos.

Palabras clave: Enfermedad celíaca; Derecho Humano a Una Alimentación Adecuada; Legislación.

1. Introduction

Celiac Disease (CD) is an immune-mediated enteropathy triggered by exposure to gluten, the main protein fraction present in wheat, rye, barley and oats, in genetically predisposed individuals (Ordinance MS/SAS n° 307, 2009; Ludvigsson et al., 2014). The presence of gluten in diet of celiacs triggers the production of antibodies that cause inflammatory process in the mucosa of the small intestines, leading to atrophy of the intestinal villi and malabsorption of nutrients (Paula et al., 2014; Parzanese et al., 2017; Zhu et al., 2019).

Among the physiological manifestations of CD are: symptomatic malabsorption; weight loss; chronic diarrhea; bone diseases, such as premature osteoporosis; herpetiform dermatitis; oral ulcers; growth disorders; abdominal pain; thyroid disorders; irritable bowel syndrome; and others less common manifestations (Kotze, 2009; Rubio-Tapia et al., 2013; Cobos-Quevedo et al., 2017).

The only effective treatment for CD consists of a totally gluten-free diet for a lifetime, regardless of clinical manifestations (Ordinance MS/SAS n° 307, 2009; Rubio-Tapia et al., 2013; Brazilian National Federation of Celiac Associations, 2014). It implies the strict restriction of all products containing wheat, barley and rye (Rubio-Tapia et al., 2013). Adherence to the diet allows healing of the intestinal mucosa and remission of symptoms, therefore it improves quality of life and avoids complications (Ludvigsson et al., 2014; FENACELBRA, 2014). In the post-diagnosis period, celiac patients need

proper nutritional guidance (Rubio-Tapia, 2013; FENACELBRA, 2014; Castilhos et al, 2015). Since the treatment of CD fundamentally requires the restriction of gluten, access to adequate food and nutritional assistance are indispensable conditions for the health and well-being of celiac patients (Rubio-Tapia, 2013; Freeman, 2018; Labrada et al., 2020; Moscoso & Quesa, 2016; Parzenese et al., 2017).

In Brazil, there are so far no nationwide studies on the prevalence of CD. Studies with blood donors found prevalence of 1/214 in São Paulo, (Oliveira et al, 2007) and 1/286, (Alencar et al., 2012) in Brasília, 1/681, (Gandolfi, 2000) in Ribeirão Preto 1/273 (Melo et al., 2006) and in Curitiba 1/417 (Pereira et al, 2006). However, it is estimated that only 10 to 15% of celiacs are properly diagnosed. Due to weaknesses in the current diagnostic process, studies speculate that the actual population prevalence is much higher than that detected among healthy blood donors (Oliveira et al., 2007; Gandolfi, 2000). Therefore, in Brazil, possibly, CD is less rare and more neglected pathology and some authors conjecture that the incidence is similar to that of Europe and the USA 1:100.

In 2010, due to the approval of Constitutional Amendment No. 64, adequate food was included in the Federal Constitution (CF) as a social right for all (The Food and Agriculture Organization of the United Nations [FAO], 2013). By assuming adequate food as a social right, the Brazilian state has become the bearer of the duty to respect, provide, promote and protect the Human Right to Adequate Food (HRAF) (FAO, 2013) for all Brazilian citizens. From then on, therefore, it should have constituted a normative apparatus that would ensure the conditions for the implementation of HRAF for the celiac population.

Nevertheless, there are still countless situations of violations of the HRAF experienced by celiacs, such as: difficulty of access to gluten-free food in public or private food services (bars, restaurants, hospitals); high cost of gluten-free food; low variety of gluten-free food compared to traditional foods; undue labeling of food; incipient offer of Social Assistance and Nutrition Care services (Kotze, 2009; FENACELBRA, 2014; Oliveira et al., 2007; Gandolfi et al., 2000; Cassol et al., 2007; Falcomer et al., 2018; Crucinsky et al., 2021).

Such violations signal an eventual inefficiency of the Brazilian State as to the legal guarantee of care for the needs of patients with CD. The objective of this work is to evaluate if the normative set currently in force in Brazil meets the demands of the celiacs in the sense of legally guaranteeing them the realization of the HRAF.

2. Methodology

Documentary analysis was adopted, according to the methodology proposed by Pimentel (2001). On such methodology, sets of documents assume an elementary role for the understanding of the theme of study. According to Pimentel (2001), initially a process of meticulous survey of documents related to the subject (laws, institutional norms and scientific publications) is carried out in order to, afterwards, extract from them all the analysis, organization and interpretation according to the proposed objectives.

In accordance to the present methodology, at first, the demands of the celiacs were surveyed. In the exploratory search for scientific publications, the following descriptors were adopted: "Celiac Disease and Food and Nutritional Security", "Celiac Disease and Human Right to Adequate Food", "Celiac Disease and Public Policies", both in Portuguese and in English languages. The survey was carried out in the electronic databases Pubmed, Science Direct, Medline Bireme, Lilacs, Scielo and Periodicals of CAPES.

