

The principle of human right to adequate food and celiac disease: advancements and challenges

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Abstract

Celiac disease is characterized by partial or total intestinal villous atrophy, caused by gluten ingestion in wheat, rye, barley, malt and oats. In the general population, the prevalence average is about 1%. The recommended nutritional therapy is the complete removal of gluten from the diet, since this causes the symptoms regress and nutritional status is restored. This paper seeks to contextualize the food and nutrition insecurity that afflicts individuals with celiac disease, specifically with regard to the principle of the Human Right to Adequate Food (HRAF). This, in turn, establishes as a fundamental human right to food availability in quantity and quality and also values welfare, promoting the health of the entire population. However, the limited availability of products intended for celiac individuals in the market, the high cost and the gluten contamination, contribute to a constant situation of food and nutritional insecurity to holders of this special dietary need. Diet is the single most secure treatment form for this disease, enabling its control. It can be said, therefore, that the public needs actions, or even public policies to materialize this right, thus ensuring access to adequate food to this population.

Key words: Celiac Disease. Food Security. Diet. Gluten-Free.

Introduction

Celiac disease (CD) can be considered the most common food intolerance in the world. In a brief history, Aaron¹ explains that it is an autoimmune condition that accompanies the individual throughout his life. After the diagnosis, the celiac individual goes on living on a restrictive diet, since most products have wheat as their main constituent and it contains gluten. Gluten is wheat's storage protein and its gliadins, soluble in alcohol, are responsible for the onset of the disease. Rye, barley, malt and oats have molecules structurally related to the wheat gliadin and thus, the intake of gluten triggers the disease, because there is resistance to its digestion by digestive enzymes developing the same immune process² that affects the gastrointestinal tract, especially the small intestine of genetically predisposed individuals.¹

Araújo & Araújo,³ in turn, claim that the celiac diet must be completely gluten free, since dietary guidance is what allows them to have a life relatively free of major pathological complications. Therefore, they reinforce the need for the family to assume the same rules in their daily diet. However, we must be clear that the diet has a complex and restrictive nature. It has a high cost when compared to what is considered a conventional diet,⁴ which causes the celiac to have difficulties in the availability and access to food without gluten. This condition violates the principle of the human right to adequate food as it conditions the celiac individual to a permanent food and nutrition insecurity, which could cause loss of quality of life, socialization and health of the individual, both in the short and the long term.

In this sense, the present article aims to contextualize and problematize the situation of food and nutritional insecurity that afflicts individuals with celiac disease, specifically with regard to the principle of the human right to adequate food (HRAF) from the perspective of Food and Nutrition Security (FNS).

Methods

A literature search was performed in the databases Science Direct and SciELO, using the following key words in Portuguese and English: celiac disease, food security and nutrition, gluten free diet, epidemiology, treatment and human right to adequate food. Current legislation and other official documents on Food and Nutrition Security were also analyzed. There was no date limit for the researches.

The criteria used to select articles were discussions of celiac disease, food and nutrition security and the human right to adequate food, being excluded from the search bibliographic material that did not directly address the scope of this review, although showing the selected descriptors.

The total study population consisted of 97 articles, 48 of which were excluded in a first screening performed by reading the abstracts, and 17 after full reading. For the preparation of this article, 32 references were used.

Celiac disease: epidemiology and clinical manifestations

Some epidemiological data indicate that in Europe and the United States, the prevalence of CD is between 0.5 and 1.0%.⁵ This same prevalence occurs in west Indian and Arab populations.⁶ Although it is present in one in every 100 people, it is estimated that only 10 to 15% of celiacs are properly diagnosed.⁷

However, it is noteworthy that the prevalence of cases of this disease depends on the region under study and also the methodology. Studies in blood donors showed that in the United States, for example, the frequency of cases is 1:250; whereas in Brazil, in the Federal District, the frequency is 1:681, and in Ribeirão Preto, 1:273.⁸ CD occurs predominantly in Caucasians, and the non-Caucasians represent a tiny fraction of the population with this disease.⁸ First degree relatives of CD patients are individuals with a greater chance of developing the disease, often 10-20 times higher than the general population, they share environmental and genetic risk factors for CD.⁹

The clinical forms of CD have been compared to an *iceberg*, where the classical form of the disease is at the tip, while the non-classical forms remain asymptomatic or submerged.¹⁰ Thus, only patients with the classic form of the disease are diagnosed, while others remain undiagnosed. This fact ends up not generating the required notifications for a greater and better understanding and action on the part of state and society, in favor of greater investment in respect, especially, to strategies of elaboration and availability of food products to guarantee the safety required for individuals with CD.

