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Original Article

What people living with celiac disease say about the health–illness–care continuum: a qualitative study

O que dizem pessoas que vivem com Doença Celíaca sobre o processo saúde-doença-cuidado: uma pesquisa qualitativa

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ABSTRACT

Objective: this paper aims to analyze the psychosocial experiences and care needs of people living with celiac disease, with the purpose of helping guide person-centered care in Primary Health Care. **Methods**: this was an exploratory qualitative study based on the online administration of a semi-structured questionnaire comprising two open-ended questions, answered by 97 participants diagnosed with celiac disease for more than one year. Data were analyzed using qualitative content analysis, with support from artificial intelligence. **Results**: we analyzed responses from 93 people, most of whom were highly educated adult women. Participants reported feelings of exclusion, frustration, and anxiety associated with dietary restrictions, the risk of cross-contamination, and the delegitimization of suffering. They described coping strategies such as avoiding social situations, bringing their own food to work and social events, and reorganizing daily practices. Social support fostered acceptance, trust, and safety. Participants also emphasized the importance of multiprofessional care, nutritional and psychological guidance, professional training, and health policies focused on food safety, labeling, access to gluten-free foods, and social awareness. **Conclusion**: the experience of living with celiac disease is multidimensional and requires healthcare teams to adopt humanized, interdisciplinary and person-centered strategies for comprehensive care.

KEYWORDS: Celiac Disease. Patient-Centered Care. Primary Health Care.

RESUMO

Objetivo: este artigo tem como objetivo analisar as experiências psicossociais e as necessidades de cuidado das pessoas vivendo com doença celíaca, visando contribuir para orientar o cuidado centrado na pessoa na Atenção Primária à Saúde. **Métodos**: trata-se de um estudo qualitativo, exploratório, constituído da aplicação *online* de questionário semiestruturado, composto por duas questões discursivas, respondido por 97 participantes diagnosticados com doença celíaca há mais de um ano. Os dados foram analisados por técnica de análise qualitativa de conteúdo e apoio de inteligência artificial. **Resultados**: foram analisadas respostas de 93 pessoas, majoritariamente mulheres adultas com alta escolaridade. Identificaram-se sentimentos de exclusão, frustração e ansiedade, associados às restrições alimentares, ao risco de contaminação cruzada e à deslegitimação do sofrimento. As estratégias de enfrentamento incluíram evitar situações sociais, levar alimentos próprios ao trabalho/eventos sociais e reorganizar práticas cotidianas. O apoio social produziu acolhimento, confiança e segurança. As participantes apontaram a importância do cuidado multiprofissional, da orientação nutricional e psicológica, da capacitação profissional e de políticas de saúde voltadas à segurança alimentar, rotulagem, acesso a alimentos isentos de glúten e conscientização social. **Conclusão**: a experiência de viver com a doença celíaca é multidimensional e demanda, das equipes de saúde, estratégias humanizadas, interdisciplinares e centradas na pessoa para um cuidado integral.

PALAVRAS-CHAVE: Doença Celíaca. Assistência Centrada no Paciente. Atenção Primária à Saúde.

INTRODUCTION

Food is part of our cultural and social identity[1], whereas clinical conditions that require changes in eating habits as part of care directly influence individual perceptions of well-being. Celiac disease (CD), a food intolerance that affects 0.7% to 1.4% of the population, is one such condition[2]: the only effective treatment to prevent complications and improve symptoms among people living with celiac disease (PLCD) is a strict gluten-free diet (GFD)[1,3].

In July 2025, the Brazilian Ministry of Health published a revised Clinical Protocol and Therapeutic Guidelines for Celiac Disease[4], improving diagnostic criteria and emphasizing the need of nutritional support as part of comprehensive care for PLCD. Although considered a condition that requires specialized care, Primary Health Care (PHC) services provide diagnostic suspicion and integrated care of PLCD. Care teams supporting people with this condition should consider that living with gluten restriction involves, besides clinical prescription, subjective, social, and relational issues[5]. Adherence to GFD and vigilance against accidental exposure to gluten (cross-contamination) are related to emotional burden, anxiety, and social isolation[5], aspects that should be taken into account.

Nonspecific symptoms, delegitimized suffering

Malabsorption syndrome is a group of disorders characterized by inadequate absorption of nutrients in the small intestine. The diagnosis of celiac enteropathy can be confirmed by the anatomical presence of villous atrophy and positive serological markers.

