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Impacts on education in Children with Celiac disease

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Abstract

Food that is considered by most of us to be a common activity represents for people with celiac disease a source of emotions. Their conduct must be adapted to it, it affects relationships and concerns about coping with this vitally important need every day are sources of many problems. The aim of this study is to present social context of education of children suffering from celiac disease. The study is based on research findings realised with these children and their parents. The study presents a qualitative method research procedure. As a data collection method, we used interview with children suffering from celiac disease and also with their parents. The data gathered in the study suggest that aspects related to the celiac disease inevitably shape and change identity and self-perception of a child with celiac disease, and the way a child is capable of accepting and coping with the disease and measures depends very much on environment. Teachers may become a great source of support for a child but also a source of many problems due to their ignorance and trivialisation. Teachers should have at least basic information about celiac disease, symptoms, diagnostics and treatment. It is though necessary to have also information about how a child himself and his family experience the disease and what special needs a child has. Then, it is possible to consider a special approach in the field of education.

Keywords: Celiac disease, education of children with celiac disease, impacts of celiac disease.

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1. Introduction

Celiac disease is a lifelong autoimmune disease triggered by consumption of gluten in genetically predisposed individuals. Gluten, more precisely peptides, which are produced by fission and which trigger reaction are found in cereals—wheat, rye, barley and oat. Chronic infectious changes lead to damage in the small intestine with consequent destruction of the intestinal mucous membrane accompanied by chronic maldigestion (indigestion) and malabsorption (Falt, Fojtik, & Smajstrla, 2014). Celiac disease is not such a rare disease, as it used to be considered. Neither is it a childhood disease, it does not disappear in adulthood, it is a lifelong disease, absence of symptoms do not mean curing. Unfortunately, diagnosis of this disease is problematic.

Celiac disease can be manifested in any age, the clinical picture is diverse, and it does not have to manifest itself at all. It exists in four forms—classical, typical form, atypical, subclinical form, silent form without any symptomatology and latent form (Latta, 2012).

Classical form is manifested by classical gastrointestinal symptoms. During childhood, voluminous greasy diarrhoeas appear and a child fails to thrive (to grow and gain weight), his stomach can be big and bloated. Sometimes, celiac disease symptoms in children are accompanied by skin problems, swellings, slow growth or problems caused by iron deficiency. Constipation can be also a symptom. Atypical form, which is unfortunately more frequent, is defined by a diverse clinical picture. Diagnosis of this disease, both in children and in adults, is complicated by the number of up to 200 described symptoms affecting different body systems. Unfortunately, celiac disease can be also without symptoms, silent (Kohout, 2006).

Moreover, new research shows that celiac disease can be manifested by psychological problems, which interfere with cognitive sphere (thinking), emotions, behaviour and social interaction. Unfortunately, the mechanism how celiac disease increases the risk of psychiatric problems has not been explained up to now, however, it is probably a consequence of malnutrition that affects normal brain function (Zingone et al., 2015).

The gluten-free diet (GFD) is absolutely crucial in celiac disease treatment. It is an *adequate diet, unfortunately it is very demanding financially* (Pribylova, 2012). Gluten, more precisely peptides, which are produced by its fission and trigger, the reaction that leads to damage of the intestinal mucous membrane is found in some cereals—wheat, rye, barley and oat (Prokopova, 2008).

2. Method

This part of the study is based on testimony of seven parents and their children suffering from celiac disease, which was gained by the method of semi-structured interview. The aim of this study is to present psychosocial context of education of children suffering from celiac disease. The study is based on research findings realised with these children and their parents. The authors of the study believe that teachers should have at least basic information about this serious chronic disease, symptoms, diagnostics and treatment. It is though necessary to have also information about how a child himself and his family experience the disease and what special needs a child has. Then, it is possible to consider a special approach in the field of education.

