

ASSESSMENT OF THE KNOWLEDGE AND ATTITUDES OF MEĐIMURJE COUNTY POPULATION ON CELIAC DISEASE

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Abstract

Celiac disease or gluten-sensitive enteropathy is a chronic autoimmune disease characterized by persistent intolerance of gluten, or proteins of prolamine (gliadin, hordein, sekalina, avenin) found in wheat, barley, rye and oats. Earlier studies have shown that people are not sufficiently familiar with celiac disease. The aim of this research is to collect information about the knowledge and attitudes of the Međimurje County population on celiac disease and compare whether there are differences between male and female responses.

The survey about the knowledge and attitudes of the Međimurje County - Croatia population on celiac disease was conducted in the period from April 27 to June 21, 2017 via social network Facebook. A representative sample consists of 210 respondents (22 male and 188 female), all of whom participated voluntarily and anonymously, fulfilling a customized 22 question questionnaire. The first four questions relate to the socio-demographic data, i.e. gender, education and the area of residence in Međimurje County and the other 18 to the knowledge of celiac disease. The results obtained were analysed using descriptive statistics

The results have shown that residents of Međimurje County, regardless of gender are well informed about the illness itself. They are aware that celiac disease is incurable illness that affects people of all ages and that the basic treatment consists of a life-long gluten-free diet that requires the release of gluten found in wheat, barley, rye and oats. However, it is noticed the lack of information in more detailed issues.

Considering that the most of respondents were women we cannot conclude with certainty about differences in responses among gender but the differences are small. The most obvious difference is that 4 respondents who suffer from celiac disease and 16 respondents who have a family with a celiac disease, are female. The reason for this may be a small number of male respondents but it would be great to conduct research on a larger number of male respondents to see if the reason is something completely different.

Key words: Celiac disease, Gluten-free diet, Gluten, Knowledge, Attitudes.

1. Introduction

Celiac disease or gluten enteropathy is a chronic autoimmune disease characterized by persistent gluten intolerance, whose presence in the diet leads to the small intestine damage of various degrees (Marsh-Oberhauber classification) as well as a variety of clinical symptoms, intestinal or extraintestinal ("a disease with thousands faces"). Gluten is a protein consisting of two fractions: glutenin and gliadine, and gliadine is a cause for genetic predisposition, gluten intolerance, found in: wheat (wheat), flour, rye, barley, bee, and oats (contaminated with wheat cultivation). The lifelong gluten-free diet is the only solution to the condition improvement, symptoms removal, and at the end, the body's condition could become like in every healthy person [1, 2, 3, 4, and 5].

Besides two basic and most common clinical images: classical and non-classical, i.e. atypical, there are also silent, potential, latent and refractory celiac diseases [2]. For the proper conduct of the diagnostic procedure, five key elements are important: clinical suspicion of celiac disease, serological tests, histopathological analysis of the small intestine, genetic analysis of the DQ2DQ8 heterodimers and a positive clinical response to the gluten-free diet [5, 6].

When talking about celiac disease, some terms such as gluten allergy and gluten intolerance are inevitable, which we must not equate with the concept of celiac disease. Allergy to gluten or flour belongs to the group of food allergies, and is a result of disturbed immune response to antigen - gluten from wheat, i.e. flour. On the other hand, gluten intolerance is characterized by intolerance of gluten, but tests on allergy are negative, small intestine mucous membranes are not atrophic, and there is no development of specific gluten-related antibodies (EMA, tTG) in the blood [6, 7].

Since it is known which foods are banned in a diet of celiac disease, it is important to mention which foods can be consumed without fear, and the only condition is that no additives are added and cross contamination is excluded. Some of these foods are: poultry, fish, eggs, milk and dairy products, all types of fresh, frozen or preserved fruits and vegetables, all kinds of nuts, coffee, tea, corn, rice, buckwheat, legumes, vegetable oils, honey, sugar and many others. There is also a range of products available on the market (flour, bread, pasta, biscuits and the like) that we recognize by the "crossed grain" symbol, with the permitted gluten content according to Codex Alimentarius [2, 7].

By placing a diagnosis of celiac disease, the life of the patient changes from the ground up, and community awareness of this disease can greatly help him. Celiac disease is increasingly mentioned in daily conversations due to its growing number of patients. Therefore, it is important to carry out continuous education, but also to encourage individuals to inform themselves about the complexity of the disease and how much they can contribute to it.

2. Materials and Methods

The research was conducted in the period from April 27 to June 21, 2017 via social network Facebook for the purposes of the final work for study at the Department of Biomedicine - Nursing, University North, in Varaždin. The obtained results give an insight into the Međimurje County population's knowledge and attitudes on celiac disease.

2.1 Materials

The results were obtained by conducting a survey on a representative, non-probabilistic sample consisted of 210 respondents, with different sociodemographic background (Table 1), all of whom participated voluntarily and anonymously, fulfilling a customized survey of 22 questions.

2.2 Methods

The survey method used in the research was a questionnaire. The first four questions relate to sociodemographic data of the respondents, i.e. age, gender, education and the area of residence in Međimurje County, and the other 18 relate to the knowledge of celiac disease. Most of the questions, 13/18, had the scale yes or no, and the rest 5/18 were with the multiple choices. Respondents answered questions about: the cause of the disease, the treatment, a gluten-free diet and which are gluten-free foods, but also whether they are suffering from celiac disease or someone in their family. Then, do they prefer a gluten-free diet even if they have no health problems and the reason for that. At the final question, they should express their own opinion whether people are sufficiently / insufficiently educated about the danger of gluten foods for the sufferers. We have grouped answers to questions by gender to see if there is a difference in knowledge and attitudes between male and female. Since celiac disease, a disease that is not yet known enough, many have not even heard about, it was assumed that less than half of Međimurje County population would be familiar with the concept of it and its general facts.

