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Living with celiac disease in Kazakhstan: a qualitative study

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by

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Abstract.

Introduction: Celiac disease represents a problem to Kazakhstani population not only because of its growing prevalence in children, clinical manifestations and possible health complications. Another issue celiac disease poses to society is a diminished quality of life in patients and their families. This study aims to explore what people with celiac disease are going through, and what are the main obstacles to maintain a gluten-free diet.

Method: A qualitative study was conducted through semi-structured in-depth interviews with patients diagnosed with celiac disease. In a series of interviews, nine women and three men described their perspective of learning the diagnosis, living with the disease and challenges of adhering to treatment. The transcripts of interviews were qualitatively analyzed for emergent themes and subcategories.

Results: Patients experienced a variety of symptoms before the diagnosis. None of participants were aware of symptoms being signs of chronic, genetically predisposed illness. Delay in diagnosis was due to complete unawareness of public of celiac disease and its signs and symptoms, as well as lack of knowledge about the disease among health professionals. Participants responded with strong emotions to diagnosis. There were more negative impacts on life from celiac disease including social isolation, recurring symptoms, reduced traveling, persistent anxiety and economic burden leading to depression. Support from family and close friends was helpful over the course of illness. However, the absence of support from society and healthcare was a devastating factor. Main challenges to maintaining a gluten-free diet were low choice and price of gluten-free products on the market. Unfavorable taste and texture were reported as issues when adapting to a gluten-free diet.

Conclusion. A number of future studies and interventions are suggested. Increasing awareness of celiac disease in general population and medical professionals should decrease the delay in

diagnosis, provide with social support, instead of isolation, and also introduce medical monitoring. Production of local certified gluten-free food should increase availability on market and decrease the prices. Recipes with adjusted taste and texture may improve adaptation and adherence to a gluten-free diet. A community or at least mobile application uniting celiacs around the country should help them better understand the disease, and cope with anxiety and depression.

1. Introduction.

Celiac disease is a multifactorial illness, mainly expressed as inflammation in small intestine triggered by the ingestion of certain cereals (Ludvigsson *et al*., 2013). Celiac disease affects genetically predisposed people causing an autoimmune reaction to gluten, proteins found in wheat, barley, and rye (Sapone *et al*.,2012). The symptoms of celiac disease are divided into classic and non-classical (Lebwohl *et al*., 2018). Classic symptoms of celiac disease usually appear among infants at ages between 6 months and two years old (Paul and Spray, 2014). Clinical manifestations of classic celiac disease include problems in the gastrointestinal tract and consist of abdominal distention, diarrhea, malabsorption, loss of appetite and growth delay (Paul and Spray, 2014). On the other hand, non-classical symptoms (also called atypical symptoms) are more common among adults. These symptoms usually include but are not limited skin rash, osteoporosis, thyroid disorder, iron-deficiency anemia, arthritis, and other autoimmune conditions, abnormalities of liver function, peripheral neuropathy, vitamins deficiency (B12 and folic acid), recurrent miscarriages in women and many others (Nadhem *et al*., 2015).

The diagnosis of celiac disease is done by a serologic test for antibodies. In certain cases, diagnosis is confirmed by a duodenal biopsy showing the presence of villi atrophy (Paul and Spray, 2014). The only available treatment is a strict gluten-free diet, i.e. complete exclusion products containing wheat, barley, and rye (Watkins and Zawahir, 2017). Undiagnosed coeliac disease or a failure to follow gluten-free diet leaves individuals to elevated risks of long-term complications such as infertility, cancer and higher mortality rates (with standardized mortality rates of 1.26-3.8) (Biagi and Corazza, 2010).

The global prevalence of celiac disease is estimated at around 1%, confirmed by various studies in Europe and North America (Taylor et al., 2013). Prevalence of the disease in Kazakhstan is currently unknown. However, one study estimated the frequency of predisposing genotype to be present in 1 child out of 262 (Sharipova, 2009).

In addition to, a growing number of diagnosed cases among children, as well as possible complications associated with the illness, celiac disease poses an another problem to a society – quality of life. Celiac disease negatively affects the quality of life of diagnosed patients and their families. Improvement of quality of life of those who affected by celiac disease is a public health concern. Understanding celiac disease patients concerns and issues associated with the disease that they face in daily life will help in developing public health interventions to improve their quality of life.

To this date, previous studies concerning celiac disease in Kazakhstan discussed the pathomorphology, clinical picture and diagnostic methods (Sharipova, 2009, Iskakov and Kapasova, 2017). There are no studies describing the issues that Kazakhstani people with celiac disease face over their lifetime. Therefore, the aim of this study is to explore how people with celiac disease live in Kazakhstan, the burden of the disease and the barriers towards gluten-free diet.

2. Methods.

A qualitative approach was used in order to explore main concerns and issues of living with celiac disease and barriers towards maintaining a gluten-free diet. Data was collected through a series of semi-structured in-depth interviews until data saturation was achieved.

The interviews were developed according to previous literature (Crocker *et al*., 2018) in English, Russian, and Kazakh languages. The interviews were pre-tested before actual interviews were scheduled and conducted. The copies of guidelines of interviews are attached in Appendices 5, 6 and 7.

Eligible participants included any adult person, 18 years or older, diagnosed with celiac disease. Excluding criteria were: being younger than 18 years old, inability to understand Russian, Kazakh or English language and not giving a consent. Purposive sampling was done in Republican Diagnostic Center, city out-patient clinics №2, №3 and №10. In addition, respondents were recruited through Internet social networks, such as, vk.com. Non-probability snowballing sampling technique was used. Recruitment was done in a period between January 2019 and mid-March 2019.

