Sociedade e Cultura | ISSN: 1980-8194 DOI: 105216/sec.v27.77467

The diagnosis of celiac disease as a turning point in food choices and new foodways

O diagnóstico da doença celíaca como ponto de virada nas escolhas alimentares e novas práticas alimentares

El diagnóstico de la enfermedad celíaca como punto de inflexión en la elección de alimentos y de nuevas formas de alimentación

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Abstract: This qualitative study aimed to understand how food choices and practices occur in the daily and social lives of people who have celiac disease (CD). Seventeen participants were interviewed. The Food Choice Process Model was adopted as a theoretical framework for the Content Analysis. Diagnosis was a turning point, that led to changes in the personal food choice systems, either abruptly or gradually. Having CD affected moments of commensality and generated constant negotiations for safe food choices. Health was the main determinant that guided food choices and practices, interrelated with the other four determinants: availability, cost, relationship management, and know-how.

Keywords: Food anthropology; commensality; eating behavior; adverse reaction to food.

Resumo: Este estudo qualitativo objetiva entender como são feitas as escolhas e práticas alimentares no cotidiano de pessoas com doença celíaca (DC). Dezessete participantes foram entrevistados. Adotou-se o Food Choice Process Model como referencial teórico para a Análise de Conteúdo. O diagnóstico foi um ponto de virada na vida dos participantes, levando a mudanças nas escolhas alimentares, de maneira abrupta ou gradual. A DC também afetou momentos de comensalidade, gerando negociações constantes para realizar escolhas alimentares seguras. A saúde foi o principal determinante que conduziu as escolhas e práticas alimentares, inter-relacionada com outros quatro determinantes: disponibilidade, custo, gerenciamento das relações, e saber-fazer.

Palavras-chave: Antropologia da alimentação; comensalidade; comportamento alimentar; reação adversa aos alimentos.

Resumen: Este estudio cualitativo tiene como objetivo comprender cómo se toman las decisiones y prácticas dietéticas en la vida diaria de las personas con enfermedad celíaca (EC). Se entrevistó a diecisiete participantes. Se adoptó el Food Choice Process Model como marco teórico para el Análisis de Contenido. El diagnóstico supuso un punto de inflexión en la vida de los participantes, ya que provocó cambios en la elección de alimentos, ya sea de forma abrupta o gradual. La EC también incidió en momentos de comensalidad, generando negociaciones constantes para la elección de alimentos seguros. La salud fue el principal determinante que impulsó las elecciones y prácticas alimentarias, interrelacionada con otros cuatro determinantes: la disponibilidad, el costo, la gestión de relaciones y el saber-hacer.

Palabras clave: Antropología de los alimentos; comensalidad; conducta alimentaria; reacción adversa a los alimentos.

Submetido em: 8 de outubro de 2023
Aceito em: 8 de julho de 2024

Introduction

Eating is a daily act, necessary for our survival, and it does not happen arbitrarily, since each society and culture defines, in its own way, what is edible, what should be eaten regularly or on special occasions, as well as what is forbidden (Fischler, 1990). Food choices, a frequent eating behavior in which some foods and beverages are chosen over others, involve conscious, automatic, usual, as well as subconscious decisions (Alvarenga; Koritar, 2015). Food choices are multifaceted (incorporate several eating behaviors), situational (encompass where and when it happens, as well as the social context), dynamic (change according to historical and individual time), complex, and may involve judgments based on several attributes such as taste, health, convenience, preferences, cost, ethics, ecology, among others (Sobal; Bisogni, 2009).

Frequently food choices are based on health concerns (Furst *et al.*, 1996). Among the daily conscious and unconscious negotiations, food can simultaneously be considered to provide health, vitality, and energy, or generate a sense of risk and be seen as a source of harm, either because of possible toxicity or because of its nutritional composition, leading to a paradox (Poulain, 2004). In the last three decades, consumers' behavior has been changing, and as scientific evidence emerged stressing the relationship between food and disease risk, a niche has been created for the food industry to explore the development of "healthy" products. Since the 1990s, the food industry has been attentive to consumers' concerns about the food-health-disease relationship, aiming at the development of nutritionally modified foods that are easy to prepare and, at the same time, maintain their sensory attractiveness (Marins; Araújo; Jacob, 2011). Furthermore, in addition to perceiving the market niche for these products, the food industry is constantly developing technologies that enable increased product options (Wang *et al.*, 2017), including "free-from" products, such as gluten- or lactose-free foods. Marketing strategies are used intensively by the food industry to stimulate the consumption of new products through advertising, including these specially designed/formulated foods, based on which, the concept that "free-from" foods are healthier, is explored. This creates consumer expectations in this market, both for greater availability and lower prices or even the willingness to bear the extra cost (Németh *et al.*, 2020). However, many of these products are ultra-processed foods - in the case of gluten-free foods, usually presenting a lower protein and a higher fat and salt content compared to their equivalent gluten-containing products (Melini; Melini, 2019) thus, with a nutritional profile of debatable "health" quality.