Abdominal pain, persistent diarrhea, and weight loss are the most common symptoms. In addition to gastrointestinal complaints, nonspecific symptoms and extraintestinal manifestations are common, contributing to delayed diagnosis or underdiagnosis. Many of those symptoms result from micronutrient malabsorption (iron-deficiency anemia, for example, occurs in up to 40% of patients). Changes in bone density, such as osteopenia and osteoporosis; neurological disorders, such as headache or paresthesia; and menstrual changes, such as late menarche or amenorrhea, are common manifestations[6].

Such general and nonspecific symptoms hinder timely recognition of the disease and tend to be disregarded and delegitimized[7] during clinical encounters. Consequently, the condition worsens, while the person may develop chronic malnutrition, fractures, reproductive complications, persistent fatigue, and impaired quality of life[6].

Learning to live with the disease

After diagnosis, the experience of living with the disease and following clinical

recommendations includes adaptation to the GFD[5]. Research on CD in Brazil is limited, but care recommendations apparently follow the reviews: in addition to dietary guidance, patients should be introduced to psychological support strategies[6].

Clinical practice, based on the assessment of signs and symptoms and on therapeutic guidance, tends to neglect or delegitimize psychosocial aspects[7]. In PHC, the Patient-Centered Clinical Method (PCCM), which integrates biomedical and subjective dimensions, and the FIFE model for history taking (exploring the person's Feelings, Ideas, Function, and Expectations) consider the illness experience[8] and promote broader and more effective care of PLCD.

Within such context, the gap of knowledge guiding this study involves understanding of how people living with CD recognize, narrate, and express their care needs, as well as the daily burden of diagnosis that extend beyond dietary changes. Awareness of such perceptions, besides alerting PHC professionals to timely diagnostic suspicion, can help in the development of person-centered therapeutic plans that integrate the medical, dietary, emotional, family, and social dimensions of living with CD.

This study therefore aims to deepen understanding of the challenges involved in the care of PLCD in Brazil by investigating how the experience of the disease affects those patients, by emphasizing their psychosocial experiences, the strategies they develop for everyday life, and their care expectations. Such understanding may serve as guidance for person-centered care practices in Primary Health Care.

METHOD

This was ~~an~~ a qualitative exploratory study embedded in a cross-sectional survey, with online administration of a mixed instrument composed of 28 Likert-type quality-of-life questions and two open-ended questions, applied to PLCD. The motivation for the study was the illness experience of one of the authors, including her medical care journey, social experiences, and participation in a PLCD group ~~of~~.

The study was conducted between May and October 2024. Ninety-three individuals were enrolled, recruited through a direct invitation at a local event for people with celiac disease, ~~and~~ through dissemination on social media (Instagram™) and in gluten-free restaurants and coffee shops, using posts and explanatory posters for the study and a QR code invitation to access the questionnaire. The instrument used was the Celiac Disease Quality of Life (CD-QoL), a structured questionnaire validated in Portuguese[9], consisting of 28 Likert-type questions to which two open-ended questions were added.

The questionnaire was ~~made~~ available online through Google Forms. The two guiding open-ended questions addressed the social dimension, feelings, questions, and needs of people

living with the condition, namely, their experience of the illness process and care expectations (Chart 1). We received ninety-seven responses to the form. After excluding one person who declined to participate, one participant under 18 years of age, one respondent living abroad, and one duplicate record, 93 people living with CD were included in the qualitative analysis.

This article focused exclusively on the qualitative analysis of the open-ended responses. Before responding, participants were informed about the study objectives and voluntarily agreed to participate after reading the Informed Consent Form, made available on the online form. Before consent, access to the questionnaire was not possible. The study was approved by the Research Ethics Committee at Anhembi Morumbi University (opinion No. 6,881,960; CAAE No. 79832824.8.0000.5492).

Chart 1 – Research questionnaire questions

THEME	QUESTION
Feelings and social relationships	How did your social circle (family, friends, and coworkers) deal with or what feelings did they express when you had to change your eating habits after receiving a diagnosis of celiac disease? Perhaps this questionnaire brought back some memories to you. Share one of those experiences with us; tell us how you felt and what you learned from it
Life with celiac disease	What is it like to live with celiac disease? Is there anything you would like to know about the disease, diagnosis, or care?