Fourteen patients diagnosed with celiac disease were introduced to the research topic and were invited to be interviewed. Two of them refused to participate or did not respond. Twelve participants arranged interviews at a convenient public location. Data saturation was achieved after 10 interviews, but in order to include more people with different demographics, the last two interviews were conducted. Interviews lasted between 30 minutes and one hour. The interviews were recorded and later transcribed verbatim, and translated to English. Each new transcript was analyzed individually for emerging topics and then compared thematically to other interviews. Emergent topics and subcategories were identified according to guidelines of qualitative research (Austin and Sutton, 2014).

Ethical approval was received from the Nazarbayev University Research Ethics Committee on December 2018 (Appendix 1). Verbal informed consent was obtained from each participant. Each participant was explained that they are able to withdraw from the research as well as skip any sensitive questions or end the interview without any explanation nor consequences. Participants also permitted audio recording of the interview with subsequent transcription verbatim. No identifiable information was used and all data was kept confidential. There were no known risks to participants. The minimal risks included time inconvenience, and some question regarded as sensitive and were explained prior to beginning of the interview. There were no direct benefits to participants. However, the findings of this study may benefit participants and/or other people with celiac disease by better understanding their conditions and helping develop better intervention programs to increase the quality of life.

3. Results.

Twelve people with celiac disease were interviewed. Participants were 19-54 years old and were diagnosed for at least six months.

The inductive analysis of the transcribed interviews showed the themes and subcategories. The main themes included the life before the diagnosis, learning diagnosis, impact of celiac disease on everyday life, and barriers to maintain a gluten-free diet. This section provides a description of the main themes using quotes from participants to illustrate the reported issues.

3.1. Life before diagnosis.

All the participants experienced a variety of both classical and atypical symptoms of celiac disease before learning the diagnosis. Most prevalent reported symptoms include abdominal discomfort including constipation, diarrhea, and pain (11 out of 12 participants), fatigue and tiredness (8 out 12), iron-deficiency anemia (5 out of 12) and dermatitis or skin rash (4 out of 12).

Although symptoms were recurring repeatedly, participants did not suspect any chronic disease.

"I had these {fatigue and diarrhea} symptoms all the time. I just assumed everyone feels the same and do not talk about that". (Participant 8)

"When I had diarrhea I thought it was either food poisoning or that I had "weak intestines". I did not know that I was expressing symptoms of a disease". (Participant 2)

Moreover, participants believe that medical professionals have low awareness of the celiac disease. All participants visited doctors multiple times before being diagnosed.

"I visited lots of doctors, gastroenterologists, before my diagnosis was confirmed. They never mentioned that there is an allergy to bread!" (Participant 8)

3.2. Learning the diagnosis.

There are strong emotional reactions involved in learning the diagnosis. More than half of the participants responded that they felt anxiety and fear. A feeling of anxiety was due to the chronic nature of celiac disease while fear was due to experiencing possible complications in the future.

"When I learned the diagnosis, the doctor couldn't say much about future, I felt anxious like something was wrong with me." (Participant 4)

"I was reading about the {celiac} disease in the Internet and possible complications on the way home from the doctor. I was terrified that I will eventually get cancer or die because of celiac disease." (Participant 1)

However, half of the participants were relieved to learn the diagnosis and understand that symptoms were manageable.

"After reading about celiac disease, I was relieved that I know the diagnosis. To know what was causing the problems and having the opportunity to deal with it was much better than having constant tiredness and chronic diarrhea". (Participant 3)

One-third of participants were angry that despite earlier signs of disease, the diagnosis was received with delay.

"I felt angry that I wasn't diagnosed way before. When I was reading the symptoms online later that day, I couldn't stop crying. I felt that {previous} doctors had no idea this disease even existed! It cost me so much money and depression going through symptoms all over again!". (Participant 5).

3.3. Impact of celiac disease on everyday life.

All of the participants transitioned to a gluten-free diet. The period of adaption to GFD was challenging. 11 participants noted that support from relatives and friends was important in that period.

"Family supports me. Their support was invaluable to me at the beginning when I was learning to live with celiac". (Participant 3)

"Friends did not understand my disease at first, but now they go extra lengths to find a place where I can eat. Their constant support helps me go through the disease". Participant 7)

Remaining participants said that the family did not support their condition.

"When I told the family about my disease, they were very aggressive. They did not understand me". (Participant 2)

Ten participants reported a positive impact of living with celiac disease. Their arguments included a balanced diet and improved well-being after adapting to a gluten-free diet.

"I felt much better after I started the diet. Most of the symptoms are gone and my well-being is much better now. I would recommend a gluten-free diet to everyone, even to people without celiac disease". (Participant 3)

However, participants indicated that there was more negative impact of having the disease. For instance, all participants reported experiencing symptoms of celiac disease despite a strict gluten-free diet. Mostly, participants attributed these symptoms to cross-contamination when eating outside.

"I am on a strict gluten-free diet. I still have symptoms sometimes. But I can certainly say when food was cross-contaminated". (Participant 11)

According to respondents, a gluten-free diet leads to social isolation and unwanted attention. Participants said that the absence of menus at cafes and restaurants for customers with celiac disease makes socializing with friends and colleagues challenging, ultimately leading to isolation. Then, the feeling of isolation leads to anxiety and depression.

"There is a strong feeling of isolation. Whenever my colleagues or friends go out, I have to stay home or go there and have a coffee or a drink. I feel that they are bonding over the food they share, and I have to watch them". (Participant 3)

"I had to miss so many events, gatherings either due to having symptoms or the fact there is no food for me". (Participant 9)

"I usually avoid social events if there is no food for me". (Participant 10)

Another reported negative impact was limited ability to travel within the country and outside of it. The interviews implicated that planes do not provide any food for someone with celiac disease, and traveling via train or car requires a lot of preparation. Even after arriving at another city, there is a problem of obtaining gluten-free products or finding a place to eat. Cooking at relatives' house also was worrisome for respondents due to cross-contamination. Respondents found traveling outside of the country a major challenging activity. Respondents stated that problem arises when explaining the needs of a special diet, ordering gluten-free food at restaurants or hotels. This also brings unwanted attention, which amplifies feeling of social isolation.

