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Celiac people health care weaknesses in the Unified Health System (SUS): a user's perspective

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Abstract

Celiac disease is a multisystem autoimmune disease that can manifest at any age, in genetically predisposed individuals, whose only treatment is based on the adherence to gluten-free diet throughout lifetime. This essay aims to list points and counterpoints on the weaknesses of and in health care to the people with celiac disease in the Brazilian Unified Health System [the so-called SUS), based on the experience reported by system users. The authors are members of the ACELBRA (Association of Celiac People in Brazil) and requests received by this entity served as the basis for this essay. The situations summarized here refer to routine requests for information, and guidance, complaints, questions, produced in-person meetings or materialized during mediation in online forums by the tools of co-help groups during the period 2007-2014, involving about twenty thousand members from different regions of the country. Given the increase in the number of diagnosed cases of celiac disease after the approval of the clinical protocol in 2009, this text is not just a list of complaints, but a map of weaknesses and bottlenecks in a system.

Key words: Food. Celiac Disease. Health Education. Health Services.

Introduction

Considering the increased number of celiac disease cases diagnosed after the approval of the clinical protocol and therapeutic guidelines of celiac disease in the SUS (Brazilian Unified Health System) in 2009, this paper aims to summarize daily requests for information and guidance, questions and complaints made at in-person meetings and / or materialized during the on-line mediation of tools used by collaborative groups. More than recording a list of complaints, the intention was to map the weaknesses and bottlenecks of a system.

Celiac disease (CD) is an autoimmune condition present in genetically predisposed individuals. In fact, it is the only autoimmune disease which trigger is effectively known: gluten.[1] A production of antibodies is triggered by the presence of gluten in the diet and these antibodies elicit an inflammatory process on the mucosa of the small intestine, leading to the atrophy of intestinal villi, malabsorption of nutrients and a variety of clinical manifestations related to duodenal mucosal destruction and inflammation. The CD is activated by the consumption of gluten, found in cereals such as wheat, barley and rye, and it hinders the absorption of water, medicines, vitamins, minerals and macronutrients (proteins, carbohydrates and lipids). The clinical manifestations of CD may involve the gastrointestinal tract,[2] as well as skin, nervous system, reproductive system, bones and endocrine system.[3] Epidemiological data indicate that in Europe and the United States, CD occurs from 0.5 to 1.0% of the population.[4] Although it occurs to one in every 100 people, it is estimated that only 10-15% of celiacs are properly diagnosed. First-degree relatives of celiac patients are individuals with a greater chance of developing this disease, often 10-20 times higher than the general population. According to Green, over 36% of people with CD had previously been diagnosed with IBS (Irritable Bowel Syndrome).[5]

Note the fact that the prevalence of cases of this disease depends on the region under study and also on the methodology used. Studies on blood donors have shown that, in the United States, for instance, the frequency of cases is 1:250; As for Brazil, in Brasilia, it is 1:681, and in Ribeirão Preto, 1:273.[6] However, the methodology used for determining such prevalence has already indicated an important fact: blood donors might be a group with lower probability of presenting CD compared with the general population. That's because this group consists of mostly male subjects, who are healthy, asymptomatic, with no anemia, nor autoimmune alterations, no weight problems nor malnutrition. In other words, a group that differs from the group of people with celiac disease, which most common characteristics include: female gender, with several complaints, anemia, autoimmune alterations, weight problems or malnutrition. This makes us think of a first weakness of the situation diagnosis: its prevalence, its underdiagnosis, and decreased prospects of impact on the system and families.

Although we have no studies on the occurrence of celiac disease in the total population, it can be inferred that, in Brazil, it is much greater than among healthy blood donors. That explains why the idea that celiac disease is rare in Brazil, and, in the perception of people with celiac disease, it ends up becoming a subgroup of neglected diseases. In Brazil, CD probably occurs similar to what has been observed in Europe and in the United States, ie., 1:100 people.

In contrast with respect to occurrence: in Brazil, tuberculosis has an estimated coefficient of 62:100.000 inhabitants.[7] A study by Lorete Kotze,[8] in which she reviews forty years of clinical practice in the care of people with celiac disease, recommends a periodic assessment of complications and diseases associated with CD, since childhood, regardless of age at diagnosis or of duration of gluten-free diet.

