

Psychological Aspects in Celiac Disease: Step by Step from Symptoms to Daily Life with Celiac Disease

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Abstract Celiac disease (CD) is a worldwide disease with continuously increasing incidence particularly in Western countries. It is a chronic autoimmune inflammatory disease. Combination of genetic (HLA antigens) and environmental (gluten) factors is known to be responsible for disease development. Despite intensive research in the field of CD the only to date known option of treatment is gluten free diet (GFD). That means for patient complying with lifestyle changes. We found out that despite there are published many papers concerning CD, only a few of them are focused on psychological aspects of disease. In our opinion it is underestimated field, because up to now GFD is only possible option of treatment causing significant limitations in patient's daily life and thus affecting quality of live (QoL). Knowledge of psychological aspects and possible following interventions can improve acceptance and compliance concerning GFD. We found out that sufficient communication and providing adequate information seems to be one of the most important factors. Information should be provided in appropriate quantity and quality. Knowledge of psychological aspects can be helpful just in that respect. Surprisingly, there are practically missing publications concerning psychological aspects in relation to serious possible complication of CD such as infertility or risk of some cancers. Also there is a lack of publications dealing with diagnostic procedures themselves. We mean that also this area is underestimated, because diagnostic procedures can be also a source of negative feelings as some of them are invasive and painful.

Keywords: celiac disease, gluten-free diet, psychological aspects, experiencing

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1. Introduction

Celiac disease (CD) is a worldwide disease with continuously increasing incidence particularly in Western countries. Mentioned rise is related to increase of autoimmune diseases generally (rheumatic, endocrinological, gastrointestinal and neurological) whose incidences and prevalences increased highly significantly over the past 30 years [1,2,3,4]. In Europe and the USA, the frequency of CD in general population is reported to be approximately 1% with regional differences. Higher rate is mentioned in females, concrete ratio is 2:1 [1,2,3,5].

CD is a chronic autoimmune inflammatory disease. Combination of genetic (HLA antigens) and environmental (gluten) factors is known to be responsible for disease development. Incidence of CD is higher in families where the CD has been already diagnosed. Particularly higher risk in first- and second-degree relatives is mentioned [2,5].

Concerning genetic base of disease, CD is registered to occur almost exclusively in people having HLA-DQ2 or

DQ8 antigens. Gluten, contained in some cereals is known as a trigger of CD in susceptible individuals [6].

CD was described as a disorder predominantly specific for childhood, but nowadays it is known that it can occur also in adulthood. In that respect, there are mentioned differences in manifestations between children and adults. Initial symptoms are nonspecific but unpleasant complaints, such as diarrhea, flatulence, cramps, fatigue causing difficulties to patient and sometimes even limiting his or her daily activities. Weight loss, decreased bone density, unexplained iron deficiency and infertility are another symptoms usually noted in CD [6,7].

Also other symptoms from various fields are mentioned. They are for instance neuropsychiatric such as ataxia, neuropathy, headache, epilepsy and depression and anxiety relatively frequent in CD [8]. From another field we can mention infertility [9].

Despite intensive research in the field of CD the only to date known option of treatment is gluten free diet (GFD). That means for patient complying with lifestyle changes [6].

There are published many papers concerning CD, but there is a relative lack of publications concerning

psychological aspects of CD. In our opinion it is underestimated field, because up to now GFD is only possible option of treatment causing significant limitations in patients' daily life and thus affecting quality of live (QoL). So, we consider psychological aspects to be important because of possible interventions directed to this and related areas.

2. Material and Methods

A review concerning psychological aspects in various phases of CD was performed. Additionally the references of the selected articles were also consulted for relevant articles to the subject. Only relevant papers were included and the topic was discussed interesting form focused predominantly on aspects of experiences. Attention is paid mainly to daily life with CD because of its chronicity and serious restrictions caused by CD just in daily life.

3. Results

3.1. Before Diagnosis is Determined

Since the CD can be connected to various symptoms it may be difficult to diagnose it. Therefore the patients often experience significant delays (up to many years) between the appearance of first symptoms and the correct diagnosis. Some studies mention mean delays in several years, e.g. in the study conducted in Canada the mean delay in diagnosis was between 4.9 - 11.7 years. The patients also deal with misdiagnoses including lactose intolerance, anaemia, stress, chronic fatigue and irritable bowel syndrome [10,11]. According to the study made in Greece the long-lasting undiagnosed CD and misdiagnosis associate with worse QoL [12]. These situations are more common in so called "non-classical CD". As was mentioned above symptoms can concern various areas such as haematology, endocrinology, rheumatology or even gynaecology or some other fields while intestinal symptomatology is not clearly expressed [13].

