

# PSYCHOLOGICAL DISTRESS OF PATIENTS AND THEIR FAMILIES IN CELIAC DISEASE

Magdalena Iorga<sup>1,2</sup>, Dana-Teodora Anton-Păduraru<sup>1,2</sup>

## Abstract

The aim of this paper was to discuss patient support in celiac disease, with a more attention to children. We point the physical and psychological problems related to this chronic disease and the fact that a proper medical surveillance of the patient should be doubled by strong psychological and educational guidance. Family support increases the adherence to gluten-free-diet and also assures a better quality of life. Some data also indicate that psychological stress may be involved in the development of celiac disease and primary stress and secondary stress should be taken into account regarding the therapy for this disease. Successful management of celiac disease both from the medical and the psychological aspects requires proper education of patients and their families and use the most efficient coping mechanism. Even if quality of life of these patients is relatively positive comparing to other chronic disease, patients should be empowered regarding the fact that not all symptoms will vanish after diagnosis and gluten-free-diet.

**Key words:** celiac disease, coping mechanisms, stress, child, adult, quality of life.

## Introduction

Celiac disease (CD) is a chronic inflammatory immunomediated disease from which we know the environmental trigger: gluten. It is a common condition with prevalence in the western world of about 1: 100 and can be diagnosed at any age. CD is a digestive disease characterized by intolerance to gluten, a protein composite found in wheat, rye, and barley. Even minimal exposure to gluten results in small intestinal injury that can lead to a variety of symptoms, including abdominal pain, weight loss, diarrhea and irritability, and long-term complications such as osteoporosis, infertility, and malignancy (1).

The exact causes of celiac disease have not been identified yet. The existence of a family member suffering from this disease increases risks by 5-10%.

The key treatment is lifelong adherence to gluten-free diet (GFD) with dietary restrictions requiring constant management. Because celiac disease is a multisystemic

disorder, physicians need to be aware of the potential autoimmune, nutritional and malignant complications.

A proper team must approach to the follow-up of the newly diagnosed patient and should include regular supervision by an interested physician, medical nutritional counseling by a dietician and access to local and national support programs (2). Psychological and educational support must doubled medical support in order to increase the adherence to GFD.

## *Physical and psychological development*

Early CD diagnosis correlates with better physical health, lower Celiac disease associated burden and fewer social problems. So, medical diagnosis done as soon as possible is a must in case of this chronic disease (3).

Adult presentations of CD are more common than children cases and there are even patients now being diagnosed and recognized who are elderly. Most cases of celiac disease in children are detected between 6 months and 2 years of age, because food diversification and the introduction of new foods throughout this stage may determine reactions from the child's body, which may easily be observed by the parents (malabsorption and poor growth).

Celiac disease is a chronic issue; it can appear and disappear throughout life, so that some people will only be diagnosed with this disease late in life.

Some of the common symptoms of celiac disease are diarrhea, decreased appetite, stomach aches and bloating, slowing growth rate in children and weight loss. The symptoms can often be mistaken for other medical problems, but a mere blood test can eliminate or confirm the suspicion of celiac disease. Detecting this disease as early as possible is important, because its effects on the physical and mental development of the organism are important. From a physical point of view, celiac disease causes a deficiency in the absorption of nutrients and vitamins that reach the small intestine. Without their contribution, the organism cannot develop harmoniously and it cannot maintain a normal growth rate.

<sup>1</sup>“Gr. T. Popa” University of Medicine and Pharmacy Iasi, Romania,

<sup>2</sup>“Sf.Maria” Children Emergency Hospital, Iasi, Romania

E-mail: magdaiorga@yahoo.com, antondana66@yahoo.com

In addition, the effects of celiac disease may determine other imbalances at the level of the body. For instance, iron absorption deficiency will determine iron deficiency anaemia. Iron is important not only for the physical development of the organism, but also for the optimal functioning of the human psyche. It is well known that iron contributes to the myelination of the axon sheath. An intact myelin sheath facilitates a much faster transmission of information than an intermittent one. Thus, iron deficiency anaemia has consequences on the person's ability to retain and update information. The absence of iron up to the age of 2 may have important consequences on the child's intellect, determining thinking latency, decreased intellectual capacity, memorization difficulties, and decreased ability to maintain focus.

#### Family support and adherence to GFD

The effects of celiac disease on family functioning are not to be neglected. The role of the family in diet is of course even greater when the patient is a child. In the beginning, the mother is extremely disconcerted by the fact that the ingestion of considerable quantities of food cannot be noticed in the child's weight. The child can eat large quantities of food, but this ingestion is followed by weight loss. On the one hand, mother is feeling guilty about her skills. Mothers should be informed that "lack of breastfeeding" is never the sole reason for developing CD. On the other hand, mother should be also assisted in monitoring other members of the family (siblings) in order to diminish her fear about the CD among the family members.