"I had to limit traveling or visiting relatives. There is a process of preparation for the road if you travel by train. Airplanes do not have any option for us neither. Then, it is hard to find gluten-free products in other cities. At home, I can cook and not worry about contamination". (Participant 6)

Many participants reported that celiac disease brings an economic burden to the family. The burden comes from the need to maintain gluten-free diet, as well as purchasing medications and supplements.

"The prices for gluten-free food are unbelievably expensive. One certified gluten-free bread may cost up to 2000 tenge. We buy ordinary rice, buckwheat, corn because they are cheap, but they are often contaminated. We spend so much money trying new foods, sometimes ending up not using them at all." (Participant 2)

"I work more and harder to provide me and my kid with gluten-free food. There is constant fear: "Will I have the {gluten-free} products at home? Will I able to provide me and my son with them?" (Participant 10)

"I had to quit work when my kid was diagnosed with celiac disease too. I had to stay at home because my daughter requires special attention and diet. Kindergartens do not want to take responsibility for the kid, and nannies refuse to take care of him because of the special diet. Husband tries to provide the whole family and we are desperate now." (Participant 1)

The economic burden brings anxiety and depression. Another reason for anxiety among participants was worry about complications due to the disease and a possibility that a family member might develop celiac disease.

Anxiety about comorbidities was persistent in more than half of the respondents. Interviewee were aware that different types of cancer, autoimmune diseases, and death are possible.

"I always worry about comorbidities. I am terrified to get cancer or any other disease because of my condition. This worry often gets worse, and I get depressed over the fact that I have celiac disease". (Participant 2)

Three-quarters of participants stated that they feel there is no support from the government and healthcare. The absence of medical follow-up as well as the absence of social payments makes them feel isolated and invisible and also leads to depression.

"There is no medical follow-up. It is like we are on our own. People with diabetes and other chronic conditions have regular check-ups and free medications. I can't even get my son a kindergarten or hire a nanny because he requires special care and specific diet. There are no social groups to support people with celiac disease". (Participant 12)

"When my son was a baby, he expressed a lot of symptoms. I called paramedics, but they did not know what medications are allowed to someone with celiac disease. They were like completely unaware." (Participant 10)

3.4. Barriers to maintaining a gluten-free diet.

One of the major obstacles to maintaining the gluten-free diet was the lack of choice of gluten-free products on the market and restaurant. All certified gluten-free products on market were imported from Russia and other European countries. The situation is even more difficult in restaurants and cafes, where no menu is provided for people with celiac disease.

"I prepare my meals at home and carry my lunch box with me all the time. I know from experience that I can run into a situation where I will not be able to eat anything or

order food. There is no option in menus in cafes and restaurants. Even in the market, there is very little choice what to buy and what to cook" (Participant 12)

"Sometimes I feel frustrated with the choice on market. It is all the same products every time". (Participant 4)

Another barrier to maintaining the diet was the high cost of gluten-free products. Almost all participants reported that prices were unacceptably expensive.

"The price and choice in market in disappointing. I don't know. Kazakhstan has agricultural resources but we have to buy expensive imported products. Imagine paying thousands tenge for bread made of corn! It is really frustrating and infuriating". (Participant 10)

While price and lack of choice of gluten-free products were main obstacles in maintaining the diet, the adaptation to diet was challenged by the taste and texture of gluten-free food.

"The food is crumbly and tastes very different {unusual} from ordinary food. You get used to the taste and texture but you will never start enjoying them. Eventually, you just start recognizing which manufacturers make products you can consume". (Participant 5)

4. Discussion.

4.1. Diagnosis.

This study shows that delay in diagnosis is commonly observed in Kazakhstan. The similar delays were reported in previous studies as well (Taylor et al., 2013, Cranney *et al*., 2007, De Rosa *et al*., 2004). Delay in diagnosis was common despite the range of symptoms experienced by participants. The symptoms were both classical including diarrhea, constipation, abdominal pain as well as atypical, such as iron deficiency, tiredness, dermatitis. Similar symptoms are reported in other studies (Taylor et al., 2013). However, none of the participants realized that they were experiencing symptoms of the chronic disease. This lack of awareness about celiac disease and its clinical manifestations may lead to the delay in diagnosis, as also reported by Ciacci *et al*., 2003. Another reason for the long delay in diagnosis is suggested by participants. All participants presumed lack of knowledge and low awareness of the celiac disease among health professionals leading to inability to recognize the symptoms as part of chronic illness.

This delay in diagnosis, as well as multiple visits to a doctor's office without recognition of illness often led to strong emotional response when it was confirmed. The most prevalent emotions were anxiety and fear, and relief. Anxiety was due to the chronic nature of the disease. The possible comorbidities, most commonly cancer, diabetes and infertility and often learned from the internet were frightening to the patients. Half of the respondents were relieved to learn that symptoms are manageable by diet. This is similar to the findings by Ciacci *et al*., 2003. One-third of the participants felt anger and frustration due to delayed diagnosis. They reported that the symptoms should have been recognized by doctors and the delay have impacted their budget, as well as physical and emotional well-being.

After learning diagnosis, all participants switched to a strict gluten-free diet. High adherence to the gluten-free diet is common (Cranney *et al*., 2007). However, the adaptation to a gluten-free diet was a challenge. During the time of diagnosis and adaptation to diet, constant support from family members and close friends was significantly helpful.

4.2. Impact of celiac disease on everyday life.

Adherence to the gluten-free diet improved the well-being of patients, similar to other reports (Hallert *et al*., 2003). However, living with celiac disease exposed them to new challenges.

Despite strict diet, all participants still experience periodic occurrences of symptoms. The symptoms occur when eating outside, usually because of cross-contamination with gluten, according to interviewees.