However, there are situations in which the body presents adverse reactions to a certain food/ingredient, and the main strategy to deal with this condition is for the person to eliminate the food/ingredient that causes the reaction, restrict their diet, and break with previous food habits/choices marked by cultural aspects (Araújo *et al.*, 2010). The pathological aspects encompass food allergies, food intolerances, celiac disease, diabetes, and heart disease, among others. This study will only focus on people diagnosed with celiac disease (CD).

The CD is considered an important global health problem (Singh *et al.*, 2018). It is a chronic, multi-organ autoimmune disease that affects the small intestine in genetically predisposed children and adults. It is triggered by the ingestion of food/ingredients that contain gluten, a storage protein found in wheat[1] (Biesiekierski, 2017), and it may appear combined with other adverse reactions, such as secondary lactose intolerance (LI), due to damage to the small intestine mucosa and, consequently, a decline in lactase activity, causing lactose malabsorption (Bodé; Gudmand-Hoyer, 1988; Ojetti *et al.*, 2005). It may also be referred to as celiac sprue, gluten-sensitive enteropathy, or non-tropical sprue (WGO, 2016). Its symptoms are prevented by gluten withdrawal from the diet, with symptoms reappearing if/when gluten is reintroduced (Igbinedion *et al.*, 2017).

In the case of CD, there is, to date, no other treatment than the total exclusion of gluten from the diet. Its symptoms may be severe, as they cause several problems, such as growth deficit and short

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[1] Similar storage proteins exist as secalin in rye, hordein in barley, and avenins in oats and are collectively referred to as "gluten" (Biesiekierski, 2017).

stature in children, while in adults it can generate iron deficiency anemia, bone or joint pain, and infertility, among others (Morrell; Melby, 2017). If it is not diagnosed, the consequences range from micronutrient deficiencies to the development of cancers of the digestive tract (Morrell; Melby, 2017).

Dietary restrictions imposed by diseases impact the daily lives of those who have them due to changes in eating practices, ranging from going to the supermarket to choosing what to eat, and to eating out, as restaurants do not always have safe options (Olsson *et al.*, 2009; Sommer *et al.*, 2012; Jakobsen *et al.*, 2021).

A review of the literature did not yield studies addressing the impacts on eating and on the individual and social spheres of those diagnosed with CD by Brazilian social science researchers. Nevertheless, we found few studies from the health science areas (nursing and nutrition) in which qualitative research tools were applied for a deeper understanding of the phenomenon (Brancaglioni *et al*., 2016; Rocha *et al*., 2016; Nascimento *et al*., 2017; Santos; Ribeiro, 2019). These studies brought insights into the impact of CD on children and adolescents (Brancaglioni *et al*., 2016) and adults (Rocha *et al*., 2016; Nascimento *et al*., 2017; Santos; Ribeiro, 2019), discussing the changes in eating dynamics brought by the diagnosis of CD, and its social and emotional aspects. Although these studies provide some insights, much remains to be explored. Therefore, this study aimed to further explore, from a social science perspective, how food choices and practices occur in the daily and social lives of those who have CD, including the difficulties and negotiations adopted and how these may generate cultural conflicts and affect social situations and relationships.

Methods

Design and Ethical Aspects

This is a qualitative study, which aims to portray the sociocultural dimension of the practices of people with CD by identifying their beliefs, values, opinions, representations, symbologies, and eating practices. Data were collected through interviews and complemented with photo elicitation and mobile ethnography.

The results here presented are part of the study approved by the Research Ethics Committee (CEP) of the Universidade Federal de São Paulo under CAAE #29779320.8.0000.5505/2020 on May 5, 2020. After expressing interest in participating in the study, all participants were informed of the purpose and justification of the research and the detailed procedures for data collection. Volunteers signed digitally the Free and Informed Consent Form (FICF), and only after their return, the interviews were scheduled. Names were substituted by fictitious names to guarantee anonymity.

Participants and Procedures for Producing Data

In this intentional sample, all participants were contacted after expressing interest in the invitation shared in groups about celiac disease on social networks, and through the *snowball* technique, when participants also indicated other potential participants and so on, in a repetitive and cumulative process (Morgan, 2008). Saturation was the criterion for defining the final number of participants, reached when the data collected did not bring new clarifications for the studied object (Minayo, 2017), allowing to portray the multiple dimensions of the phenomenon, and the repetition and complementarity of the information (Minayo, 2017; Saunders *et al*., 2018). The final number of participants was discussed among the authors after careful analysis of all transcripts, to ensure that the criteria had been met. To participate in the study the inclusion criteria were to be over 18 years old, reside in Brazil, and have the diagnosis of CD, in combination or not with other adverse reactions to food such as LI, and/or cow's milk protein allergy.

Data collection took place virtually via web conference in real-time (Ferraz; Alves, 2017) between November/2020 and October/2021, on the day, time, and platform (Zoom, Google Meet, WhatsApp) most convenient for the participant due to the circulation restrictions of the COVID-19 pandemic. Interviews were recorded in audio (after the participant's consent), for later analysis. In one of the interviews, the participant's husband participated briefly, with some comments, at her request. A pilot study to evaluate the initial script was conducted with a volunteer with lactose intolerance (whose participation was restricted to the pilot only), after which some questions were included, and others reformulated. During the interviews, the final script with guiding and probing questions (Table 1) allowed participants to discuss having CD and its influence on eating practices, ensuring that the hypotheses and assumptions of the study were contemplated (Minayo, 2014).

