CLINICAL
NUTRITION

DOI: 10.12957/demetra.2019.33310

DEMETRA
Alimentação, Nutrição & Saúde

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Celiac patients' perceptions about the clinical and social consequences of possible late diagnosis of celiac disease

Percepções de doentes celíacos sobre as consequências clínicas e sociais de um possivel diagnóstico tardio na doença celíaca

Abstract

The aim of the current study is to identify patients' perceptions about the clinical and emotional impacts of the late diagnosis of celiac disease. The way celiac patients see themselves as ill, their feelings about new eating and social habits, society's vision and behavior towards their comorbidity, and the clinical symptoms in their body affect their clinical and emotional state. Only female celiac patients who attended meetings held by the Celiac Association of Paraná State (Brazil) were interviewed based on a semi-structured script in order to fulfill the aims of the present study. Quantitative-qualitative analysis was carried out based on content. Results showed that 77% of participants categorized their diagnosis as late; among them, 38% stated that the clinical symptoms of the disease appeared during childhood. The knowledge produced in the current study can make professionals and society aware of the clinical and emotional impacts generated by the late diagnosis of celiac disease on the human body, and help these professionals and individual more supportive and comprehensive with celiac patients.

Keywords: Celiac disease. Delayed diagnosis. Social vulnerability.

Resumo

O objetivo deste estudo foi identificar percepções em relação às consequências clínicas e emocionais dos possíveis diagnósticos tardios da doença celíaca. O modo como o celíaco se vê enquanto doente, seus sentimentos quanto aos novos hábitos alimentares e sociais, a visão e comportamento da sociedade diante de sua comorbidade, bem como os sintomas clínicos sofridos pelo corpo, se refletem no seu estado clínico e emocional. Foram entrevistadas exclusivamente doentes celíacas do sexo feminino, sendo todas frequentadoras de reuniões da Associação de Celíacos do Estado do Paraná (ACELPAR), com base em um roteiro semiestruturado. A pesquisa, de cunho quanti-qualitativa, teve sua análise realizada através do conteúdo, e seus resultados retratam que 77% dos participantes consideraram seu diagnóstico tardio, sendo que dos mesmos, 38% declararam que os sintomas clínicos da doença surgiram na infância. O conhecimento produzido a partir deste estudo pode conscientizar profissionais e a sociedade sobre as consequências clínicas e sociais geradas pelo diagnóstico tardio da doença celíaca no corpo que já sofre, transmitindo suporte e compreensão.

Palavras-chave: Doença celíaca. Diagnóstico tardio. Vulnerabilidade social.

INTRODUCTION

Celiac disease (CD) can be described as the intolerance to the intake, and contact with, gluten protein, which affects genetically predisposed individuals. It is characterized by an inflammatory process that affects the mucosa of the small intestine and leads to atrophy of intestinal villi, to malabsorption and to a variety of clinical manifestations. CD clinical manifestations can involve the gastrointestinal tract, skin, liver, nervous and reproductive systems, bones and the endocrine system.[1]

The prevalence of celiac patients corresponds to approximately 1% of the global population; there may be high variation in it from country to country. Estimates have shown that such prevalence has increased, despite the high percentage of affected individuals who were not diagnosed.[2,3] This disease mainly affects descendants from European individuals and its development is strongly influenced by genetics. Brazilian Southern and Southeastern regions hold the highest prevalence of celiac cases due to the strong European colonization in these regions and to the greater availability of diagnostic tests.[2]

CD can be classified in two basic types: symptomatic and asymptomatic. The symptomatic form of the disease presents classic and atypical clinical cases.4 Classic cases are the most frequent form of it; they start in early childhood and present symptoms such as chronic diarrhea, vomiting, irritability, lack of appetite, stunting, abdominal distension, decreased subcutaneous cellular tissue and atrophy of gluteal muscles. Atypical forms of the disease do not often present digestive symptoms or, when they do, these symptoms remain in the background. This form of CD starts later in life; patients belonging to this group can present different manifestations such as short stature, iron deficiency, anemia refractory to oral iron therapy, arthritis, constipation, dental enamel hypoplasia, osteoporosis and sterility.[5]

Classical clinical manifestations of the disease have become less frequent in the last two decades, whereas the number of atypical CD cases has increased.[4] The time between symptom emergence and diagnosis with access to, and follow-up of, gluten-free diet are factors that have great repercussion on the nutritional status of celiac patients.

