



## The psychosocial impacts caused by diagnosis and treatment of Coeliac Disease\*

Os impactos psicossociais gerados pelo diagnóstico e tratamento da doença celíaca

Los impactos psicossociales generados por el diagnóstico y tratamiento de la enfermedad celiaca

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### How to cite this article:

Rocha S, Gandolfi L, Santos JE. The psychosocial impacts caused by diagnosis and treatment of Coeliac Disease. Rev Esc Enferm USP. 2016;50(1):65-70. DOI: <http://dx.doi.org/10.1590/S0080-623420160000100009>

\* Extracted from the dissertation: "Os impactos psicossociais da Doença Celíaca", Programa de Pós-Graduação em Ciências da Saúde, Universidade de Brasília, 2015.

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### ABSTRACT

**Objective:** To comprehend the psychosocial effects that Coeliac Disease diagnosis entails. **Method:** Qualitative study, achieved through semi-structured interviews, analyzed in accordance to the Association of ideas map Technique. A total 12 recently-diagnosed patients from the Centro de diagnóstico, tratamento e apoio ao paciente com doença celíaca (Coeliac Disease Prevention, Support and Treatment Diagnose Centre) from the Hospital Universitário de Brasília (University Hospital of Brasília) were enrolled for the study, between the years of 2013 and 2014. **Results:** The interviewed patients presented negative impacts in three categories: psychoaffective, family and social relationships, indicating issues with social readaptation once the treatment had started, as well as difficulty coping with a gluten free diet. **Conclusion:** Coeliac Disease holds substantial impact on psychological functions, family and social relationships to diagnosed patients, requiring a clinical biopsychological assistance for better adherence to treatment and patients quality of life.

### DESCRIPTORS

Celiac Disease; Diagnosis; Therapeutics; Psychosocial Impact; Quality of Life.

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Received: 08/11/2015  
Approved: 10/27/2015

## INTRODUCTION

Coeliac Disease (CD) is a permanent intolerance to gluten, a protein found in some grains such as wheat, barley, rye, malt, and oat. It occurs to genetically predisposed individuals and can be defined as an autoimmune disorder of the small intestine, triggered by constant hypersensitivity of the immune system against peptides found in gluten. Coeliac Disease involves genetic, environmental and immunological spectrums, in other words it is a multifactorial disorder, and as such it entails several clinical manifestations<sup>(1)</sup>.

In a study in Brasilia<sup>(2)</sup> a 0,34% (1:294) coeliac disease prevalence was found, which enhances the significance of the studies in Brazil. CD can arise at any age in two forms: Atypical, Not classified or Subclinical, categorized by mixed clinical scenario or even no gastrointestinal symptoms, and Classical or Typical in which there is a specific positive serology and compatible biopsy with signs and classical symptoms, such as difficulty digesting (malabsorption), chronic diarrhea, anorexia, abdominal distension (gastric insufflation), muscle tissue loss, flatness of the buttocks, steatorrhea, edema by hypoalbuminemia, flatulence, weakness, irritability<sup>(3)</sup>.

Coeliac Disease patients require a gluten-free diet (GFD), thus the patient must deprive him or herself of food that contain gluten for the rest of his or her life. Small quantities may trigger reactions stem from severe lesions that such protein causes in the small intestine, flattening and atrophy of the intestinal villi thereby resulting in poor absorption of nutrients which can delay growth, cause diarrhea and chronic constipation, vomiting, pain and abdominal distension, iron-deficiency anemia, osteoporosis, infertility, among other symptoms<sup>(4)</sup>.

When analyzing related literature, research data were found on the importance of psychosocial factors in the assistance to coeliac disease patient, as well as symptoms relief. Psychiatric distress may also arise along with CD diagnosis. Previous research<sup>(5)</sup> have shown psychological symptoms and negative impact on the patient's quality of life and adherence of a gluten-free diet. In the United States, a study performed on 101 adult patients concluded that psychosocial factors have a stronger effect on patient's health and gastronomical symptoms incidence than the disease activity as discovered by serologists and historical data.

