

Psychosocial impact of celiac disease diagnosis on patient's quality of life in Armenia: A qualitative study

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Table of Contents

<i>List of abbreviations</i>	<i>iv</i>
<i>Acknowledgments</i>	<i>v</i>
1. Abstract	<i>vi</i>
2. Literature Review	<i>1</i>
2.1 Introduction	<i>1</i>
2.2 Psychological burden of celiac disease	<i>4</i>
2.3 Study Aim and Research Question	<i>7</i>
3. Methods	<i>7</i>
3.1 The study setting and participants	<i>7</i>
3.2 Study design	<i>7</i>
3.3 Study Instrument	<i>8</i>
3.4 Data collection and analysis	<i>8</i>
3.5 Ethical considerations	<i>9</i>
4. Results	<i>10</i>
4.1 Theme 1. Symptoms	<i>11</i>
4.2 Theme 2 Difficulties of getting the diagnosis	<i>12</i>
4.3 Theme 3. Gluten-free diet	<i>13</i>
4.3.1 Difficulties of keeping a gluten-free diet	<i>13</i>
4.3.2 Misconceptions of the disease	<i>15</i>
4.3.3 Eating outside home	<i>15</i>
4.3.4 Cross-contamination	<i>16</i>
4.4 Theme 4. Emotional health	<i>17</i>
4.4.1 Unwanted visibility	<i>17</i>
4.4.2 Feelings	<i>18</i>
4.4.3 Concerns and worries	<i>19</i>
4.4.4 Isolation and exclusion	<i>19</i>
4.5 Theme 5. Relationship	<i>21</i>
4.5.1 Lack of understanding	<i>21</i>
4.5.2 Support	<i>22</i>
4.6 Theme 6. Financial issues	<i>23</i>
4.7 Theme 7. Suggestions for the future	<i>25</i>
4.7.1 Raising Awareness	<i>25</i>
4.7.2 Experience sharing	<i>25</i>

<i>5. Discussion</i>	26
<i>6. Conclusion</i>	33
<i>References</i>	34
<i>Table 1. Qualitative interview themes and subthemes</i>	38
<i>Table 2. Demographic characteristics of the study participants</i>	39
<i>Table 3. Identified themes and subthemes</i>	40
<i>Appendix 1. Study guide</i>	41
<i>Appendix 2 Demographic questionnaire</i>	47
<i>Appendix 3 Demographic data collection form</i>	49
<i>Appendix 4. Consent form</i>	50
<i>Diagram 1. Wheat consumption and production in different parts of the world</i>	53
<i>Diagram 2. Volume of cereals used for feed and food in Armenia</i>	54
<i>List of Appropriate Journals</i>	55

List of abbreviations

CD – Celiac Disease

GF- Gluten free

GI - Gastrointestinal

Anti-tTG - Anti-tissue transglutaminase

Anti-EMA - Anti-endomysial antibodies

IgG - Immunoglobulin G

Ig A – Immunoglobulin A

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1. Abstract

Introduction: Celiac disease (CD) is an autoimmune disorder that needs a lifelong gluten-free (GF) diet. Gluten is a protein found in wheat, barley, rye, malt, and oat. 50% of food consumption in Armenia consists of staples, including cereals, wheat bread, in particular, potatoes, rice, and pasta. Due to the CD, patients should follow a strict diet rest of their lives, which causes a huge psychological burden on the patients and creates many difficulties in various life spheres.

Aim: The study aimed to understand the disease-related experiences of people who got a CD diagnosis and the difficulties that Armenian patients could face after being diagnosed with CD.

Methods: The study population were patients 18 years and over who were diagnosed with CD either by serology testing or by intestinal biopsy and could read and understand Armenian. The study participants were chosen using convenience and snowball sampling. The participants were identified using the personal network of the student researcher. The study applied a qualitative research method through in-depth interviews. The data was transcribed verbatim, and a thematic analysis was conducted. As an analytical approach, the combination of inductive and deductive methods was used. During the data collection, to address researcher's reflexivity research diary was kept, also to increase credibility and trustworthiness of the study findings member checking technique applied.

Results: Overall, 14 face-to-face interviews were conducted. The majority of the participants passed a challenging path to get their diagnosis, spending two years on average. Most of the participants mentioned about difficulties of keeping a gluten-free diet because of the low availability of gluten-free food in Armenia, issues with food labeling, and cross-contamination. For participants, getting the diagnosis was very stressful and emotionally

hardly acceptable; they felt isolated, stigmatized, and depressed. The majority of the participants faced financial difficulties after the diagnosis.

Conclusion: The findings suggested that although there were some choices of GF food in Armenia, these were expensive, not accessible for all patients, and available only in some stores. To mitigate the effect of CD diagnosis on patients' quality of life, the following recommendations have been developed: launching some awareness rising activities that will help to increase the Armenian community's knowledge about the disease and the GF diet; creating an online platform for CD patients for experience sharing; and finding local food brands that will agree to produce some cheaper choices of GF food.