Table 1. Interview script with guiding and probing questions

GUIDING QUESTIONS	PROBING QUESTIONS
Tell me how and when you discovered you had CD...	Did you have a laboratory diagnosis? If so: how did having the diagnosis change your way of looking at food?
How do you deal with CD in your daily life?	Do you remove gluten-free foods from your diet? How is your food routine currently? (Identify the current housing arrangement and with whom you eat) What was the eating routine like at home before?
What is it like to eat in social situations?	What strategies do you adopt? How do your friends, family, and partner perceive your eating situation? Describe a situation
What is it like to eat out?	What strategies do you adopt? Explore determinants of food choices. Is it possible to compare before and after diagnosis?
What is it like to go shopping?	
In what other situations do you think having a food intolerance affects you?	Explore travel and other situations.
Is there any situation where you eat something with gluten?	Why? Explore the meaning of the food(s). Are there consequences? How do you deal with it?
How do you rate your relationship with food?	Explore barriers, facilitators, meanings, representations, and emotional aspects.

Source: Elaborated by the authors, 2022

To have a better understanding of the influence of CD on food choices in the supermarket or restaurants, or in situations of commensality, the method of mobile ethnography was used. Mobile ethnography (ME) is a technique that implies the use of a mobile device (cell phone, for example) for data collection via audio, allowing receiving data directly from the user at the place and time in which they occur (Muskat *et al.*, 2013). The photo-elicitation (PE) strategy (Harper, 2002) was also applied. Participants were invited to send messages and audio or to photograph situations when their food choices were influenced by CD.

With an average duration of 50 minutes, all interviews were conducted by the first author, who wrote insights about them immediately after they happened, which later helped in the analysis. Audios and messages were transcribed in their integrity constituting, together with the transcripts of the interviews, the *corpus* for analysis which was conducted through Content Analysis (Minayo, 2014).

Data analysis

The Content Analysis was conducted in three stages (Minayo, 2014): 1) pre-analysis: a floating reading that allowed the organization of all transcriptions. Based on the literature, objectives of the study, and the interview script, nine aprioristic codes and five emergent codes, representing themes, were defined for the next stage of the analysis by both authors; 2) for the exploration of the material a new reading of the transcripts and their encoding led to the identification of significant words and expressions (registry units) and also to identify the excerpts of the interviews (context units) contextualizing these registry units. From there, three thematic nuclei were defined, considering the themes identified and the frequency with which they appeared in the reports: “The quest for a diagnosis and perceptions about eating”, “Transition and Turning point: rebuilding food choices”, and “Sharing food”; 3) finally, in the third stage, the authors conducted interpretations of the contents that made up each of the thematic nuclei.

For the interpretation of the data, the Food Choice Process Model (Furst *et al.*, 1996; Sobal; Bisogni, 2009) was adopted, which points to three main integrated dimensions: life course, influences, and personal systems. The life course dimension explores food events and experiences lived by individuals throughout their lives, considering past, current food choices, and expectations regarding the future, over time and in different contexts (which can be macro i.e., cultural, political, economic contexts; or micro i.e., family, workplace, community, etc.) that facilitates or restricts changes. Trajectories are marked by transitions and turning points that lead to reconstructions of food choices (Sobal; Bisogni, 2009). The life course dimension was used to investigate the feelings and emotions concerning food and eating, before and after the diagnosis of CD as a transition point/turning point.

The second dimension of the Food Choice Process Model points out five main influences: ideals (cultural and symbolic factors), personal factors (reflect taste preferences and aversions, eating styles), resources (purchasing power, utensils, equipment, and space for cooking, skills, knowledge, and time), social context, and food context, to understand the factors that motivate the food choices made by the participants (Furst *et al.*, 1996; Sobal; Bisogni, 2009). In addition to these aspects, how having CD may also affect food choices.

The third dimension, the personal food system, develops from all the events of the life course, the impact of the influences, and how values, classifications, and situations are balanced. The personal food systems contributed to the understanding of the negotiation strategies and definition of routines adopted by participants when making individual, as well as collective (e.g., sharing a meal) food choices (Furst *et al.*, 1996; Sobal; Bisogni, 2009).

Results and Discussion

Participants' characteristics

Table 2 summarizes the main characteristics of the participants. Seventeen volunteers, aged between 22 and 60 years, with a medical diagnosis of CD, participated in the study. In addition to CD, six presented lactose intolerance (LI), and 16 were female.