Methodology

This is a study whose methodological design of qualitative research is focused on action-research.[9] The participants of this research are celiac people, or their relatives, who have spontaneously contacted researchers or the group of collaborators, in which the researchers take part, in person, by phone, on-line (through the celiac support groups in social networks), or by email, to request information or other interactions from 2007 to 2014. Such interactions consisted of requests for culinary tips, travel advice, disclosure of culinary preparations that have worked, telling of family events, information on labeling, complaints, questions and concerns on health issues, which were written and described by the subjects themselves, resulting in a large text corpus.

Thus, the empirical basis of this essay consisted of the written demand or the questions the participants made to researchers through emails, chats or forums without using a previously structured instrument. For this work, from the large text corpus, we have selected the topics addressing health services. The criterion for the selection was the recurrence of the questions / requests / complaints on SUS. Among these occurrences, we have summarized in this essay the so-called “weaknesses” or “bottlenecks” of the care to celiac people and their families in SUS.

For exposition purposes, they have been organized in: weaknesses in diagnosis; weaknesses in post-diagnosis, in access to nutritional and psychological support, in basic care, in education for health and self-care and support groups; weaknesses in hospitalizations, and weaknesses in professional training and dissemination of information on CD.

Weaknesses in diagnosis

A review has shown that the ratio of patients diagnosed and undiagnosed with CD can reach 1:7.[10] In discussion forums, some of the most common situations are requests for information on diagnosis, which include: reports of symptoms from other family members, names of required examinations, doubts on which medical specialty to search for and where to look, indications for reliable professional and reports on processes experienced.

The process of trying to diagnose CD has been described by people with celiac disease as being an uncertain and upsetting pursuit for the right medical specialty, having to go to appointments with several different physicians. In Brazil, as in Europe and in the United States, the diagnosis of an adult celiac individual can take up to ten years after the onset of first symptoms. Even after considering the possibility of it being celiac disease, it is not always easy to get to its diagnosis. Anecdotally, it is said that one must suspect the possibility of celiac disease in every patient who enters a doctor's office carrying a folder with multiple tests from different specialties, with a history of alterations in the past years.

Objectively, one should suspect celiac disease in every first and second degree relative of a CD patient or people with chronic diarrhea or constipation, chronic abdominal bloating and pain, flatulence, recurrent canker sores, enamel hypoplasia, bullous dermatitis, weight changes without any apparent cause, anemia (especially if chronic and / or poorly responsive to supplementation), premature osteoporosis, elevated transaminase levels, irritable bowel syndrome (IBS), hypocalcemia, as well as folic acid and fat soluble vitamin deficiencies. Also, CD is associated with several diseases such as type I diabetes mellitus, hypothyroidism and hyperthyroidism, especially of autoimmune origin, Sjögren's syndrome, primary biliary cirrhosis, autoimmune hepatitis, depression, epilepsy, cerebellar ataxia, recurrent miscarriages and infertility, delayed puberty , selective IgA deficiency, heart failure, arthritis, Turner syndrome, Down syndrome, child deafness and peripheral neuropathy.[11-14]

Anyone with autoimmune alterations should be tested for CD. However, there is no justification in the literature nowadays, for the population screening of CD diagnosis, only for family members of people with CD - after all, only 30% of the population have genetic predisposition to develop a celiac condition.

In Celiac Disease Clinical Protocol,[15] the anti-tissue Transglutaminase Antibody (anti-tTG) is used as marker, since it is sensitive and specific. Due to the research performance of anti-gliadin antibodies - AGA (which is more sensitive) and of the endomysial antibody - EMA (which is less sensitive and very specific), they were not included in the protocol. Still, they can be used as serologic indicators, once they help compose the characterization of the profile, but are no longer covered by SUS. The withdrawn of anti-gliadin from the clinical protocol of SUS, however, brings the problem of history loss, useful to compare data produced before and after 2009.

IgA deficiency is the most common human immunodeficiency, being ten to 15 times more prevalent in patients with celiac disease. Approximately 3% of patients with CD have this deficiency, which can cause false-negative test results for EMA serological tests, anti-tTG IgA and AGA IgA, based on IgA.[14] Thus, clinical protocol recommends total immunoglobulin IgA dosage for everyone, along with anti-tTG IgA.[1, 2,4,7,10,14] Clinical protocol also suggests that, in the presence of IgA deficiency in the diagnostic phase, patient should be referred directly to duodenum endoscopy and biopsy.