Keywords: Celiac disease, gluten-free, psychological impa

2. Literature Review

2.1 Introduction

Celiac disease (CD) is an autoimmune disorder that needs a lifelong gluten-free (GF) diet¹. To have a label GF, the food should contain less than 20 ppm (parts per million) presence of gluten, which is a FDA approved limit². Gluten is a protein found in wheat, barley, rye, malt, and oat³. CD has a genetic predisposition factor, DQ2, DQ8 gens, but to develop the clinically manifest disease, some triggers are needed including pregnancy, childbirth, viral infection, or emotional stress.^{4,5,6} In other words, it is a multifactorial disease. It has gastrointestinal (GI) and not gastrointestinal manifestations. As GI symptoms, the patients most frequently mention stomach pain, bloating, constipation, and diarrhea; as non-GI symptoms, they mention fatigue and headaches.⁷

A recent comprehensive study and meta-analysis found that according to positive anti-tissue transglutaminase (anti-tTG) and/or anti-endomysial (anti-EMA) antibody findings, the global prevalence of CD was 1.4 percent, and 0.7% worldwide prevalence based on biopsy-confirmed cases⁸. (0.6% vs 0.4%; $P < 0.001$)⁸. “The prevalence values for celiac disease were 0.4% in South America, 0.5% in Africa and North America, 0.6% in Asia, and 0.8% in Europe and Oceania ”⁸. Females had a greater disease frequency than males. According to the meta-analysis, a biopsy-confirmed CD is twice as frequent in children as it is in adults (0.9% vs 0.5%; $P < 0.001$)⁸.

The CD is associated with various complications, especially when undiagnosed, misdiagnosed or without adherence to a GF diet after diagnosis. Continuous damage of intestinal tract with auto antibodies can result in malnutrition, which would lead to anemia and weight loss, also growth restriction and short stature in children. As a result of malnutrition, there can be deficiency of vitamin D, Ca, which can cause rickets,

osteomalacia in children and osteoporosis in adults. Also, if left untreated, it affects reproductive system resulting in miscarriages and infertility. One of the worst consequences of the disease is that it could cause intestinal lymphoma and small bowel cancer if not maintaining a GF diet^{9,10}.

Diagnosing Celiac disease starts from identifying the medical history and conducting a physical examination of the patient. Then a screening test is used to detect the disease-specific antibodies: anti-tTG Immunoglobulin A (IgA) or anti-EMA IgA, and the total IgA . If there is a selective IgA deficiency, instead of IgA test, Immunoglobulin G (IgG) tests should be used. The gold standard test for determining the definitive diagnosis of CD is an intestinal biopsy. Specific findings of intestinal biopsy that are pathognomonic for CD are intestinal villa atrophy, crypt hyperplasia and increased number of intra-epithelial lymphocytes¹¹. However, in some cases, when a very high titer of anti-TG IgA is detected (> 10 times the upper limit of the normal), the biopsy can be omitted. Other reasons for omitting biopsy in practice are the instances when endoscopy is impossible or there are no qualified pathologists available¹².

For 35% of the world's population, wheat is considered a staple crop. Nowadays, there is an increasing demand for wheat products, especially in countries undergoing industrialization and urbanization¹³. Global wheat consumption rates differ in different parts of the world; “the highest annual per capita food demand for wheat is in Central Asia (171 kg) followed by North Africa (165 kg), West Asia (122 kg), and Eastern Europe and Russia (120 kg).”¹⁴ Wheat accounts for around 47 % of daily calories in Central Asia, and 40-43% of proteins come from wheat in North Africa and West Asia.¹⁴Wheat is a major source of nutrients and calories in the diets of South Asia (20–24%) as well as Eastern Europe and Russia (28–29%). Also, China and India use 17–18 percent of world wheat.¹³ (Diagram1). In low and moderate-income countries Wheat provides about 500 kcal of energy per capita on daily

basis. Besides being a primary energy source, wheat also provides vitamins (mainly vitamin B), protein, and dietary fibers essential to people's healthy diet¹⁵. As a result of processing to make white bread, it loses vitamins, minerals and dietary fibers¹⁶, that is why in many countries there is a law of mandatory fortification of flour with at least folic acid and iron¹⁷. According to some study results, staple cereals will continue to supply 50% of daily calorie intake and protein in low- and middle-income countries until 2050¹⁴.

According to World Bank's 2018 upgrades, Armenia is categorized as a country with an upper-middle income.¹⁸, and almost 50% of food consumption in Armenia consists of staples¹⁹, which are cereals, wheat bread, in particular, potatoes, rice, and pasta²⁰. A study done in Armenia in 2013 found out the level of consumption of different cereals among Armenians¹⁷. In this study, the cereal group included wheat, rice, barley, rye, oats, maize (corn), and millet (gluten is found in wheat, barley, rye). The results showed that in the total annual supply of cereals, the wheat consumption was about 70%. Second, the most used cereal was barley (20 percent of the total cereal supply), mainly used for beer manufacturing²¹ (Diagram 2).