The results obtained were analysed using descriptive statistics, i.e. described in the words and presented in graphs or tables.

3. Results and Discussion

Celiac disease is a disease that wasn't so much known a few years ago, so it hasn't been so much written or spoken about it. Therefore, today it is increasingly encountered and diagnosed, so it is important to inform the public about it, its symptoms, treatment, or gluten-free diet and encourage early detection and diagnosis.

The aim of this research was not only to examine a small part of Međimurje County population and get a picture of their knowledge and attitudes about celiac disease but also to compare whether there are differences between male and female responses.

In the study, most of the respondents were female, and the most common age group was 21 - 30 years. Furthermore, most of them have completed bachelor education and come from rural areas (Table 1).

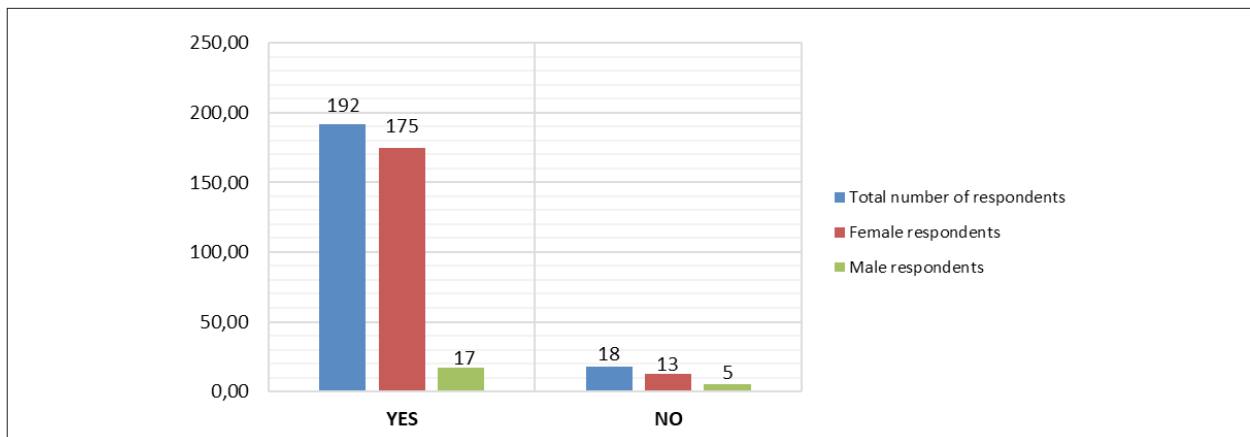
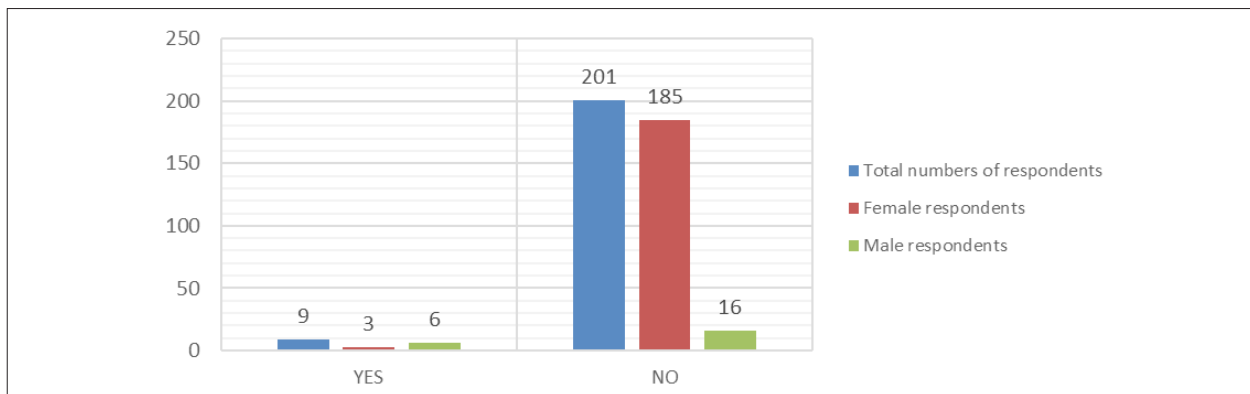
Table 1. Sociodemographic data of respondents

Sociodemographic data		N	%
Gender	Female	188	89.5
	Male	22	10.5
Age	< 20	47	22.4
	21 - 30	99	47.1
	31 - 40	31	14.8
	> 40	33	15.7
Qualification	Secondary education	126	60
	Bachelor	36	17.1
	Master and doctor	48	22.9
Area housing area in Međimurje county	Rural area:	135	64.3
	Urban area:	33	35.7

In addition to sociodemographic data, we also collected data on their knowledge and attitudes about celiac disease. Since data is grouped by gender and we know that the number of female respondents was considerably higher, the comparison of the data does not give

objective results, but we can see in what direction the differences go. We notice that there is not too much difference in the answers to the question “what is celiac disease?” because 175/188 female and 17/22 male or 91% of all respondents gave a positive answer to the question (Figure 1). At the identical question 2nd, 3rd and 4th grade students of secondary medical school in Varaždin have responded positively in a slightly smaller percentage, 63%, in the study “how much do we know about celiac disease?” by Maja Golubić [8].

A total of 185 female respondents and 16 male respondents know that this is a disease of all age groups, and not only children as it was considered before (Figure 2). They could easily notice it, because scientists are trying to talk more about celiac disease as a disease of all ages. Former beliefs related to age can be supported by the fact that previous studies on celiac disease included only the children’s population, their disease symptoms, early diagnosis, and connection between celiac disease and related diseases. As examples can be cited researches from year 2000 under the title: “Epidemic of celiac disease in Swedish children; Celiac disease in Turkish children: presentation of 104 cases”, but also some Croatian studies, for example: “Gluten enteropathy in Croatian children is primarily associated with the HLA-DR3-DQ2 haplotype” [9, 10 and 11].