Source: prepared by the authors

The analysis method was the qualitative content analysis, grounded on constructivist theories. The approach allows for creation of analytical categories based on the study participants' responses[11]. This technique is suitable for studying subjectivity and the illness experience, because:

> Reflecting on the illness experience and its suffering expands the view beyond the limits of objectification in biomedical knowledge and practice, which usually ignores the life-world and existence of those who are ill, their everyday life, their ways of acting, reacting, and dealing with the body, health, disease, and care, all of which are inexhaustible in subjectivity because they are socially shared[7]

The analysis considered the following stages: individual floating reading of the material by four researchers; identification of units of meaning; coding and sharing of the individual products among the researchers; joint construction of analytical categories; and subsequent aggregation into themes and subthemes. We followed the concepts defined by Graneheim and Lundman[10]. After those stages, we used artificial intelligence (Microsoft Copilot™) as a tool to validate the categories and themes by extracting excerpts from the narratives in the response document, organized as a Word™ file, and assigned them to the categories and themes we developed. The categories and themes were maintained and considered representative of the narratives.

RESULTS

Of the 93 people included in the study, 88 were female and five were male. Age ranged from 20 to 59 years, with ~~a~~ mean ~~of~~ 38 years. Most respondents lived in the state of São Paulo (83; 89.2%). Mean family income was BRL 12,820.00 (BRL 1,800.00 to BRL 50,000.00), and the mean level of schooling was 15 or more years of education.

The narratives were ambivalent both in relation to the participants' own feelings about the disease and in relation to the reactions of friends and family members, and to medical care. Participants reported multiple strategies to cope with difficulties. These ambiguities were expressed in the categories and subcategories of the generated themes, which aggregated five units of meaning: (1) Me and the others: social exclusion mitigated by empathy and welcome; (2) Me with myself: reorganization of habits and attitudes, facilitated by social support; (3) CD has a high economic and social cost; (4) Clinical care should be comprehensive and timely; and (5) Expectations for advances include the scientific and social fields (Charts 2 to 6).

The first theme constructed was the feeling of social exclusion, mitigated by empathy and welcome (Chart 2 - Me and the others: social exclusion mitigated by empathy and welcome). PLCD feel frustrated by the way people in their social circles communicate about the condition: they delegitimize discomfort, treat dietary restrictions as "fussiness" or a passing event, are ironic or use pejorative expressions, and adopt an attitude of distrust or "pity." The condition must be reaffirmed, repeated, and explained constantly, to the point of exhaustion, which generates fatigue and loss of pleasure. Repeated negative experiences lead people to reduce social interaction and to isolate themselves. Isolation is a reaction to ~~the~~ belittling of the celiac condition.

People begin to select the moments and companies they feel comfortable with. In respectful and loving relationships with friends and family, they feel welcome. Understanding and concern, presence, and support are expressed as help and change of habits, such as offering gluten-free foods, making changes at home, reorganizing environments, and being careful with household utensils. These changes are perceived as acts of love and respect.

At the same time, many participants reported empowerment as they learned to manage their health and food safety better (Chart 3 - Theme 2. Me with myself: reorganization of habits and attitudes, facilitated by social support). They learned to listen to their own bodies, to value physical and subjective feelings, and to recognize themselves as having a condition that requires adaptation, in an ongoing process experienced daily. Practical changes involve changes in their relationship with food, such as preparing packed meals, eating before going out, and acquiring and carrying their own cooking utensils to avoid cross-contamination. They also involve collective changes, with structural reorganization and new household and family routines. Self-acceptance, supported by social circles, strengthens them to "go on with life" and give voice to what bothers

them.

The costs involved in the disease are high and ~~are~~ not limited to the economic dimension, although this is evident in the price of foods (gluten-free foods are more expensive, and eating away from home is also more costly), diagnostic tests, and, in some cases, medical care (Chart 4 - Theme 3: CD has a high economic and social cost). Other dimensions are added to the economic one and are perceived as burdens: emotional, related to the need and difficulty of changing life habits (food becomes a constant concern; one must relearn), and relational (the condition must be communicated repeatedly; there is a risk of being defined by the disease in social contacts).

There is a desire for comprehensive and timely care (Chart 5). Professionals - physicians, nutritionists, psychologists - are unprepared for the diagnosis and care of PLCD: they do not identify symptoms, they are unaware of sequelae, do not understand complaints, and, because of such lack of knowledge, may fail to value the illness experience. Participants feel that they are not taken seriously, that there is a lack of knowledge “of the extent of the sequelae, symptoms of celiac disease”, and that they would need “much more financial and psychological support.”