In some regions of Armenia, food insecurity is a huge problem. The study done in 2019 showed the national average level of food insecurity in Armenia is 16%, while it is 24.2% in Shirak, 22.6% in Tavush, and 19.5% in Lori²². Food insecurity is one of the main reasons for poor dietary intake and malnutrition among people who live in these regions. Given the high rates of food insecurity in the country, and the long-standing reliance on bread as a staple food and source of calories, it becomes even more difficult for poor people diagnosed with CD to get all needed nutrition for a healthy life. It becomes a major public health problem to find ways to make GF food available in the country and affordable for all CD patients.

2.2 Psychological burden of celiac disease

In recent decades, there has been increased interest among scientists, psychologists, and health care professionals in the psychological burden that celiac disease can cause due to the disease itself, also lifestyle changes that patients should keep. In these aspects, it is essential to understand celiac patients' perception of the disease and its symptoms and how a special diet can modify their health, everyday life activities, and the psychological effects of the GF diet. Due to the CD, patients should follow strict diet rest of their lives, which creates many difficulties in various life spheres. The new lifestyle affects the patient's quality of life, mostly negatively⁷. Therefore, this diagnosis has a major psychological impact on the patients. Most of them learn for the first time in their life that there is a diagnosis named CD or gluten-sensitive enteropathy, which demands serious and life-long lifestyle changes. This creates a sense of fear and hopelessness among them³. People do not understand how the diagnosis will affect their health, and what to expect from the disease. The CD diagnosis and its treatment influence people's family life and relationships with family members³. It becomes a real problem when a patient is a mother of that family, who usually prepares food for all family members. Either she should prepare her food separately in new dishes, or the entire family should eat the same GF food. The issue is that the family members will not like the new taste of the food, or maybe they will want to eat the same things they used to, which may create some stress for the person with CD¹⁹. Perhaps, this is why many studies confirm that women with the disease are more prone to anxiety and depression²³. Besides all of these, the new condition impacts the person's social life and interactions³. Once they are aware of their diagnosis, in each place they visit (it can be a café, restaurant, grocery, etc.), they carefully look for something that they can eat or prepare food with, which is time-consuming and requires some planning skills²⁴. If the person who has a GF diet is invited to some social events and there is no available food, they can avoid going to such a meeting or

go but not enjoy it²⁵. Also another difficulty created with the disease is that if the food was not labeled as GF, the patients should carefully read the label on each packaged food and be familiar with ingredients which can contain gluten to avoid that particular product²⁶. Some studies showed that correctly understanding the food label was associated with good Adherence to GF diet, patients not knowledgeable in this sphere had persistent celiac symptoms even after following the GF diet^{27,28}.

The disease can create economic difficulties as well because GF food, as well as GF vitamins and/or food supplements to be taken daily, are more expensive and less accessible than the same items that are not GF²⁹.

The patients need to get their family members' and friends' support and understanding to have good adherence to their new diet, which is the only available way of treating the disease³⁰. Some studies show a negative impact of keeping a GF diet on different aspects of life, such as family events, traveling, dining out³¹. According to some studies, people diagnosed with celiac disease after 20 years of age had more problems in their social life, such as going out with friends, having some meetings with relatives and family members due to the stress of not consuming food that they used to. Also, they have reported that their high level of anxiety and depression was connected to feeling different from the others in their surroundings³².

A recent survey done in 2021 found out that celiac patients report difficulties with dating and it affects their intimate life. The study reported that half of the patients 18 years and older avoid dating. Also, 40 percent of the responders said that they feel uncomfortable because of the necessity to explain in the restaurants what GF food is and whether that place had special food for them or not. Some patients even reported that they had to eat gluten knowingly during dating only for not putting the person who invited them in an uncomfortable situation because there was nothing for them in the menu.³³

To analyze high anxiety and depression levels among celiac patients, it is important to understand when those psychological symptoms started, because besides the restrictions caused by the diagnosis of CD, the disease itself, if left unknown and untreated, may cause nervous system damage because of persistent symptoms and deficiency of many nutrients including vitamins³⁴. In many patients, depression already existed before the diagnosis due to many factors. First of all, these patients have various health issues and cannot understand their symptoms before the diagnosis. Usually, before getting the disease, they had passed much analysis, medical procedures, and repeated consultations, which could give them more worries. Also, the disease causes malabsorption of many essential macro and micronutrients needed for the body's normal functioning and predominantly impacts the nervous system³⁵. This means that these patients already had problems due to vitamin deficiency. The stress caused by the new diagnosis and the need for dietary restrictions can seriously affect a patient's quality of life. The high level of depression and fatigue also affects patients' adherence rate to treatment and dietary modifications³⁶. However, some studies suggest that starting a GF diet in some patients can improve depression and fatigue; maybe it is connected with the fact that the intestinal mucus starts to recover after dietary changes, and needed vitamins start to absorb³⁷.