Figure 1. Display of answers: Do you know what celiac disease is?

Figure 2. Display of answers: Celiac disease is a disease that only affects children?

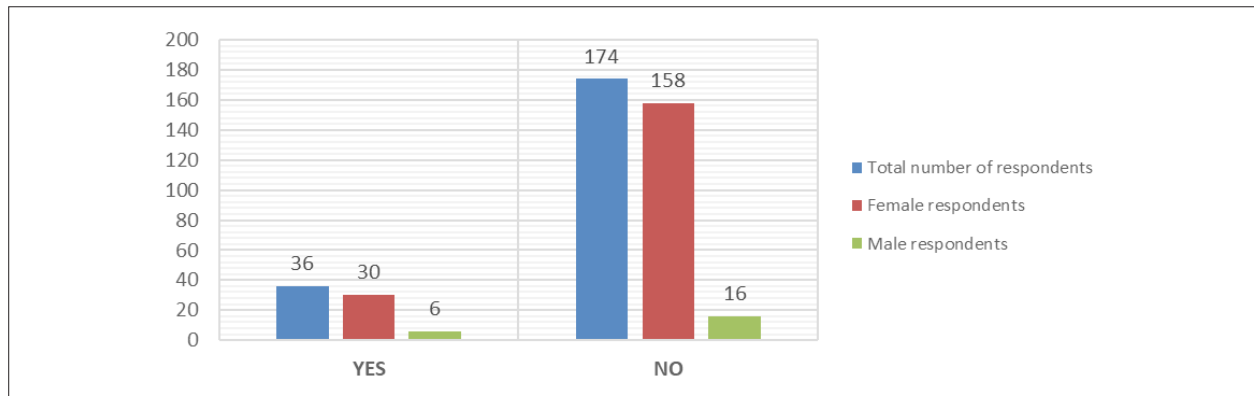


Figure 3. Display of answers: Can celiac disease be cured?

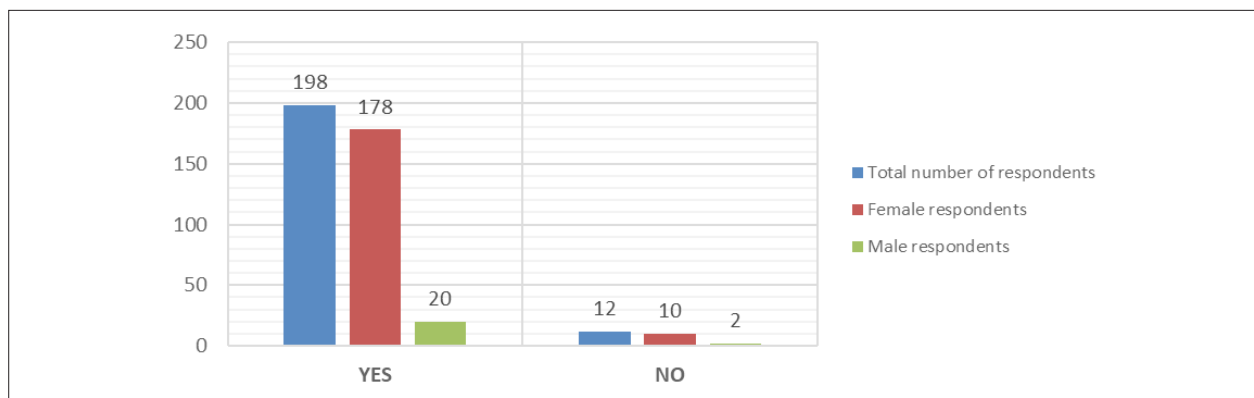


Figure 4. Display of answers: Primary treatment is a gluten-free diet?

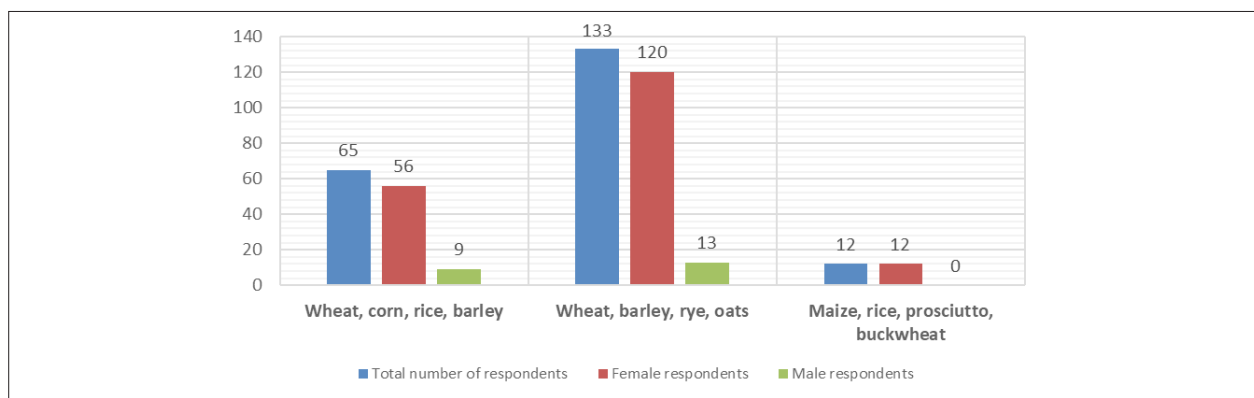


Figure 5. Display of answers: Which cereals should not be consumed in celiac disease?

The respondents, namely 158 of female respondents and 16 of male respondents, showed a certain level of knowledge stating that they are aware of the fact that the disease is impossible to cure (Figure 3). Equally, 178 of the female respondents and 20 of male respondents know that the basic treatment consists of a gluten-free diet (Figure 4).