Diagnosis leads to subjective suffering and physical impairment, affecting the metabolic and immune systems. Participants emphasize the need for nutritional and psychological support, they value welcoming medical care and receiving appropriate guidance when diagnosis is timely.

Finally, expectations regarding future life include advances in the scientific and social fields (Chart 6). Collective knowledge includes public awareness through campaigns, investment in scientific research, and legislation that enables greater safe supply of gluten-free foods in commercial establishments. Therapeutic innovations should focus on medications, nutrition, reduction of cross-contamination, and preventive interventions.

Chart 2 – Theme 1: Me and the others: social exclusion mitigated by empathy and welcome

Theme	**Me and the others: social exclusion mitigated by empathy and welcome**					
Category	Communication		Isolation		Empathy	
Subcategory	Others: Delegitimization	Me: Emotional burden	The others	Me	Feeling and expression	Collective action
Codes	Fussiness, phase Exaggeration Distrust; pity Mockery, irony Pejorative expressions	Fatigue Exhaustive repetition Loss of pleasure Loneliness	Belittling Insistence	Selectivity Reducing socialization	Understanding Concern Help Being present Expressing love	Offering gluten-free foods Concern about cross-contamination Changing habits Reorganizing environments
Units of meaning (examples)	""It was awful; they thought it was fussiness ...". "I heard many comments such as 'oh, poor thing' or 'that is the secret to your slenderness [...]"	""It upsets me a lot having to explain trillions of times that I cannot eat anything prepared with shared utensils; it is SOOO tiring".	"Some seem to pretend they understand; others insist that I stop eating those bad things, ... like the party cake is delicious"	"Now what I do is to stay away; I prefer not to go to places with that kind of people"	"My husband established that gluten would not enter our house in any way; it was a demonstration of love"	"It is even nice that my friends and people who live with me always read labels and send me messages like look, it has no gluten, you can eat it".

Source: prepared by the authors, based on the empirical research

Chart 3 – Theme 2: Me with myself: reorganization of habits and attitudes, facilitated by social support

(Continued)

Theme	**Me with myself: reorganization of habits and attitudes, facilitated by social support**					
Category	Learning		Changing eating routines		Self-acceptance	
Code	Learning process	Resilience	Individual action	Collective action	Before oneself	Before others
Subcode	Slow adaptation / Listening to the body	Daily challenge	Bringing packed meals Eating before going out	Offering gluten-free foods Concern:	Exposing oneself	Giving voice to discomfort (communication))

(Conclusion)

Theme	**Me with myself: reorganization of habits and attitudes, facilitated by social support**					
Category	Learning		Changing eating routines		Self-acceptance	
Code	Learning process	Resilience	Individual action	Collective action	Before oneself	Before others
Subcode	Valuing feelings		Having one's own cooking utensils	cross-contamination Changing habits Reorganizing environments	Enjoying life	Giving voice to discomfort (communication)
Unit of meaning (example)	"I learned: we should always listen to the body and take into account anything we are feeling, no matter how 'silly' it may seem"	"Resilience	"I plan ahead, eat before going out, bring packed meals, I am always prepared!"	"[...] they try not to eat near me so as not to bother me"	""Today I do not hide; I say I am celiac and I live!! I do not stop doing anything!!"	""I make a point of showing my discomfort that they did not remember."."

Source: prepared by the authors, based on the empirical research

Chart 4 – Theme 3. Celiac Disease has a high economic and social cost

Tema	**Celiac disease has a high cost**			
Category	Economic cost		Emotional	Communication
Code	Food	Healthcare	Change in habits	Me: emotional burden
Subcode	Cost of gluten-free foods Cost of eating away from home	Cost of tests	High caloric value of gluten-free foods Dietary restriction	Fatigue Exhaustive repetition Loss of pleasure, loneliness
Unit of meaning (example)	"The first and most difficult item is buying the products (financially)." / "... the costs of gluten-free foods are the greatest challenge for me""	"I need to take a SIBO test... but it is expensive."."	"[...] you put on weight because bread and pasta are terrible" / "... the personal restriction ... is the greatest challenge for me."	"[...] it is extremely tiring to be worried 100% of the time and not being able to simply switch off the mind and truly relax, especially ... at social events and when traveling