The scarcity of studies on CD from this thematic perspective led to an complementary survey in websites of governmental and non-governmental institutions related to the realization of HRAF, thus consulting documents available on the website of the National Health Surveillance Agency (ANVISA), the Association of Celiacs of Brazil (ACELBRA), the National Federation of Celiac Associations of Brazil (FENACELBRA), Ministry of Social Development (MDS) and National

Council for Food Security (CONSEA). Given the universality of the National School Food Program (PNAE), the website of the National Fund for Education Development (FNDE), the agency responsible for regulating the PNAE, was also consulted. In summary, the set of documents analyzed in this study is composed of every publication found that expressed the demands of the celiacs, including: articles, manuals and letters of claims of the representative instances (Pereira et al., 2007; FENACELBRA, 2009; FENACELBRA, 2012).

After filtering by titles, in approximately 80 articles containing the term "Celiac Disease", it was found that only 02 publications discussed the demands of celiac patients and measures to meet them. The first one referred to a research conducted with members of the Brazilian Celiac Association - Santa Catarina Regional Office, which surveyed the knowledge of the population and health professionals regarding celiac disease, including the appropriate criteria for diagnosis (Pimentel, 2001). The second article analyzed the day-to-day needs appointed by a group of celiacs regarding information, guidance, complaints (Kotze, 2009).

The survey for legislation related to CD was made by consulting government websites. The following normative apparatus was found and analyzed: 02 ordinances, 03 resolutions, and 01 law of national coverage, 06 state laws and 11 municipal laws that regulate on issues of interests of celiacs.

Subsequently, we proceeded to organize the documents, in order to arrange it in an elucidative manner for the objective of the research (Pimentel, 2001). First, the documents were organized according to type of content: demands or legislation. As predicted by Pimentel (2001), the construction of the analytical tables facilitates to relate the documents. In this study, the analytical charts were constituted into a database that made it possible to assess the satisfaction of the demands of celiacs according to the current legislation, distributed into five categories, namely: 1) related to diagnosis and clinical care; 2) related to the production, supervision and marketing of gluten-free food; 3) related to policies for access to gluten-free food; 4) related to conducting research on CD; 5) related to educational actions and social activities. It was also analyzed whether the studied legislation had federal, state or municipal coverage. The outcomes were compared using as a theoretical parameter of discussion the duties of the State as defined by the United Nations High Commissioner for Human Rights, namely: to respect, to protect, to promote and to provide (United Nations Organization [ONU], 2002).

3. Results and Discussion

The Federal Law n° 11.346/2006 - Organic Law of Food and Nutritional Security (LOSAN) - promulgated in 2006 reaffirmed the duty of the Brazilian state to respect, protect, promote and provide the realization of the human right to adequate food, as well as to guarantee the mechanisms for its fulfillment (Law n° 11346, 2006).

As to respect, the State shall not institute any legal measure that would hinder the capacity of individuals to provide their own food and, when it does so, it must quickly create mechanisms for redress (Cassol et al., 2007). The absence of regulations in favor of the HRAF characterizes disrespect by the State, since, as the bearer of duties, it should not posit a neglecting stance in relation to the institution of legal measures necessary to guarantee any fundamental right of citizens.

From this perspective, the recurring slowness and failure in the diagnosis, treatment and monitoring of CD, as expressed by the celiacs (Table 1) represent disrespect to the right to health and to adequate feeding of the celiacs. Specifically, related to diagnosis, there were demands for training and updating of health professionals; implementation of educational actions for the general population regarding the correct diagnosis of CD.

Such demands were partially contemplated in Rio de Janeiro, State Law n° 4,840/2006, when establishing free access to the performance of specific tests for diagnosis (Law n° 4.840, 2006). However, this law does not provide for deadlines, locations and qualification of professionals to perform such diagnostic tests. Municipal Law n° 9.012/2012 (Law n° 9.012, 2012), of the city of Florianópolis/SC, differentiates itself by, in addition to ensuring the diagnostic examination for the patient

with CD, screening of first-degree consanguineous relatives of the disease carrier. It is noteworthy that this last claim was not manifested by the celiacs in the documents consulted. It may have been expressed in other channels of communication, by a government initiative, positing an act of protection to the health of the celiac family members.

At the federal level, in 2009, the Ministry of Health (MS) instituted Ordinance n° 307, which was repealed and replaced by Ordinance n° 1149 in 2015 (Ordinance n° 1149, 2015). Both ordinances address Clinical Protocol and Therapeutic Guidelines for CD (1). The protocol defines the criteria for diagnosis, treatment, prognosis, and mechanisms for regulation, control, and evaluation that states and municipalities should adopt to structure the care network, establishing the flows and defining the services of medical clinics, contemplating gastroenterology and pediatrics care at all stages, and the regulation of care access (Ludvigsson, 2014). However, one year after the publication of the first normative that instituted the protocol, the National Federation of Celiac Associations of Brazil (FENACELBRA), in an open letter to the candidates for the presidency of the Brazilian republic, asked for its effective implementation, and the granting of resources compatible with its demands (FENACELBRA, 2014). To this date, past a decade since the creation of the protocol there is still a prominent difficulty of diagnosis, according to FENACELBRA publications, signaling the persistence of difficulties in implementing the referred clinical protocol (FENACELBRA, 2015).