Most studies for assessing Quality of Life in CD patients used instruments developed for other chronic diseases²². All health care providers working with celiac patients should be aware of all these issues that the disease and all the restrictions related to it can cause, to be able to support and give needed consulting to their patients.³⁸

This is the first study done in Armenia about CD, where there was a lack of information about the disease and its consequences. The study sought to discover the problems connected with CD diagnosis and identify issues that patients with this disease face in their

everyday lives, which can help to find solutions for these people and implement programs that can make these patients' lives less stressful.

2.3 Study Aim and Research Question

The study aimed to understand the disease-related experiences of people who got CD diagnosis and difficulties that Armenian patients might face after being diagnosed with CD.

The research questions that this study answered are:

- (1) What was the psychosocial impact of CD diagnosis on patient's quality of life in Armenia?
- (2) What could be done to mitigate the psychosocial impact of CD among patients in Armenia?

3. Methods

3.1 The study setting and participants

The participants included patients living in Yerevan city and Armavir marz (this particular marz was selected for feasibility reasons). The study population was patients 18 and over, who were diagnosed with CD either by serology testing or by intestinal biopsy and could read and understand Armenian.

3.2 Study design

The study applied a qualitative research method through in-depth interviews with adults diagnosed with CD. The study participants were chosen using convenience and snowball sampling. The participants were identified using the personal network of the student researcher. By telephone calls, the potential participants were contacted to understand their willingness to participate in the program. The sample size was large enough to reach the needed data saturation level. The interviews were conducted face-to-face in a place

comfortable for the participant (workplace, house, university) after obtaining his/her oral informed consent to participate. The interviews were recorded with the agreement of the participants. To keep the confidentiality, the names of the patients were coded and only the ID number of the participant was written on the demographic questionnaire and on the written notes. Only the student researcher had access to the list of ID number-to-name matchups.

3.3 Study Instrument

An interviewer-administered celiac disease assessment guide with open-ended questions was developed (Appendix 1). For creating the interview guide, the themes identified during another qualitative study were used³⁹. These included six questions/domains regarding the celiac disease patient's quality of life (Table 1)³⁹. The developed guide modified after each interview as needed, based on the answers of participants, to better reflect the situation and the needs of the respondents. Besides the in-depth interview guide, a self-administered demographic questionnaire (Appendix 2) was used to get information about participants' age, sex, marital status, education, and years passed after the diagnosis. The demographic questionnaire was chosen as a result of a literature review from another qualitative study and modified according to this study²⁸. From these questionnaires, the data was transferred into Demographic data collection form (Appendix 3) and used for the analysis.

3.4 Data collection and analysis

The data collection started at the end of March 2022 and ended in the middle of April 2022. After finishing the interviews, the data was transcribed verbatim, codes were created according to the data, and a thematic analysis was conducted. As an analytical approach, the combination of inductive and deductive methods was chosen because there were preexisting themes that guided the analysis; also, findings after the interviews resulted in identification

of new themes. Using initial coding method, subthemes were identified according to data. The student-investigator, who worked with participants, conducted the interviews and did the analyses, completed the qualitative research methods course during her MPH studies. During the data collection, measures were undertaken to address reflexivity – to prevent the researcher's own thoughts and disease perceptions from affecting the study results, hence, the quality of collected data. This was particularly important as the student-investigator had a particular interest in CD for some personal reasons. These measures included keeping a researcher diary during the study to reflect participants' answers and the researcher's own opinions and thoughts, keeping a detailed history of the study, and providing the reference points when the opinion of the researcher was changed. All of these were used in the data analysis stage to enhance the interpretation of the study findings, minimize bias and increase the study's accuracy and credibility. Besides the researcher diary, the member checking technique was applied after each interview to further increase the trustworthiness of the findings and validity of the qualitative study.

3.5 Ethical considerations

The researcher applied for ethical approval to the AUA IRB and provided all the needed documents. Verbal informed consent (Appendix 4) was obtained from the participants before the interviews. They were informed that their participation is voluntary and that at any time; they can make a withdrawal from the study. They were also notified about the study confidentiality and that their personal information and recordings were kept in the documents with passwords, and only the student researcher had access to those files. After the research, all those files, including identifying information about the participants, were destroyed.

4. Results

Overall, 18 participants were contacted, and 14 agreed to participate. One participant refused to participate because she was uncomfortable speaking about her disease; one person had a very busy graphic and could not allocate time for the interview. Two people were not in the country at that time. The interviews lasted from 25 minutes to 1.5 hours. All interviews were face-to-face, and all were audio recorded. Seven interviews were conducted in a café, five in a library, one in the participant's workplace, one in the participant's house. All the participants were women. Their ages varied from 21 to 43, with the average being 26. Two participants were from Armavir Marz. The rest were from Yerevan. The time passed since the diagnosis ranged from two months to four years. The educational level of participants was the following: one had high school degree, one college, five had bachelor degree and seven had master degree. One of the participants was engaged, two of them were married and the rest were single (Table 2). Based on age, the participants were divided into young (30 years old or younger) and middle aged (over 30 years) categories. Based on the time passed since the diagnosis, they were divided into newly diagnosed (less than a year ago) and early diagnosed (more than a year ago) categories. These categories and the place of residence (Yerevan or Armavir) were used under each quote to describe the respondent.