For Strauch & Cotter,¹¹ classical celiac disease has variable gastrointestinal symptoms, the most common being the reduction of body weight for no reason, lack of appetite, diarrhea, constipation, steatorrhea, vomiting, bloating and abdominal pain. However, the authors also argue that much

of the diagnosis in adults is performed on the non-classical or asymptomatic form of the disease. In general, the first signs and symptoms related to non-classical forms and asymptomatic disease involving endocrine, hematologic, neurologic, psychiatric, rheumatologic and dermatologic manifestations, not including the gastrointestinal tract. Kumar et al.⁶ bring the realization that the classic form of the disease with symptoms such as diarrhea and malabsorption are less common, while non-classical and asymptomatic forms have increased. This higher prevalence is explained by the fact that the diagnosis (serology) for this disease has become more accessible and there was greater awareness in clinical practice.

Ingestion of gluten by people with CD can bring numerous health ailments, such as malabsorption of nutrients that are essential for the physiological maintenance of the body - in this case, iron, folic acid, calcium, and fat-soluble vitamins can be mentioned. It can also be considered a risk factor for the onset of other chronic diseases such as, for example, type 1 diabetes, autoimmune thyroid disease, rheumatoid arthritis, Addison's disease, Sjögren's syndrome, intestinal cancer, osteoporosis, infertility in women, neurological diseases, as well as psychiatric disorders⁵ and death.¹²

Ludvigsson et al.¹³ show that there is a direct relationship between CD and depression, and the mechanism of this association may include conditions of the central nervous system (CNS), somatic comorbidities, low quality of life and also financial difficulties due to greater care with health; addition, there is a need for a "special" diet or even the combination of these factors. Because of the association of CD with psychiatric disorders, particularly depression, there is a likelihood that there is a greater risk that might lead to the occurrence of suicide in this group.

However, as already evidenced earlier and now reinforced by studies by Kotze,¹⁴ the possibility of adhering to a gluten-free diet causes symptoms such as defects in the absorption of macronutrients and micronutrients, diarrhea and edema to disappear quickly. This can take days or weeks, leading to the emergence of appetite and improvement of the nutritional status. The adhesion and maintenance of the gluten free diet for three to five years causes the mortality risk relative to the general population to disappear.¹⁵

Corroborating this assertion, it is important to note that we cannot just join any diet, it needs to be gluten-free and possess attributes that qualify as a proper and healthy variety in the requirements and availability in quantity and quality.

Food and Nutrition Security (FNS) and the principle of the human right to adequate food (HRAF)

Food and Nutrition Security (FNS) has become a global concern and assumes an increasingly complex dimension, given the situations that present themselves (explicitly or implicitly). Thus, the National Food and Nutrition Policy (NFNP)¹⁶ should interact with the National Food and Nutrition Security Policy (FNSP) and other policies for economic and social development, so as to play an important role in the strategy FNS policies development, mainly relating to diagnosis, monitoring food and nutrition situation and promoting adequate and healthy nutrition for normal individuals as well as individuals with special food needs, such as celiac individuals.

So, to know and recognize the real need of the people who live in some way under threat of food insecurity enables thinking and acting mainly in the construction, improvement and implementation of health policies,¹⁷ in order to meet the needs of the population. It is imperative to state that both the State and the society should promote actions that provide access to adequate food, either in quantity or in terms of nutritional quality, to ensure that food, biological, social and cultural needs are achieved. The joint between the Unified Health System (SUS) and the National System of Food and Nutritional Security (SISAN) must invest in public health policies to facilitate the diagnosis of diseases and implement the actions of diet and nutrition in primary health care to promote the FNS and therefore reduce the health risks to individuals, regardless of social, physiological and/or disease status. Also for implementing an NFNP for celiac individuals, investments must arise for the development of research in order to show a diagnosis of the condition of food and nutritional insecurity of celiac individuals.¹⁶ Brazil does not have a specific program for early diagnosis and monitoring of celiac disease. While the diagnosis is not made, eating habits will remain inadequate and will contribute to the illness and death of celiac individuals.

In this sense, for Pinheiro & Carvalho,¹⁸ food and nutrition should be seen as a citizen's human and social right. Corroborating these authors, reference should be made to the principle of FNS as being inherent to all citizens: the human right to adequate food (HRAF). By understanding food as a basic human right, it is less complex to understand the fact that the absence of foods that address this particular need, such as that of celiac individuals, represents a concrete case that this group of people are having, constantly, their rights – to adequate nutrition – violated and, in turn, they are in a state of food and nutrition insecurity.