Still on diagnosis, a study conducted with members of ACELBRA in the state of Santa Catarina revealed that there is a deficit of knowledge both of the population and of health professionals regarding CD (Cassol et al., 2007). According to the authors, this situation may conduct to inappropriate diagnoses in healthy individuals, imposing them to the restrictive diet unnecessarily, but also preventing that actual celiacs from being diagnosed.

Table 1 presents a series of demands related to clinical care the needs: to establish therapeutic support groups after diagnosis; for multi-professional care; of adequate food availability; among other demands. The Municipal Law n° 9,012/2012 (Law n° 9.012, 2012) of Florianópolis/SC and the Federal Ordinance n° 1149/2015 (Ordinance n° 1.149, 2015) are the only to mention clinical care after diagnosis, despite not contemplating the specifics required by the representatives of celiac patients. In this case, the State's accountability lies in its omission from proper representation. This situation leads us to reflect on the effective representativeness foreseen among the foundations of management in a democratic state under the rule of law. It is expected that there will be ongoing dialogue between civil society and legislators, who will have to institute laws that are fully compatible with the interests of those whom they represent (Avritzer, 2016). The omission of the normative content in relation to the various demands in clinical care indicates that this interlocution has not occurred satisfactorily, and that there is a fragility of the political representation of the celiac citizen(s) in the legislative power.

Table 1 Demands of patients with Celiac Disease regarding diagnosis and clinical care and current legislation.

Demand	Legal Regulations	Federal Level of Coverage	Normative Content
Adoption of a policy of interdisciplinary and multiprofessional care, monitoring performed by physicians, nutritionists, psychologists, dentists and social workers (FENACELBRA, 2014; FENACELBRA, 2009).	Law n° 7.013/2007	Municipal Victory/ES	Establishes the Assistance Program for celiacs and ensures multidisciplinary celiac care in the Municipal Public Health Units.
	Federal Res. RDC n° 460/2012	Federal Brazil	Creates the Intersectorial Technical Committee for Integral Care of Celiac People with the objective of elaborating, planning, monitoring and evaluating the "Intersectorial Policy for Integral Care of Celiac People".
Effective implementation and regulation of the Clinical Protocol and Therapeutic Guidelines for CD in the SUS, making available resources compatible with the size of the demand	Portaria MS/SA n° 307//2009	Federal Brazil	Approves the Clinical Protocol and Therapeutic Guidelines for CD that defines the concept of CD, criteria for diagnosis, treatment and prognosis, and regulatory,

(FENACELBRA, 2014).			control and evaluation mechanisms.
Carrying out diagnostic tests in any health unit (Paula et al., 2014).	-	-	No corresponding legislation found
Post-diagnostic support groups in the SUS, with teaching (associated diseases, options for food exchange, cross-contamination), guidance and welcoming, individual psychotherapeutic care and groups of celiac people and their families (Paula et al., 2014).	-	-	No corresponding legislation found
Consulting a nutritionist, and collective courses for teaching and learning the ways of food production that address techniques, ingredients and balanced food menus (Paula et al., 2014).	Law nº 9.012/2012	Municipal Florianópolis/SC	Ensures clinical and nutritional follow-up of CD patients by the Municipal Health Network.
Protocol regulating the availability and supply of vitamin, mineral, pre- and probiotic supplements (Paula et al., 2014).	-	-	No corresponding legislation found
Implement health actions approved at the Seminar on National Food and Nutrition Policy (PNAN - 2010) - Fenacelbra Letter (FENACELBRA, 2014).	-	-	No corresponding legislation found

Fonte: Autores.

As to protect, the State must prevent companies, individuals, and groups of interest from interfering on the fulfillment of HRAF or acting towards its violation (Brazilian Association for Nutrition and Human Rights, 2007).

The duty to protect includes ensuring that the food placed on the market is safe for consumption and nutritious. The State must therefore establish and implement food quality and safety standards, and ensure fair market practices (Cassol et al., 2007). Table 2 summarizes the demands of celiacs regarding the production, inspection and marketing of gluten-free foods and the corresponding legislation.

The Federal Law nº 10.674/2003 (Law nº 10.674, 2003) can be interpreted as a protective measure since it determines the obligatoriness of the insertion of the warning "Contains or Does Not Contain Gluten" in food labels. More comprehensively, State Law nº 9.788/2012 (Law nº 9.788, 2012) and Municipal Law nº 9.012/2012 (Law nº 9.012, 2012), in force in the state of Espírito Santo and in the municipality of Florianópolis/SC, respectively, extend the obligation of informing about gluten content on food ready for consumption to many establishments (schools, restaurants, bars, snack bars and bakeries). In addition, Resolution nº 26, published by the National Health Surveillance Agency (ANVISA) in 2015 (Resolution RDC nº 26), requires the declaration on food labels regarding "Allergic" ingredients that it may contain. This represents a complementary protection standard, since CD is not configured as a food allergy, but is caused by exposure to gluten, a component of wheat that must be declared on labels due to its immunogenic potential (Sapone et al., 2012).

Table 2 Demands from Celiac Disease carriers regarding the production, supervision, marketing of gluten-free foods and current legislation.