Unfortunately, consumption of fruits and vegetables in celiac patients still confuses the respondents, 90 of female respondents and 12 of male respondents believe that people with celiac disease should not consume all kinds of fruits and vegetables. But in the other hand, it is prohibited to the celiac disease patients to eat cereals containing gluten and 180 of female respondents

and 20 of male respondents agree with that statement. Also, most of them know that forbidden cereals are: wheat, barley, rye and oats, but there are also those who believe that other cereals such as rice and buckwheat are forbidden. With these responses, we can confirm that more than 50% of respondents have information on how to treat celiac disease, i.e. the gluten-free diet and forbidden food (Figure 5). Students from Maja Golubić's research are also aware of this fact since 78% of respondents know that gluten is the cause of the symptoms in the disease and 89% of them know that the patients should not consume wheat flour, 74% of them know they should not consume barley flour and 66% respondents know that they should not eat rye flour. [8]

For those suffering from celiac disease it is very important to know that gluten can be found in some products as a concealed ingredient, but it is also a great benefit for them that all of us get to know this fact. It is encouraging and commendable that almost all respondents know this. By reading product declarations, we can see that in almost all products there are traces of gluten, and we also see that respondents often pay attention to that part and are aware of the presence of gluten (Figure 6). Research with the title “Celiac disease: understanding the gluten-free diet” confirms that we need pay attention to gluten as a concealed ingredient in some food. In this research, a Meta-analysis was carried out by searching bases with keywords such as “gluten-free”, “celiac” and “gluten”, and in all studies it was noted that for gluten-free nutrition it is important not only to avoid certain food with gluten but also to pay attention to foods with potentially disguised gluten. Also, the unwanted contamination of food shouldn’t be neglected, since such foods are equally harmful to those suffering from celiac disease [12].

However, about the more detailed questions about gluten-free food and gluten, there is visible a lack of information in the respondents, so they have divided opinions about certain facts. Even 93 of female respondents and 11 of male respondents believe that the gluten-free diet cannot completely remove the symptoms of celiac disease. With that question we can confirm that we talk about celiac disease but not so much about the benefits of gluten-free diet and the important facts related to celiac disease (Figure 7). According to the study “Celiac disease: prevalence, diagnosis, pathogenesis and treatment”, 23% of patients had a normal endoscopic appearance of the lymph node. This was not a good result, but all respondents had a good clinical response to the gluten-free diet [13].

Celiac disease is a confusing disease and individual for every patient, so it is no wonder people often think that the terms of intolerance to gluten and celiac disease are actually the same disorder. But these are two different terms that also know 135 of female

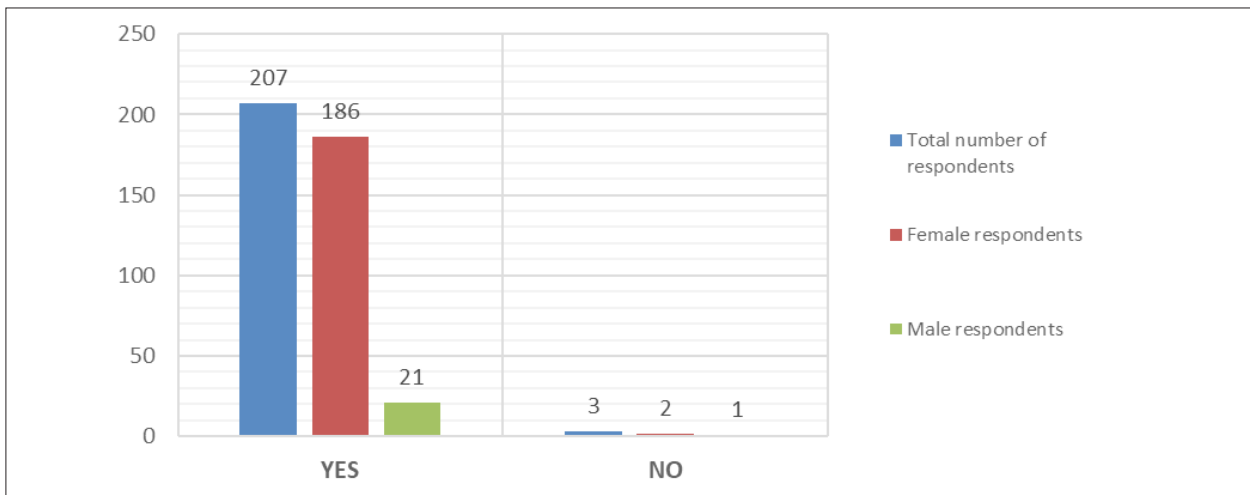


Figure 6. Display of answers: Can gluten be found as a covered ingredient in some products?