Clinical protocol[15] determines that SUS should provide for the dosage of IgA class immunoglobulins and duodenal biopsy. However, this document does not specify whether the tests should be offered in any health facility or in reference centers, which hinders its conduction. In this aspect, another weakness, come to light, as in many places, the Health Care Network does not have kits, equipment and trained personnel to perform serology, nor do they have a digestive endoscopy department, where biopsy may be conducted according to protocol. Moreover, depending on the location or care unit, the time period between scheduling and conducting the endoscopy may be too long, delaying diagnosis and favoring the onset of complications associated with CD.

It is common sense that CD is a condition of complex inheritance, which requires the monitoring of all family members, but how to guarantee that? Other weaknesses are associated with the configuration to build the characterization framework of diagnosis of celiac patients. Elements from five different areas must be joined: symptoms and clinical history, serology, presence of relatives with CD or genetic examination, endoscopy with biopsy or dermatological examination with biopsy, clinical improvement when excluding gluten. In case of doubt, where to turn?

While there are good and active researchers on celiac disease in Brazil, there is not a reference center. Even if CD reference centers are deployed, not all patients will have access to them, due to distances and travel costs.

Most of patients diagnosed with CD report feeling lost because of the changes on their diets, on their everyday routine, and due to the acceptance process of living with a chronic, permanent non-drug condition that involves self-caring. People acknowledge the weaknesses of the relationship between health care and social assistance.

Weaknesses in post-diagnosis, in access to nutritional and psychological support, in basic care, education for health and self-care and in support groups

The perception of the post-diagnosis families have well-known features in the psychological literature, as in the Kübler-Ross model[16]: grief, fear, denial, anger, mourning or victimization, depression, and acceptance on the fragility of life, in which the hegemonic food becomes the enemy. Acceptance for some people with celiac disease, includes information, struggle and engagement.

Common reports in post-diagnosis include: feeling lost, not knowing which and where to buy proper food, panicking with the necessary changes on how to eliminate gluten from kitchen utensils, and with the prescription of avoiding any contact with gluten, not knowing how to deal with the disruption of eating routine, since in the current historical moment all meals will have to be prepared at home, given the lack of laws requiring bars and restaurants to inform the gluten content of their food or to offer safe non-gluten food. Such data on the perspective of celiac Brazilians agree with a study[17] conducted by Boston, which records that the perception of the impact of CD on the lives of patients is only lower than that of dialysis to the families.

This scenario also increases with regional economic inequalities and educational inequalities, because a policy of emergency care cannot be universalized, with the provision of gluten-free food baskets for the initial adaptation to the diagnosis.

During the post-diagnosis, it is very important to remember that celiac patients will need to undergo a process of learning, guidance and care, to acknowledge that they are responsible for their own treatment: marking tests, and scheduling appointments and returns. They will be responsible for seeking test results instead of expecting someone else to do it for them, knowing, however, that they can ask for help and do not need to go through this alone; they are also in charge of relearning how to cook all of their meals.

Patients must be guided and embraced, to avoid the feeling of being the victim, and to focus on their health and their well-being, seeking to draw up negative feelings and prejudices. They need to be able to rearrange their lives and reflect on their routine, by asking: “Can I keep on working?”, “Do I want to keep on working?”, “How will my treatment be?”, “Can I apply for a temporary license?”, “Can I apply for temporary health leave to accompany my celiac child or other relative?”. Talking with their families about having CD, describing limitations and decisions, and planning a life in the short, medium and long terms.[18]

Thus, it is important to get informed on CD, on gluten restriction, associated diseases, food options to diversify their diet, and o do so, it is essential to have a talk with doctors and nutritionists. Talking and asking about all the trimmings for your specific case. Ask for recommendations on trusted Internet web pages on the matter. Propose a partnership and remain in charge of your health. Educate yourself and do not be afraid of information.

Accepting and becoming responsible for your own treatment means to: get more informed; have greater control and participation in choices and decisions; feel more secure, confident and prepared to face treatment and all the necessary decisions; coping with real expectations; being the defender of yourself and of your life; exercising your role as responsible and active citizens.[19] Celiac patients educate themselves, ie., are humanized and become social subjects in their own fight (a social / individual fight around the issues of life and death) that is directly triggered.

However, SUS post-diagnosis support groups and social assistance groups are rarely found, even nonexistent in most Brazilian states. The existing post-diagnostic support currently occurs via celiac groups, which are associated or not, on a voluntary basis, unpaid, non-certified, non-governmental and often with no even physical space provided within a basic health unit.