Demand	Legal Regulations	Federal Level of Coverage	Normative Content
Mandatory insertion of the warning "Contains or Does Not Contain Gluten" on food labels (Paula et al., 2014).	Law nº 10.674/2003	Federal Brazil	Obliges that the industrialized foods must contain on its label and package leaflet, obligatorily, the inscriptions "contains Gluten" or "does not contain Gluten", as the case may be.
	DRC nº 26/2015	Federal Brazil	It requires that major foods causing food allergies including beverages, ingredients, food additives, and adjuvants intended exclusively for industrial processing or food services declare to be "allergenic" and specifically state the name of the food and/or its derivatives causing allergy.
	Law nº 16.085/2009	State Paraná	Determines that bars, snack bars, restaurants and similar establishments, as well as canteens and kiosks that operate within the schools of the private school system, must disclose among the nutritional information the presence of gluten in the food marketed.
	Law nº 15.447/2011	State Santa Catarina	Establishes the mandatory nature of restaurants, bars, snack bars, confectioners, bakeries, rotisseries and similar establishments that sell and deliver food for immediate consumption, providing information on the ingredients used in the preparation.
	Law nº 9.788 /2012	State Espírito Santo	It provides that foods prepared in shops are to be identified in the form of labels and, where menus are to be displayed in a visible place or supplied in printed form to consumers indicating the fresh, industrialised ingredients containing gluten.
	Law nº 9.012 /2012	Municipal Florianópolis/SC	Obliges restaurants, bars, snack bars, confectioners, bakeries, rotisseries and similar establishments that sell and deliver food at home ready for consumption to provide information on the ingredients used in the preparation of food.
Obligation for bars, restaurants and the like to inform the gluten content of their food and offer some option of gluten-free food (Paula et al., 2014).	-	-	Not observed corresponding legislation
Development of specific procedures to be included in Food Service Good Practice Manuals (FENACELBRA, 2012)	-	-	Not observed corresponding legislation
Inspection actions and creation of a guiding program for the prevention of cross-contamination in the production, storage and commercialization process, including elementary and higher education schools (FENACELBRA, 2009).	-	-	Not observed corresponding legislation
Creation of tax incentives for food industries that produce gluten-free food (FENACELBRA, 2014; FENACELBRA, 2012)	-	-	Not observed corresponding legislation

Fonte: Autores.

More extensive, the Law nº 9.888/2012 (Law nº 9.788, 2012) and the Law nº 9.012/2012 (Law nº 9.012, 2012), in force in the state of Espírito Santo and in the municipality of Florianópolis/SC, respectively, extend the obligation of information in ready-to-eat foods consumption in several places (schools, restaurants, bars, snack bars and bakeries). In addition, Resolution nº 26, published by the National Agency for Sanitary Surveillance (ANVISA) in 2015 (Resolution RDC

n° 26, 2015), compels the declaration in labels of the condition "Allergic" followed by the name of the food and/or derivative which causes the allergy. This is a normative of complementary protection, since DC is not a food allergy, but it is caused by exposure to gluten, a component of wheat that must be declared on the labels in function of its allergenic potential (Sapone et al., 2012).

The development of specific procedures to be included in ANVISA's Manuals of Good Practices for Food Services, surveillance actions and creation of a guiding program to prevent cross-contamination in schools and hospitals are also protection measures that are not yet covered by the legislation content searched. These demands are justified by the risk of cross-contamination when gluten-free foods are handled in the same or near environment as foods containing gluten. There is also the possibility of contamination caused by the shared use of utensils and equipment used to prepare foods with gluten (Paula et al., 2014; Falcomer et al., 2018; Pinto et al., 2020). In both cases, there are harmful effects to the celiac person health.

In some countries the presence and gluten content control in products is better protected. In Australia, the products are reviewed and approved by the celiac association and have a nationally and internationally recognized trademark. The products are still tested to have no detectable gluten and are subject to laboratory testing every 12 months and random annual audit tests (Coelic Australia, 2014). Such measures help in the purchase of gluten-free products with confidence. In Spain, there is the Laboratories Network for Food Safety (RELSA) created with the purpose of sharing and promoting the accreditation of test laboratories and analytical methods of official control (Federación de Asociaciones de Celiacos de España, 2015).

Some other protective measures of the celiacs HRAF would be to institute laws that oblige bars, restaurants and similar, besides informing the gluten content of their food, to provide alternative menus without this protein compound. Law n° 15.447/2011 (Law n° 15.447, 2011) in Santa Catarina, Law n° 16.085/2009 (Law n° 16.085, 2009) in Paraná, Law n° 9.788/2012 (Law n° 9.788, 2012) in Espírito Santo and Law n° 9.012/2012 (Law n° 9.012, 2012) in Florianópolis/SC are limited to appoint the obligation to report on ingredients and on the presence of gluten (Table 2). The lack of legislation requiring the provision of gluten-free options limits the public spaces for food consumption and, therefore, leads to a breach of the principle of non-discrimination in the conduct of celiac HRAF. In increase, considering the sociocultural dimension of food, the impossibility of consuming in usual places of social interaction causes loss of cultural identity and psycho-affective disorders among celiac disease patients (Canesqui & Garcia, 2005; Carvalho et al., 2011; Korinth et al., 2010).