The main criterion of choice of investigated persons was that all the respondents were to be parents of a school child suffering from celiac disease. The second requirement was that children had been diagnosed with this disease and at least 2 years had passed since the diagnosis. Questions for interviews were formed based on literature review according to research strategy. Questions were used rather as guides and anchors for the interview. As the research is still being carried out, we will not publish exact questions but only categories.

The study was conducted with agreement of all participants. All participants were informed about the purpose of the study and were asked for permission for recording the interview using a voice

recorder and assured that their testimonies would be recorded anonymously. The length of interviews was different, on average, they were 20 minutes long conversations. In most cases, the participants did not have problems making a quick contact and created an atmosphere of mutual understanding.

In the analysis of interviews, it was necessary to transcribe the interviews, go through transcripts of interviews with all respondents, analyse and search for important and the most illustrative message according to aims of the research. Acquired information was subsequently categorised and described.

3. Results

Understanding psychosocial aspects of people with celiac disease is significant for improving quality of their life. With ill people, it is necessary to distinguish a few fundamental areas which can be divided into three basic areas:

1. The first area of problems is related to the disease itself and its diagnosis, when the problems are related to symptoms as such and diagnosis of the disease.
2. The second area concerns consequences and treatment in context of lifelong, a financially demanding gluten-free diet, especially in social sphere. Constant fear of cross contamination of own gluten-free meals with gluten, cravings for common food containing gluten or accidental gluten ingestion, need of constant meal planning.
3. Another significant problem in this area is stigmatisation of the patients at social events, which they might avoid as a consequence of their disease.

3.1. Problems related to symptoms as such and diagnosis of the disease

Children suffering from celiac disease may have classic symptoms, but they can also suffer from asymptomatic symptoms and can have an asymptomatic celiac disease. Celiac disease can be though manifested by neurological and psychological disorders such as headaches, ADHD, learning disabilities, anxieties, depressions, sleep disorders and fatigue, which unfortunately leads to a lower quality of life of the ill paediatric patients and their education (Zingone et al., 2015).

...We did not even think of celiac disease, she was having joint pains and was like....well, she didn't look like a healthy kid,.... and was tired all the time....

....I was breastfeeding for a long time and when we started with a normal diet she used to cry for a long time...we were thinking....what's wrong with her...

...she was restless all the time, she would not stay still, then as older, she was doing something all the time....we were in Croatia and there was a huge..., well, a huge slide and a hundred steps to it she always ran up...slid down....ran up....slid down....we were sitting there....everyone left after an hour, we were sitting there and watching her for three hours....always up, down....up, down....like a thousand times...

We must be aware of the fact that celiac disease is a very treacherous illness, which can manifest itself in thinking, emotions, behaviour and teachers themselves can be involved in diagnostics, as they spend a considerable part of the day with children and they may notice changes in a child which may not be noticed by parents. Parents informing teachers about changes in health condition of pupils is just as important as teachers informing parents about changes and concerns with children's health condition.

Patients not only suffer from symptoms but also from uncertainty and ignorance of the cause. As five parents confirm, setting a diagnosis is for many patients and their families accompanied by an initial shock and at the same time by relief and euphoria, which are followed by confusion, fear and worrying about future. They have to accept the disease as such and get used to a gluten-free diet, which can be for many patients and their families a very demanding challenge.

...it took a long time, she had problems all the time, she had a stomach ache...and when they gave me the diagnosis, he was having a snack, he was eating, like that...I wasn't happy with the information they told me –'you have to get a bread machine'....I was gradually getting information, as I was searching for them by myself...

...for me it was a relief, I thought thanks Godness it is not something worse...but I didn't realise what problems people with celiac disease may have...then I had a glass of wine and threw out all flour or gave it to my friends....but it is not only in flour, it can be anywhere...

...we kind of accepted it..., although we did not realise that people with celiac disease have such great problems, we thought we were glad it was only celiac disease...