The psychosocial influence on health, on human development, and mechanism that can contribute to the development of inadequate behavior. The term psychosocial has been used to refer to a variety of psychological and social factor related to mental health, describing personality traits, defense mechanisms, emotional cognitive status, and social and environmental factors as stress promoters<sup>(6)</sup>.

Based on the above mentioned premise as well as the experience of coeliac disease patients from the Ambulatório de Doença Celíaca of the Hospital Universitário de Brasília (CD ambulatory of the Brasilia University Hospital), we decided to study what psychosocial impacts are triggered by coeliac disease diagnosis and treatment. The aim of the study was to verify how the psychosocial spectrums affect

health and whether there is an impact on psychosocial relations caused by CD diagnosis and treatment on patients assisted by the ambulatory.

## METHOD

This is a qualitative study of the descriptive and transversal type which contemplates subjective aspects using patients reported actions and speech on coeliac disease. A convenience sample composed by 12 patients undergoing psychological treatment from the Centro de Prevenção, Diagnóstico, Tratamento e Apoio ao Paciente com Doença Celíaca (Coeliac Disease Ambulatory of the Coeliac Disease Treatment and Support Diagnosis Centre) located at Hospital Universitário de Brasília (Brasilia University Hospital). In the city of Brasilia – Distrito Federal, between the years of 2013 to 2014. All patients accepted to partake the research and signed consentment term.

The criteria to participate were patients from both genders, between the age of 15 and 50, recently-diagnosed, thereby on the initial phase of the CD treatment, assisted by the Ambulatório do Hospital Universitário de Brasília (University Hospital Ambulatory); patients that were able to discuss about their own experiences, with no mental or cognitive limitation which could disable them from answering for their own actions. By chance, all participants were female. The research was approved by the Comitê de Ética em Pesquisa da Universidade de Brasília (Research Ethics Committee of the University of Brasilia) assent vote nº 389.680 on 09/10/2013, in accordance with the Conselho Nacional de Saúde (National Health Council), resolution nº466, December 12 2012.

The study used semi structured interviews, which were all recorded to ensure reliable data for analysis, that thoroughly registered the subject's narrative, ensuring reliable data for analysis. The recordings were typed for analysis. Aiming to preserve the confidentiality of the informants names were not display at any stage. The Association of Ideas Map Technique was used to analyze the interviews along with the Social Constructionism<sup>(7)</sup> methodology approach to comprehend the dialog between interviewee and interviewer.

## RESULTS

Three categories were elaborated based on interview script reading: *Psychoaffective*: psychoeffects, reactions, emotions or feelings stem from adjustment to diagnosis. *Family members*: adjustments, difficulty and facilitations experienced in the family circle. *Daily routine*: changes and social relationships, at work, leisure, etc.

## PSYCHOAFFECTIVE

The compromising of psychoaffective aspects emerges when the patient, once aware of the diagnoses, develops a reactive symptomologic that may consist of a mild depression, a simple anxiety, to a disturba that affects the emotional processing, triggered by the lack of knowledge of the disease.

In literature<sup>(8)</sup>, pain and anxiety are words implied in the psyche, they are ancient feelings of discomfort and malaise that in some way seek psychological representation, which surface, initially, on the body, as identified on the following quote:

(...) *The chest pain, an anxiety, hands that go hot and cold, a lack of motivation... That is how I feel, a giant anxiety. This anxiety, a bit of sadness, is what is taking a toll on me. But sometimes I... It is anxiety, a pain my chest* (A.M.).

The social roles and status changes to which a CD patient goes through necessarily implies the building of a new identity which causes anxiety. Psychoanalysis<sup>(8)</sup> understands anxiety as the imminent loss of object and proclaims it has undeniable relation to expectations anxious for something. There is an undefining trait and lack of object. Which at CD's case, happens because of the lack of gluten, that was part of former diet.