The obligation to promote means that the State must get involved proactively by instituting public actions and policies that increase the ability of families to feed themselves (FAO, 2013). This includes appropriate education, training, promotion of non-discrimination and structuring and strengthening of the institutional accountability, including through administrative and/or legislative measures (FAO, 2013).

CD patients expressed their awareness of this issue and, among their express demands, it was observed the planning and execution of educational actions for the general population regarding procedures and diagnostic exams of CD, professionals and reference sites (Table 3). Likewise, they expressed the need for training and updating of health professionals to implement the Clinical Protocol and Therapeutic Guidelines of CD (Ordinance MS/SAS n° 307, 2009) and food handlers at all stages of the food chain.

These demands were accepted by the legislative assemblies of the cities of Vitória/ES (Laws n° 7.010/2007 and n° 7.013/2007) (Law n° 7.010, 2007; Law n° 7.013, 2007) and Florianópolis/SC (Law n° 9.012/2012) (Law n° 9.012, 2012), and Rio de Janeiro state assembly (Law n° 4.840/2006) (Law n° 4.840, 2006) by legally establishing the occurrence of continuous educational actions for family members and for the general population. However, this set of legislation in force does not specifically refer to the implementation of the protocol, since the legal institution of it is subsequent to the enactment of such laws.

Table 3 Demands of CD patients regarding the development of educational actions, social control, epidemiological monitoring and the current legislation in Brazil.

Demand	Legal Regulations	Federal Level of Coverage	Regulation
Planning and execution of educational actions for the general public regarding a) procedures and diagnostic exams for CD; b) professionals and reference sites to seek school and worker food (Paula et al., 2004; FENACELBRA, 2014; FENACELBRA, 2012).	Law No 13.349/2002	Municipal São Paulo/SP	The Executive Branch will make efforts to hold lectures and seminars to commemorate celiac day.
	Law n° 4.840 /2006	State Rio de Janeiro	Promotion of educational programs with the purpose of clarifying the characteristics, symptoms and treatment of CD, through the elaboration and distribution of posters, brochures and leaflets in health centers, schools and public institutions, hotels, bars, restaurants and the like.
	Law n° 7.010/2007	Municipal Victory/ES	On the celiac municipal day it will be promoted lectures, public audiences, scenic and audiovisual presentations.
	Law n° 7.013/2007	Municipal Victory/ES	Elaboration and distribution to the celiac family of explanatory booklets, about the disease and the necessary care for the correct adherence to the diet and food preparation. Elaboration and distribution of posters, brochures and explanatory leaflets available in Health Units, Schools and Public Institutions, hotels, bars, restaurants and the like.
	Law n° 9.012/ 2012	Municipal Florianópolis/S C	The Municipal Secretariat of Health will promote educational programs with the purpose of clarifying the characteristics, symptoms and treatment of CD through the elaboration and distribution of posters, booklets and explanatory leaflets available in health units, schools and public institutions, hotels, bars, restaurants and the like.
Training and updating of health professionals to implement the Clinical Protocol and Therapeutic Guidelines for CD (Paula et al., 2004; Cassol et al., 2007; FENACELBRA, 2012).	Law n° 4.840/2006	State Rio de Janeiro	Organization of seminars and training aimed at training professionals in the public health area in order to clarify the characteristics, symptoms and treatment of CD.
	Law 7.013/2007	Municipal Victory/ES	Organization of seminars and training aimed at training professionals in the public health area, including dentists, nutritionists, laboratory technicians, nurses, community agents and others in order to clarify the characteristics, symptoms and treatment of Celiac Disease.
Training and updating of health professionals to implement the Clinical Protocol and Therapeutic Guidelines for CD (Paula et al., 2004; Cassol et al., 2007; FENACELBRA, 2012).	Law n° 9.012/2012	Municipal Florianópolis/S C	Organization of seminars and training aimed at training professionals in the public health area in order to clarify the characteristics, symptoms and treatment of Celiac disease.
Training of food handlers at all stages of the food chain (FENACELBRA, 2014)	Law n° 7.013/2007	Municipal Victory/ES	Due to the training of professionals involved in the manipulation of school meals.
Creation of specific strategies for the inclusion of people with CD in public policy councils, conferences, forums, among others (FENACELBRA, 2012).	-	-	No corresponding legislation found.
Conducting research on epidemiological conditions of CD in Brazil and to verify if the current form of diagnosis is compatible with the appropriate diagnosis of the disease (FENACELBRA, 2014; Cassol et al., 2007).	Law n° 4.840/2006	State Rio de Janeiro	Determines the creation of a quantitative cadastre to determine the incidence of the disease in all municipalities of the State.
	Law n° 7.013/2007	Municipal Victory/ES	Encourages research into Celiac Disease, through municipal agencies, especially in its epidemiological determination in the city of victory;
	Law n° 9.012/2012	Municipal Florianópolis/S C	Determines the creation of a quantitative register to determine the incidence of the disease in the city of Florianópolis.

Fonte: Autores.