There was a number of factors leading to depression Anxiety and depression were prevalent among celiac people in previous studies (Zingone *et al*., 2015). One major factor for depression in Kazakhstan was the constant feeling of social isolation and unwanted attention to the disease. Inability to order food at restaurants/ cafes or take-outs lead to isolation from colleagues and friends. The need to explain the specifics of diet captured unwanted attention at work and restaurants, which led to embarrassment and misunderstanding. For instance, participants reported feeling awkward when refusing a piece of cake or pizza, and the trouble of explaining the disease. Another reason for depression was persistent anxiety about complications. Most participants learned about the disease through the internet and expected dire complications of celiac disease, such as cancer, autoimmune disease, and premature death. The constant fear for the future was reported as another cause of depression. Moreover, participants reported fear that children and siblings developing signs of celiac disease as a source of anxiety and depression. The fear of possible complications and family members getting celiac disease were also reported as common companions of disease in Ciacci *et al*., 2003.

Another common factor of depression was constant frustration with the prices of gluten-free products and the limited choice of those on the market. Expensive prices of gluten-free products, as well as the continuous requirement of other medical supplements, led to economic burden. If a child was diagnosed with celiac disease as well, one of the parents had to quit work, exacerbating household income. Participannt felt fear of not being able to provide for the family with required products. The economic burden of celiac disease was studied in other countries extensively (Mearns *et al.,* 2019). Similarly to findings of this study, Mearns *et al* concluded that gluten-free diet was economically challenging in number of countries.

One of the most stressed points of interviews was the absence of medical and community support for celiacs. Adults diagnosed with disease reported no medical follow-up after diagnosis. Respondents were highly dissatisfied that celiac disease was not recognized as a disability. Also, participants pointed out that patients were not provided with governmental help, unlike in diabetes. Interviewee complained that medical personnel and paramedics were unaware of how to deal with symptoms and illnesses in celiacs. Participants indicated that the Internet was the only source of information in dealing with disease and wished that they were able to ask a person for help. Presence of a supporting community was proven to be very helpful in other countries (Violato *et al.*, 2012, Taylor et al., 2013).

4.3. Barriers to maintaining gluten-free diet.

There were three obstacles to maintain a gluten-free diet. As mentioned before, the expensiveness of gluten-free products was a major challenge. The products are imported from Russia and European countries. Thus there is a small assortment with increased cost. The limited choice of gluten-free products on the market was also reported as a challenge to maintaining the diet. In addition, there is no available menu for celiacs at public places, such as café, restaurants. Moreover, gluten-free products were reported to have undesirable texture and taste. Bakery, pasta made of corn, rice and buckwheat were crumbly with unwanted taste. This poor taste and texture was an issue during adaptation to a gluten-free diet.

5. Conclusion.

There were many studies exploring the experience of living with celiac disease using qualitative methods in European countries, Australia and North America (Rose and Howard, 2014, Almagro *et al.*, 2016, Sverker *et al.*, 2007). However, this study is the first of its kind in Kazakhstan, and to our knowledge in Central Asia and post-soviet region. This research explains how people with celiac disease in Kazakhstan cope with illness and demonstrates main issues in dealing with disease and maintaining gluten-free diet. The findings of this study may guide future research, and help design interventions to improve the quality of life of these patients.

A lack of awareness of the celiac disease and its signs and symptoms in the general population leads to delay in diagnosis. A study to assess awareness among medical professionals is required as well. Awareness in population and medical professionals may be increased by awareness campaigns, similar to reported in Taylor *et al.*, 2013. Low awareness in healthcare professionals leads to poor monitoring of patients, which will be solved by continuous training. Increased public awareness of celiac disease will also help with social isolation and unwanted attention, persistent in patients with celiac disease. This will encourage celiacs to socialize with friends and colleagues, improving their mental health.

Production of domestic certified gluten-free products may increase the availability of food on the market. Moreover, adjusted recipes for taste and texture preferences may help in transitioning to a gluten-free diet.

In addition, there is need in research in the economic burden of celiac disease to society, including direct and indirect costs associated with illness. For instance, whether screening of suspected patients would be more cost-efficient than dealing with symptoms, quality-adjusted life years, absences from school and work. Introduction of serological screening in suspected patients may help with earlier diagnosis and treatment of celiac disease.

A supporting society for diagnosed with celiac disease proved to play a fundamental role in helping patients to cope with the disease (Taylor *et al.*, 2013, Almagro *et al.*, 2018). The absence of such society in Kazakhstan, in addition to absence of medical follow up, patients are turning to the Internet for support and advice. Creating such an organization should provide the necessary support for celiacs and their families. Due to bureaucratic complication in creating such an organization, a short-term solution would be launching an online application in lieu of a society. This application may unite people with celiac disease over Kazakhstan, and maybe Russian speaking countries and give them an opportunity to speak to each other, help with advice and coping strategies, and share information about gluten-free products available on market and restaurants offering options with specific diets.

However, there are some limitations to this study. Due to the qualitative nature of the research, the results are not generalizable to the entire population. Also, there was a purposive sampling of patients of clinics in Nur-sultan (previously Astana). People with celiac disease in other cities and urban areas of Kazakhstan may not have similar resources for diagnosis, support, and maintaining a gluten-free diet. Further research is required including people with celiac disease from different regions of the country. Understanding what these patients with celiac disease are going through will help address one of the key functions of public health, improve the quality of life of these citizens.