As a deductive approach, following predefined themes were used: (1) symptoms, (3) gluten-free diet, (4) emotional health, (5) relationship and (6) financial issues. The data were additionally analyzed using an inductive approach, which resulted in the following new themes: (2) difficulties of getting the diagnosis and (7) suggestions for the future. The identified themes and subthemes are provided in Table 3.

4.1 Theme 1. Symptoms

The participants mentioned a wide variety of symptoms of the Celiac disease that they experienced but the most bothersome ones were nausea, which accompanied them all day, abdominal pain that created many difficulties with everyday life, and diarrhea or constipation, which were in some cases unbearable. There was a case when bloating was the most disturbing symptom, which forced her to apply to the doctor.

"The most common symptoms were bowel pain, nausea that I have had all my life, easy bruising, weakness, nausea, and constipation, which made my life very difficult."

(Middle aged, early diagnosed, Armavir)

"Nausea, I was already waking up with nausea, I also had diarrhea from time to time, I was generally weak, feeling very tired, and I was having steatorrhea lately."

(Young aged, newly diagnosed, Yerevan)

"Bloating, gases, pain in my abdomen, my abdomen was so swollen that people might think I was pregnant and it bothered me a lot, once they give me a place in the transport thinking I was pregnant. After that incident, I went to the doctor."

(Middle aged, early diagnosed, Yerevan)

All the participants mentioned that these symptoms created many problems in their lives, to the extent that they could not concentrate on their everyday activities, job, education, and family. The symptoms disturbed patients' daily lives; some of them could not continue their education and even dropped out of the university because of the symptoms. Some participants lost their job because of the disease. Relationships with friends also suffered for some respondents, partially because of the symptoms they experienced.

"My symptoms affected my daily life. Especially, my nervousness, and my bloating limited me from leaving my house. I was more isolated because of it, and I avoided any contact. I think I was depressed, and I quit my job during that time; I did not want to work."

(Young aged, early diagnosed, Armavir)

"It was the first year I went to university, and it coincided with the peak of my symptoms. I just could not go to class, and I left the university that year; I had constipation for 16 days, I felt terrible, and nothing helped me, even the laxatives. I was hired, and I lost my job, because it was impossible to leave the house."

(Young aged, early diagnosed, Yerevan)

4.2 Theme 2 Difficulties of getting the diagnosis

The participants passed a challenging path to get their diagnosis, and it took them from one month to seven years, in average 2 years and considerable expenses. Passing many diagnostic tests that did not give the desirable result was very stressful and overwhelming for most respondents. For several years, the respondents visited variety of specialists including gynecologists, gastroenterologists, and radiologists, underwent many unnecessary diagnostic tests and could not get their diagnosis. During those years they had received wrong diagnosis and even had taken wrong treatments that did not improve their health condition.

"It took six years; I consulted with different doctors; I visited gynecologists several times. Then they advised me to check my intestines. They did not really understand what I had; at first, I was diagnosed with dysbiosis. I had even received the treatment for it. Since my childhood, I have had anemia, and there was no cure for it, which made the last doctor I applied to think about sending me for a celiac test. Every visit to the hospital was a big stress for me."

(Young aged, early diagnosed, Yerevan)

"It took five years to get the diagnosis; first I passed the rotavirus analysis, then many blood tests, gastroscopy, all my tests came clean, five years ago I was diagnosed with dyspepsia, got the treatment, but the symptoms did not go, two years later I went to the doctor again, and that time they said that all my symptoms were coming from my nervous system. Then I kept a diet and excluded bread and sweets, and my symptoms completely disappeared, so I decided to get tested for celiac disease, and my diagnosis was confirmed."

(Middle aged, early diagnosed, Yerevan)

"Seven years, I went to different doctors who did not understand what I had, I gave blood tests, passed gastroscopy, and colonoscopy. I even underwent a CT scan of the whole body during that time, and seven years later, a doctor suspected celiac disease, and I had a gastroscopy then with a biopsy and got my diagnosis. All those tests and visits to doctors were very stressful for me and expensive."

(Young aged, early diagnosed, Yerevan)

4.3 Theme 3. Gluten-free diet

4.3.1 Difficulties of keeping a gluten-free diet

When speaking about the difficulties of keeping a GF diet, all respondents mentioned that there is a lack of assortment of GF products in Armenia. Also, the majority of them said that in our local food, there is no labeling on whether it contains gluten or not, so they did not know to buy it or not, but in many cases, they bought it on suspicion because there was no choice for celiac disease patients. There is a lack of knowledge about gluten and celiac disease among waiters in cafes and restaurants and sales assistants in the markets. Some participants also mentioned that some GF foods in our stores are less accessible for them, especially for people living in the marzes, because these foods are only available in big supermarkets located in the center of Yerevan.