The development of specific procedures to be included in ANVISA's Manuals of Good Practices for Food Services, as well as the creation of a guiding program for the prevention of cross-contamination in schools and hospitals are some protective demands not yet contemplated in the set of the researched legislation. These demands are justified by the risk of cross-contamination present when foods that do not contain gluten are handled in the same environment or close to foods that contain gluten. There is the possibility of contamination caused by the shared use of utensils and equipment used to prepare food with gluten (Paula et al., 2014; Crucinsky, Damião & Castro, 2021). In both cases, there are harmful effects on the health of the celiac person.

In some countries the regulation concerning of gluten content in food is more clearly stated. In Australia, the products are reviewed and approved by the celiac association and carry both nationally and internationally recognized food seals. The products are still tested for no detectable gluten and are subject to laboratory testing every 12 months, as well as random annual audit testing (Celic Australia, 2014). Such measures facilitate safe acquisition of gluten-free product. In Spain, there is a network of Laboratories for Food Safety Network (RELSA) created in order to promote the accreditation of testing laboratories and analytical methods of official control (Federación de Asociaciones de Celiacos de España, 2015).

Other protective measures for the celiac HRAF would be to institute laws that oblige bars, restaurants and establishments, in addition to informing the gluten content of their food, to make alternative menus available without this protein compound. State Law n° 15.447/2011 (Law n° 15.447, 2011) in Santa Catarina, State Law n° 16.085/2009 (Law n° 16.085, 2009) in Paraná, State Law n° 9.788/2012 (Law n° 9.788, 2012) in Espírito Santo, and Municipal Law n° 9.012/2012 (Law n° 9.012, 2012) in Florianópolis/SC are limited to determining mandatory information about ingredients and the presence of gluten (Table 2). The absence of regulations requiring the provision of gluten-free options limits public spaces for food consumption and therefore leads to the violation of the principle of non-discrimination in the implementation of the celiac HRAF. Considering the sociocultural dimension of food, the impossibility of consumption in usual places of social interaction leads to loss of cultural identity and psycho-affective disorders among carriers of celiac disease (Canesqui & Garcia, 2005; Carvalho et al., 2011; Korinth et al., 2010).

As for its duty to promote, the State must be proactively involved, instituting actions and public policies that enhance the capability of families to feed themselves (FAO, 2013). This includes appropriate education, training, promotion of non-discrimination, and structuring and strengthening institutional accountability, including administrative and/or legislative measures (FAO, 2013).

Patients with CD expressed their awareness of this issue and, among their expressed demands, the planning and execution of educational actions for the general population regarding the procedures and diagnostic tests for CD, professionals and reference sites (Table 3). They expressed the need for training and updating of health professionals in order to implement the Clinical Protocol and Therapeutic Guidelines for CD (1), and food handlers in all stages of the food production chain.

These demands were accepted by the legislative assemblies of the municipalities of Vitória/ES (Laws n° 7.010/2007 and n.º 7.013/2007) (Laws n° 7.010, 2007; Laws n° 7.013, 2007), and Florianópolis/SC (Law n° 9.012/2012) (Law n° 9.012, 2012), and state assembly of Rio de Janeiro (Law n° 4.840/2006) (Law n° 4.840, 2006) legally establishing the occurrence of continuous educational actions for relatives and for the population in general. Nonetheless, this set of current legislation does not specifically refer to the implementation of the protocol, since its legal institution is subsequent to the enactment of such laws.

Moreover, whenever demands involving processes of Permanent Education of health professionals are discussed, it urges to be contextualized, considering the structural aspects such as working conditions and financial resources necessary for the implementation of training. In 2007, the Ministry of Health instituted the GM/MS Ordinance n° 1.996 (Ordinance n° 1.996, 2007), providing guidelines for the implementation of the National Policy of Permanent Education in Health, though issues of underfunding of the sector and precarious working conditions persist as limiting factors to its implementation and its adherence by professionals in training actions (Health Ministry, 2009).

Still on continued education for health care professionals, the municipal law of São Paulo/SP (Law n° 13.349/2002) foresees, in punctual character, that it is up to the executive power to “make efforts for the accomplishment of lectures and seminar in the commemoration of the day of the celiac” (Law n° 13.349, 2002) (Table 3). This form of approach, which is not very incisive, implies a reduction in the power to enforce it. The term "making efforts" allows for the noncompliance with the rule, since it is devoid of the sense of obligation on the part of the State and endorses the historical practice of political action as a courtesy. In this perspective, public policies and programs in favor of HRAF are carried out as indulgences, with a strong conception that they can be delivered in any way, by any means and without the need for the participation and social control (Burity, Cruz & Franceschini, 2011).

Opposing this form of approach, Valente and Beghin (Valente & Beghin, 2006) conclude that it is necessary changes in the processes, in the ways of implementing the policies. For both authors, the construction of a more just and egalitarian society, as well as the strengthening of the capacity to demand the realization of human rights, demands a cultural revolution within society and the administrative structure of the State (Valente & Beghin, 2006).