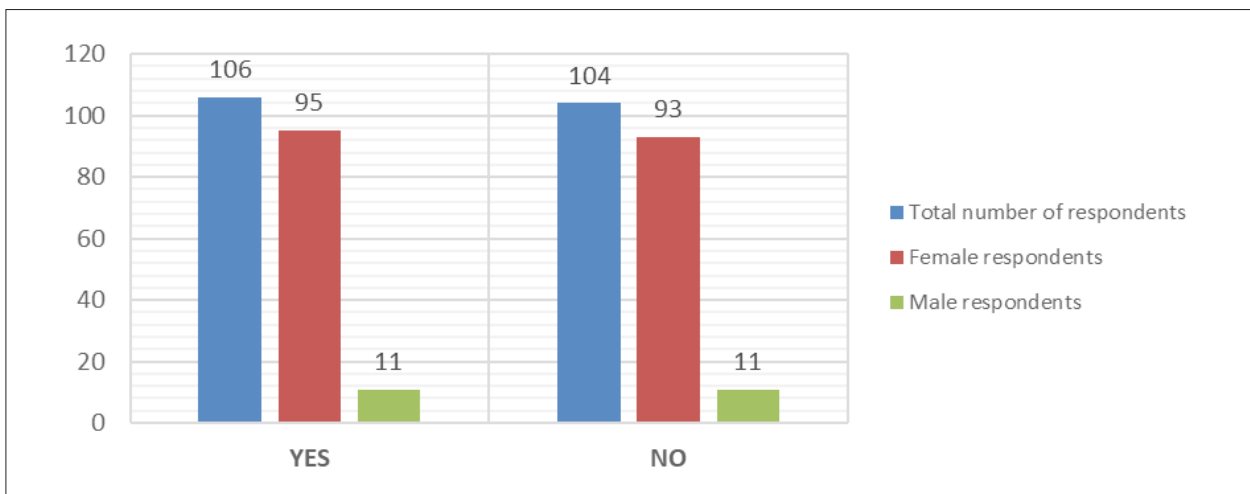


Figure 7. Display of answers: Can a gluten-free diet completely eliminate the symptoms of celiac disease?

respondents and 12 of male respondents (Figure 8). In order to raise awareness of it among the human population, many researches were conducted as research under the title “Characteristics of autoimmune enteropathy in adults compared to refractory celiac patients”. To make people aware of it, research like one under the heading “Features of adult autoimmune enteropathy compared with refractory celiac disease” are being conducted. Research has shown that immune mediated non-celiac atrophies such as autoimmune enteropathies cannot be treated just like celiac disease, in this case refractory celiac disease, because it is a direct proof that these concepts cannot be equated. They have a common cause, gluten, but they need to be treated differently [14].

The study involved 4 (1.9%) people with celiac disease and all 4 were female. Also 16 (7.6%) female respondents indicated that their family member is a person with celiac disease, while in the male gender that number was zero (Figure 9, Figure 10). According to Maja Golubić’s research [8], 8 out of 100 respondents have a celiac disease patient in the family, while 2 respondents are celiac disease patients. When we compare these results, we can see that the average of both studies is the same, i.e., in 100 respondents, two are diseased, and 8 out of 100 have a person with celiac disease in their families. Studies from foreign countries such as the study entitled “Going Gluten Free: the History and Nutritional Implications of Today’s Most Popular Diet” and research titled “Development of a novel rapid non-invasive screening test for coeliac disease”

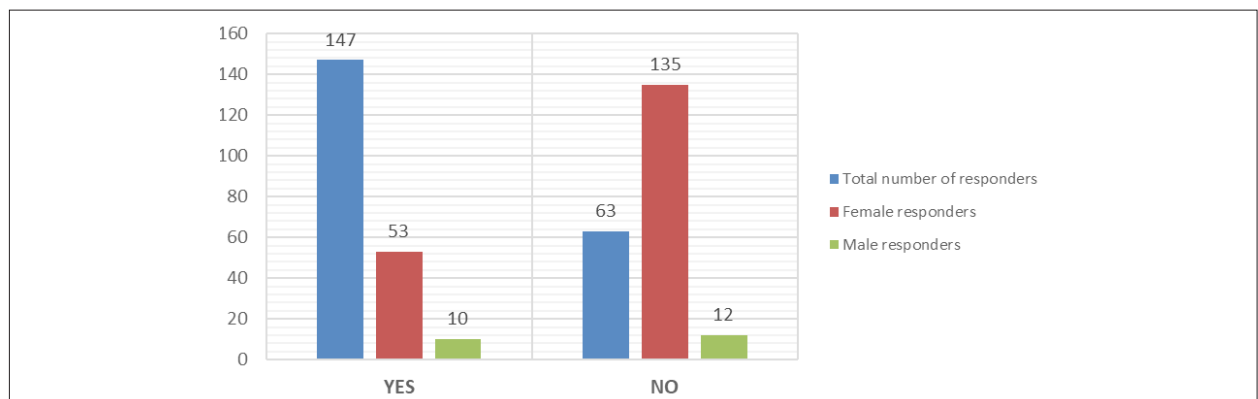


Figure 8. Display of answers: Gluten intolerance is the same as celiac disease?

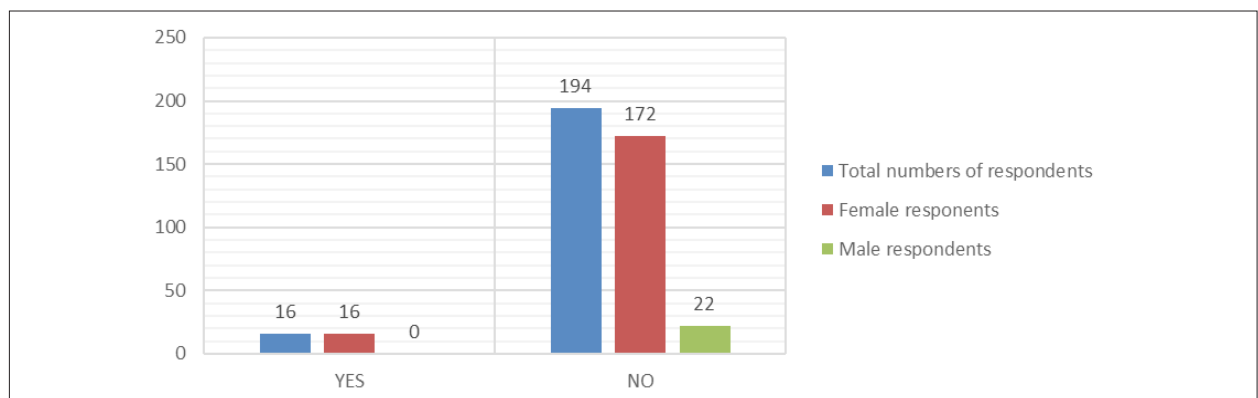


Figure 9. Display of answers: Does anyone in your family suffer from celiac disease?