Table 2. Sociodemographic characteristics of the participants with celiac disease diagnosis (n=17)

Characteristic		Total n =17
Sex	Female	16
	Male	1
Age (years)	20 –| 30	9
	30.1 –| 40	1
	40.1 –| 50	4
	50.1 –| 60	3
Diagnosis	CD	11
	CD+LI	6
Time living with diagnosis (years)	<5	7
	5 –| 10	8
	10.1 –| 20	1
	>20	1
Region of residence	North	1
	South	5
	Southeast	7
	Midwest	4
Household composition	Lives alone	2
	Partner/spouse	4
	Partner/spouse and children	2
	Family members	9

Source: Elaborated by the authors, 2022

Studies show a higher prevalence of CD and gluten sensitivity in women, with a ratio of 2:1 (Arámburo-Galvez *et al.*, 2020; Crucinsky *et al.*, 2021), what can explain why in studies reporting effects of diagnosis and quality of life people with CD, women's adherence occurred in a majority (Matos, 2015; Rodríguez-Almagro *et al.*, 2016; Santos; Ribeiro, 2019), as seen in this study.

At the time of the interviews, participants were living with the CD diagnosis from 4 months to 25 years and reported that finally finding out they had CD was an important milestone for their adaptation to the new condition. By defining that data collection would be online and not presential, due to de COVID-19 pandemic, it increased the possibility of contacting people from various regions of Brazil. Participants reside in four of the five regions of Brazil. No sociodemographic questionnaire was applied, but there was a predominance of participants in medium and large cities, mostly capitals (10/17), a factor that probably influenced access to specialized food products and diagnosis.

The quest for a diagnosis and perceptions about eating practices

Unusual symptoms after eating specific foods motivated the participants' search for medical specialists. The diagnosis path varied in the number of tests requested including colonoscopy with biopsy, anti-tissue transglutaminase test, antinuclear factor test, and other blood tests, as well as several diagnosis hypotheses until finally the identification of CD was reached. CD may present a multiplicity of symptoms, some quite unspecific which make diagnosis very difficult. The symptoms that affected participants also varied in type and severity ranging from intestinal distress (diarrhea or constipation; bloating and/or abdominal pain) to joint pain, and which affected their daily lives in diverse ways - acute intestinal symptoms, for example, were reported by participants as particularly uncomfortable in eating out situations.

For some participants, the CD diagnosis took years, as seen in other studies (Cichewicz *et al.*, 2019; Santos; Ribeiro, 2019). Finally having the diagnosis of CD, was a turning point moment in their lives as they reported having been through a “pilgrimage” involving inconclusive diagnoses and various specialties in the health area, which caused uncertainty, discomfort, and anguish (Santos; Ribeiro, 2019; Crucinsky *et al.*, 2021). Some participants were given other diagnoses based on the symptoms, which may also be present in other diseases such as fibromyalgia, irritable bowel syndrome, gastritis, anemia, and renal disease, producing more anxiety. In those cases, health professionals did not provide a conclusive diagnosis that explained patients’ symptomatic picture, no guidance on food restrictions and cross-contamination until the final diagnosis.

> A doctor diagnosed me with fibromyalgia, I had fibromyalgia, and he sent me to physiotherapy (...) And then she [the gynecologist] sent me to a hematologist (...) to investigate autoimmune diseases and when I got there to see this doctor, he thought it could be lupus. (Beth, F, 29y, Southeast, CD)

Having CD requires continuous care that begins with a complex change in diet, that is, total exclusion of gluten must occur, which affects daily and social life, unlike people with other adverse food reactions, such as LI, who can consume lactase exogenously. It is worth remembering that for six participants the association of CD and LI yielded further restrictions albeit the possibility of using lactase exogenously.

If, on one hand, the diagnosis brought relief as gluten (and lactose in some cases) restriction led to suppression of symptoms, on the other hand, dietary modifications led participants eating practices that are not socially expected (Rocha *et al.*, 2016; Brancaglioni *et al.,* 2016) by people they eat with, as well as to several and mixed feelings, such as anger, conformism to the need to restrict certain ingredients/preparations, sadness, in addition to feeling having CD as a difficulty and a limitation in their lives.

> And then, not eating what other people are eating is very bad (...) it's really bad to feel different, to feel excluded, to not feel part of that moment, you know? (Leah, F, 28y, Southeast, DC+LI)

Albeit all the difficulties related to dietary restrictions, nine participants stated that the necessary dietary modifications due to CD diagnosis culminated in an improvement in the overall quality of their diet, and 14 pointed to fruits as a facilitator for following the gluten-free diet, replacing snacks with gluten (sometimes industrialized and processed foods) that they used to have.

> Now I eat better than I did when I didn't have CD, infinitely so (...) Because I ate very badly anyway, I had no time to eat, I ate things with a lot of sugar, you know? (Lily, F, 32y, Southeast, CD)

Studies seeking to evaluate the quality of life of persons with CD and adherence to gluten-free diets (Dowd *et al.*, 2014; Casellas *et al.*, 2015; Rodríguez-Almagro *et al.*, 2016; Santos; Ribeiro, 2019; Dimidi *et al.*, 2021), found that diagnosis was a key-element for patients to follow the nutritional recommendation to completely exclude gluten, making them more observant of the foods they ate. The exclusion of gluten-containing foods and other adjustments with consequent remission of symptoms motivated the continued adherence to the gluten-free diet and not transgressing nutritional recommendations (voluntarily or through accidental cross-contamination), despite the high cost of gluten-free foods and certain limitations such as eating outside home (Casellas *et al.*, 2015; Dimidi *et al.*, 2021).