ACELBRA members expressed a demand for research on the epidemiological profile of CD, and on the compliance with the diagnostic and treatment procedures currently provided in the Clinical Protocol and Therapeutic Guidelines for CD (Ordinance MS/SAS n° 307, 2009; Cassol et al., 2007). The results of this study revealed a scarcity of legal instruments that regulate the conduct of research and monitoring of the epidemiological profile of CD and compliance with the clinical protocol. State Laws n° 4.840/2006 (Law n° 4.840, 2006), Municipal Law n° 7.013/2007 (Law n° 7.013, 2007) and Municipal Law n° 9.012/2012 (Law n° 9.012, 2012) in force, respectively, in Rio de Janeiro, Vitória/ES and Florianópolis/SC (Law n° 9.012, 2012), determine the creation of a quantitative register to determine the incidence of the disease in the municipalities (Table 3). The non-standardization of epidemiological studies on the distribution of CD and on the implementation of the protocol compromise the planning of health care to patients with CD, making it erroneous to direct actions, as well as to prioritize and to optimize resources in a way compatible with the reality of health institutions and the needs of the population (Catassi et al., 2014).

The full realization of HRAF requires that governments inform the population about their rights and strengthen their capability to participate in both decision-making processes and enforceability of their rights. It is noteworthy that in the entire process of enforceability, it's called upon citizens to get hold of the legally established achievements. The appropriation of legal instruments is essential for the enforcement of their compliance, enabling social actors to effectively assume an active condition in the defense of their constitutionally established rights (FAO, 2007). It is noteworthy that the creation of specific strategies for the inclusion of people with CD in public policy councils, conferences, forums, among other participatory spaces, was a diagnostic demand (Table 3).

Completing the discussion of the range of duties of the state in relation to HRAF, it ought to be noted that it carries with it the obligation to provide celiac gluten-free food both within the scope of governmental programs of SAN, and in situations in which celiacs and their family do not have the conditions to guarantee by themselves their food. Table 4 lists the current demands and regulations related to accessibility and provision of HRAF.

Table 4 Demands related to the accessibility to gluten-free diet and current legislation in Brazil.

Demand	Legal Regulations	Federal Level of Coverage	Normative Content
Celiac Care in School Feeding (FENACELBRA, 2009).	Law n° 6.545/2004	Municipal Blumenau/ SC	It is mandatory to have a special meal in the school lunch, adapted for children with DC, in all schools of the Municipal Education Network. It will be guided by medical prescriptions and nutritionists, who will be responsible for supervising the use of food.
	Law n° 17.254/2006	Municipal Recife, PE	It authorizes the executive branch to maintain in the school meals of all schools and municipal daycare centers, differentiated and adequate food for children with CD.
	Law n° 971/2006	Municipal José dos Pinhais/SP	The Public Education Institutions of the Municipal Network are obliged to provide differentiated snacks for celiac students.
	Law n° 7.013/2007	Municipal Victory/ES	Guarantees the obligation to be offered to the celiac, school meals appropriate to their pathology, in daycare centers and public schools, through joint action of the Secretariats of Education and Health.
	Law n° 4.573/2008	Municipal Cariacica/ES	The Executive Branch is authorized to provide differentiated snacks in public schools for celiac students.
	Resolution n° 26/2013	Federal Brazil	Menus should meet students with specific nutritional needs, such as CD.
	Law n° 12.982/2014	Federal Brazil	Determines the provision of adequate school food to students with state or specific health condition.
Gluten-free and cross-contamination-free feeding in hospitals (Paula et al., 2014).	-	-	No corresponding legislation found.
Creation of a cash transfer program, due to the higher cost of gluten-free food (FENACELBRA, 2012). Emergency care policy, with gluten-free food baskets, for the initial phase of adaptation to the diagnosis (Paula et al., 2014).	Law No 1.784/2003	Municipal Biguaçu/SC	Authorizes the Chief of the Municipal Executive Branch to grant financial aid to Mrs. Maria* in the amount of R\$ 100.00 (one hundred reais), for a period of 06 months, to pay for the treatment of her daughter, who is celiac, according to the referral form of the Secretary of Social Assistance.
	Law n° 4.840/2006	State Rio de Janeiro/RJ	Ensures the monthly transfer of a basic basket composed of gluten-free products, provided that the financial impossibility of meeting the basic needs of food is proven.
	Law n° 7.013/2007	Municipal Victory/ES	It ensures the access of the celiac family to the assistance programs of the Municipality, provided that it is proven to be financially impossible to meet the basic needs of food for the patient. Ensures the supply of basic monthly basket, composed of gluten-free products. This will be prepared by teams of nutritionists, in order to ensure the daily amounts of recommended nutrients.
	Law n° 9.012/2012	Municipal Florianópolis/SC	Ensures the monthly transfer of a complete basic basket, composed only of gluten-free products, as long as it is proven to be financially impossible to meet the basic needs of food.
Partnership between the Municipal Secretariat of Health and the Special Secretariat of Human Rights for the development of integrated care networks for celiacs in situations of social discrimination (FENACELBRA, 2009).	-	-	No corresponding legislation found.

*Fictitious name to ensure secrecy and privacy of the beneficiary of the Law. Fonte: Autores.