...I didn't feel anything because back then I was in a rooming house of Motole with mothers who had children in the department of oncology and every day they talked about their experience. And I was thinking—this condition is just nothing in comparison with what they have...

3.2. Gluten-free diet and its compliance

3.2.1. Acceptance of gluten-free diet is crucial

The only treatment is a gluten-free diet. As all the respondents confirm, it is a demanding dietary regimen that means a specific choice of food, food preparation and has a big financial impact on family. Adaptation to the diet requires many skills that include ability to look at products' ingredients and read correctly food products' labelling, always bear in mind possibility of accidental cross contamination of gluten-free food with gluten ingredients or preparation and constant pre-preparation of own food and also preparation of food which patients have to take to any social event they attend (Mazzone et al., 2011).

...Now I have a magnifying glass in my wallet and when I can't read ingredients, that helps...sometimes the labelling is terrible...when I don't know, I just don't buy it...

...it is incredibly financially demanding...and we live in a village, you can't get gluten-free food there, I must go to the city...for shopping...but now she greatly appreciates when my sis, who lives in Italy, gives her a large Christmas basket full of gluten-free food and cookies you can't get here...

...I get home from work and I cook, actually I am cooking all the time...and when I'm not cooking I'm thinking about what to cook...and if she will enjoy it, if she's not hungry....it's depressing sometimes...you have food in your head all the time....

3.2.2. Gluten-free diet and home conditions

At home, the families face many challenges. One of them is whether the whole family starts a gluten-free diet that is financially very demanding or establishes a special area for gluten-free food and its preparation. There is a traditional gender problem related to this, as it is the mothers of ill children who are the most affected by requirements and responsibility when complying with dietary measures—when shopping, preparing and planning and providing food for ill child (Ryee, 2016).

...step by step we bought cabinets and divided our household into gluten and gluten-free and learnt to...we don't have money for all of us to start a gluten-free diet. It is cheaper to make baked products at home, but store-bought baked products are better.... you never make it that good...it tastes better...

...our household is more or less gluten-free, I buy only baked products and pasta for the other healthy child and for my husband...but I learnt to cook gluten-free...there was a time when I didn't let Hanicka (a sibling) eat Ondra's food or even just try it, it is so expensive...

...well, it's a problem, it's something else, it's getting the parents down all the time, it is still on your mind, it's in your head all the time...

...it would be more comfortable if she went to the canteen...

...my husband used to leave it all up to me and he still does ...even though he could cook and he can do it...he doesn't want to, maybe he is scared...

Family relatives can be an important source of support. On the other hand, they can cause quite big problems because they have only a limited opportunity to get information and experience with a gluten-free diet.

...there was also a problem with the grandmother, she didn't want to cook gluten-free...and when she brought a gift of food on St. Nicholas day, she didn't consider that she couldn't put there everything...and then he is sad and I think it is not just because he can't it all but that she doesn't think about it at all...

...the grandmother is really old school...but the fact is that they mostly want to have only Hanicka for a longer holiday because Ondra is a problem...they are afraid of the cooking, even though it is only from time to time...

3.2.3. Gluten-free diet in school conditions

After entering nursery schools and schools, families face other problems and stresses. In case of people with celiac disease, any nutrition outside home—all-day eating in nursery school, lunch at school, trips, residential outdoor school, visiting a foreign country—is problematic.

For integration of these children into common primary schools, information from parents and raising awareness about this serious disease is a significant problem. The pupils themselves and perception of their disease and their parents and their attitudes to the disease are an important source of information that must be constantly updated. Unfortunately, in spite of parents' awareness, teachers may trivialise this disease.

Some teachers trivialise the disease seriously and they don't admit possible complications, especially in case of the necessity of dietary compliance, which can be mainly manifested outside school, for example at outdoor school, when it is important to consistently watch what the child eats, etc. For example a child at outdoor school even says that he can't eat something and the teacher replies that nothing will happen if he eats it only once....you just have to communicate...when you don't, it is always the child who pays for it...