Without the correct diagnosis the patients' state worsens, some of them cease to believe their health status could improve and the symptoms of CD interfere with their ordinary life; for instance most of those with the illness have to deal with unexplainable tiredness and fatigue [10].

Periods around diagnostic procedures are described in following separated chapter, because this period is very important in patients' life and rather undervalued in our opinion.

3.2. Around the Diagnosis – Diagnostic Procedures and Acceptance of Diagnosis

The diagnosis is an important moment in the life of the patient. Rose & Howard (2014) say that for some patients the diagnosis may be a positive affirmation of their identity. Most of patients describe the diagnosis as an euphoric experience [14] and in most cases patients experience relief and reassurance after diagnosis [10,15]. This positive reaction interrelates also with the fact that they realise the cause of their long-term health problems and unexplainable symptoms [10,14]. Mentioned positive

feelings after a while again decreases despite the previous experience of relief [15]. Rose & Howard (2014) describe that patients are going through a sad period prior to acceptance of the disease itself [14].

There is a relative lack of publications dealing with undergoing diagnostic procedures in CD patients in respect to experiencing. So, we will use another example of chronic disease which is also influencing daily life because of lifestyle changes and it is causally incurable – chronic obstructive pulmonary disease (COPD).

Also before they are diagnosed with COPD patients have to undergo many diagnostic procedures (including those invasive). That means diagnostic process takes a relatively long time when patient lives in uncertainty. Lindgren et al. have applied a phenomenological-hermeneutic analysis. They received one main theme "living in negotiation", and three other themes "living with a body out of step with the diagnosis", "dealing with the past", and "being challenged by the future". They mentioned these themes to be reflecting the processes of acceptance and looking for new balance in life [16].

Patients in mentioned study specify that found diagnostic processes confusing. Main problem was seen in unclear messages leading to fluctuation between an understanding of the condition as "not too severe", insecurity, and fear. Mentioned negotiations are not meant only with the past, but also with the future. Diagnosis itself is felt as "a slap in the face". Based on these findings authors emphasize great significance of temporal aspects for the processes of finding acceptance. In that respect they highlighted the necessity of the sufficient communication and providing of adequate information from medical staff [16].

3.3. After Diagnosis is Revealed

The first months are still mostly related to experiencing relief and accepting [15]. However, after the first primarily positive feelings the first negative emotions begin to show – frustration, fear, depression, anxiety, anger, sadness, and others [10,14,15]. These negative emotions are caused mostly by GFD and their dietary restrictions which CD patients can experience as something sinister [10,14]. Women usually experience negative emotions more than men, but with time, more of them are accepting GFD in comparison to men [10,15].

According to Taylor et al. (2013) the experiencing of relief in the first months after diagnosis interrelates with the realisation that due to GFD the symptoms of CD may decline [10].

Important problem in this period is also disease-related stigma experienced especially by younger patients who were recently diagnosed caused predominantly by need of GFD [17,18]. An important view resulting from difficulties related to GFD thus should not be overlooked is also negative effect on patients' social life [19].

3.4. Daily Life with Celiac Disease

The only possible treatment leading to reduction of symptoms is total GFD. Its adherence presents a lot of complications which can be seen in social, personal, and work life of patients. According to the Zarkadas' (2013) study, people who live with GFD for more than five years perceive limited food choices in restaurants, cafeterias,

hospitals and nursing homes as the greatest difficulties. Authors divide experienced difficulties into these areas: Purchasing gluten-free foods, gluten-free food preparation, eating with family/friends, eating in restaurants, eating at school/work and travelling [15]. Sverker et al. (2005) define in a similar way the five situations in which people with CD experience dilemmas: food situation at work, during purchases, when travelling, in relation to meals at home and meals outside the home [20].

As mentioned above CD patients usually experience relief after diagnosis. Experienced relief decreases with time, however the acceptance of diet itself gradually increases. Experiencing most of the negative emotions also decreases with time, for example, those who live with GFD for more than 5 year experience difficulties and negative emotions less often. However, frustration and feeling of isolation that most people suffering from CD experience often persist even several years after diagnosis. As well as in first months after diagnosis, still the same is true – women experience negative feelings more than men [15]. In a Swedish study women also showed lower level of well-being [21].

Despite most studies connect CD to negative emotions [15,22,23], most of the CD patients from the English study reported to be in good physical and emotional condition. However almost half of the subjects sometimes experienced depression as a result of the CD and some of them experience it all the time [23]. According to Urban-Kowalczyk (2015) depression is one of the main psychiatric disorders related with CD (besides anxiety, psychosis and anorexia nervosa) [24]. According to the meta-analysis from Smith & Gerdes (2012) depressions are more common in adults with CD than in healthy individuals [22].