It was observed among CD patients the demand for emergency care actions, such as distribution of gluten-free food baskets in the initial phase of adaptation to the diagnosis, as well as the creation of a cash transfer program due to the high cost of food. Similar to what was observed in relation to other demands, there was an absence of a federal law that guarantees financial aid or distribution of basic food baskets to patients with CD. Partially meeting these demands, state law (Law n° 4.840/2006 - Rio de Janeiro) (Law n° 4.840, 2006) and municipal laws (Law n° 1.784/2003 - Biguaçu/SC (Law n° 1.784, 2003); Law n° 7.013/2007 - Vitória/ES (Law n° 7.010, 2007) and Law n° 9.012/2012, Florianópolis/SC (Law n° 9.012, 2012) were observed. It is noteworthy that Law n° 7.013/2007 (Law n° 7.013, 2007) provides for food baskets planned by nutrition team, ensuring greater nutritional adequacy.

Law n° 9.012/2012 (Law n° 9.012, 2012) discriminates the products that must compose the basket, establishing that the food must have gluten exemption proven by its supplier, through a report issued by specialized laboratories. It also requires adequate food storage, free from the risk of cross-contamination. As for the demand for cash transfer, it was validated by municipal Law n° 1.784/2003, promulgated in the city of Biguaçu/SC (Law n° 1.784, 2003). However, it provided financial assistance to a single beneficiary, including a name registered in the body of the law. Such a procedure sounds like a mistake on the part of the legislature, given the fact that the scope of the law is so limited, referring to a single citizen at time. In line with the HRAF approach, it is emphasized that emergency provision actions should be implemented on a temporary basis, and the state should seek to permanently establish actions of respect, protection and promotion of HRAF towards reducing the demand for emergency actions (FAO, 2013).

In regard to the mandatory provision of gluten-free diets in FNS programs, there was a predominance of legal measures in the context of the National School Feeding Program (PNAE). Therefore, Federal Law 12.982/2014 [48], in compliance with Resolution n° 26/2013 (Resolution n° 26, 2013), which determines the provision of adequate school meals to students with state or specific health condition. Anticipating the federation, some municipalities - Blumenau/SC, Recife/PE, São José dos Pinhais/SP, Vitória/ES and Cariacica/ES - had already legally ensured the provision of gluten-free food to celiac students. However, compliance to these laws led to the demand for training of professionals, a factor that has hindered effective compliance with the legislation as pointed out by Fenacelbra (FENACELBRA, 2010).

In spite of not having been observed any manifest demand in relation to access to gluten-free food in the work environment, it was detected that Ordinance n° 193/2006 (Ordinance n° 193, 2006) was in force. It establishes that companies benefiting from the Workers' Food Programme (PAT) must provide adequate meals for the treatment of their pathologies for workers diagnosed with diseases related to food and nutrition, ensuring the enforceability of the workers' HRAF.

On the other hand, throughout this study, it was observed that several demands of the patients with CD were not contemplated in the legislation, presenting a detachment from the legislative power to the patients with CD.

Such scenario conflicts with the very sense of representativeness that legitimizes the structure of the Brazilian State, in which members of the executive and legislative power are democratically elected to represent the interests of the people. Representativeness is expressed in the ability to perceive, understand, articulate and propose measures compatible with both the interests of the specific bases, as well with the general interests of the population, thus prevailing consensual propositions in favor of the collectivity, to the detriment of individual, private and, or, corporate interests (Siqueira, Cotta & Soares, 2015). Therefore, federal, state and municipal deputies are elected by the people to represent the people, and must propose and approve the laws that regulate the State, the conduct of citizens and public and private organizations, and must prioritize the interests of citizens.

Nevertheless, there is numerous scientific evidence about the weaknesses of representative democracy (Urbinati, 2006; Luchmann, 2011; Lavalley, & Vera, 2011; Escorel & Arouca, 2016). In Brazil, representativeness as proposed has been hardly achieved, since there is a prevalence of a democratic culture in which individuals act more in favor of the personal

benefits they expect to extract from the political system than for social interests (Avritzer, 2016). In this study it was observed that many demands of the celiac population have not yet been met by the legislators.

4. Conclusion

The results of this study lead us to conclude that the Brazilian State, notwithstanding the recognition of food as a constitutional right, has not satisfactorily fulfilled its role as a bearer of duties in relation to the HRAF of the celiacs. There has been an incipency of legal instruments that compromise the possibility of celiacs demanding the fulfillment of their HRAF before the competent public bodies both to prevent violations of these rights and to redress them. It deserves to be highlighted that there is a scarcity of studies related to the rights of the celiac population. Apparently, the academic community has turned its attention to clinical aspects of celiac disease, in an approach that privileges the discussion centered on the pathology, to the detriment of the celiac patient as a person. Such an approach reduces the possibility of understanding the socioeconomic and political dimension of the disease, which requires investigation in order to ensure the effective realization of the HRAF of celiacs.

It is suggested that future research and publications expand and deepen the CD debate considering the celiac citizen as a subject with rights in relation to health and adequate food. In this perspective, the results point to the possibility of research clippings on the participation of celiacs in the proposition of health and food policies in the various formal instances that provide for the participation of civil society, such as the councils of public policy managers. In the context of health services, investigations about the adequacy of human and material resources destined to care for the celiac population are seen as timely. Finally, an in-depth analysis of the articulation of the celiac population with the legislature is perceived as equally relevant, observing possible potentialities and limiting factors for legislators to dialogue, accept demands and act efficiently in the supervisory role of guaranteeing the DHAA of the celiac.

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