In addition, according to psychoanalysis<sup>(8)</sup>, the object institutes the "lack" essential for the operation of desire, and if this lack becomes absent anxiety takes its place, a signal that can be emitted when the subject is at risk of losing its object, as considered by literature<sup>(9)</sup>, and thus at the mercy of it unconscious impulsive urges.

This way, when the individual is diagnosed with CD, he or she begins a new moment in their lives, marked by change which alters the pace of life. The treatment requirements trigger, in many cases, the feeling of loss and castration<sup>(9)</sup>, on a psychical family environment – as well as social relationships circles. The abdication of some particular roles, becomes status loss, earned throughout the individual's entire life to be replaced by a new status, which causes fear, as shown on the quote below:

*It is, fear of what might happen (next)* (D.A.).

*I think it is a matter of loss, what I feel mostly... Yes it is loss. So I am losing...* (A.M.).

Castration is the main trait indicated by the interviewees, a situation where the individual distances him or herself from the pre-diagnosis condition, lifelong conquests and starts to experience a new condition as a CD patient. Coeliac Disease takes away from the individual the option of choosing whether to consume a certain type of food, creating something that can be called frustration, that results in feelings of anger and sadness, which makes following the GFD more difficult:

*Then I am like, a little angry... And that annoys me, I think: Damn, it is forever, I am never going to be able to eat what I like anymore. That makes me angry, a bit sad, too* (A.C.).

*What a scare! I got a bit depressed* (R.R.).

It is important to observe, that besides the surprises, the anxieties, and the displacement that the conditions holds, the CD patient starts to rationalize the disease's various aspects in order to further comprehend it, and therefore become more at ease with the new dietary restrictions. We understand this rationalization, the search for logical thoughts and answers on an attempt to ease or move away

from the struggle, as a defense mechanism in a pursuit to adapt to the new condition:

*It has improved my diet. Everything that contains gluten is sometimes very fatty, very sweet, and it causes diabetes, right? But apart from that...* (C.L.).

Analyzing the quote alone, it is noticeable patients see positive aspects about the CD diagnosis, however the grief prevails. To psychoanalysis<sup>(9)</sup>, the rationalization of certain events works as a defense mechanism, which is a way to adapt to psychological unpleasantness, it is a self-barrier to protect from fear, anxiety, guilty, among others:

*I was happy with a diagnosis to which there is treatment. But then, throughout the past month, was when I could really vividly experience the illness. It really depressed me* (AC.C.).

When encountering all spectra triggered by CD diagnosis, we understand, even though the treatment may, at first glance, look simple, since its sole requirement is the removal of gluten from one's diet, when analyzing psycho-affective aspects implicated, there is evidence of great grief, especially regarding maintaining GFD.

## FAMILY MEMBERS

In this study family has emerged as a strong network for health care, weaved by people experiencing a chronic illness in the family system. Since the family is constantly linked to the ill person, it becomes a support center, characterizing a permanent nucleus to the biography and care production<sup>(10)</sup>. These relations along with experiences lived in common, creating a feeling of belonging and sharing of life.

This support, presented in the form of belonging, gives the individuals sustainability to keep going day to day. Literature defends that human families are an emotional unit, in which members are interconnected in such a way that the functioning of each of them affects the others automatically<sup>(11)</sup>. In this sense, the impacts on one of the member's changes can influence the entire family system, as seen in the following testimonies:

*It is my husband that helps me a lot, it is with him I talk to. He went in on it too* (A.M.).

*I think my mom too, she helped me a lot. She tried to buy as many normal things as possible. Gluten-free pizza, different bread, different cookies. She is going after as much as possible* (A.C.).