CD doesn't affect only the feelings of CD patients, but it can be also underlying significant long-term loss of energy. Only a minority of patients is feeling full of energy most of the time, while a large proportion of patients felt constant lack of energy [23].

As mentioned before, several studies found out that women experience more negative feelings due to CD and GFD than men. For this reason, Jacobsson et al. (2012) decided to focus in detail on the experiences and lives of woman suffering from the CD, and their result is that women seek normalized lifeworld. They experience higher levels of safety, control and feelings of being seen and included the closer they are to having normalized life. The result of their efforts depends on which nuances of these feelings dominate the persons' thoughts [25].

The impact on social life was also studied. According to Black & Orfila (2011) most patients does not feel that the CD had negative impact on their work or leisure activities and didn't feel that the CD would affect their ability to work. In contrary greater negative impact of CD on patients was perceived in social activities. This effect was more apparent among women - more women said that they have avoided some social situation (such as eating in a restaurant) [23]. Rose & Howard (2014) describe social anxiety that comes from the violation of social rules of decency - patients are afraid that others will negatively perceive their non-conformist behavior. People that are nervous about eating outside of the home are changing their strategy towards lowering their social activities [14].

Strategies of avoiding eating in restaurants or traveling are also described in other studies [23,26].

Based on their study Rose & Howard (2014) perceive change of identity as the central theme of life with CD. The change of identity is involved in these categories: living with widespread ignorance, social invisibility (and lack of understanding, support and provision by others), creating a celiac community and grief from loss. Identity change also affects all of these categories [14].

People suffering from CD use different strategies in order to cope with the difficulties caused by GFD. Zarkadas et al. (2013) divide different strategies to the same categories that have been mentioned above [15]. In contrast Rose & Howard (2014) described for example these strategies: replacing meals with gluten by other meals, measuring food prices and its benefits (health impact versus the price of food) [14]. Many people with CD use strategy of carrying their own food at them all of the time. Comparing the CD with chronic diseases that are generally considered it seems to be less manageable [23]. The results of study provided by Ford et al. (2012) show that due to higher adherence to the diet with higher self-efficacy patients believe more in their own capability of managing CD and its symptoms. Also adherence to the diet correlated in their study with higher age, belief in chronicity of the disease (not in cyclicity), strong perception of the serious consequences [27].

Zarkadas et al. (2013) state that women use different strategies compared to men and the greater number of strategies patients use, the more they adhere to the diet [15].

3.5. Possible Interventions – Current Situation

During the treatment of patients with celiac disease it is necessary to base upon psychological and social aspects [20]. Psychosocial support and interventions are needed primarily in the period following the diagnosis, but a certain degree of support is needed even for the people who are on a diet for several years [15].

Patients mainly need sufficient information (education) about their illness and GFD and an offer of specific coping strategies that can be used in everyday situations [14]. According to the study Ring Jacobsson et al. (2012) the attending of a course targeted at providing information about CD (coping strategies, knowledge, obstacles in daily life etc.) positively affected the well-being of participants [28]. Given that men and women choose different strategies, it is appropriate to take account of this diversity in a particular intervention [15].

Contact with other patients suffering from CD also has a positive effect. Intervention is also needed for health care personnel, relatives, colleagues and for the public in general. Greater awareness in society will alleviate the negative impact on the social life of people suffering from CD. Patients need the medical staff to be open to discussion [14].

As CD is closely related to serious complications such as infertility or risk of some cancers [9, 29] we would expect that interventions concerning this area of CD are often mentioned in literature, but we have to state that this area is rather overlooked.

4. Conclusions

CD is a worldwide disease with permanently increasing prevalence. We found out that despite there are published many papers concerning CD, only a few of them are focused on psychological aspects of disease. In our opinion this area is rather underestimated. Published papers are concerning mainly daily life with CD. We concur that in CD daily life is really important area which should be paid attention to because of significant limitations resulting from GFD just in daily life. Knowledge of psychological aspects and possible following interventions can improve the acceptance and compliance concerning GFD.

In our opinion, greater attention should be paid to periods of diagnostic processes and acceptance of diagnosis. These periods are very sensitive and related to uncertainty for patients. Sufficient communication and providing of adequate information seems to be one of the most important factors in these periods. Information should be provided in appropriate quantity and quality. Knowledge of psychological aspects can be helpful in that respect.

Surprisingly, there are practically missing publications concerning psychological aspects in relation to serious possible complication of CD such as infertility or risk of some cancers. Also there is lack of publications dealing with diagnostic procedures themselves. We mean that also this area is underestimated, because diagnostic procedures can be also a source of negative feelings as some of them are invasive and painful.

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