The full development of the citizen refers to the concept of Food and Nutrition Security (FNS), as a fundamental right, which should ensure people's access to a dignified and full life.¹⁹ Law No. 11.346, of September 15th, 2006, in its Article 3 lays down that

*[...] food and nutrition security is the accomplishment of everyone's right to regular and permanent access to quality food in sufficient quantity, without compromising access to other essential needs, based on health promoting food practices that respect cultural diversity and that are environmentally, culturally, economically and socially sustainable.*²⁰

In these terms, it is clarified that the FNS comprises two dimensions: the food dimension, which deals with the production, availability and access to food; and the nutrition dimension, which determines the relationship between food, body and man: "HRAF is a human right for all and ensuring food and nutrition security for all is the State's duty and society's responsibility".²¹ In Brazil, the definition of FNS gained prominence when it incorporated in its concept the terms that reference the quality and quantity of food and also about the need for these to be suitable for the whole population without distinction of social classes, special, cultural and/or ethnic and religious conceptions.²²

For Pinheiro & Carvalho,¹⁹ the HRAF principle should be guaranteed by the State, in particular, through concrete actions such as public policies that enable resources for purchasing, production, selection and consumption increasingly focusing on meeting this right. However, one must consider the fact that the composition of the diet, the specific nutritional needs and the biological utilization of food (for those who consume them) are factors that directly reflect the individual's nutritional status, as advocated by Monteiro.²³ Thus, it is necessary to consider that following this principle is fundamental to the maintenance of the good nutritional status and, considering celiac individuals, these components become vital.

As with other special dietary needs and considering the specifics of celiac disease, the HRAF principle brings other requirements as the characteristics that require the process of food production, availability, accessibility and consumption. On the first requirement listed, which concerns the production process, the need to provide gluten free food/products, as well as ensure that they are free from contamination, particularly by gliadin residues, is considered essential. Thus, these food/products will be considered safe and suitable, which can be properly utilized by the body through absorption.

However, as already mentioned previously, the food must not only be suitable and available, it is essential that it is financially accessible to the individual. It is known that most industrial and/or artisanal gluten-free products have high prices. This condition can lead to reduced frequency of consumption, which can contribute to severe food monotony. About this statement, Burity et al.²¹ emphasize that

[...] the adequate feeding implies access to healthy foods that have as attributes: physical and financial accessibility, flavor, variety, color, as well as cultural acceptability such as, for example, respect to religious and ethnic issues and to the peculiarities of the diverse groups and individuals.

The right to adequate food for celiac individuals is supported by Burity et al.,²¹ when arguing that this kind of diet is inherent to a population group that has a different physiological condition and therefore, physical and financial access to gluten-free foods becomes predominant. However, this is not enough; there are religious and cultural factors that are involved in this context, which must also be observed. It is important to note that the dietary treatment is the only option available for the maintenance of health and quality of life of celiac individuals, therefore, the nutrition adequate to their condition must indeed be maintained throughout life. However, one must consider the fact that the consumption of food must be done consciously, seeking safety in terms of quality as regards to the production, supply and hygiene, minimizing potential health risks.¹⁹

HRAF violations: dietary difficulties of celiac individuals

When referencing the simple act of *eating* and *feeding others*, Poulain & Proença²⁴ claim that the human diet can (and should) be seen as a phenomenon with a high level of complexity as it involves physiological, psychological and sociocultural factors. This assertion has been made clear by Diez Garcia²⁵ in the 1990s, when - referring to the act of eating - he stated that “by having a key role in people’s lives, eating habits, ranging from preparation to consumption of food, includes subjective concepts such as cultural, religious, socioeconomic and family concepts.” In fact, as stated by Lee and Newman,²⁶ eating is more than a physiological act, is also a form of socialization, an emotional need of the individual, food being the link between individual-friends-family, which in turn affects social coexistence. The diet, by itself, ensures more than a sense of survival and biological requirements of vitamins, minerals, macro and micronutrients.

Confirming these assertions, Araújo et al.²⁷ stated that eating habits are connected directly to people's feelings, because they are linked to family and cultural values. Thus, returning the focus to the special dietary needs of celiac individuals, the authors explain the cause of personal suffering when there is a need to restrict certain foods, which can symbolize a break of affection for the individual.

Treatment of CD requires eating habits to be changed and adherence to new eating habits. In another study, Araújo & Araújo³ resume debate and come to defend that the celiac diet depends not only on the individual who has the disease, but largely on the family, being important to inform all those interested what foods should or should not be ingested. Such care ranges from the purchase of the adequate groceries to the preparation of food. The authors also noted that a large number of celiac individuals have little access to special products, which may probably be due to the fact that gluten-free products have a high cost, or alternatively, to the non-availability in stores. These individuals reported their dissatisfaction not only with the prices of these products, but also with their availability in supermarkets, and the little satisfaction regarding taste and texture.

Celiac disease, therefore, brings difficulties to the lives of their patients in everyday situations like having meals out, traveling, working, it imposes yet limitations of living in the family and promotes a negative impact on their well-being and quality of life of all family members. Often in social events, the diet ends up being interrupted due to the restricted number of foods allowed in their diet, as stated by Lee and Newman.²⁶ Singh & Whelan²⁸ also demonstrated similar situations and advance in this questioning, to argue that the limited availability and higher costs of gluten-free food products trigger a major impact in the financial field and can have consequences on the quality of life of the celiac individual, compromising compliance with the gluten-free diet.