Such transformations when in the family unit, we notice, generate feelings of belonging to this system. On the other hand, this feeling of belonging may come with guilt particularly when these changes alter the family's social conditions and its environment. In literature<sup>(11)</sup>, we see family ties are built, kept and undone throughout the biographic experience of family care, as shown:

*I feel as though I am in his way a lot, in people's life. When I am somewhere and he does something different for me (...) I am causing trouble* (AC.C.).

Coeliac Disease can cause family issues, not only because of restrictions but also due to necessary care on the whole environment, impacting the family system:



*I cook for everybody, food I am allowed... My younger daughter hates it... Pedro is eating it, but complaining! He find everything different, you bake a cake: Ouch this is awful, it is not like you used to make it (S.B.).*

One can see by the statements that family relations are eventually infiltrated by the illness, pointing how the patient's dietary restrictions can cause interaction problems among family nucleus. The GFD can put unprecedented pressure on everyone who lives with the patient.

Such issues may passively lead to total or partial abandonment of GFD or the contamination of food and utensils used thus making the entire treatment liable. It is recalled that family support is a great enabler or motivator for the CD treatment, as quoted by the author: "Family is a system in which the change that affects one of its parts chains on among all other component parts"<sup>(11)</sup>.

### DAILY ROUTINE AND SOCIAL RELATIONSHIPS

Dietary restrictions and contamination avoidance experienced by the celiacs lead to a new social behavior which eventually modifies the individual's entire routine, altering not only eating habits but also social habits. According to literature<sup>(12)</sup>, by changing one's diet, the subject can start a process of rebuilding a new social identity, as shown:

*Then there is that psychosocial thing, of: Oh no, I will not be able to come with you guys to the Pizzaria, with my husband, with my kids. Sit there and eat some nice pizza... (R.R.).*

Along with family relationships, friendships are also infiltrated by replacement or food consumption, for example, meetings, lunch and work dinners, and even religious rituals and ceremonies that have particular food symbols<sup>(12)</sup>. In some religious ceremonies bread (which contains gluten) holds great importance as main symbol.

The GFD consequently becomes a complicating factor to the patient, since it requires change in social habits on different areas of coexistence. We have observed in this research that many customary venues frequented by the patients, pre-diagnosis, or most basic social events such as birthdays, and social gathering in general, do not provide gluten-free dining options, nor do they guarantee no contamination, triggering a feeling of exclusion at social events:

*If I am told it is a birthday party, there is cake, there are nibbles, I do not go (R.S.).*

The CD condition can be considered a life experience that involves a permanence in something that is outside of the normal social functioning, which can result in stress movements concerning image alteration and social adaptation. To the people affected by this comorbidity such alteration make CD a pathology that causes losses, dysfunction and changes to the daily routine.

Exclusion, derives from these changes, it is constantly experienced by patients with coeliac disease, especially because gluten-free food is not easily found. In this study the result of alterations is presented through feelings of sadness and anxiety, as shown in the statement:

*The restaurants there said they offered dining options and when you would get there they did not. Travel agency said the hotel*

*I would stay had gluten free food. It did not, everything had gluten. So I have to worry about all that (E.T.).*

Gluten holds special meaning to our society, because it is culturally linked to most people's social eating habits, which makes its consumption and contamination by it not only a health issue, but also a social issue to the celiac.

We understand humans act on relative ways to things, according to what these things mean to them, and this meaning originates based on the subject's social relationships<sup>(13)</sup>. As a consequence the struggle to manage the removal of gluten from the celiac's life and social environment, since it is found in most cultural dishes present at the majority of Brazilian's table, the necessary care with contamination and its absence on dining options eventually becomes a form of social exclusion:

*I think we become a bit, excluded... But I reckon what scared me the most, was the part, well, of exclusion itself. We cannot go out anymore... Everything is a risk. It is something a bit scary... (A.M.).*

Another feeling triggered by social changes, derived from dietary restrictions, which frequently appears on the interviewees speeches, is guilt. Such feeling occurs due to the fact that the people nearest to the patients eventually change eating habits and previously frequented venues. After all, to have the patient's company they must opt for venues that provide gluten-free menu:

*I stop myself from going, I tell André to go by himself. Because I do not want to go. It is really annoying sometimes (E.T.).*

When observing the interviewees colocations, it is noticeable the diagnosis' impact on the patients social relationships. Habits such as going out with friends, or family are approached by the patient as problematic topics:

*I cannot go out to eat with my friends (A.C.).*

*You think your friend is going to change? Not even my kids will and I do not want them to. If they are healthy enough to eat some good pizza, eat up!... So, really, I do not want them to change no one needs to change for me, got it? (R.R.).*

Gluten restriction can be interpreted as a food restriction with one of the greatest impact on the patient, since it causes great impacts socially and generates feelings of social exclusion due to how challenging it is to find venues that ensure no contamination.

The Symbolic Interactionism (SI)<sup>(13)</sup> supports such analysis because it understands the meaning of things can be replaced by or modified through interpretative process used by people when encountering issues. If patients start to correlate CD with social loss, the diagnosis acceptance and the adherence of a Gluten-free diet (GFD) (as sole treatment) are completely compromised and it becomes a burden to the celiac, who may start to develop psychological conditions such as depression, anxiety, among others:

*Something that we really like is travelling. And it kind of lost its appeal to me. We are planning a trip and we might not go anymore. So, you know, I am crying, you see? (A.M.).*

The lack of information on CD in general is another factor that frequently appears in the patient's statements, who recall having to explain about the illness constantly:

*I do not like talking about it all the time, because, first of all not everyone understands it. Secondly, if you do say it, the person is like afraid to catch something...!* (E.R.).

The importance given by the patients in regards to the lack of information about Coeliac Disease has presented itself as a crucial point on improving the CD patient quality of life. This datum was also discovered by in the United Kingdom<sup>(14)</sup> where the better knowledge of CD was associated with a greater self efficacy in relation to the well-being of the patient. It is also explained by the SI<sup>(13)</sup> which understands that social interaction involves a collective formative process, thus the action of a collectiveness must be understood as an act separate from its participants. In other words, the general unawareness on CD increases or assists to the feeling of difference and exclusion reported by the interviewed patients.

Every aspects that occurs in the patient's life, along with living with dietary restriction, eventually restrict social life, and makes the patient have difficulty maintaining relationships and often stop partaking in social events:

*I can no longer get in on birthdays which nowadays are celebrated in pizzarias, then I get a bit sad about that. My mom does not let me go because of the trouble it causes. Everyone celebrates and I do not. So this part makes me a bit sad* (C.L.).

## DISCUSSION

Individuals recently-diagnosed with Coeliac Disease present a high psychological impact correlated not only to finding the illness, but also with the strict diet required by the treatment, which implies food consumption loss that used to be part of their lives. We can hypothesize that the obligation to the diet triggers defense mechanism psychological reactions, denial of the illness, fear and anxiety in regards of the loss of the desired food, which supports studies done in Germany, where anxiety and depression symptoms were directly linked to CD and GFD<sup>(15)</sup>, and in Italy<sup>(16)</sup>, where feeling of rage, fear and sadness were also with CD treatment.

In the data analyzed by this research, the support and understanding of the family base group were notably important to acceptance of the diagnoses and GFD commitment, apart from reducing psychological impacts of living with a chronic illness and dietary restriction. However, CD can cause new conflicts in the family environment and in this case create feelings such as lack of belonging, revolt and depression.