CD diagnosis is a challenging task, mainly due to great variation in the clinical expression of the disease; thus, if one takes into consideration the symptoms and signs of this pathological condition in separate, none of them is an absolute indicator to be adopted for CD diagnosis.[6] CD Diagnosis should be investigated in all patients with chronic diarrhea, abdominal distension, flatulence, iron deficiency anemia, early-onset osteoporosis, elevated transaminases, hypocalcemia, folic acid and fat-soluble vitamin deficiencies, as well as in first- and second-degree relatives of CD patients. In addition, CD is associated with several diseases such as diabetes mellitus type I, hypo and hyperthyroidism, Sjogren's syndrome, primary biliary cirrhosis, autoimmune hepatitis, autism, depression, epilepsy, cerebellar ataxia, infertility, late puberty, selective IgA deficiency, Turner syndrome, Down syndrome and peripheral neuropathy.[1]

CD diagnosis requires individuals with associated symptoms to be subjected to tests such as D-xylose absorption, fecal fat excretion, antigliadin antibody titer and small bowel biopsy. However, CD diagnosis is not always an easy task; thus, clinical manifestations are seen as early symptomatology if the diagnosis is performed in 24-month-old (or younger) patients, and as late symptomatology if it is performed in patients older than 24 months, based on standards set by Sdepanian et al.[7] According to Silva,[1] approximately 10% of cases are hard to be diagnosed due to discordant serological, clinical and histological findings, fact that tends to delay the beginning of the treatment.

Gluten-free diet is the only treatment currently available to CD patients. Once it is adopted, it stops clinical symptoms, improves nutritional deficiencies and reduces the risk of having CD patients developing other autoimmune diseases and CD-associated neoplasms. Gluten-free diet must meet the nutritional needs of CD patients, such as energy, macronutrients, minerals and trace elements.8 The difficulty in finding gluten-free food, the high cost of the diet, the negligent consumption of food containing the substance and changes in individual and family eating habits have been indicated as contributing factors to lower adherence to the diet and to the difficulty in maintaining it.[2]

The beginning of CD treatment represents a new moment in patients' life, which is marked by changes in their pace of life, in their habitus, as well as in their physical, psychological and social body. Their biological body - now perceived as ill - is no longer a place for social condemnation, for family rules and for collective limitations.[9] The concept of habitus can reconcile the apparent opposition between external and individual realities. The present study used habitus to harmonize the social reality and the reality of CD patients and their restrictions, by taking into consideration their cultural and family heritage.[10]

CD treatment demands often lead to feelings of loss and castration both within the family and in the circle of social relationships. Forgoing certain roles leads to the loss of a status earned over a lifetime in favor of a new and scaring status.[11]

Many studies have analyzed gastrointestinal symptoms, CD screening and management strategies, as well as adherence to the gluten-free diet. However, only limited data describing the diagnosis associated with social and emotional components are available for CD patients.[3] Therefore, the greater the knowledge about the disease and about its treatment by celiac patients and their peers, the greater the adherence to the gluten-free diet. Both health professionals and the State have the responsibility to clarify the population in the most detailed way possible, as well as to help them finding information and improving their knowledge about the disease and about the diet to be adopted, and to provide them access to adequate food.[12] Moreover, the State must assure conditions to enable health professionals to carry out CD diagnosis in a full and brief way.

Thus, the aim of the present study was to identify interviewees' perceptions about the clinical and social consequences of late diagnosis of celiac disease. The way the celiac patients see themselves as ill, their feelings about new eating and social habits, society's view and behavior towards their comorbidity, as well as how the clinical symptoms affecting their body reflect on their clinical and emotional condition.