Finding out the diagnosis is the second stage the parents must face. On the one hand, there is the diagnosis in itself. On the other hand, there is the difficulty to permanently create a menu according to medical indications, that is, a gluten-free diet. The parents must constantly preoccupy themselves with the daily menu, which makes it more difficult to provide meals, to socialize during meals within or outside of the family, precisely because of the difficulty of respecting the restrictions imposed by the diagnosis. The younger the child, the less (s)he understands and respects the dietary restrictions. If there are other children in the family, the process of preparing meals also becomes difficult. Healthy and balanced nutrition must be ensured for all family members, without depriving them of the foods necessary for healthy growth and development. For the child suffering from celiac disease, it is precisely the removal of many foods that ensures development without many complications, such as stomach aches, bloating and diarrhea. A gluten-free diet considerably reduces these symptoms. Many studies have shown the positive effects of GFD on children's muscle mass and weight, even a year after starting the diet.

The health-related quality of life of children with celiac symptoms improved significantly after 1 year of gluten-free diet. Ten years after screening, the health-related quality of life of children with celiac disease was similar to that of the reference population (4). So, in general, the children reported an adequate quality of life, similar to that of the reference sample (5).

#### Depression, anxiety and psychological disorders

The association of celiac disease with various psychological disorders has generated many controversies in scientific studies, as early as the 1950s, when behaviors such as tantrums, irritability and a negative attitude were described in a group of children suffering from this malady, behaviors which disappeared after the introduction of the GFD (6).

In adults, the symptoms were connected to sleep disorders, depressions and headaches. The numerous studies have identified a series of psychological disorders associated with CD, but many of these had also been present before the diagnosis and continued after the introduction of the GFD. For this reason, researches associating psychological illnesses with CD have often reached the conclusion that, in what concerns psychological disorders, they are hereditary in nature. Depression, often associated with CD, actually has a genetic nature (7). Some data indicate that psychological stress may be involved in the development of CD.

Depression has been reported to be more prevalent and severe in celiac patients than in the general population. The rates of depression proven in various studies show a 21-50% prevalence of depression in subjects with CD (8). Depressive symptoms have been identified in various researches as being independent from CD and the GFD treatment: reactivity, pessimism, asthenia and anhedonia. There is an inverse relationship between depressive symptoms and adherence to the diet. As emphasized by researches on CD, depressive elements are closely linked to this disease.

These two symptoms, anxiety and depression, are important for quality of life (QoL). Assessments of physical and psychological well-being depend on the level of anxiety and depression. Both anxiety and depression determine somatic reactions. Depression has a biological component (associated with CD), but it is also a consequence of the lifestyle which the diseased person must adopt: dietary restrictions (limited participation in family meals, difficulties related to travel and problems in the workplace), but also the effects on one's personal and social life caused by temporary relapses and the accompanying pains. Anxiety may also be related to the ongoing fear of food being gluten-contaminated and, thus, of reactions to it making a tempestuous return. A lot of studies show that, compared to other groups of chronic patients, those who suffer from CD have a very good score during the first years after the diagnosis, as well as higher adherence to treatment, after which the level of QoL diminishes as the years go by.

Gender differences within the disease emphasize that there is an important difference in the way of experiencing the disease between female and male subjects. Hallert et al. found that women with celiac disease had a lower level of subjective health than men; they were less satisfied with the outcome of treatment and expressed more concern with the impact of their disease on socialization and having to abandon important things in life. Such differences have not been emphasized for other chronic diseases. The emotional experience of the disease is harder to bear for women. Some

studies show that the most affected activities are: work, shopping, travelling, eating out and at home. On the other hand, patients, especially female ones, feel guilty, isolated, and avoid becoming a burden to those around (9).

The purpose of medical and psychological therapy is to make the patient adapt to the disease and increase the level of QoL. Coping is the conscious, active effort to regulate emotions, actions, thoughts and the environment in response to different sources of stress.

The psychotherapy should inform the patient that not all symptoms will vanish in all patients and prepare for health-related problems from time to time.

#### Coping with CD

Successful management of CD both from the medical and the psychological aspects requires proper education of patients and their families; even it is about children or adults.

Coping with illness can be divided into the following: active or primary control coping (acting on the source of stress or one's emotions); accommodative or secondary control coping (adapting to the source of stress); and passive or disengagement coping (avoiding or denying the source of stress). Adaptive mechanisms are linked to the type of locus of control, external or internal. The internal locus of control seems to characterize children and teenagers with a high degree of adherence to treatment (10). Good knowledge of celiac disease and dietary treatment was found in 87% of children, while dietary compliance was 81%. Girls and younger children (aged 12-14) were more compliant than boys and older children (aged 15-17) (11).