With the diagnosis of CD, a new moment in the participant's life began, marked by changes that altered their rhythm of life. In many cases, the dietary demands lead to feelings of inadequacy in the family environment and the social relationships circle (Rocha *et al*., 2016). According to the model of the stages of grief over death proposed by Kübler-Ross and Kessler (2005 *apud* Netto, 2015), there is a construction of a model of emotions and reactions, expressed by patients after the diagnosis of a serious disease or death of a loved one. There are five stages of grief: denial, anger, bargaining (wanting to reverse the situation through negotiations with God), depression, and acceptance. This was expressed by one of the participants who has been diagnosed four years ago:

> ... It was very difficult... I went through... through stages of grief, (...) of anger, of bargaining, you know? All those stages of grief anyway, I think now that I've managed to come to acceptance after all this time, but sometimes it still gets out of hand. (Lily, F, 32y, Southeast, CD)

Transition and Turning point: rebuilding food choices

As already stated, the diagnosis was the determining factor for changes in food choices, based on the nutritional recommendations of excluding gluten-containing foods. Before the diagnosis, participants ate these foods frequently, suffering from the symptoms and without knowing why. In the case of some participants whose symptoms were more severe, the exclusion of food happened through trial and error, but again, without knowing the exact reason. When the diagnosis was finally defined, it was a milestone for the participants, who experienced it in diverse ways, with food choice changes occurring abruptly, gradually, or partially.

Five participants mentioned that the transition occurred radically, confirming that the diagnosis was a turning point in their lives. The turning point is a landmark in the behavioral trajectory, which occurs drastically, causing changes - in these cases, in the eating trajectory which alters all future decisions, promoting a reconstruction of the food choices process (Devine, 2005; Wethington, 2005). Some participants expressed how difficult it was because new eating practices conflicted with their food system before diagnosis, requiring a period to complete the exclusion process of gluten-containing foods and for participants to fully adhere to the recommendations.

> ... I simply suspended the pasta (...) then I had to suspend both things: the lactose and also the gluten. (Ed, M, 60y, North, CD + LI)

Other participants opted for a gradual transition in their eating practices, slowly removing gluten-containing foods, even if they still had symptoms when eating them. Participants did not report whether such a decision occurred due to a lack of nutritional guidance or by their own decision. Gradual transitions are usually more common than turning points as they give time for changes in practices to be reconfigured (Devine, 2005; Wethington, 2005). It is possible that for these participants their symptoms were not acute or severe, which led them to consider the consumption of gluten-containing foods in everyday negotiations.

> ... It was a process, it wasn't like, overnight I was eating 100% gluten-free, it wasn't that. So, it was a process, but now it is a completely gluten-free diet, without contamination... (Beth, F, 29y, Southeast, CD)
>
> I used to love to eat ham and cheese sandwiches, pizza... these things, right? But you end up having to accept that, if you want to be healthy, you have to stop eating them. (Tess, F, 49y, Southeast, CD)

Participants reported that dietary changes based on gluten withdrawal and the inclusion of other foods in their eating routines led to symptom control and improvement in their quality of life. The choice to eliminate gluten-free foods - even if not immediately - reverberated in their personal and social lives, leading to the adoption of adaptive strategies, and conscious choices to improve personal and family well-being, in response to social and economic circumstances (Wethington; Johnson-Askew, 2009). However, even being aware of the need to exclude gluten-containing foods from the diet, the process was burdensome due to the difficulty of readjusting the diet regarding the acquisition of permitted and new foods, cooking strategies, and routines, adaptation to food preferences, and to family eating dynamics.

In CD cases, not only gluten withdrawal is enough: cross-contamination is the unintentional presence of gluten in the final product (Barnett *et al.*, 2008), and can occur at any point of the food production process - as the food is grown, harvested, manufactured, processed, or prepared, including at home (Thompson, 2008) or in restaurants. Examples of cross-contamination are when utensils (cutlery, plates, pans, cups) that are used to prepare gluten-containing foods are also used in the preparation of gluten-free foods; when the same oil is used in frying gluten-containing and gluten-free foods; or when gluten-containing and gluten-free foods are stored and/or packaged in the same place. Therefore, people with CD are in a constant state of alert. Adherence to a gluten-free diet leads to changes in how foods are prepared at home. Changes go beyond altering eating habits deeply rooted that include an array of gluten-containing food (Dimidi *et al.*, 2021), but also the restriction of other gluten-contaminated products such as cosmetics and medications (Thompson, 2008). A participant reports her efforts to secure her gluten-free food supply (Figure 1).

Figure 1. Participant's gluten-free food supply

Source: Photograph sent by participant Mia (F, 29y, South, CD)

> Figure 1 caption: “Freezer, the celiac’s best friend. I even changed the refrigerator to have a bigger freezer (laughter). And Sunday is the day to make lunch boxes to freeze and eat on days of hurry or laziness.” Mia, F, 29y, South, CD)

In addition to all the care in food preparation at home, another of the strategies adopted by people with CD is to include industrialized gluten-free foods in their diets. Going to the supermarket changed after the participants were diagnosed. For participants diagnosed 10 years ago or more, there were reports of a difference in the number of products available then and the economic impact, as gluten-free foods were scarce and used to cost even more in the past. If on the one hand, these gluten-free products may expand the options for people with CD, on the other hand, they may have other negative health consequences, as they are usually ultra-processed foods.