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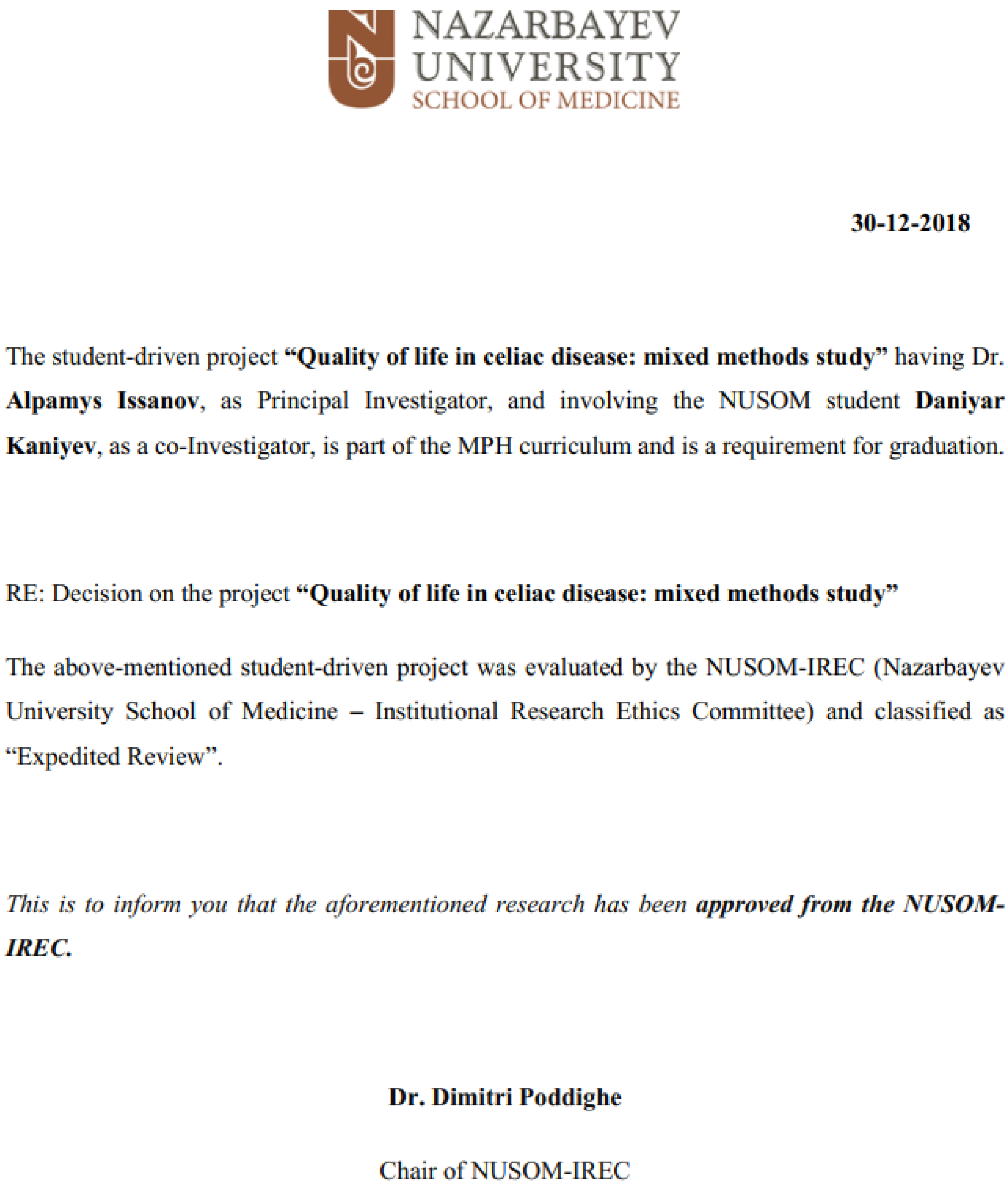
Appendix 1. Ethical approval.



NAZARBAYEV
UNIVERSITY
SCHOOL OF MEDICINE

30-12-2018

The student-driven project **"Quality of life in celiac disease: mixed methods study"** having Dr. **Alpamys Issanov**, as Principal Investigator, and involving the NUSOM student **Daniyar Kaniyev**, as a co-Investigator, is part of the MPH curriculum and is a requirement for graduation.

RE: Decision on the project **"Quality of life in celiac disease: mixed methods study"**

The above-mentioned student-driven project was evaluated by the NUSOM-IREC (Nazarbayev University School of Medicine – Institutional Research Ethics Committee) and classified as "Expedited Review".

This is to inform you that the aforementioned research has been ***approved from the NUSOM-IREC.***

Dr. Dimitri Poddighe

Chair of NUSOM-IREC

Appendix 2. Script for informed consent in English.

Living with celiac disease in Kazakhstan: a qualitative study
Researcher: Daniyar Kaniyev

Oral Consent Script

Introduction:

Hello. I'm Daniyar Kaniyev. I am conducting interview about Quality of life in celiac disease. I'm conducting this as part of research for Master's thesis at Nazarbayev University's School of Medicine, Public health program.

I located/found your name by searching for potential participants in one of the medical centers in Astana, and social groups dedicated to celiac disease.

Study procedures:

I'm inviting you to do an interview that will take about 30 minutes. The survey will ask you questions about your experience living with celiac disease such as "how did you feel, when you were diagnosed with the celiac disease?" or "what are the main barriers in following gluten-free diet?"
Risks:

*The risks of the interview are not higher than everyday risks. The questions in this interview will not be personal, nor sensitive. However, please note that, y*ou do not need to answer questions that you do not want to answer or that make you feel uncomfortable. The interview will be audio recorded. The recordings will be transcribed verbatim and after that destroyed. You can withdraw (stop taking part) at any time.
I describe below the steps I am taking to protect your privacy. The names or personal data that could identify you will not be recorded in this interview or in the research. Any identifiable information will be deleted. The transcript of the interview will be stored in an encrypted file on a personal computer protected with a password.

Benefits:

It is unlikely that there will be direct benefits to you, however, by better understanding experience of someone with celiac disease researchers and others may be able to address the main issues that people with celiac disease struggle the most.
I will keep the information you tell me during the interview confidential. Information I put in my report that could identify you will not be published or shared beyond the research team unless we have your permission. Any data from this research which will be shared or published will be the combined data of all participants. That means it will be reported for the whole group not for individual persons

Voluntary participation:

- Your participation in this study is voluntary.
- You can decide to stop at any time, even part-way through the questionnaire for whatever reason.