METHODS

The current study is a qualitative research based on a descriptive quantitative core of meanings that allowed understanding not the phenomenon itself, but its meaning for people who experience it. The study was based on the application of a semi-structured script containing a set of previously defined questions focused on investigating respondents' spontaneity and feelings.[13]

Adult individuals diagnosed with celiac disease, who attended one of the monthly meetings held by the Celiac Association of Paraná State (ACELPAR), were invited to participate in the study. Interviews focused on the application of the semi-structured script were only performed after participants had signed the Informed Consent Term (ICT).

Although all participants who attended the ACELPAR meetings were invited to participate in the study, only female celiac patients older than 18 years accepted the invitation.

The herein adopted semi-structured script addressed basic identification matters such as patients' age at the time symptoms emerged, symptoms perceived before CD diagnosis and their manifestation time, CD perception, access to gluten-free food and the habit of eating it, body reactions after eating gluten food, family support and emotional changes.

The clinical manifestation of the disease was categorized as early symptomatology when the diagnosis was performed in 24-month old (or younger) patients, whereas diagnosis performed in patients older than 24 months was categorized as late symptomatology, based on standards set by Sdepanian et al.[7]

The interview was recorded and fully transcribed by faithfully respecting its content. After data transcription was over, information was grouped based on the content analysis technique, by adopting the thematic categories model.

RESULTS AND DISCUSSION

Based on overall results, the herein investigated population (n = 13) comprised 24-to-55-year-old women, who lived in Curitiba County - PR. Although all patients who attended the meetings held by ACELPAR were invited to participate in the study, the herein analyzed sample comprised 33% of them.

Core of meaning: symptoms perceived by celiac patients

Clinical symptoms emerged during childhood in 38% (n = 5) of celiac patients participating in the current study, 9% (n = 1) had their symptoms emerging during adolescence, 23% (n = 3) in adulthood (n = 4) and 30% of participants declared themselves asymptomatic.

The most prevalent symptoms presented by the herein investigated 9 (100%) symptomatic celiac patients before CD diagnosis were diarrhea (55%), chronic anemia (55%), skin rash (44%), nausea and abdominal distension (33%), constipation (22%), joint pain (22%), irritability (22%), depression (22%), closed throat (11%), weight loss (11%), lactose intolerance (11%), headache (11%) and low immunity (11%). Most patients had more than one symptom associated with CD. One of them described the onset of symptoms:

> First, I had abdominal distension, so doctors thought I had gastritis and I was subjected to several tests. Then, they thought I had irritable bowel syndrome and I was treated for some time until they did the biopsy. (CA, 30 years old).

CD symptoms stated emerging in the herein investigated patients during their childhood; this outcome shows that the classic form remains the most often clinical manifestation of celiac disease, since it presents symptoms such as chronic diarrhea, vomiting, irritability, lack of appetite, stunting and abdominal distension.[5,14]

Core of meaning: previous celiac disease diagnosis processes

With respect to the time when CD was diagnosed in the herein investigated 13 (100%) participants, 77% celiac patients categorized it as late diagnosis, i.e., they were older than 24 months when the diagnosis was confirmed (the longest diagnosis period was 39 years). However, 15% of the herein analyzed patients were diagnosed with CD when they were younger than five months. In addition, 61% of participants attributed the time of diagnosis to health professionals, who were more attentive to the classic signs of the disease and treated individual symptoms without taking into consideration their etiology. One of the interviewees reported that:

> Nowadays, doctors are medical specialists rather than generalists, they do not think about things as a whole [...] and none of them has seen me as a whole (AD, 35 years old).

One of the asymptomatic interviewees expressed her struggle to be diagnosed:

> [...] Professionals' lack of knowledge made them follow that line of weight loss, diarrhea and abdominal detention, which were symptoms I did not have. (MI, 43 years old).

A study conducted in Mexico has found that the mean duration of clinical manifestations before CD diagnosis was 10 years; besides, 64% of patients had been previously diagnosed with irritable bowel syndrome.[15]

The classical manifestations of the disease often lead patients, and their caregivers, to seek health professionals for appropriate diagnostics. However, several studies have suggested that CD may only be diagnosed in patients' adulthood, due to the emergence of milder or atypical symptoms, or to previous incorrect or asymptomatic diagnoses.[16]

In total, 77% of the 9 (100%) participantswere treated for irritable bowel syndrome, gastritis and Crohn's disease, whereas comorbidities started emerging without receiving the adequate treatment, as in the case of the 30-year-old interviewee:

> "I was diagnosed with other diseases such as irritable bowel syndrome, Crohn's disease, so I was subjected to several treatments until I actually figured out what it was. (MA, 30 years old).