For instance, the dietary guidelines for the Brazilian population (Brasil, 2014), although directed to the general population, without focusing on diseases, emphasize that food should be based on *in natura* and minimally processed foods. The consumption of traditional dishes is encouraged, such as rice and beans, a combination, strongly related to our food culture and Brazilian identity, and naturally gluten-free.

> Lunch did not change much because rice, beans, meat we always had at home, and we always ate it. (Liz, F, 26y, Southeast, CD)

Regarding industrialized products, a careful reading of the labels is necessary to ensure that the product is safe for consumption, that is, that it does not contain gluten as an ingredient or “may contain traces” of gluten. As also found by Cenci (2015) in an investigation on motivations for buying gluten-free foods by persons with CD in Brazil, the search for safe food, that is, gluten-free, became a priority since the diagnosis.

> It's just hard because in the market they don't usually separate products containing gluten and gluten-free, then sometimes when you find the gluten-free product mixed with products with gluten, side by side. There is a contamination problem there as well. (Kate, F, 52y, Midwest, CD + LI)

Regarding Brazilian legislation on labeling, labels must indicate the presence of wheat, rye, barley, and oats (Brasil, 2015).

Although tiring, as it makes the moment of shopping take longer than before, the reading of labels is a fundamental practice for people with CD and other adverse reactions to food. Some food companies indicate on the label the presence of gluten in the product, even if it may be present only by cross-contamination. If on the one hand, possible cross-contamination is alerted by this measure, on the other, people with CD have fewer options of gluten-free foods - it would be important that companies could offer these products produced without risk of cross-contamination. If labels do not contain clear information, the result is difficulty in accurately identifying whether there is gluten in the food (Jakobsen *et al.*, 2021; Oliveira, 2022). Therefore, correct labeling is essential to ensure consumer safety, and it urges for more appropriate labeling legislation.

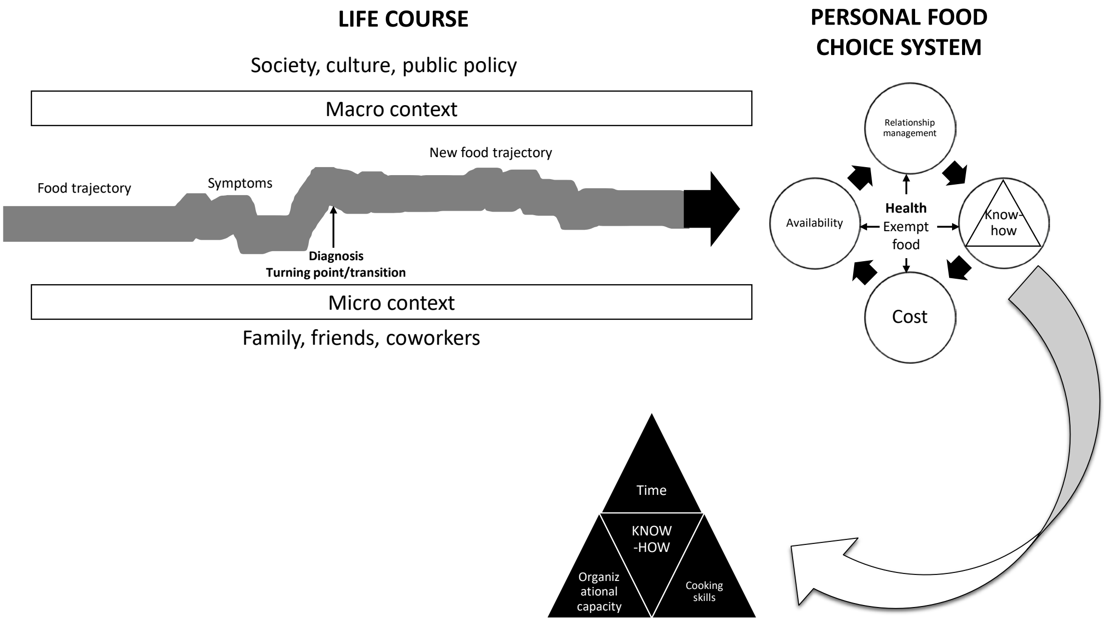
> ... Label in the beginning was very impactful because you had to read those little letters, right? And then that thing is gluten-free, and it contains traces, that there you see, my God how illogical, it contains traces of gluten, soy. (Emma, F, 52y, Midwest, CD + LI)

Participants reported the lack of availability of gluten-free products in markets, general stores, and restaurants, which varied depending on where participants lived, according to the region of Brazil, the area (rural or urban), as well as to the size of the municipality. However, when available, participants reported the higher cost of gluten-free foods as a limiting factor for purchasing these products.