Source: prepared by the authors, based on the empirical research

Chart 5 – Theme 4: Clinical care should be comprehensive and timely

Theme	**Clinical care should be comprehensive and timely**					
Category	Professional unpreparedness		Diagnosis		Assertive care	
Code	Lack of knowledge	Lack of interest	Late	Timely	Absent	Present
Subcode	Unaware of symptoms Unaware of sequelae Do not understand Do not instruct	Not taken seriously	Effects on the digestive, metabolic, and immune systems Subjective effects	Early diagnosis	Lack of nutritional support Lack of psychological support	Feeling safe
Unit of meaning (example)	"[...] many physicians, nurses, and nutritionists have no idea of how complex the disease is".	""I wish it were a disease taken more seriously by health professionals"	"Most people, when they receive the diagnosis, are only told to stop eating gluten. But what has already been damaged?"	"I am celiac with an early diagnosis, which greatly limited my answers to the life questionnaire"	"I do not have psychological or nutritional follow-up"	"I had a lot of understanding from my doctor, who provided and still provides amazing follow-up.".'

Source: prepared by the authors, based on the empirical research

Chart 6 –Theme 5. Expectations for advances include scientific and social fields

Theme	**Expectations for advances include scientific and social fields**				
Category	Collective knowledge			Therapeutic innovation	
Code	Awareness	Research	Legislation	Medical field	Dietary
Subcode	Information	Science	Facilities	Drugs Contamination Vaccine	Food with gluten
Unit of meaning (example)	"I wish there was more information available to people."	""I feel this 'delay' of information in science, and I think future celiacs will be luckier."	"there is a law there requiring restaurants to have gluten-free food."	"Could a vaccine possibly help us?"	""that advances be discovered in some treatment other than the complete exclusion of gluten from food."

Source: prepared by the authors, based on the empirical research

DISCUSSION

The study made it possible to understand the social, emotional, and practical experiences of people affected by CD. The qualitative analysis revealed central aspects related to the difficulties faced by PLCD, as well as the respondents' coping strategies and clinical care expectations ~~for~~.

The first theme, "Me and the others: social exclusion mitigated by empathy and welcome" (Chart 2), emphasizes, on the one hand, the feeling of social isolation (common after a CD diagnosis) and, on the other hand, the importance of communication, empathy, and welcome by family members, partners, and colleagues as a pathway to resuming social life. Feelings of constant vigilance over oneself, repetitive communication, and an existence modified and defined by the disease are corroborated by review studies[12].

A thematic literature review[12], predominantly based on European studies, identified three axes of experience with CD: altered identity (life organized around the disease, the presence of stigma, but also neutral or positive views), mitigated by participation in support groups; continuous burden, which includes repeated explanations, sadness, anger, overload, and a constant sense of risk, a state of ongoing anxiety. In this review[12], corroborating our findings, shame, emotional burden, and feelings of exclusion affect quality of life among PLCD.

The social isolation highlighted by the interviewees was presented in a study with adolescents[13] as a dilemma between either preserving health or maintaining social life, which points to eating habits as a central social and cultural element. Change of habits entails challenges for social interaction. For younger people, the diagnosis meant making "social sacrifices," giving up gatherings, parties, and trips, with an outcome considered negative, even though they recognized health gains.

If social limitations constitute one of the main challenges for PLCD, empathy, participation in groups, respect, understanding, and the strengthening of bonds are protective factors[14]. Social support is a pillar to change life dynamics and to adapt to the disease, attenuating feelings of isolation and facilitating adherence to the diet[5]. Personal acceptance and social support are related to self-esteem and lower fear of rejection, especially among adolescents and young people, groups more vulnerable to social pressure[15]. Thus, empathy, respect, practical help, and collective reorganization of eating habits among people who live with CD can give a new meaning to the experience of exclusion and isolation

PLCD also experience a change in their relationship with themselves (Chart 2): a slow and gradual process of self-knowledge. Resilience develops from learning to deal with CD. An Italian multicenter study quantified resilience by using a psychometric scale[16]. The main variables influencing the high resilience found among people living with celiac disease were

sociodemographic: men, people aged 35 years or older, and those in stable relationships scored higher[16]. There was a positive relationship between resilience and quality of life, as well as a negative relationship with symptoms of anxiety and depression.