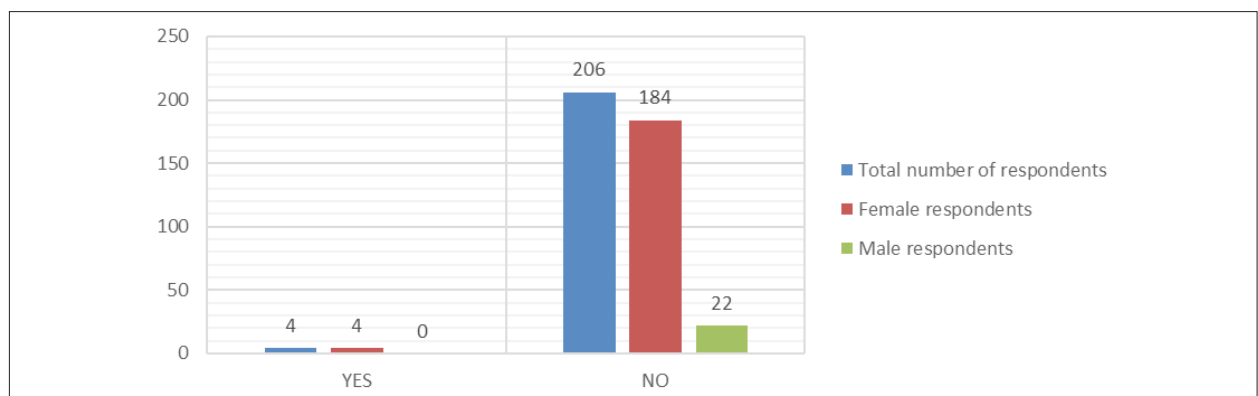


Figure 10. Display of answers: Do you suffer from celiac disease?

confirm our results as they say that 1%, or 1 - 2% of the Europe population suffer from celiac disease. A study entitled "Epidemiology of coeliac disease in children of the County of Međimurje" was also conducted in the period 1985 to 1994 and in that period were noted all cases of children born in Međimurje County with celiac disease. According to cumulative incidence results were 1.9 : 100 live-born [15, 16, 17, and 18]

According to the results, less than half of the respondents know that gluten is a protein whereas most of them consider gluten is a carbohydrate. But when we talk about foods in which we find gluten, most of them 200 of all respondents know that we find it in cereals (Figure 11, Figure 12).

Gluten-free diet has unfortunately become a trend that many people follow without health care needs or without having previously informed enough. The public, in fact, the media broadcast that celebrities go on gluten-free diet, which often encourages people to do the same thing so they unadvisedly turn to gluten-free food. Therefore, we checked whether there were any respondent who doesn't eat gluten food and not having a medical reason, i.e. celiac disease. The results showed that 39 of female respondents and 4 of male respondents prefer gluten-free food without having celiac disease (Figure 13). The main reason for this was personal knowledge (e.g. health) but also media influence, candidiasis, gluten intolerance, and way of los-

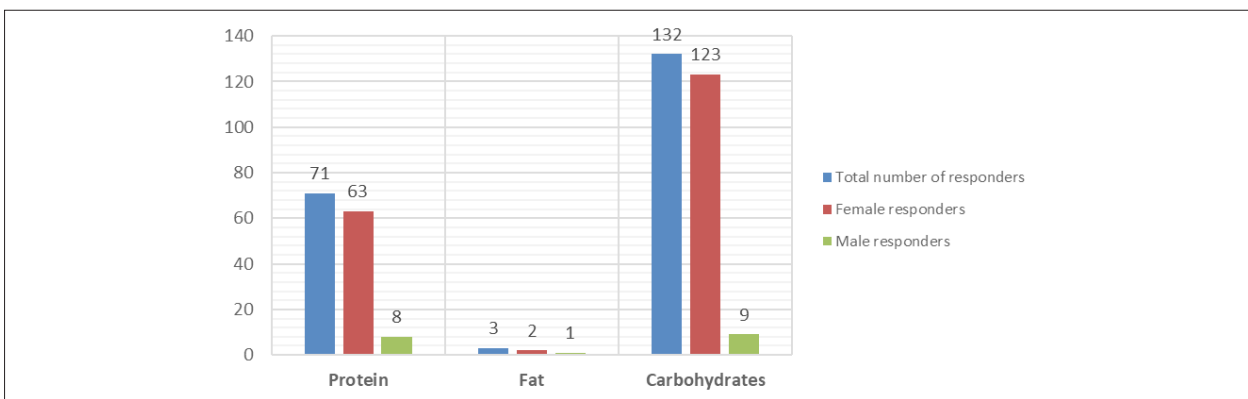


Figure 11. Display of answers: What is gluten?

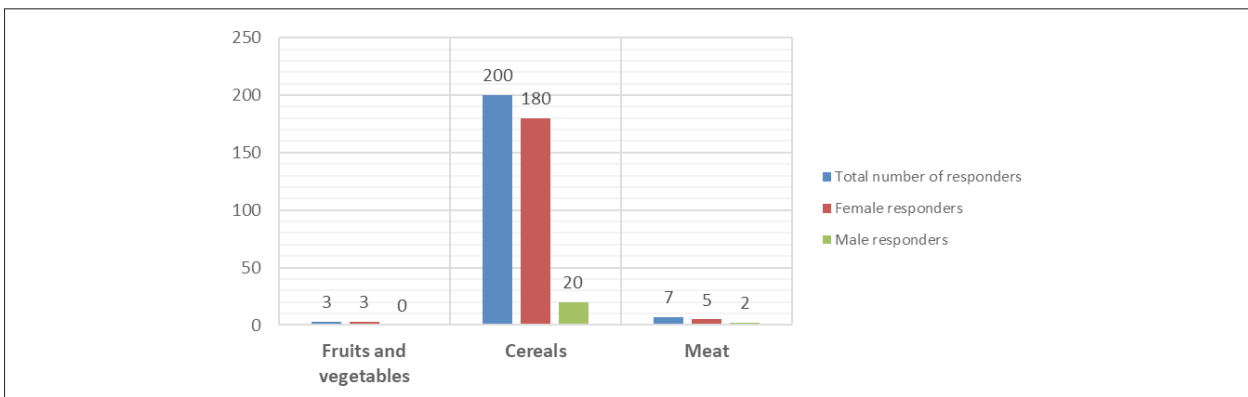


Figure 12. Display of answers: Which foods contain gluten?