"There are many problems in Armenia, first of all, there is no assortment here, we have no choice when visiting somewhere, there are about three types of products in stores where you can find a note "gluten-free" on the labels. These are placed in the section for diabetics. The workers lie in restaurants and cafes that the product does not contain gluten, but in fact it does."

(Middle aged, early diagnosed, Armavir)

"The choices of gluten-free food are small here; I know that in other countries there are even supermarkets with only gluten-free foods and only for that reason I will leave Armenia with great pleasure to improve my quality of life."

(Young aged, newly diagnosed , Yerevan)

"There is no labeling on Armenian products whether it contains gluten or not, and that makes my job very difficult, either I should not buy local products because there is a labeling problem, or I should buy with suspicion whether there was gluten in it or not; also the prices are very high for products that have a gluten-free label."

(Young aged, newly diagnosed, Yerevan)

"First of all, there is a minimal assortment of gluten-free food in our stores, and there is no gluten-free menu in restaurants; I can only find some gluten-free products in shops far from my house. For example, I have to drive for 40 minutes to reach such shop, and it is very time-consuming. Employees of other stores have no idea what gluten is, they can put wheat-containing bread in the gluten-free section, there was the case when I bought it by mistake."

(Young aged, early diagnosed, Yerevan)

"The lack of knowledge among the waiters is the first problem for me, when I ask whether the food contains gluten or not. They ask – what it is, and when you ask many questions to understand what the composition of the food is, they answer very roughly. There are not enough assortments in stores; whatever is available is placed in such an invisible part that even when you go for shopping, you feel isolated from the society, as out of 100 products, there are only three names of products for you."

(Middle aged, early diagnosed, Yerevan)

"I can find meat, vegetables, and fruits in the shops near our house, and I will not find any certified gluten-free food in the nearby shops."

(Young aged, early diagnosed, Yerevan)

4.3.2 Misconceptions of the disease

There were cases when the patients had a misconception of the disease, and first of all, it came from a lack of information that they got from their doctors. Some patients even understood that the GF diet they should keep is temporary and that after some period; the disease would be gone itself. Also, some of them did not know exactly which products contain gluten and what they should avoid in their whole life. Those of them who failed to follow a strict GF diet reported still experiencing some symptoms of the disease.

"I did not get any detailed information about the diet from the doctor, at first I was told that I cannot eat only wheat, barley and rye and I was even happy. I thought I could not eat only bread and cakes until I realized how many hidden sources of gluten there are, I understood from the beginning that gluten-free diet is temporary, not for whole life"

(Young aged, early diagnosed, Armavir)

"I read only whether there is wheat or barley in the ingredients part. I did not know that gluten can be in different additives and sauces; I only knew that it is in bread and pastries; I do not pay attention to anything else, and my symptoms continue to bother me even after keeping GF diet. "

(Middle aged, early diagnosed, Yerevan)

4.3.3 Eating outside home

Some respondents mentioned that they were doing some special preparations before going to an event where they were invited or they take some snack with them each time, because it is difficult to find something safe to eat when they are outside. Also, in some cases,

participants mentioned that these preparations were very time-consuming and created some difficulties.

"Of course, I do different things before I go somewhere; first I take my bread, put it in a bowl, bake or buy a cake to take with me, I always take chocolate, and we emphasize to the waiter in the restaurant that they bring my barbecue without bread (lavash), that it does not touch the barbecue, and I ask what is in the salads so that I can understand whether I can eat it or not. At first, all of these are very time-consuming and make me upset, but I have learned already how to plan everything."

(Young aged, early diagnosed, Yerevan)

"Especially I have a shortage of snacks in Armenia and I always have containers with almonds, walnuts, and chocolate with me to eat outside."

(Young aged, newly diagnosed, Yerevan)

4.3.4 Cross-contamination

Besides all the difficulties that celiac disease patients face in Armenia in keeping a GF diet, the respondents mentioned another issue: cross-contamination of the food. It is when during processing or cooking a naturally GF food, it is contaminated with gluten if GF and gluten-containing foods share the same environment. The majority of the participants mentioned that it is a real problem in Armenia because we do not have separate GF cafes or restaurants.

"Even at home, it was a little bit difficult to explain to my family members that the same knife, the spoon should not touch both the gluten-free and gluten-containing food. Outside home, it is a serious problem, you cannot know for sure whether all the safety rules were kept in the kitchen or not. In Armenian cuisine, lavash [Armenian national soft thin unleavened flatbread] is put under everything, even as a decoration."

(Young aged, newly diagnosed, Yerevan)

"There is no confidence in any food outlet that the food will not be contaminated with gluten, as there is no cafe or restaurant with only gluten-free menu in Armenia."