Changes in life habits occur, as expected, in personal eating habits and in the surrounding environment. Reorganization of the home and work environments helps people with the disease to deal with the condition. The gluten-free routine, difficult at first, changes over time with the support of family members, friends, and social networks, creating opportunities for balanced habits and varied alternatives[12]. Changes are motivated by the desire to reduce undesirable effects, both symptoms and discomforts as well as weight changes and nutritional deficiencies. Over time, individual and collective learning increases safety in dealing with the condition. As in the findings of this study, acceptance of CD, reinforced by social support, favors adaptation to dietary changes and better management of ongoing risks[12].

In the process of personal transformation, the interviewees in this study emphasized self-acceptance as the first step toward building a new identity, facilitating their positioning before others and their expression of dissatisfaction with certain attitudes. Over time, the disease no longer defines them. Among young people and adolescents, self-acceptance is essential ~~for~~ to deal~~ing~~ with social and affective contexts[15]. Young people with high self-esteem manage dietary restrictions better and are less worried about negative evaluations from their peers[15].

In addition to subjective and relational issues, celiac disease comes with a high price (Chart 3) and is a burden in several respects. Economic costs involve medical and laboratory care and access to the diet. The reports in this study highlight the high price and lower availability of industrialized gluten-free products, which makes full adherence to the diet difficult. Internationally, gluten-free foods are likewise more expensive, less accessible, and sometimes nutritionally inferior[17,18]. Studies on the global burden of CD point to the high cost of gluten-free products as a significant barrier to dietary adherence[18].

In addition to the economic impact, people in this study reported emotional and social harms: feeling excluded; being constantly afraid of cross-contamination; feeling frustrated by limited food choices are feelings that weigh heavily, a “burden,” as Rose[12] describes. Restrictions and the constant risk of cross-contamination are associated with anxiety and depression among PLCD[12,18], a burden that can be alleviated by empathy and welcome from peers.

What, then, should be expected from care? Timely diagnosis is the first step, along with comprehensive, assertive, interprofessional care (Chart 4). Professional unpreparedness was emphasized in the responses; people experienced consultations in which physicians, nutritionists, and nurses were unfamiliar with the symptoms and complications of CD, failing to provide adequate guidance. This lack of knowledge, described in studies, reinforces the need for greater

training of physicians (generalists and specialists) to diagnose the condition[18]. It is important to emphasize that nonspecific symptoms are often delegitimized by health professionals and, as Canesqui[8] emphasizes, are reflected "in the body, in subjectivities, in social relationships, in their identities of being or not being ill, in the strategies used in health services" (p.415).

Diagnosis thus legitimizes the condition, as one patient stated: "when we discovered celiac disease, everyone was 'relieved.'" When late, it is interpreted as a direct consequence of professionals' lack of preparedness and leads to clinical worsening and psychological suffering. In many cases, the person receives only the instruction to remove gluten from the diet, without a comprehensive assessment of the clinical condition and without multiprofessional support. When diagnosis is made in a timely manner and by a multidisciplinary team, there is greater adherence to treatment, better symptom management, and therefore improved quality of life. Integrated care (medical, nutritional, psychological) leads to better outcomes[18].

In a survey conducted among generalist and specialist physicians in Spain, nearly all respondents (96%) reported a need for greater training in CD and the gluten-free diet[19]. Patients considered consultations superficial and insufficient, whereas the lack of opportunity to clarify doubts and uncertainties influenced adherence to the diet[19]. These findings reinforce that overcoming barriers to comprehensive, person-centered practice involves continuing education and strengthening interdisciplinarity.

And what to expect beyond current care? Expectations include scientific and social advances for disease management (Chart 6). Awareness campaigns and public policies that ensure adequate food labeling are necessary. Strict legislation significantly reduces the risk of cross-contamination and increases consumer confidence: the European Commission regulated the labeling of gluten-free foods in 2009, and in 2017 Italian researchers demonstrated reduced gluten levels in foods labeled as gluten-free[20].

In Brazil, access to safe foods is difficult for people with celiac disease, especially away from home, due to the risk of cross-contamination[21]. A qualitative study accessed more than 500 posts on a social network of a PLCD group over 65 months and identified common paths of peregrination. In the first journey, people with celiac disease move through several services until diagnosis and then continue in search of qualified care and safe food[21]. Despite advances in care, a gap persists in meeting their clinical, subjective, and social needs.