The practice of checking food labels and, when unsure, asking questions about gluten content can be described as "primary control coping", as a problem-solving response to coping with CD and GFD.

Regarding coping mechanisms, avoiding behavior creates the most complicated problems. It seems that this disclosure avoidance, which has been used in order to maintain solidarity and a sense of belonging to the group, in reality has increased the feeling of being an outsider and different (12).

Quality of life correlates with the subjective experience of the disease and the acceptance of the diet. In addition, the personality structure and the coping mechanisms which the person uses to adapt to disease-related situations serve as a guarantee of psychological and physical well-being.

Despite the abundant literature on this theme, which proves the negative effects of the disease on physical and psychological health and on the patient's behavior, there are few studies focusing on ways of individual psychological counseling and on couple or family relationships. The effects of CD are important both at a personal level and for intrafamily balance. Some studies show that gender and cultural factors are as important as individual factors. CD patients adapt to the disease by two mechanisms: coping with food and coping with social situations. The support received within the couple and the family ensures a better level of QoL (13). For example, some studies indicate a correlation between CD and eating disorders. High bulimia

scores have been registered in CD patients, without being linked to the presence of anxiety and depression; the higher results have been encountered especially in male subjects (14).

#### Quality of life

The findings of some studies further delineate the importance of caregiver vigilance regarding the recognition of eating disorders in celiac patients; therefore, the life partner's involvement and family members' support are important factors for ensuring quality of life in CD patients. The patients (especially children and teenagers) and their parents sometimes minutely prepare socialization situations, taking an interest in menu options beforehand or proposing an alternative to what has already been settled by the hosts or those who celebrate an event. Successful diet adherence strategies used by families include planning ahead and taking their own food to social functions (15). More than half of the families with children who are on a GFD avoid restaurants all or most of the time, and 83% always carry gluten-free food (16).

Strategies of adapting to social life are most important during childhood and adolescence. Sometimes, intending to avoid embarrassing situations, patients break the rules of the gluten-free menu, bearing the consequences. Noncompliance to the gluten-free dietary regimen is seen in 18% of cases. Dietary noncompliance is more common in the adolescent age group, in joint families and in those who have a large number of siblings (17).

The diagnosis in itself is an important event in the person's life, and changing one's lifestyle may sometimes be traumatic. Optimistic and pessimistic coping strategies are important factors in assessing the level of QoL (18). Incidentally, results are sometimes contradictory. Some recent studies performed on large student populations show that health-related quality of life is not impaired in children with either undetected or diagnosed celiac disease (19). Chronic fatigue was identified in patients on partial diet; anemia and delayed puberty were identified only in noncompliers. Moreover, data regarding noncompliers proved that this specific diet posed a major burden to such patients and that they usually did not visit a gastroenterologist on a regular basis (20). Studies indicated several areas of negative impact in maintaining a gluten-free diet. They included the difficulties of dining out (86%), travel (82%) and impact on family (67%), but less of a negative impact on career or work (41%) (21).

The studies aimed at the importance of school integration for children suffering from CD have proven that optimal school integration significantly improves good compliance. A better understanding within the school environment about issues related to this chronic disease improves motivation to follow the GFD. Children included in the study of Errichiello et al. (22) reported, to a great extent, good family relationships (88.7%), social relationships (91.2%), school integration (88.2%). On the other hand, adolescent subjects claimed that their social life had limitations (54.5%). The study proved good compliance

in patients who reported higher rates of school integration and social relationships.

In what concerns adults' quality of life, researches have only focused in the past few years on stressful events which may decrease the level of psychological and physical well-being. A poor social network and unemployment are additional important factors of vulnerability to stress. A study of Ciacci et al. (23) revealed that life events are associated, to some degree, with the recent diagnosis of celiac disease in adults. Rather than the severity of events, their number appeared to be the determining factor. Researches on pregnant women with celiac disease have indicated that stressful events preceding the diagnosis are frequent among women. The study proved that pregnancy is

defined as a stressful event only by celiac women comparing it to other diseases, like gastroesophageal reflux.

#### Conclusions

Celiac disease involves many changes in various aspects of the life of patients suffering from it. The main goal is to ensure their physical and psychological well-being, to diminish the negative physical symptoms and the psychosocial consequences of CD. Medical treatment should be doubled by psychotherapy in order to increase the adherence to treatment and to individually find the best coping mechanism. One's family, profession and social network are important factors in countering vulnerability and ensuring a high QoL.

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**Correspondence to:**

Dana-Teodora Anton-Păduraru  
"Gr.T.Popa" University of Medicine and Pharmacy  
16 Universității Street, Iași, Romania  
E-mail: antondana66@yahoo.com