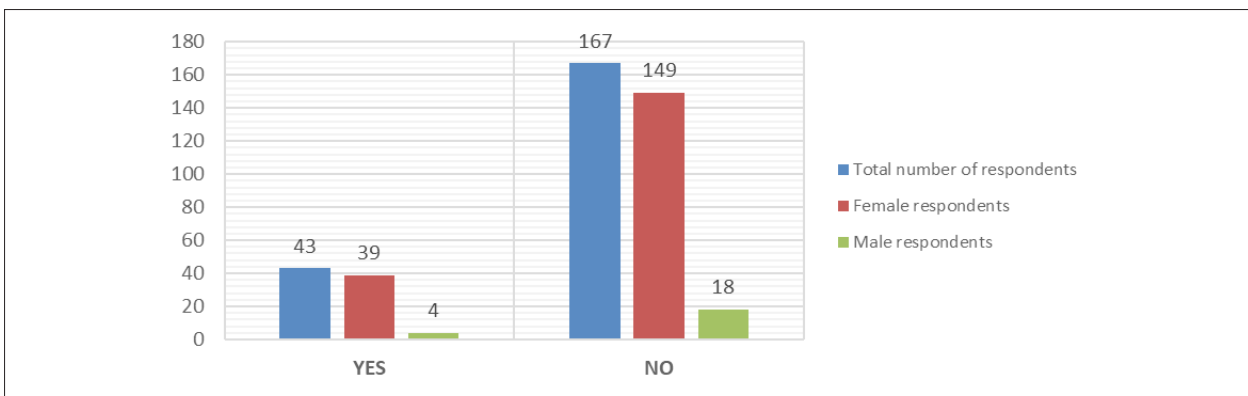


Figure 13. Display of answers: Do you prefer a gluten-free diet regardless of the fact that you do not suffer from celiac disease?

ing weight (Figure 14). According to the study “Going Gluten Free: the History and Nutritional Implications of Today’s Most Popular Diet”, a quarter of the population adheres to this gluten-free diet without having previous problems with the gluten-induced disorder. Because of the lack of gluten food, people are having calcium, vitamin B and fibre deficiency, and increased intake of fat and simple carbohydrates. That is not usually the case for the human body, so unpredictable complications may occur in the diet what is a problem that should be solved. In a similar study “Characteristics and comorbidities of inpatients without celiac disease on a gluten-free diet”, it has also been shown that gluten-free diet without justified health needs is not useful. Thus, according to the study, people on a

gluten-free diet without celiac disease tend to have inflammatory bowel diseases, irritable bowel syndrome, thyroid disease, lupus, and autistic spectrum disorders [16, 19].

In order to recognize gluten-free foods, we need to know that they are labelled with cross-grain symbol. Results about that symbol are a bit below of our expectations because 99 of female respondents and 14 of male respondents do not know it (Figure 15).

There were different answers on question if gluten free products can be bought in any store, multiple choices were available (Figure 16). When we talk about stores with gluten-free products, it is inevitable to mention their price. Therefore, people with celiac disease need

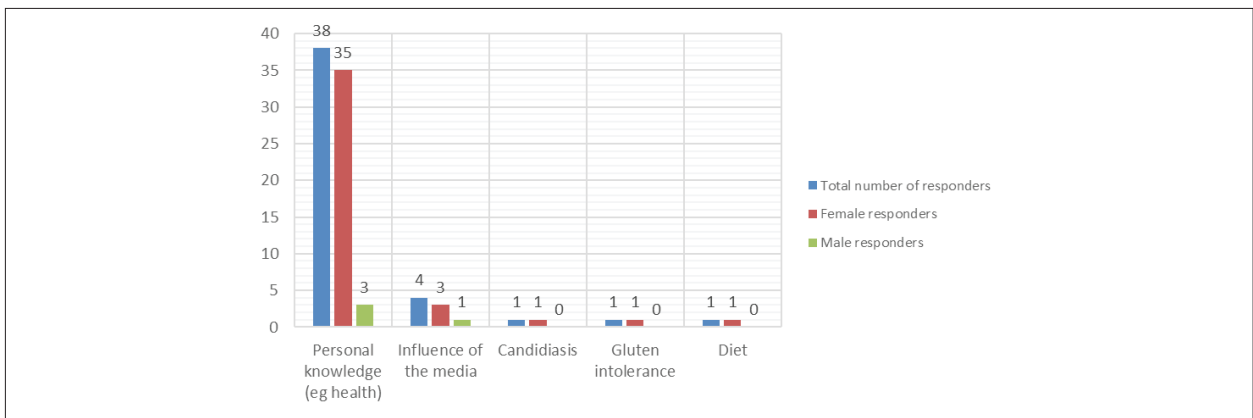


Figure 14. Display of answers: If the answer to the above question is true, state the reason why?