Finally, PLCD have many expectations for the future, in medicine, food safety, education, and public policies, and several actions are underway. Academic production and regulatory standards related to the disease have increased over the past ten years. The horizon is promising for patients in the coming years[22]. Therapeutic innovations under development, to be combined with the gluten-free diet, include immunotherapy, enzymes that degrade gluten fragments, and

modulators of intestinal permeability[22]. Advances in food technology are needed because gluten-free foods, besides their high cost, are often less palatable, have low nutritional value, and contain high levels of sugars and fats[22], as reported by patients in this study.

Finding healthy and safe foods depends on public regulatory policies. Among 192 World Health Organization member states, 40.6% regulate industrialized gluten-free products, and the role of celiac associations, present in 34.4% of countries, is strategic[23]. A path has been outlined, but policies aimed at both the supply and inspection of gluten-free foods/products need to be expanded[23]. Safety certification reduces the risk of cross-contamination. Other indicated actions include financial incentives to adopt measures and food assistance for PLCD and, as public policy, awareness and knowledge of the disease[23], aspects also highlighted by other studies[12].

In short, the findings reveal that living with CD, as with other chronic conditions, involves physical, moral, and relational suffering that may be delegitimized in social relationships and health care when reduced to the prescription of a gluten-free diet. The categories constructed express a care trajectory that begins with nonspecific symptoms, delayed diagnosis, and delegitimization of suffering; continues with the reorganization of daily life and the search for family, social, and professional support; and remains sustained by high economic and social costs. These results dialogue with national and international studies that describe CD as a condition associated with states of permanent vigilance and anxiety, often accompanied by social isolation, difficulty accessing safe foods, and insufficient multiprofessional care. Evidence of such elements based on the narratives of PLCD in Brazil may provide tools for person-centered care for this population in primary health care.

Final considerations

This study explored the subjective experiences of people living with celiac disease, highlighting aspects related to feelings, ideas, function, and care expectations. The findings may guide the planning of comprehensive care for people with this condition in Primary Health Care services.

The social and emotional experiences related to illness make the disease the axis of life for the person with the celiac condition: before diagnosis, lack of knowledge of the condition and nonspecific symptoms are delegitimized by health professionals, and the person feels misunderstood and unsupported; afterwards, gluten restriction and changes in eating habits modify sociability. Health maintenance and well-being is achieved by developing practices and new eating habits and routines, with learning by the person as well as by the person's social circle. The findings of this qualitative study are in line with Brazilian studies and the international literature.

As a contribution, the study reinforces that care of PLCD should include timely diagnostic

suspicion, validation of suffering, and, in addition to qualified dietary guidance, longitudinal and interprofessional follow-up. In PHC, the person-centered approach can support listening to feelings, ideas, function, and expectations, favoring therapeutic plans that integrate medical, dietary, emotional, family, and social dimensions. As study limitations, we highlight online recruitment, a sample composed predominantly by women of higher income and education, and low sociodemographic diversity, which restricts the transferability of the findings to other social and care contexts. Still, difficulties in the care trajectory, such as delayed diagnosis, access to gluten-free foods, and specialized care, may be even more pronounced among socially vulnerable populations

It is therefore evident that the management of CD is not limited to dietary guidance: it requires a multidisciplinary and person-centered approach, rarely experienced in our study sample. Multiprofessional teamwork in PHC, including nutritionists and psychologists, can facilitate longitudinal follow-up of people with celiac disease, as long as care is integrated. The community health worker, once trained, can support the necessary changes in nutritional practices at home. The family physician legitimizes the condition before the family. Group activities for PLCD and their family members are important care strategies for education, learning, self-knowledge, and self-esteem.

Regarding timely diagnosis, it is essential to train health professionals to recognize, in manifestations labeled as nonspecific, the experience of the disease, welcoming the person through listening and expanded clinical practice, ~~and~~ interrupting the vicious cycle of misunderstanding that perpetuates and worsens the clinical condition. Within the political dimension, supply of economically accessible and safe foods, combined with promotion of educational actions for society, would improve PLCD quality of life and reduce the stigma.

Thus, if understood in its complexity, which involves clinical, subjective, social, political, and scientific dimensions, celiac disease may be given a new meaning. Comprehensive care requires political actions, such as access to adequate foods and social awareness; technical actions, such as professional training and multiprofessional support; and innovation actions, with resources for scientific research. Within this scenario, person-centered medicine and multiprofessional work in PHC appear to be effective strategies to promote comprehensive well-being and social inclusion of people living with celiac disease.

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