(Young aged, early diagnosed, Yerevan)

4.4 Theme 4. Emotional health

4.4.1 Unwanted visibility

The majority of participants faced problems when surrounding people did not understand their health issues. Sometimes they were forced to eat gluten-containing food; also, the respondents mentioned the difficulties they face when trying to answer some inappropriate questions that people ask when learning that they could not eat that particular food. Some participants felt uncomfortable speaking about their intestinal symptoms with unfamiliar people.

"It is challenging for me when people whom you do not want to tell about your illness, start forcing you to eat a little of that food, and there are even people whom I do not visit just because I do not want to explain them why I do not eat. And when telling about your problem, everyone asks what your symptoms are, but I do not want to share private information about my digestion, intestines."

(Young aged, newly diagnosed, Yerevan)

"I was initially psychologically stressed because no one around me had this problem, and with whom I was sitting at the table I had to explain and tell about my illness; it was challenging to explain especially to my grandmothers that even one piece of wheat-containing bread is dangerous for me."

(Young aged, newly diagnosed, Yerevan)

4.4.2 Feelings

There were very controversial answers about the feelings of the participant's when they first learned about their diagnosis and the way they perceived their disease. Some cannot accept their diagnosis even after one year; they also continue to break the GF diet once a month. There was a case when the participant was so irreconcilable with the diagnosis that she tried to find some treatment for the disease with the help of psychics and acupuncture. On the other hand, there were cases when people felt so bad and all that different symptoms affected their life so badly before the diagnosis that after the diagnosis, they felt relieved. Their symptoms disappeared after the GF diet that is why they have mentioned that the diagnosis gave the feeling that they are a healthy people.

"It was very stressful, especially when I went home and read what the disease was; I was depressed for a month, I felt like I was going to be hungry, there would be nothing for me to eat at home, and I would become someone trapped inside and isolated from others until I got used to the situation a little bit. I have been on a very strict gluten-free diet for six months, but now I break my diet once a month; I cannot restrain myself from breaking it."

(Young aged, early diagnosed, Yerevan)

"It is uncommon in our family to get sick, and the thought that I will have to live with this disease for the rest of my life depresses me a lot. I believe that I will be able to get rid of this disease. For example, once I went to a psychic. He told me that he would cure me, but the efforts were ineffective at that time. Now I'm thinking of going to acupuncture; maybe it will help, don't know."

(Middle aged, early diagnosed, Yerevan)

"At first, I was unfortunate because I like bread very much, but when I excluded gluten from my diet, I felt better and realized that I am healthy, which I had never felt."

(Middle aged, early diagnosed, Armavir)

4.4.3 Concerns and worries

The diagnosis had a strong impact on the participants. They have mentioned about their worries and psychological problems after the diagnosis. Some even said that they were crying all night thinking about their future, and even there were thoughts about committing suicide. Also, some of them found ways to cope with stress, like reading about the lives of famous people who also suffered from celiac disease.

"The diagnosis affected my psychological state a lot. I did not sleep at night, cried, thought about taking very serious steps, even irreversible ones (silence), had such bad thoughts, and was tired of my life."

(Young aged, early diagnosed, Yerevan)

"Yes, this was a trauma for me; this disease requires new skills from me in communicating with people, in self-presentation, or how to manage your desires not to eat forbidden foods."

(Middle aged, newly diagnosed, Yerevan)

"I am often told to go to a psychotherapist by my family members, but I still do not want to. Sometimes tea helps me a lot when I am depressed, and I have such a habit that I open and read about all the famous people who have celiac disease; it inspires me learning that so many people with Celiac disease live normally. Hence, I will be able to too"

(Young aged, early diagnosed, Yerevan)

4.4.4 Isolation and exclusion

After the diagnosis, some participants started to feel isolated from their surroundings and felt different from others, which made them sad and depressed. It created many difficulties in social interactions and in visiting some events. Almost all participants have mentioned avoiding the social activities, and it is first of all because of unavailability of GF food in many public places, also people's attitude toward the disease and strange comments about the GF diet. Feeling isolated affected the participant's personal relationships. Many respondents have mentioned that they had faced difficulties communicating with their family members, friends, and relatives after the diagnosis. Also, they have postponed many important life events because of the diagnosis.

"I still feel very isolated when I go somewhere, and when someone eats my favorite food next to me, I may cry. When I go to a birthday party or baptism and start telling the waiters to be careful with my food, that it does not touch (bread) lavash or what sauce there is in the salad, I feel very different from everyone. I get upset about it. Sometimes the waiters look at me strangely when I start to ask many questions about the food's ingredients and do not understand the seriousness of the issue."

(Young aged, early diagnosed, Yerevan)

"Yes, the disease affected my psychological state a lot; it ruined my life; before my diagnosis, I was suffering from bloating, and now I have a hard time following a gluten-free diet."

(Middle aged, early diagnosed, Yerevan)

"At first I refused to go to any event where I was invited, so that I would not eat anything wrong, but now I am trying to find an alternative so that I can go if it is not a very formal occasion, I try to take some food with me, or I go, but I do not eat anything."