The FNS and HRAF of celiac individuals and the democratization of these conceptions

If we consider that celiac disease does not choose social class, the situation may be more serious in social classes with lower purchasing power, since the special celiac diet is prepared with ingredients that have no tax incentive for price reduction. This has a major impact on the cost of food, since gluten-free ingredients are more expensive. This can be exemplified with the 45.8 million people served with the income transfer from the Bolsa Família program.²⁹ If implemented, in the Bolsa Família program population, the result of research on blood donors in the city of Brasilia, where 0.14% of celiac patients were found, the estimated number of celiac individuals in the Bolsa Família program would be of 64,120 people. This figure may even be underestimated, since in the referred sample blood donors were predominantly male and celiac disease occurs more frequently in women. Similarly, the percentage of 0.54% of children with celiac disease found in a research by the same author was not considered.³⁰

Even without official epidemiological data on the prevalence of celiac disease in Brazil, the above information, along with the reality of the higher cost of special food for celiac individuals, are facts that shape the food and nutrition insecurity of celiac individuals. There is no doubt that both celiac individuals and their diet need special attention.

The gluten-restricted diet has a number of consequences in their lives, since such products (gluten-free) are not easily found and, in general, are sold in natural and/or specialty food stores, mostly located in larger centers. Moreover, by using other ingredients substituting wheat, the cost of these products becomes higher, which may make them inaccessible to a significant portion of celiac individuals.

The exposure of the celiac individual to gluten causes damage to the intestinal villous, which becomes damaged and reduces the absorptive capacity of nutrients, compromising the nutritional status and health of the individual. Such difficulties hurt the HRAF principle of that individual. To ensure their rights, urgent actions aimed at solving these problems and a better support before their situation of food and nutritional vulnerability are needed. The adequacy and adherence to the diet must be total, so that the celiac individual holds their nutritional status in an eutrophic and quality of life condition. There is, therefore, an urgent need for specific actions and programs to meet the demands of celiac individuals that aim to ensure their basic human rights from the perspective of Food and Nutrition Security.

One measure that could be incorporated into public policy regarding the celiac individual would be the tax reduction (or even total exemption from taxes), so that the segment of homemade and/or industrial production of gluten-free products is promoted, ensuring a systematic production and quality, reducing costs and allowing the sale of these products at more affordable prices.

The financial assistance for celiac individuals can also be another way to go. The same line of investment (social and food) is regarding the opportunity of training and qualifications, by offering courses for learning techniques to produce gluten-free foods targeted to celiac individuals and their families. In this sense, it allows for a greater food and nutrition diversification, respecting regional, cultural and social aspects, as well as ensuring greater quality of life for celiac individuals.

The social program of the City of Curitiba, Armazém da Família, offers the population with an income up to R\$ 1,395.00 and individuals with special dietary needs, foods priced on average 30% less than those offered in conventional supermarkets. Under this program, the celiac individual registered, through medical evidence of his needs, can buy gluten-free products at affordable prices.

The adherence of a celiac individual to a gluten-free diet is of paramount importance to avoid compromising the structural, weight and pubertal development, fertility, bone mineral density, reduce deficiencies of micro and macronutrients and the risk of developing malignancies, especially in the gastrointestinal system. However, maintaining a totally gluten-free diet is not an easy task, because the violation of the diet may occur voluntarily or involuntarily, ranging from incorrect information on food labels, to the contamination of processed products with gluten, such as made explicit by Sdepanian et al.³¹

It should be noted, therefore, that the HRAF must be guaranteed, in particular by the State through public policies that promote activities and programs aimed at accessing resources for purchasing, production, selection and consumption of foods and focusing increasingly on providing this right, as argued by Pinheiro & Carvalho¹⁸. This assertion is consistent with that governing the Constitutional Amendment n^o 64 of 2010,³² which amended the text of Article 6th of the Constitution and, in turn, established the right to food as a social right. Thus, food must be viewed as a constitutional right of all citizens, including those with special needs, which require a special diet.

The Food and Nutrition Security of the individual goes beyond the daily availability of a certain amount of food, that is, it also encompasses sanitary conditions and issues such as the nutritional quality of the food. Moreover, it also includes other factors such as the need to address the specific eating habits cultivated throughout life, according to their culture and religious beliefs, and to provide a diet that is adequate to their health and improve their quality of life.

Final remarks

It is worth mentioning that there is no intention to exhaust the theme, but to start a debate that is still evident as incipient, especially when considering the concreteness of a HRAF violation. In this perspective, it can be stated that celiacs fall as individuals with special dietary need and have the right to access, availability and adequacy of their diet, so that it meets their nutritional needs and promotes their health and quality of life.

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