The only treatment provided for celiac patients involves their diet and consists of eliminating contact with gluten; where a gluten-free diet must be adopted for life, at every meal: in the family, away from home, while traveling, at work, in hospitals, schools and religious ceremonies, which imposes limitations or changes in living routine. Removal of contact with such protein has important impacts on the family dynamics and self-care.

Gluten is an international name for the major protein present in winter cereals: wheat, oats, rye, barley. This protein is capable of conferring elasticity to the masses and adding volume to many products it is used, and it is also an important source of vegetable protein for many people. Therefore, gluten is present as a cultural element added not only in many of our foods, but also to by-products, such as malt, wheat germ and oat bran.

According to IBGE, of the fifty most consumed products in Brazil, ten have gluten as an ingredient. However, it is still not enough to just suppress the consumption of food containing gluten. In Brazil's current culinary culture, wheat is an elemnt found in all homes, restaurants, schools, hospitals and cafeterias. Wheat flour spreads very easily in the air, on equipment and within food storage rooms.

Thus, a food which originally does not contain gluten, such as cassava, may be contaminated if handled jointly with food containing it. Moreover, much of the powdered spices, condiments and processed products may have been added wheat, in order to increase their weight, efficiency and consistency. Another important form of cross-contamination is the sharing of utensils and equipment used to prepare foods with gluten and used by a celiac person. Although such products come with the correct labeling as to contain, or not, gluten, besides being culturally difficult to replace them, they can add gluten to a wide range of foods that were originally proper for CD people consumption, limiting the options.

Another change to such coexistence could be the adequate control of gluten in cross contamination. Understanding cross-contamination in equipment, elimination of gluten residue and traces, the cleaning of utensils and ways to avoid cross-contamination of foods are part of the initiation rituals in the life of a celiac person.

However, based on reports that support this essay, such initiation is accompanied by great psychological distress and by the feeling of loneliness, because their families are not involved in this process of learning. Forums constantly bring the following question that depicts great suffering: "What can I do to make my family understand that I am not just being picky?" Become a diagnosed celiac person, so that in addition to dealing with an autoimmune alteration and associated diseases, and the diet itself, it also implies understanding that there will be a change in the form of socialization and emotional needs, mediated by individual-friends-family eating. This, in turn, affects social life. Who will support such psychosocial adjustment if, although acknowledged in clinical protocol, it is rarely referred?

Eating habits go far beyond the exclusion of gluten and the requirement of water, vitamins, minerals and macronutrients; they relate to the feelings of people, to the bonding with family and culture. Changing the eating habits of a celiac person is more than a physiological change, and teaching them what constitutes a 20ppm of gluten contamination. It also means to support them in building a new relationship with their body, family and social life. After all, the act of eating is ontological in people's lives and eating habits start in the purchase of food, go through preparation, and end in consumption; eating involves subjective, cultural, religious, socioeconomic and family aspects. Where to seek for this psychotherapeutic support?

Quickly learning which foods are allowed and how they are produced to avoid cross-contamination modes of becomes a essential for survival. The delay of the family in understanding the relevance of the hegemony of wheat and gluten cross contamination in our current life can trigger psychological distress. The fact that families do not follow the dietary changes of relatives with CD results in two events: the worsening of the situation, with thickening of associated diseases where celiac people and their families transgress the diet and the form of food production; or when celiac people, in desiring self-care, produces the feeling of disruption of affection, either by refusing to eat, by fear of the symptoms, or for feeling less loved.

These situations change the sense of well-being and / or quality of life. Situations that are aggravated by the lack of access for people with celiac disease and their families to assistance provided by a professional nutritionist, by the lack of group sessions or courses for teaching and learning about food production, addressing techniques, ingredients and balanced composition of meals. There are a few cities where this service is available. Even if it exists for diabetic and hypertensive patients, celiac people feel less prestigious on these meetings. There is difficulty in accessing. Demanding such offer is hard for celiac people, given their disbelief that this would be possible. When an appointment is made with a nutritionist, in some cases it is directed to pediatric patients, and the majority of professionals, because they have not received adequate training on how to handle CD, find it difficult to instruct patients in matters that go beyond the replacements they need to make, to assess possible nutritional deficiencies, and even other associated food hypersensitivities and the need for micronutrient supplementation, keeping their orientation only to the exclusion of gluten.[16,20-22,24]

Regarding supplementation, another weakness may be highlighted: there is no protocol governing the availability and supply of vitamin, mineral, pre and probiotic supplements, among others, for celiacs. Moreover, the supplements available in care unit pharmacies, and hospitals are mostly registered with the Ministry of Health as drugs, preventing the nutritionist to be able to prescribe them. Another issue regarding this matter is the inability to distinguish supplementation, by manipulating the nutrients in SUS-associated certified pharmacies, thus supplementation is only up to the doctors, when its need is such that it reaches pharmacological levels of nutrients.