Other patients (22%) had mild clinical symptoms and did not seek professional help, fact that hindered their diagnosis. Asymptomatic interviewees (n = 4) found out that they were gluten-intolerant because some family member who had the disease was aware of the genetic factor, or when they were treated for comorbidities generated by CD. It is known that enteropathies of different etiologies can manifest in a similar way to CD; thus, it is not possible being sure about whether, or not, CD was subsequently ruled out in these cases. Three aspects may be related to changes in these forms: conditions to diagnose atypical forms of the disease, patient referral to specialized services and population characteristics.[14] Histological findings are not specific, and symptoms may derive from different diseases; thus, CD diagnosis can only be set after clinical correlation or biopsy.

Core of meaning: celiac patients' perceptions about late diagnosis

Changes in patients' health and body were reported as consequence of untreated intolerance to gluten, according to participants' viewpoint. Comorbidities mentioned by the herein investigated group (n = 13 - 100%) as consequence of late treatments or of non-adherence to treatments were thyroid disease (40%), depression (38%), anemia (38%), cancer (15%), changed gastrointestinal tract (15%), joint pain (15%), lack of nutrient absorption (15%), weight loss (15%) and lymphoma (15%). Most participants reported to have more than one CD-associated comorbidity. It is worth emphasizing that despite the lack of symptoms in asymptomatic patients, the disease was still there.

> After facing several obstacles to get the diagnosis, interviewees' perceptions about the consequences of late diagnosis comprised health issues such as lymphoma, weight loss, lack of nutrient absorption, joint pain, changed gastrointestinal tract, cancer, anemia, depression and thyroid disease. The 50-year-old participant said: ***I had several issues. I had my uterus removed, I'm depressed, I did not get used to eat gluten-free food*** (MA, 50 years old).

All pathologies mentioned by celiac patients who participated in the current study are also reported in the literature, fact that reinforces the importance of investigating these pathologies in CD patients, as well as of investigating CD in individuals presenting some symptoms of the disease, in a more efficient way.[1,7,14,17-20]

All herein transcribed reports are patients' perceptions, rather than confirmations, since the current research did not go so deep in the matter. However, according to Melo,[18] the classic symptomatology results from intestinal intolerance - mainly the proximal portion, with defined genetic potential - to gluten gliadin and to other prolamins found in cereals such as wheat, rye and barley. These prolamins cause characteristic, although non-specific, lesions that hinder nutrient absorption and lead to complications such as osteoporosis, acute intestinal bleeding, intestinal ulceration with, or without, perforations and malignant tumors, mainly lymphomas, without previous CD diagnosis.

After CD was diagnosed, patients started treating their intolerance in a proper manner, and it improved their quality of life. Interviews evidenced the following perceptions of the 13 (100%) participants about health improvements and quality of life: improved mood (15%), anemia control (23%), no further joint pain (23%) and skin rash (23%) episodes, weight gain (15%), hair loss cessation (15%), improved bowel functioning (61%), improved willingness (7%) and emotional stabilization (38%).

Core of meaning: the diet and its subjectivities

Some patients may feel overwhelmed after being diagnosed with CD and the disease itself can affect their quality of life. In addition, the adoption of the gluten-free diet is often associated with certain difficulties in dealing with information overload and with the implementation of recommendations that influence the diet.[3]

The gluten-free diet is the only CD treatment available; therefore, interviewees were asked about their access to gluten-free products and about their adherence to the diet. Only 30% (n = 4) out of the 13 (100%) participants declared that they did not follow a complete gluten-free diet, but all participants reported to have access to gluten-free food and to gluten-free industrialized products. However, 23% of patients reported to have difficulty in finding several consumption options in the regions where they lived, whereas others (23%) thought that gluten-free products were very expensive and felt the need of producing their own food or of consuming only food in natura. Interestingly, participants who did not follow the gluten-free diet were not the ones who characterized these products as expensive. In fact, gluten-free items have been reported to be approximately 200% to 500% more expensive than gluten-based products, depending on the product and on the place of purchase.[21] Thus, the accessibility, and long-term sustainability, of the gluten-free diet keep on triggering evaluations.