It is necessary to realise that food that is considered by most of us to be a common activity represents for these ill people a source of emotions. Their conduct must be adapted to it, it affects relationships and concerns about coping with this vitally important need every day cause many problems. Alimentation and food-related activities can be a very stressful situation for children and their parents, the food must be planned and prepared ahead. Parents of ill children should make an effort to provide teachers and peers of their children with as much information as possible, to educate about this disease in order to provide a safe, informed, helpful, non-discriminating and trivializing environment for their children (Ryee, 2016).

It is essential to raise awareness not only in teachers but also in rest of the staff at school, For example, cooks and auxiliary staff. Some school canteens cannot or do not want to provide gluten-free food to children and their families thus have to take care of preparation and conservation of food by themselves.

They excluded us from the school canteen....at first we changed the school, because they didn't want to or couldn't cook food for usthen they excluded us from the other canteen,well they won't cook for one child... it hit her hard.... now she doesn't want to go to the school canteen....and she wants me to give her snacks, that she'll eat calmly at home ...she doesn't even go for it, she always wanted to have lunch with her friends and talk, she prefers to eat at home...

...I saw them serve me the food, the pasta which my Mum had given them, with the same spoon they served gluten pasta....so I asked: Is it gluten-free? They started to yell at me...the cooks...that they had been cooking it whole day, so why it shouldn't have been gluten-free....but it wasn't....then I didn't believe it was gluten free and they were doing it right...!!!...and when I didn't eat something....I just didn't feel like eating or wasn't hungry, they were saying something all the time...

...there is also a problem with transporting your own food to school and keeping it in fridge, it's forbidden for hygienic reasons, so they won't let you keep the food in their fridge, so you won't spread something, like salmonella...

...they let us heat his food in a teacher's room and then they even bought a microwave so he can heat it himself and eats it in the classroom, they let him do that...he told me once that two teachers had heated his food in the microwave and he laughed...they were nervous, two PE teachers, well guys...they tried to help us, the teachers, the Deputy Head teacher, they wanted the food to be cooked in the canteen, but it wasn't possible, because the canteen belongs to another school...and they have the room for that there....it's about people, the willingness....

3.3. Exclusion and stigmatisation

Many social events and activities are related to food. These events can be very stressful for patients, as they can be excluded from them or they themselves avoid the events, which means ill people feel certain social limitation, stigmatisation and exclusion. Food at these events has to be arranged or provided using individual transport that can provoke misinterpretation and misunderstanding, sometimes aggressive behaviour from restaurant and canteen operators (Ryee, 2016).

...it's better now...five years ago there wasn't such an offer...now we can buy a vacuumed lunches...and when she goes on a trip we pack it for her in her rucksack...stays for like a week are worse...then we have to arrange that...and still, she doesn't trust, when she doesn't see how the cook had cooked that, that he hadn't done it there, where he had contaminated it...so when she is not at home, she isn't sure she eats as right as she should...and she sees how the diet works...that her knees have improved... so she watches it, just because she feels much better...

She just can't go to some events, they tell her they are not ready for it and exclude her. It always depends on communication and on willingness of cooks and staff...they are afraid of it sometimes...!

Celiac disease results in a loss of dietary freedom, which is for some people unimaginable, so they prefer to risk violating their diet and consequent health problems.

...they were telling us we were making some mistake...the laboratory tests showed she was eating gluten...I was cooking at home and it was OK, ...then we found out, when we pushed her to tell us, that she was buying food in a food vending machine...that she craved it...and now solve that...

Celiac disease inevitably shapes and changes identity and self-perception of a child with celiac disease, and the way a child is capable of accepting and coping with the disease and the measures depends very much on the closest social environment. Children are limited and excluded from common school and after-school activities and are constantly confronted with a possibility of gluten cross contamination, exclusion and stigmatisation. This is accompanied with emotions such as anger from impossibility to eat common way, cravings for common food or gradual isolation from events, they start to suffer from social phobias. Or they want to participate and gain an identity in a group of peers, they want to take part in events without parents with their peers and thus, trying to fit in, they break strict dietary rules without their parents and teachers having an idea about it.