Thus, beyond the issues of nutrition, perceptions of loss of quality of life in the social dimension are compounded by the absence or weakness of individual psychotherapy referral to care, lack of support groups for celiac people and their families and the absence of collective psychological care, which would help rise complaints, psychological distress, relationship of affection, and to produce certain resilience.

Besides the difficulties in getting care in psychological services, one perceives (through what celiacs and their families have reported) that certain precautions that should be part of the everyday life of celiac people are neglected and ranked by professionals as an "exageration", "obsessional neurosis","eating disorders", and even a sense of paranoia by unfounded feelings against gluten. This shows how little CD, dietary restrictions and procedures for cross-contamination by proteins are covered in undergraduate health courses.

Other weaknesses can be listed: a certain neglect to the psychological distress of people diagnosed with CD, and their desire to have a "normal" social life. They are not priority for treatment at the Centers for Psychosocial Support (CAPS) from SUS, although reports of suicides are not uncommon, due to the psychic discomfort with the situation, aggravated by the prevalence of cases of depression pre and post-diagnosis, many due to malnutrition. In addition to the reduced number of professionals and poor capillary of CAPS, it is important to highlight the lack of care, in many municipalities, for children.

With or without support groups in the primary health care network of SUS and in the social care network; with or without nutritional, psychological, educational, and specific medical assistance, for each particular case, it will be up to the celiac person or their family members to learn their options for treatment: run away, procrastinate, complain and see what happens; or face it and prepare to become active and responsible for their own treatment.

It must be urgently considered that celiac disease can be a diagnostic hypothesis. Families must be urgently welcomed for new diagnoses. Post-diagnosed patients need to be urgently embraced so that CD people can learn about their rights and can assume an active behavior, getting informed on their rights in relation to: SUS, complementary health if it is the case, information on their Right to Proper Diet (DHAA), pursuit of information on food labeling, to the local social assistance projects. Post-diagnosis orientation must be urgently conducted for the benefit of SUS itself, so that it can acknowledge them ("who they are", "how many", "where they are") and "recognize" celiacs as subjects to be assisted. Finally, we consider that to engage on targets and strategies for celiac person, the right to equality needs to be addressed.

Weaknesses in the process of hospitalizations

Reports of accidents with gluten in the corpus of texts produced in emails, forums and chats do not record problems in environments of ICU, ER, surgical centers and in the process of enteral and parenteral nutrition, but there are reports on admissions to medical wards and to private rooms in health institutions.

The following report was drawn up in 2014, both via forum and email, to the association as a double aid application: legal, on how to proceed, and equipment, so that some celiac family would provide four meals free of cross-contamination with gluten to a ten year old girl hospitalized in the last days of February and her sister, admitted in March, in the largest pediatric hospital in Curitiba. The girls' mother, who often cooked for them was accompanying them in the hospital, far more than two hundred kilometers from her home. The largest pediatric hospital in Brazil, located in Curitiba, failed to provide supply free of cross-contamination with gluten (including soup with wheat noodles) for their celiac patients.

Summary of cases: children in need of intravenous medication, difficult communication between nursing and other hospital sectors with the kitchen, a statement from the nutritionist that the kitchen was not able to provide gluten-free uncontaminated foods for hospitalized children. Due to the distance from home, the family could not go to their house to prepare food and return to the hospital. Therefore, in agreement with the pediatrician, the mother resorted to the help of other people in town with celiac disease, so that gluten-free products could be taken to hospital for breakfast, afternoon snack, lunch and dinner throughout their hospitalization. For the situation of the first hospitalization in February, the family filed a complaint with the hospital and it has agreed to resolve the situation, including changing procedures for dietary requirements. On the second hospitalization in March, as the conditions and procedures had not been revised, another complaint was forwarded to the prosecutor.