- If you decide to stop participating, there will be no consequences to you.
- If you decide to stop we will ask you how you would like us to handle the data collected up to that point.
- This could include returning it to you, destroying it or using the data collected up to that point.
- If you do not want to answer some of the questions you do not have to, but you can still be in the study.
- If you have any questions about this study or would like more information you can call or email Daniyar Kaniyev at *8702 943447* or daniyar.kaniyev@nu.edu.kz .

This study has been reviewed and cleared by the Nazarbayev University Institutional Research Ethics Committee. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

Nazarbayev University Institutional Research Ethics Committee
E-mail: resethics@nu.edu.kz

Consent questions:

- Do you have any questions or would like any additional details? *[Answer questions.]*

- Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you?

[If yes, begin the interview.]
[If no, thank the participant for his/her time.]

Appendix 3. Script for informed consent in Russian.

Living with celiac disease in Kazakhstan: a qualitative study
Researcher: Daniyar Kaniyev

Вступление:

Здравствуйте, меня зовут Данияр Каниев. Я студент магистратуры факультета общественного здравоохранения в Медицинской школе Назарбаев Университета.

Я провожу исследование на тему «Качество жизни больных целиакией».
Цель исследования состоит в том, чтобы оценить качество жизни людей, страдающих целиакией, понять какие основные проблемы возникают в повседневной жизни, а также в соблюдении безглютеновой диеты.

Учебные процедуры:

Исследование включает в себя индивидуальное интервью и/или опросник, состоящий из демографической информации и 32 вопросов, связанных с качеством жизни. Интервью продлится около 30 минут и более. Вопросы на данном интервью будут интересоваться вашим опытом жизни с целиакией.

Риски:

Риски при проведении интервью не выше повседневных. Вопросы в этом интервью не будут ни личными, ни чувствительными. Однако обратите внимание, что вам не нужно отвечать на вопросы, на которые вы не хотите отвечать или которые вызывают у вас дискомфорт. Интервью будет записано на аудио, при вашем согласии. Записи будут расшифрованы дословно и после этого уничтожены. Вы можете прекратить участие в исследовании в любое время, без необходимости объяснять ваше решение.
Ниже я опишу шаги, которые будут предприняты для защиты вашей конфиденциальности. Имена или личные данные, которые могут идентифицировать вас, не будут записаны в этом интервью или в исследовании. Любая идентифицируемая информация будет удалена. Стенограмма интервью будет храниться в зашифрованном файле на персональном компьютере, защищенном паролем.

Выгода:

Маловероятно, что вы получите прямую выгоду, однако, благодаря лучшему пониманию опыта жизни с целиакией, данное исследование может иметь выгоду для всех людей, больных целиакией в Казахстане. Я буду держать в тайне информацию, которую вы мне скажете во время интервью. Информация, которую я внесу в свой отчет, которая может идентифицировать вас, не будет опубликована или передана за пределы исследовательской группы, если у нас нет вашего разрешения.

Добровольное участие:

- Ваше участие в этом исследовании является добровольным.
- Вы можете решить прекратить участие в любое время по любой причине.
- Если вы решите прекратить участие, для вас не будет никаких последствий.
- Если вы решите остановиться, мы спросим вас, как бы вы хотели, чтобы мы обрабатывали данные, собранные до этого момента.
- Это может включать возврат вам, уничтожение или использование данных, собранных до этого момента.

- Вы можете не отвечать на некоторые вопросы, но вы все равно можете участвовать в исследовании.
- Если у вас есть какие-либо вопросы по поводу этого исследования или вы хотите получить дополнительную информацию, вы можете позвонить или написать Данияру Каниеву по электронной почте daniyar.kaniyev@nu.edu.kz., или по номеру 8702 943447.

Это исследование было рассмотрено и одобрено Комитетом по этике институциональных исследований Назарбаев Университета. Если у вас есть вопросы или сомнения относительно ваших прав как участника или способа проведения исследования, вы можете связаться с Комитетом по этике институциональных исследований Назарбаев Университета Электронная почта: resethics@nu.edu.kz

Согласие участника исследования:

• У вас есть какие-либо вопросы или вы хотели бы получить дополнительную информацию?

• Согласны ли вы участвовать в этом исследовании, зная, что вы можете отказаться от участия в любой момент без каких-либо последствий для вас?

[Если да, начните интервью.]

[Если нет, поблагодарите участника за его / ее время.]

Appendix 4. Script for informed consent in Kazakh.

Қазақстандағы целиакиямен өмір: сапалы зерттеу

Ғылыми Қызметкер: Данияр Каниев

Кіріспе:

Сәлеметсіз бе, Менің атым Данияр Каниев. Мен Назарбаев Университеттің Медициналық мектебіндегі. "Қоғамдық денсаулық сақтау" факультетінің магистрантпын.

Мен "целиакиямен ауыратын науқастардың өмір сүру сапасы" тақырыбына зерттеу жүргіземін.

Зерттеудің мақсаты целиакиядан зардап шегетін адамдардың өмір сүру сапасын бағалау, күнделікті өмірде қандай негізгі проблемалар туындағанын түсіну, сондай-ақ глютенсіз диетаны сақтау болып табылады.

Оқу рәсімдері:

Зерттеу демографиялық ақпараттан және өмір сүру сапасына байланысты 32 сұрақтан тұратын жеке сұхбатты және/немесе сауалнаманы қамтиды. Сұхбат 30 минут және одан да көп уақытқа созылады. Бұл сұхбаттағы сұрақтар целиакиямен өмір сүру тәжірибесімен қызықтырады.

Тәуекелдер:

Сұхбатты өткізу кезіндегі тәуекелдер күн тәртібінен жоғары емес. Бұл сұхбаттағы сұрақтар жеке да, сезімтал да болмайды. Алайда, сіз жауап бергісі келмейтін немесе ыңғайсыздық тудыратын сұрақтарға жауап берудің қажеті жоқ екенін ескеріңіз. Сұхбат сіздің келісуіңіз кезінде аудио жазылатын болады. Жазбалар сөзбе-сөз жазылып, содан кейін жойылады. Сіз кез келген уақытта зерттеуге қатысуды тоқтата аласыз.