Gluten-free diet is the only treatment of celiac disease. It is therefore necessary to develop in children strategies and prepare them for real situations, teach them to be independent and responsible for their health.

...she calls herself gluten-free-man...when it was her birthday she brought gluten-free cookies we found for kids to try them...and then she was so happy when some classmates came for more, that they were better than normal cookies...and then it occurred to us we could give a lecture in the class...we drew pictures...

...her knees started to hurt...she was learning to skateboard and then it hurt her so badly she couldn't even ride it...they told us the X-ray showed cartilage damage and she needed an operation and we had to give up taekwondo, a martial art...but it was after she had been diagnosed...it was the hardest blow for her, because she was fighting the celiac disease with the sport, we told her she was a warrior...and she took it like that....that she would defeat the disease when she was fighting it...it was the hardest blow...not the diet, she didn't care mind about that...after 2 years of dietary compliance the X-ray showed the diet worked...she started to train again bit by bit....so she sticks to the diet very strictly and watches it...

Children with a lifelong chronic disease such as celiac disease learn to cope with their disease and treatment regimen, they learn to cope with their disease independently, but they are *still learning*. We must realise that presence, control and support from adults is essential not only from parents but also from everyone who forms a social context of a child. This way, teachers can be very helpful because with their attitude towards a pupil they influence also a peer group in class, which adopts their attitudes and can be very helpful for a child.

4. Conclusion

This study provides unique inside into parents' and childrens' views and experiences of the aspects of celiac disease. The first area of problems is related to the disease itself, its diagnosis and treatment in context of lifelong, a financially demanding gluten-free diet. Another significant problem is stigmatisation of the patients at social events, which they might avoid as a consequence of their disease.

Teachers should have at least basic information about individual significant chronic diseases, symptoms, diagnostics and treatment, however, it is necessary to know and have information about how children themselves and their family experience the disease, what special needs a child has and what special help he needs. Raising awareness about celiac disease, symptoms which may be reflected in psychological problems, possibly manifested in thinking, emotions and behaviour and about gluten-free diet, compliance of which may sometimes be psychologically demanding. In addition, this disease is often stigmatizing and patients may exclude themselves from a community.

It is vital for teachers to know that main sources of gluten are all foods containing cereals—wheat, rye, barley and oat. But gluten can be found also in foods, where it is hidden in additives. Teachers must know that a gluten-free diet is related to emotions, that children and their families experience the diet itself and its consequences—stigmatisation and exclusion—in a certain way (Cervenkova, 2006).

Cooperation of parents and teachers of school-age children is very significant. Parents can raise awareness about this disease, namely, among teachers and classmates of an ill child. Nevertheless, it is essential that teachers also observe their pupils and inform their parents about changes and concerns about health condition, experience and behaviour.

Children learn to cope with their disease and treatment regimen, they learn to cope with this disease independently and any trivialisation from those who should support them can have far-reaching consequences. These children are aware of being different from others. The gluten-free diet required special food requests, so eating at school and in public has the effect of making them visible in public. This can produce embarrassment and stigma experiences. The children must know which teachers know about their eating problems, will help them and if need be defend them in case of emergency, so they experience a minimum sense of exclusion and stress (Cervenkova, 2006).

The aim of this study was to present a psychosocial context of education of children suffering from celiac disease and whose only treatment is a gluten-free diet, which can be a stigmatizing and exclusion factor. We also need to have information about celiac disease manifestation, bear it in mind at diagnosis, about the way children and their families experience their disease and what special needs a child has. *Understanding the disease, nature and rules of gluten-free diet and appropriate estimation, understanding psychological and social aspects of this disease is significant for improvement in quality of the patients and their close ones.*

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