Preferences are set according to what one's culture deems acceptable. According to Araújo,[12] people tend to reject flavors they are not used to taste and remain restricted to preparations typical to their culture. These particularities may justify individuals' difficulty to adhere to new eating practices and habits due to specific physiological conditions. One of the participants shared her feelings about it:

> I have access [to gluten free-products], but they are expensive. So, I use my creativity at home, but it does not taste good. Food recipes require lots of oil to taste good. My biggest difficulty lies on the crave to eat, there are gluten-free pizzas, but they cannot be compared to a real pizza or lasagna ... this desperation and craving (ER, 40 years old).

According to information collected in the interview, the greatest difficulties perceived by the 13 (100%) participants about the adoption of gluten-free diets lie on the possibility of cross contamination (76%), on people's understanding about the disease (46%), on craving for gluten-based food (38%) and on the low availability and variety of gluten-free products (23%). One of the interviewees addressed all the difficulties:

> Cross-contamination often happens, and this is our greatest fear. Variety is another difficulty because I have a small child who cannot eat fast-food or any of those products children often crave for; these products are not yet available in their gluten-free version. And social isolation, right?! We end up not being able to socialize with people because they socialize through food, so we cannot do it. And our families end up having little information and think we are the boring ones who cannot participate in anything (AD, 35 years old).

One of the most common difficulties faced by CD patients lies on the experience of eating out. They are often concerned about the likelihood of finding gluten-free food or dishes in restaurants, as well as about the cross-contamination of the available gluten-free products.[2]

Since CD treatment is solely dietary-based, and due to the difficulty in excluding gluten-containing cereals, products and utensils, it is essential highlighting the importance given to the evaluation of patients' nutritional status, to orientation regarding food choices, to food preparation, to food contamination by gluten in the preparation or distribution stages, and to guidelines.[12] The greatest concern reported by the herein investigated celiac patients lied on cross-contamination; however, the literature lacks broad studies about the amplitude, and direct consequences, of such contamination. In addition, CD patients may feel socially isolated when they need to decline an invitation to go to a regular restaurant.[21]

Symptoms reported by the 13 (100%) participants when they eat gluten-based food comprise abdominal pain (7%), joint pain (7%), fever (7%), body pain (15%), nausea (15%), headache (15%), itching (15%), skin rash (30%), diarrhea (38%) and abdominal distension (46%), which was the symptom most often reported by participants. According to 46% of interviewees, many of these symptoms also happen when they have contact with gluten through cross-contamination. All the asymptomatic patients (n = 4) who adopted the gluten-free diet declared that they started having symptoms every time they ate gluten-based food, fact that had never happened before.

Human body gives several signals when it has its restrictions violated or when people do not properly meet its needs. However, people often prefer to ignore these signals, since listening to their body means changing their lifestyle and eating habits.[22] This behavior is likely to happen because the familiar memory of gluten-based products makes celiac patients eager to consume them and, at the same time, it is unpredictable because the human body is not an inert thing that mechanically obeys to the decrees of peoples' conscience; knowing the consequences of gluten-based food intake affects such choice.[23]

Core of meaning: family involvement and emotions triggered by celiac disease

Family and emotional issues were mentioned by 10 (100%) participants. When questioned about how their families behaved and manifested themselves towards the celiac disease, 90% of participants reported that their family members understood their restrictions and supported their diet. Only one of the 10 celiac patients who responded to the interview said that her family did not accept the complete gluten-free diet, fact that impaired her social relationship with her family.

Based on reports, CD patients' family members manifested themselves in many ways towards the disease. There were cases (50%) in which family members did not want to be tested in order to identify whether, or not, they also had CD, some of them kept everything separated and helped reading the labels (10%), others gave support but did not understand the complexity of the celiac disease (20%), some family members adhered to the diet along with the celiac patients, whereas others rated them as boring and even referred to the disease as picky eating behavior (20%). Some reports are highlighted bellow:

> Thank God my family helps me, they understand me, so they help me. Whenever we go out to buy something, they look at the labels to see if the products have gluten, or not, and then they buy it for me. My children understand everything, we keep things separated and they follow the gluten-free diet (MA, 50 years old).