According to participants, health is the main determinant that guides their food choices, reflected in the search and choice of gluten-free foods. Furthermore, availability, cost, management of social eating situations, and what we called “know-how”, were interrelated determinants that were taken into consideration for the everyday negotiations of what to eat. As an important aspect of food choice negotiations for the participants, we defined the “know-how” as what represents a set of interrelated determinants, in constant construction in the new food system adopted since the diagnosis. It comprises three key factors to ensure a safe diet: time, cooking, and organizational skills. The time factor includes all the time necessary to manage food/eating, for instance, to research about CD (e.g., reading the labels, how to avoid cross-contamination, searching for recipes, time spent shopping for food, etc.). The culinary skill factor represents the need of participants to learn/improve cooking to ensure more autonomy in their food choices, with risk control, as well as allowing the inclusion of favorite traditional recipes prepared in their gluten-free version, which are not easily available and, finally, organizational skills, with the adoption of personal strategies to ensure safe eating, both in everyday life and in social situations.

Figure 2 shows how food choice determinants, based on the Food Choice Process Model, were reported by participants. The adaptations shown in the model can also contribute to understanding the process of food choices of other groups with dietary restrictions, such as diabetes, heart disease, and other adverse reactions to food.

Figure 2. Proposal of adaptation of the Food Choice Process Model based on the participants' (n=17) trajectories and negotiations



Source: Elaborated by the authors, 2022

Sharing food

Home was the place where the first dietary changes occurred for participants to adhere to the treatment. That involved the participation of spouses and other family members, who may adhere to the same diet or, in case they maintain their gluten-containing food habits, be careful to avoid cross-contamination. Figure 3 shows the gluten-free options chosen to be shared with family and friends in a special occasion.

> Figure 3 caption: "I bought 'coxinha' and frozen roasted chicken pastry from a specialized gluten-free shop. Only me celiac. All gluten-free so everyone can eat [occasion: mom's birthday]." (Leah, F, 28y, Southeast, CD + LI)

Figure 3. Gluten-free options to be shared in a special occasion

Source: Photograph sent by participant Leah (F, 28y, Southeast, CD+LI)

The case of people with CD is similar to that of people with other diseases that require important dietary restrictions, for example, diabetes mellitus, because both diseases lead to adaptations of family members to ensure proper care, and to avoid symptoms and typical complications. For that, the family must undergo a process of adjustments to provide the necessary support, with ways to ensure a better quality of life for the person with the disease, positively influencing treatment adherence (Brancaglioni *et al*., 2016; Martins; Rodrigues, 2019).

None of the participants with CD reported the refusal of their spouses or family members to adapt preparations or eat gluten-free meals, although some reported some resistance from the family to accept and believe in cross-contamination. Participants reported family support as essential to assist in adherence to the dietary treatment, with participants feeling safer, cared for, and supported, as also demonstrated in studies with CD patients conducted in Brazil by Rocha *et al*., 2016; Santos and Ribeiro (2019) with adults, and Brancaglioni *et al*., 2016 with children and adolescents with both CD and diabetes mellitus.

One of the characteristics of commensality is its interactional dimension, which frequently occurs as a situation of absolute freedom and respect, which unites its members and strengthens the sense of belonging (Giacoman, 2016). Commensality was experienced in different ways by the participants, depending on the severity of their symptoms to gluten intake and what influenced their choices according to each situation, starting with the choice of whether to reveal the condition. When participants are invited to eat out, not everyone speaks openly about the condition, restricting information to their spouse, family, and close friends, highlighting the intimate nature of the disease and the diet. This strategy of hiding the condition in social situations and revealing it only to close relations helps to maintain a positive social identity, as well as intimacy in valuable relationships (Schroeder; Mowen, 2014).

> ... And of course, [I tell about having CD] for the closest people, right? That is, my family has been aware of this for a long time, and they know that when I visit, they already prepare mine next door, right? (...) Also, my closest friends know too, but others don't, I don't have to tell everyone, right? That I'm celiac. (Ed, M, 60y, North, CD + LI)

Thus, in addition to the change in daily diet, social life is another aspect strongly affected when participants obtain the diagnosis. Kleinman *et al*. (1978) refer to disease and illness, respectively, to differentiate the biological dimension from its social dimension. The authors establish that disease is the abnormality in physiological functioning, diagnosed through examinations, while illness represents the human experience of the disease, in states of being and social function. The disease process (illness) begins with the individual's perception that something has changed in his/her body, continuing until the "labeling" by the family or even by the individual himself as sick (ill) (Kleinman *et al.*, 1978). Thus, while experts seek to treat *disease*, the participants in this study clearly suffer from the *illness* in different ways, since it is culturally shaped, in the sense that the way we perceive, experience, and deal with the disease is based on our own explanations and perceptions about it (Kleinman *et al.*, 1978). These perceptions influence the choice of informing others about having CD, a decision which varied among participants according to personal criteria. The experience of diseases – and, in this case, CD - implies future self-care routines, which include the exclusion of restricted foods and a whole household reorganization (e.g., utensils, recipes, operations in the kitchen) to avoid cross-contamination.

If commensality is the act of sharing a meal, contributing to the strengthening, or weakening of group cohesion (Giacoman, 2016) and eating the food shared by all defines or not this cohesion, in the case of CD, it is usual for them to bring their own meals if they feel comfortable doing so. These strategies allow the experience of sharing meals, even if it is not the same meal. In the study conducted by Sommer *et al*. (2012) with people with food allergies (diagnosed or self-reported), this strategy was the most pleasurable way to consume food with others, although there was much difficulty in eating with others due to the condition. Sometimes patients with CD prefer to eat before the events, avoiding risks but missing the opportunity to share meals.