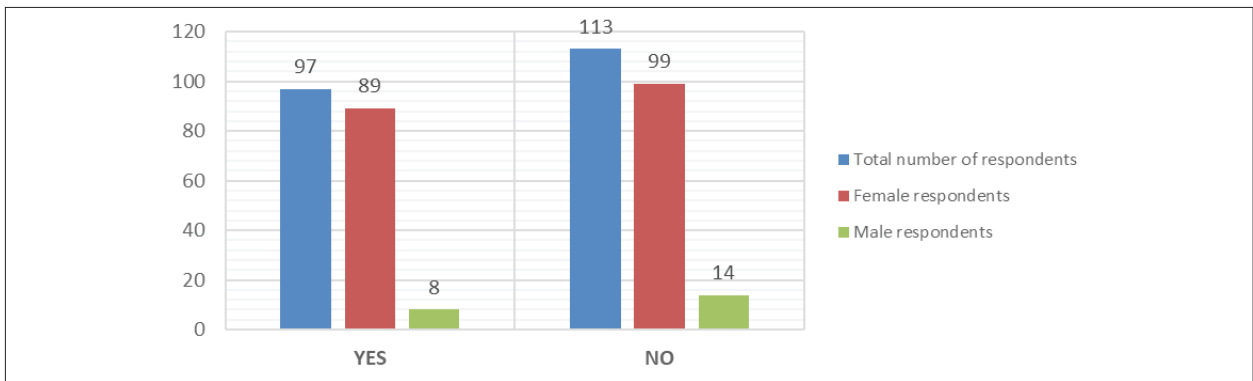


Figure 15. Display of answers: Do you know what a gluten-free product logo looks like?



Figure 16. Display of answers: Gluten-free products can be bought in any store?

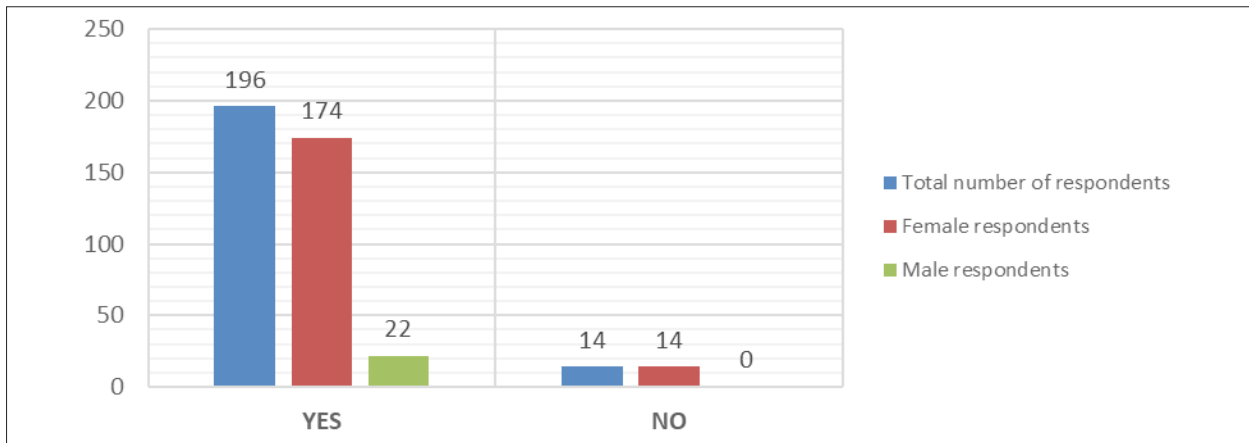


Figure 16. Display of answers: The public is not educated enough about how much gluten-free foods are harmful to people suffering from celiac disease?

to separate much more money for adequate nutrition than the rest of the population. The UK study conducted about nutritional composition of gluten-free and gluten food has also explored the difference in their price so gluten-free products are 159% more expensive than gluten food (£ 0.44/100 g versus £ 1.14/100 g) [20],

In the end, the respondents themselves should assess whether the public is or not sufficiently educated about the celiac disease. According to the responses 174 of female respondents and 22 of male respondents believe that the public is insufficiently educated about how much gluten-free food can be harmful for celiac patients (Figure 16). The students from Maja Golubić's research [8], agree with the results because 90% of them positively answered the question whether there is too little information about celiac disease in schools/clinics/hospitals. In New Zealand was also conducted a study where the main chefs, chefs and students completed the questionnaire on education, qualifications, experience and knowledge of celiac disease and the preparation of gluten-free food. According to the results, half of them didn't go through formal training, but everyone was aware of the term gluten-free diet. Celiac disease awareness was similar between the chef and the student, but the students were much more aware of the need for preparation of gluten-free food and were better evaluated in the questionnaire [8, 21].

4. Conclusions

- Celiac disease is a very complex disease, and the facilitating circumstance for the patients is educated community, especially about early detection and treatment of the disease.

- Considering the results of the research it can be said that a sample of 210 subjects is very good familiar with

celiac disease so we evaluate their knowledge on a scale of 1 - 5 with grade 4. Lack of knowledge is visible in more detailed issues related to the disease, such as the questions what is gluten by composition and which food is allowed in a diet of celiac disease.

- The data are divided by gender, but we cannot say that female respondents have less knowledge than male respondents because most of our respondents, actually 90% were female. What can we say, is that the differences even on small group of respondents are noticeable.

- We can conclude that the lack of knowledge or issues is visible on the same questions no matter female or male respondents. This suggests that education should be directed to these specific areas (the benefits of gluten-free diet for celiac patients, gluten-free food, allowed products in celiac patients' diet and cross-grain symbol). But education should be carried out not only by health professionals but also by nutritionists and non-governmental organizations who deal with this disease.

- It is also important to emphasize that knowledge about celiac disease is not related to the familiarity of a person suffering from celiac disease because only slightly less than 8% of respondents have a family member with celiac disease, and the correct answers of the respondents are almost always over 50%.

- Along with continuous education of Međimurje County population, other populations should be educated as well because even 196 (93.3%) of all respondents consider that the public is insufficiently educated about harmfulness of gluten food for celiac disease patients.

- It would be useful to rerun this research in the future because we believe that after continuous education answers would be even better. This is a disease that is increasingly becoming a public health problem and

we should make sure that the public understands how the individuals can contribute to the effort of a person who has been on gluten-free diet for a whole number of years and has completely recovered because even a small moment of ignorance can destroy their whole life.

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