Information of accidents with gluten in celiac patients in health institutions are frequent, and reports on the poor knowledge of health teams (including professionals from the Nutrition sector) on the matters of CD and especially on the risks associated with cross-contamination of gluten are common. Most of these accidents are not registered in the SUS, because in general the families do not have data nor proof of occurrences through photographs of foods that are delivered in the wards and rooms to formalize their complaints. The vast majority make outraged statements that are not documented, based on the classic symptoms of contact with gluten, reported to celic groups and associations.

In 2012, a formal search for information in the Ombudsman of SUS was conducted, and to the SESA-PR, about which of the 13 hospitals and maternities of the western region of Paraná (9th SR) would be able to meet the demands of hospitalized celiac patients. Only two institutions did not answer the poll. All 11 institutions that responded did so in writing and reported to SESA-PR that they could not meet the special dietary needs of celiac patients hospitalized there. Although SESA-PR has shown to be troubled and outraged by such a finding, the fact was no surprise to the association of celiac patients, since this was only a established fact already known to them in practice.

The frequency of accidents is such that groups of celiac patients have created an informal protocol suggestion aimed at the first stage of hospitalization. It consists of: 1) notifying upon receipt who is celiac and has "allergy" to gluten (although not the correct concept, it is the functional use of the medical record); 2) notifying the doctor and asking to be placed in the medical record; 3) notifying the nursing staff personally; 4) notifying the dietitian personally, and if possible, notifying the person in charge of the kitchen; 5) putting up posters near the bed, 6) every time the food comes to the room, the kitchen staff needs to be contacted.

These recommendations aim to minimize the risk of contamination, ensuring adequate food and contributing to the recovery of the profile that led to hospitalization, considering that a celiac patient when exposed to gluten has high chances of not responding adequately to drug treatment and also presenting complications.

Weaknesses of professional training and spreading information on CD

For many years, CD was considered mere, uncommon dietary intolerance in the general population, and without major consequences for the health of patients, unless they appeared in children, with its classic characteristics, tied to the condition of caloric-protein malnutrition and diarrhea. Currently, the autoimmune nature of the disease is already known and long-term complications as well, resulting from the non-complete exclusion of gluten and other care.[10,24,25]

Forum reports record, however, that people with celiac disease and their families observe considerable lack of knowledge of health teams with regard to CD, its autoimmune character, to essentially dietary treatment and the need for micronutrient supplementation and probiotics, the risks involved in the cross-contamination of gluten and low participation on the exclusion diet.

It is believed that this fact originates in the curricula of undergraduate courses, especially courses in Medicine and Nutrition, in which CD is often addressed in a superficial manner, and with a bias of low prevalence, low incidence and low mortality. This scenario has been perpetuated by the lack of formal training and updating courses for professionals of health teams, even after the creation of the protocol.[15]

Regarding training, given the lack of certified courses, there are some isolated and voluntary movements by regional ACELBRAs, with the support of the National Federation of ACELBRAs (Fenacelbra) and some health professionals, to offer short courses and symposia on CD. It is noteworthy that due to the treatment of celiac condition without injuries is essentially dietetics, food reeducation may or may not have supplements, formulas and medicines, one sees a commercial disinterest from the pharmaceutical industry to support, sponsor, or reward fund disclosure or professional training in acting.

This leads us to register other weaknesses of the situation materialized by complaints boards: the absence of advertising or information campaigns by the SUS about this autoimmune condition, its diagnosis and its treatment; and the absence of a program or project training for health care professionals have knowledge to suspect that the person may be celiac.

In 2005, the Ministry of Health printed brochures and informational posters about celiac disease so that ACELBRAs distribute in their states, in health, between health professionals and the general population, during the International Day Walk for Celiac. Within the Zero Hunger Program, in partnership with the Association of Celiac Brazil, directed to the public dissemination of a booklet, funded by the Federal Government (;; Ministry of Health Federal University of Viçosa Ministry of Social Development and Fight against Hunger) was printed child: a Primer on Emília.26

In addition to the protocol clínico15 have been approved in 2009, only one “Orientation Guide” 27 to celiac person, financed by the Ministry of Justice, was printed and distributed. There was also training courses on Human Rights to Adequate Food (2010), 28 made by Brazilian Action for Nutrition and Human Rights (ABRANDH), linked to the Ministry Against Hunger and the National Food Security Council (CONSEAs), via formation by through Distance Education and printed publication whose focus was food security. A training course for managers of ACELBRAs was also performed: "Empowerment Society Participation in Social Control", in Rio de Janeiro in 2010, funded by the Ministry of Health, and National Congress of Celiac Disease, held in 2012, in Fortaleza by Fenacelbra / BCA-EC, PAHO-funded / Ministry of Health.