Төменде мен құпиялылықты қорғау үшін жасалатын қадамдарды сипаттаймын. Сізді анықтайтын аттар немесе жеке деректер осы сұхбатта немесе зерттеуде жазылмайды. Кез келген сәйкестендірілген ақпарат жойылады. Сұхбат стенограммасы құпия сөзбен қорғалған жеке компьютерде шифрланған файлда сақталады.

Пайда:

Дегенмен, целиакиямен өмір сүру тәжірибесін жақсы түсінудің арқасында бұл зерттеу Қазақстандағы целиакиямен ауыратын барлық адамдар үшін пайда болуы мүмкін. Мен сұхбат кезінде айтып жатқан ақпаратты құпия ұстап аламын. Егер бізде сіздің рұқсатыңыз жоқ болса, сізді анықтауға болатын өз есебіне енгізетін ақпарат жарияланбайды немесе зерттеу тобының шегінен тыс берілмейді.

Ерікті қатысу:

- Сіздің бұл зерттеуге қатысуыңыз ерікті.
- Сіз кез келген себеппен кез келген уақытта қатысуды тоқтатуға шешім қабылдай аласыз.
- Егер сіз қатысуды тоқтату туралы шешсеңіз, Сіз үшін ешқандай салдары болмайды.
- Егер сіз тоқтауды шешсеңіз, біз осы кезге дейін жиналған деректерді өңдеп қалағымыз келеді.
- Бұл сізге қайтару, осы уақытқа дейін жиналған деректерді жою немесе пайдалану қамтуы мүмкін.
- Сіз кейбір сұрақтарға жауап бере алмайсыз, бірақ сіз әлі де зерттеуге қатыса аласыз.
- Егер сіз осы зерттеуге қатысты қандай да бір сұрақтарыңыз болса немесе қосымша ақпарат алғыңыз келсе, Данияр Каниевке электрондық пошта арқылы қоңырау шалып немесе жаза аласыз daniyar.kaniyev@nu.edu.kz., немесе 8702 943447 нөмірі бойынша.

Бұл зерттеу Назарбаев Университетінің Институционалдық зерттеулер этикасы жөніндегі Комитетімен қаралып, мақұлданды. Егер сіз зерттеу жүргізу әдісі немесе қатысушы ретінде сіздің құқықтарыңызға қатысты сұрақтарыңыз немесе күмәндарыңыз болса, Сіз Назарбаев Университетінің Институционалдық зерттеулер Әдеп жөніндегі Комитетімен хабарласа аласыз

Электрондық пошта: resethics@nu.edu.kz

Зерттеуге қатысушының келісімі:

• Сізде қандай да бір сұрақтар бар ма немесе қосымша ақпарат алғыңыз келе ме?

• Сіз үшін қандай да бір салдарсыз кез келген уақытта қатысудан бас тарта алатыныңызды біле отырып, осы зерттеуге қатысуға келісесіз бе?

[Иә болса, сұхбатты бастаңыз.]

[Жоқ болса, қатысушыға оның уақыты үшін алғыс айтыңыз.]

Appendix 5. In-depth semi-structured interview guide in English.

1. Tell me about when you first suspected that something was wrong?
   (possible follow-up)
   a. Did you have symptoms of celiac disease when you were a child?
   b. What symptoms were most often observed before you were diagnosed with celiac disease?
2. Can you tell me about the process that you went through to get your diagnosis?
   a. When were you diagnosed with celiac disease and how was it diagnosed?
   b. How did you feel about the diagnosis?
   c. What has changed in your life after receiving the diagnosis?
3. How does coeliac disease impact on your life?
   a. What are the most important changes in your life with celiac disease?
   b. What are the most unpleasant symptoms of celiac disease? How often do you have these symptoms?
      i. Other symptoms?
   c. The most difficult part of life with celiac disease? Other problems?
   d. Does the disease have any impact on your travels (trips)? work? Making plans where you should eat or buy food?
   e. Impact on social activity? Avoidance of social activity?
   f. Is there a positive side to living with celiac disease?
4. How have your friends and family reacted to your diagnosis?
   a. Did you tell your colleagues, friends, and family members about your diagnosis? What was their reaction?
   b. Do you feel misunderstanding with your friends? Relatives? Colleagues?
   c. Do you feel support from your friends / relatives / colleagues? How does support help you in this situation?
   d. Do you feel that people around you do not understand your illness?
5. How, if at all, has coeliac disease impacted on your emotional health or well-being?
   a. Do you have concerns about your health due to celiac disease? Or are you worried that you will have complications?
   b. Do you have concerns that your relatives (possibly children) will get celiac disease?
   c. Do you have concerns that your relatives (possibly children) will get celiac disease?
   d. Does it seem to you that you are getting undue attention because of celiac disease? Does that bother you?
6. What are your experiences in needing to follow a gluten-free diet?
   a. What are the problems in following a gluten-free diet?
   b. Is it hard to get gluten free products? Make an order in a restaurant?
   c. Are gluten-free products different from gluten-containing foods?
   d. Do you like the taste and texture of gluten-free products? Why or why not?
   e. Are you worried about contamination of your food with gluten? How often do you come across such a thing?

7. How would you describe living with coeliac disease to somebody who has just been diagnosed?

Appendix 6. In-depth semi-structured interview guide in Russian.

1. Расскажите мне, когда вы начали впервые подозревать, что что-то не так?

    Возможные последующие вопросы:
    а. Были ли у Вас симптомы целиакии, когда вы были ребенком?
    б. Какие симптомы чаще всего наблюдались до того, как вы были диагностированы целиакией?

2. Можете ли вы рассказать мне о процессе, который вы прошли, чтобы получить свой диагноз?