## RESUMO

**Objetivo:** Conhecer os impactos psicossociais gerados pelo diagnóstico e tratamento de pacientes celíacos. **Método:** Estudo qualitativo, realizado através de entrevistas semiestruturadas, analisadas de acordo com a técnica dos mapas de associação de ideias. Foram acompanhados pelo Centro de diagnóstico, tratamento e apoio ao paciente com doença celíaca (DC) do Hospital Universitário de Brasília (HUB) 12 pacientes recém-diagnosticados com DC, entre os anos de 2013 e 2014. **Resultados:** Os pacientes entrevistados apresentaram impactos negativos em três categorias: psicoafetivas, relações familiares e relações sociais, indicando problemas de readaptação social após o início do tratamento, e dificuldade em manter a dieta livre de glúten (DLG). **Conclusão:** A doença celíaca apresenta impactos substanciais nas funções psicológicas, familiares e de relações sociais dos pacientes diagnosticados, exigindo uma visão clínica psicossocial para melhor aderência ao tratamento e qualidade de vida do paciente.

## DESCRIPTORIOS

Doença Celíaca; Diagnóstico; Terapêutica; Impacto Psicossocial; Qualidade de Vida.

Another important aspect found in this research refers to a group of social losses that the individual faces post CD diagnosis. Feelings of social exclusion, loneliness, and revolt, are constantly experienced by celiacs due to the lack of places to dine that guarantee no gluten contamination.

In several occasions the entire social network is forced to readapt because of the subject's dietary restrictions, simple personal or work related encounter must be thought over if it involves food consumption. A change in the group that makes the CD individual develop feelings of guilt or exaggerated concern in situations that pre-diagnosis where commonly dealt with no major problems.

These finding comply with studies done in Italy<sup>(17-19)</sup> and in Sweden<sup>(20)</sup>, which show that gluten holds high value in society in general and that effective treatment, aiming the subject's quality of life, must be amplified to all spectrums experienced daily by the patient, understanding the necessary care with something further than serologic and histologic control reaching psychological treatment.

We understand that the low number of participants in this research is a strong limitation, nonetheless these results support research done in Europe<sup>(21)</sup>, Australia<sup>(22)</sup>, India<sup>(23)</sup> and in the United States<sup>(24)</sup>, where studies show a need to care for the biopsychosocial sphere. This way this study hitherto fulfills an existing gap in the literature in Brazil, that thus far had not looked to psychosocial issues and its impacts on CD treatment.

## CONCLUSION

In this study, several factors were identified that may influence the well-being of the CD patient. Yet, in the interviewees' narrative the most critical can be divided into three broader clusters: Psychoaffective, social and family relations. This categorization enables us to distinguish between verified alterations in the patient's emotional state, family relationships conflict, as well as struggle in social relationships due to GFD. At the same time, however, family and friends support proved to be a facilitator that had a significant impact on the patients adaptation to the diagnosis, especially when it comes to relationships aspects and social adaptation, enhancing the importance of biopsychosocial factor further awareness, which can contribute to an improvement on the celiac's general health scenario and quality of life.

## RESUMEN

**Objetivo:** Conocer los impactos psicosociales generados por el diagnóstico y tratamiento de pacientes celíacos. **Método:** Estudio cualitativo, llevado a cabo mediante entrevistas semiestructuradas, analizadas conforme a la técnica de los mapas de asociación de ideas. Fueron acompañados por el Centro de diagnóstico, tratamiento y apoyo al paciente con enfermedad celiaca (EC) del Hospital Universitario de Brasilia (HUB) 12 pacientes recién diagnosticados con EC, entre los años de 2013 y 2014. **Resultados:** Los pacientes entrevistados presentaron impactos negativos en tres categorías: psicoafectivas, relaciones familiares y relaciones sociales, señalando problemas de readaptación social después del inicio del tratamiento y dificultad en mantener la dieta libre de gluten (DLG). **Conclusión:** La enfermedad celiaca presenta impactos sustanciales en las funciones psicológicas, familiares y de relaciones sociales de los pacientes diagnosticados, requiriendo de una visión clínica biopsicosocial para mejor adherencia al tratamiento y calidad de vida del paciente.

## DESCRIPTORES

Enfermedad Celíaca; Diagnóstico; Terapéutica; Impacto Psicosocial; Calidad de Vida.

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