And a similar episode:

> Nowadays I do not fail to go, I participate in family events, although I do not eat anything. So, I eat before I go to avoid cross-contamination. Obviously, I have only attended very special places and occasions, so I do not attend any event. I'm often seen as boring, but when I explain how the disease is people understand its severity (AD, 35 years old).

Based on the herein analyzed data, most CD patients counted on the understanding and help of their family members, which were their main support group, fact that helped them to accept the diagnosis and adhere to the diet. According to Pimenta-Martins,16 besides reducing the psychological consequences of living with a chronic disease and a restrictive diet, CD can trigger conflicts in the family environment and generate feelings such as depression and exclusion in individuals who do not have family support.

With respect to the emotional field, CD patients were extremely vulnerable, because the reaction of their relatives and friends, the craving for food, the cross-contamination and the lack of information, or even of basic knowledge about the severity of the disease, affect celiac patients. In addition, interviewees had to be extremely patient to constantly explain to their relatives and friends why they cannot eat gluten, to overcome the craving for food and to face prejudice and exclusion.

> DOf the 13 (100%) celiac patients, 38% reported to have needed, or still need, psychological or psychiatric therapy to cope with the disease:
>
> It was really had [finding out about the disease]. I needed therapy. I still go to the psychotherapist nowadays because, as I said, the urge

> to eat and having to explain to people that I have allergy, and I have to say that it is an allergy because they tell me that it is picky eating behavior, that it is rich-people thing that I invented. So, having to continuously explain myself to people is really hard. It is boring. It is annoying (ER, 40 years old).

According to Rocha,[11] another important aspect lies on the set of social losses celiac individuals face from the moment the disease is diagnosed. Feelings of social exclusion, loneliness and anger, due to lack of places capable of assuring that the food is not contaminated by gluten, are constantly experienced by celiac patients.

It is essential involving family members to avoid affecting their relationship with CD patients, because the gluten-free diet inevitably affects eating practices at home. Individuals following a gluten-free diet need to be sure that the product or dish to be eaten does not have gluten, as well as that gluten-free products are not contaminated. Since some patients have a hard time adhering to the gluten-free diet, family support is essential to help them assuring the quality of the food they eat. This situation may also be associated with the person who prepares the food, since in many countries women are the main responsible for preparing family meals, as well as for making decisions about the purchase of the food to be consumed by the family.[12]

Given all these circumstances, it is essential identifying CD patients' perceptions about the clinical and social consequences of the late diagnosis of the disease in order to help them improving their lives and demanding their rights.

CONCLUSION

Celiac patients interviewed in the current study reported their perceptions about the clinical consequences of the late diagnosis of celiac disease, among them one finds lymphoma, weight loss, lack of nutrient absorption, joint pain, changed gastrointestinal tract, cancer, anemia, depression and thyroid disease. Therefore, CD diagnosis can only be performed before the emergence of health consequences, when individuals present clinical manifestations or compatible serological tests, besides characteristic histopathological findings in biopsy when they feed on gluten-based diets.

In addition, these patients are emotionally vulnerable, since the reaction of their family members and friends, the craving for food, the cross-contamination risk and the lack of information, or even of basic knowledge about the severity of the disease affect celiac patients and make it difficult for them to accept and adhere to the gluten-free diet.

The life of celiac patients is marked by new experiences, knowledge, relevance and changes. It is essential understanding the world of these individuals to enable their insertion in society. Knowledge produced in the current study can make professionals and society aware of the clinical and emotional impacts generated by the late diagnosis of celiac disease on the human body, and help them support and be understanding towards celiac patients.

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Contributors

Ribeiro CSG participated in all stages of the study, from its design to the review of the last version of the article. dos Santos AS participated in the design of the study, in the writing of the article and in its last version.

Conflict of Interest: The authors declare no conflict of interest..

Received: March 23, 2018
Reviewed: October 01, 2018
Accepted: October 30, 2018