When participants choose to tell they have CD, adherence to a gluten-free diet becomes visible, attracting unwanted attention and publicly reinforcing their difference from others (Olsson *et al.*, 2009). When this happens, the external reactions may be one of understanding and support, or disbelief, and skepticism, when the condition is not taken seriously, being downplayed and the person with CD, stigmatized. Jakobsen *et al*. (2021) in their study of people with CD, LI, and CD+LI, food allergy, and Irritable Bowel Syndrome observed that there are processes to deal with hypersensitivities, which run from the interest in knowing about the condition, through the process of educating others, careful reading of labels, and adjusting food strategies when necessary. Similar results were obtained by Olsson *et al*. (2009), in a study conducted with adolescents with CD through focus groups, seeking to understand how they perceived themselves, how others perceived them, and whether adherence to gluten-free food occurred.

Stigma is a negative characteristic attributed to someone who has some feature that makes them different from others, constituting a special type of relationship between attribute and stereotype (Goffman, 1988). In this case, the condition can result in social losses, since it constitutes an attribute that brings the person closer to undesirable characteristics, and a stereotype is created that often operates by excluding the person (Matos, 2015). When these reactions happen, often accompanied by curiosity or disbelief, they demonstrate how sharing the table can generate experiences of conflict, depending on the characteristics of the group (Giacoman, 2016).

> There are some people who don't understand, they think it's 'picky eating', right?. (Ed, M, 60y, North, CD + LI)

Food is like a code (Douglas, 1972). Since a code provides a general set of possibilities for sending specific messages, then the messages encoded by food will be found in the pattern of expressed social relations - degrees of hierarchy, inclusions, and exclusions, setting boundaries - and food categories encode social events. Eating with others highlights the aggregating power of food. However, eating differently from others - by adhering to a foodway that is different from other members of the group - prevents full adherence to the social ritual that symbolizes the time of meals (Masson, 2015).

The dietary restrictions generated by CD studied here are individualizing and provide an opportunity for distinction and separation, a characteristic that extends to other adverse food reactions (Coveney, 2015). By choosing to expose having the CD to family and friends, or even in the act of bringing their own food to commensality situations, the person transmits the code of their condition through their food choices and exclusions. However, the tension generated by not sharing the same meal can cause conflicts, as they are no longer following the identity shared by the group, forged in the sharing of food, and which houses the principle of incorporation (Giacoman, 2016). Incorporation is the founder of collective identity and otherness since human beings mark their belonging to a culture or any group by affirming their food specificity or by their differences from others. It is also the act that crystallizes the anguish of the omnivore since it is the movement where we make food cross “the border between the world and our body, the outside and the inside” (Fischler, 1990, p. 65). With the option not to adhere to the norms of meals, it is placed on people who have CD and who restrict food to another way of interacting with the group to which they belong. However, there are cases when the food is adapted and shared with others, be it spouses, friends, or relatives, leaving the participants more comfortable – after making sure of the origin of the food, so as not to run the risk of adverse symptoms.

Conclusions

Although this study, the result of the encounter between anthropology and nutrition, brought elements that made it possible to understand the process of food choices and practices of people with CD, there is a limitation - the lack of the demographic profile of the participants, as no instrument was applied to verify it. This information (scholarity, social class, power of purchase, etc.) would have enriched our discussion.

The CD trajectory of the participants of this study is strongly marked by the diagnosis, which played a fundamental role in determining how a person with DC will deal with necessary dietary changes to manage CD. However, although knowledge about CD has increased, diagnosis trajectories can still be time-consuming and confused with those of other diseases. Once diagnosis is achieved it may represent a turning point or transition in eating itineraries. It is also the moment of conflict between the personal food system before the diagnosis of the participants, and the new one, posed by the need to exclude gluten.

The way participants reported coping with dietary restrictions due to CD varies greatly depending on the severity of the symptoms, resulting in greater caution and/or a greater perception of risk. The main strategies that people with CD adopt to eat happen both in the home environment (the use of specific utensils/equipment) and outside it (taking their own separate food, going to events already fed, choosing places that offer gluten-free options). For the participants, assuming publicly to have CD varied according to how much the person feels comfortable exposing themselves since they can be stigmatized.

Having CD affects how one eats and shares food in an important way, generating constant negotiations for safe food choices. It impacts the special processes for the preparation of food and even the food that makes up the diet of other family members. This points to a constant negotiation in food choices to ensure that there will be no ingestion of the offending ingredient.

We now return to the title of this study: does CD lead to “new” foodways? Or are these participants just looking for “the good old foodways”: eating together, eating culturally accepted food, eating foods that mediate relationships? The results suggest that people with CD, in addition to aiming for the maintenance of their foodways, associate the constant process of “thinking” about eating, which includes fear of what to eat, the stigma of a sick body, and the quest for a healthy life, frequently in detriment of pleasure.

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