After the perceived need for more targeted information to key aspects of the supply of the celiac, the RJ-BCA released a booklet called The Ten Steps to feed the celiac, 19 available for free with a didactic approach to international recommendations, [20,21,29-40] in PDF format on the website of Fenacelbra, associations of celiac and other web pages. Points raised in this course material are described below:

1) **Delete completely gluten feed**. This means foods containing wheat (grain, the germ, the oil and white or wholemeal flour, and bread crumbs and wheat kebab), rye, oats and barley (including malt, a substance obtained from the fermentation of barley, used in brewing, chocolate, biscuits etc..).

2) **Replace the prohibited ingredients** for "insurance" in recipes such as rice flour, corn starch, corn flour, potato starch, sweet and sour cassava starch, tapioca, buckwheat (which is not wheat "real"), flour foods white beans, chickpeas.

3) **Do not overdo the intake of breads, cookies and prepared** with ingredients listed in section 2 masses, since they are very calorie foods, high glycemic index and poor in fiber (are rapidly absorbed, transformed into glucose, thus contributing to the increased blood glucose, insulin levels and the rapid weight gain, which is neither healthy nor for celiacs who are underweight).

4) **Use the naturally gluten-free foods** like fruits, vegetables, rice, corn, beans, peas, lentils, chickpeas, meat, chicken, fish, eggs, nuts, almonds, walnuts, dried fruit.

5) **Prioritize always fruits and vegetables**, especially those of time, which are cheaper and more nutritious. If possible, give preference to organic. Appreciate the food of their region who are always freshest, cheap and nutritious.

6) **Use salt and sugar in moderation**. Avoid processed condiments and sauces. Invest in natural herbs and spices, such as parsley, chives, bay leaves, rosemary, oregano, basil, thyme, garlic, onion, tomato, pepper, turmeric, ginger, cinnamon.

7) **Avoid fried foods on the street, because of cross-contamination with gluten** and harms caused by reusing the oil in frying, and at home, because even without the oil contamination and not being reused, the fries are very caloric and oxidize fat naturally present in foods, contributing to the increase in cholesterol levels.

8) **In case of lactose intolerance (very common in celiacs, especially in newly diagnosed), avoid dairy products** (cheese, yogurt, condensed milk, cream). Replace with juices containing fruits and vegetables of dark green (like kale). Add in food (in salads, in juices etc..) Sesame, pumpkin seed and sunflower, to increase the intake of calcium and magnesium and ensure healthy bones.

9) **Increase your intake of foods containing vitamin D** (eggs, butter, meat and fish), and moderately expose yourself to the sun, to activate the vitamin D produced by the skin.

Vary the most on food. All celiac, depending on the intestinal mucosa lesions and increased intestinal permeability, is more likely to develop secondary food hypersensitivities. Therefore differ frequently consumed foods is one way to prevent or at least minimize this risk, and ensure greater coverage of all nutritional needs.

These guidelines are often the only ones that a newly diagnosed celiac and their families have access, due to low supply of Poles service targeted at celiac and little information about this disease by health professionals.

Thus, the disclosure of both the diagnosis and the treatment has materialized in Brazil in two ways: via publications in scientific journals, the result of research in Brazilian universities, or via patient organizations / celiac people. As an initiative of the Ministry of Health or SUS, no billboards, no calls on television, no brochures. No advertising campaigns, no continuing education for health professionals.

Register here an unusual situation in the care of patients and their diseases: are the users of the system, patients and their families who draw up the organized dissemination of research texts on the subject. Also prepared proposals for host of health professionals, their adherence to the cause, training proposal for both families and for health professionals, either by conducting scientific congresses or editorial material. It is noteworthy that this is a volunteer, unpaid, unsponsored, and that does not supply an absence of performance in health education of the celiac and health professionals.

Final remarks

The monitoring by a multidisciplinary team and regular evaluation of complications and diseases associated with CD, since childhood, regardless of age at diagnosis or duration of the gluten-free diet measures are necessary to life and quality of life of celiac person that if properly implemented, would produce less financial impact on SUS. For this to happen, it is necessary to address the weaknesses and bottlenecks towards guaranteeing the right to health and overcoming inequalities and political commitment.

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