    а. Когда вам поставили диагноз целиакии и как его установили?

    б. Как вы себя чувствовали, узнав о диагнозе?

    в. Что изменилось в Вашей жизни после получения диагноза?

3. Как целиакия влияет на вашу жизнь?

    а. Какие наиболее важные изменения случились в вашей жизни с целиакией?

    б. Каковы наиболее неприятные симптомы целиакии? Как часто у Вас проявляются эти симптомы?

    в. Самая сложная часть жизни с целиакией? Другие проблемы?

    г. Имеет ли заболевание какое-либо влияние на ваши путешествия (поездки)? работу? Составление планов, где вы должны есть или купить еду?

    д. Влияние на социальную активность? Избегать социальной активности?

    е. Есть ли положительные стороны жизни с целиакией?

4. Как ваши друзья и родственники отреагировали на ваш диагноз?

    а. Вы рассказывали о своем диагнозе Вашим коллегам, друзьям, членам семьи? Какая реакция была у них?

    б. Чувствуете ли вы непонимание у своих друзей? Родственники? Коллеги по работе?

    с. Вы чувствуете поддержку со стороны своих друзей / родственников / коллег? Как поддержка помогает вам в этой ситуации?

    д. Чувствуете ли вы, что окружающие люди не понимают Вашу болезнь?

5. Как целиакия влияет на ваше эмоциональное здоровье или благополучие?

    а. У вас возникает обеспокоенность о вашем здоровье из-за целиакии? Или вы обеспокоены тем, что у вас будут осложнения?

    б. У вас есть опасения, что ваши родственники (возможно, дети) заболеют целиакией?

    в. Вы предпочитаете избегать социальной активности из-за болезни? Вы чувствовали себя расстроенными из-за этого? Депрессию? Изолированными от общества?

д. Вам кажется, что вы получаете излишнее внимание из-за целиакии? Это смущает Вас?

6. Каков ваш опыт в необходимости следовать безглютеновой диете?

   а. Каковы проблемы в следовании безглютеновой диете?

   б. Трудно ли получить безглютеновую продукцию? Сделать заказ в ресторане?

   в. Отличается ли безглютеновые продукты от продуктов, содержащих глютен?

   г. Вам нравится вкус и текстура безглютеновой продукции? Почему или почему нет?

   д. Вы беспокоитесь о заражении вашей еды глютеном? Как часто вы сталкиваетесь с подобным явлением?

7. Как бы вы описали жизнь с целиакией для кого-то, кто только что был диагностирован?

Appendix 7. In-depth semi-structured interview guide in Kazakh.

1.Сіз алғаш рет бір нәрсе емес деп күдіктеніп бастаған кезде маған айтып беріңізші?

Мүмкін келесі сұрақтар:

а. Сіз бала болған кезде целиакия белгілері болды ма?

б. Целиакия диагностикаланғанға дейін қандай симптомдар жиі байқалды?

2. Сіз диагнозды алу үшін өткен процесс туралы айтып бере аласыз ба?

а. Целиакия диагнозын қашан қойды және оны қалай қойды?

б. Диагноз туралы білу арқылы өзіңізді қалай сезіндіңіз?

в. диагноз алғаннан кейін сіздің өміріңізде не өзгерді?

3. Целиакия сіздің өмір әсер етеді қалай?

а. Целиакиямен өміріңізде қандай маңызды өзгерістер болды?

б. Целиакияның ең жағымсыз белгілері қандай? Бұл белгілер жиі кездеседі?

в. целиакиямен өмірдің ең күрделі бөлігі? Басқа мәселелер?

г. сіздің саяхатыңызға (сапарларыңызға) қандай да бір ауру әсер ете ме? ? Жоспар құру, онда сіз жеуге немесе сатып алу?

д. әлеуметтік белсенділікке әсері? Әлеуметтік белсенділіктен аулақ болу керек пе?

е. целиакиямен өмірдің оң жақтары бар ма?

4. Сіздің достарыңыз бен туыстарыңыз диагнозға қалай жауап берді?

а. Сіз өз диагнозыңызды әріптестеріңізге, достарыңызға, отбасы мүшелеріне айтыныз ба? Оларда қандай жауап болды?

б. Достарыңыздың түсінбеуін сезінесіз бе? Туыстары? Жұмыс бойынша әріптестер?

в. сіз достарыңыз / туыстарыңыз / әріптестеріңіз тарапынан қолдауды сезінесіз бе? Бұл жағдайда қолдау қалай көмектеседі?

г. сіз қоршаған адамдар сіздің ауруыңызды түсінбейсіз бе?

5. Целиакия сіздің эмоционалдық саулығыңызға немесе әл-ауқатына қалай әсер етеді?

а. Целиакия сіздің денсаулығыңыз туралы алаңдаушылық бар ма? Немесе сіз асқынулар болады деп алаңдаасыз ба?

б. Сіздің туыстарыңыз (мүмкін балалар) целиакиямен ауырады деген қауіптеріңіз бар ма?

в. сіз аурудың салдарынан әлеуметтік белсенділікке жол бермеуді қалайсыз ба? Сіз бұл үшін ренжіген сезіндім? Депрессия? Қоғамнан оқшауланған?

6. Глютенсіз диетаны ұстануға сіздің тәжірибеңіз қандай?

a. Қандай проблемалар жүруі диеталар безглютеновой?

б. Глютенсіз өнімді алу қиын ба? Мейрамханада тапсырыс беру керек пе?

в. глютенсіз өнімдер құрамында глютен бар өнімдерден ерекшеленеді ма?

г. сіз глютенсіз өнімнің дәмі мен құрылымы ұнайды ма? Неге немесе неге жоқ?

d. сіз сіздің тағамды глютенмен жұқтыру туралы алаңдаасыз ба? Сіз бұл фактіні жиі кездестіресіз бе?

7. Сіз целиакиямен өмірді қалай сипаттаған еді, кім ғана диагноз қойды?