(Young aged, early diagnosed, Armavir)

"Going out with friends, communication has decreased, getting out of town is very difficult now because it is impossible to find gluten-free food outside of Yerevan, or I should take it with me."

(Young aged, newly diagnosed, Yerevan)

"First of all, the diagnosis had a big impact on my pregnancy planning; I deliberately postponed it for a year because I was under much stress. At that time, I was very isolated, and I was locked in the house. I did not want to communicate with anyone."

(Young aged, early diagnosed, Armavir)

"I sometimes avoid family gatherings because there are delicious home-baked pastries, and I get upset."

(Middle aged, early diagnosed, Yerevan)

"Personal, interpersonal relationships have suffered because of the diagnosis with the people closest to you. You want to keep those people away from your feelings, but as a result, it negatively affects your relationships with your friends and your family members. This disease seems to reduce your social well-being as I understand."

(Middle aged, newly diagnosed, Yerevan)

4.5 Theme 5. Relationship

4.5.1 Lack of understanding

After the diagnosis, some participants have noticed that their family members and friends did not accept their diagnosis or did not trust that this kind of disease could exist, even there were cases when family members said that respondents lay or thought that they kept a GF diet only for being trendy. These comments hurt participants, affect their psychological and physical well-being and cause much stress. The lack of understanding from family members and close friends made the participant's journey of keeping the diet and accepting the diagnosis even more difficult.

"The main problem was with older people, for example, they say, well, how long do you have to keep this strange diet? One of my close relatives said in their house that one day

my water may become special too, these kinds of opinions make me to feel very stressed and nervous."

(Young aged, early diagnosed, Armavir)

"My father took it very hard; my father's wife said from the beginning that there is no such diagnosis, that she has not seen it in her practice. By the way, she is a nurse (my mother died early, she is my dad's second wife). Of course, I do not talk to her about my diagnosis since that incident."

(Young aged, early diagnosed, Yerevan)

"My mother still does not believe me. She told me that the disease is a result of my fantasy, my aunt and my mother can say eat a little of this cake, nothing will happen from it, it makes me nervous."

(Middle aged, early diagnosed, Yerevan)

"I took my food to my place of work once, but the reaction was negative; some colleagues told me that I take my diagnosis very seriously, I give myself much trouble because of it."

(Middle aged, newly diagnosed, Yerevan)

4.5.2 Support

In contrast, many participants mentioned the support and understanding from their family members, friends, and relatives after the diagnosis. Some of them support participants by cooking something GF, buying food without gluten for them, and finding new public places where GF food is available. One of the participants mentioned that understanding and accepting your diagnosis is dependent on the surrounding people's educational level and socio-economic status.

"My mother kept reading about the celiac disease to find out something new, or even if there are people here in Armenia who makes gluten-free food, she was looking for buying it for me. When I go to my grandmother's house, she always has something prepared for me without gluten, and my friend, for example, yesterday stayed in our house, she woke up earlier than me to make gluten-free sweets for me."

(Young aged, newly diagnosed, Yerevan)

"In my opinion, all the problems come from the lack of education of the family members and the surrounding people. Everyone around me is adequate and gave a normal reaction to my diagnosis."

(Middle aged, early diagnosed, Armavir)

"My friends organize our gatherings in such a way that I have something to eat. My family members do not buy and eat gluten-containing food in my presence."

(Young aged, early diagnosed, Yerevan)

4.6 Theme 6. Financial issues

Many participants have faced financial difficulties after the diagnosis, because GF food is expensive. The majority of them have mentioned that now they should allocate more money for their food. Also, there were cases when respondents personally did not feel financial problems because they were not working but they understood that their family members deprived themselves of many things to provide GF food to them. Besides difficulties with GF food prices, participants mentioned that diagnostic tests for getting the diagnosis were expensive. The participants do not have insurance to cover those expenses in most cases.

"I did not have many financial problems because my family members cover all my expenses but you get upset when most of your finances are spent to buy food. One can buy sweets for a few hundred drams, and you spend a few thousand drams on it, and your family members can deprive them of many things to provide your food. It is challenging for those living in Armenia when you spend 30,000 drams a month only for bread, it is too much in my opinion"

(Young aged, early diagnosed ,Armavir)

"The diagnosis had a huge impact on my financial situation because my food has become ten times more expensive. I am lucky to have a job. If I did not have the job, it would be much harder and more stressful. Then I could not eat so many various foods."

(Young aged, early diagnosed, Yerevan)

"Since gluten-free foods are costly, I buy less, and I try to find more affordable options, all my earned money is spent only on my food"

(Young aged, early diagnosed, Yerevan)

"My food has become much more expensive, 3500 AMD for spaghetti is a little expensive for me, and not everyone can afford it in Armenia. Even the middle class cannot allow themselves to have gluten intolerance."

(Middle aged, early diagnosed, Armavir)

"Yes, of course, I have encountered financial difficulties. I have chosen not to buy many products because of the price. In this case, you are stressing your body, because you have no choice and whatever is available gluten-free is very expensive."

(Middle aged, early diagnosed, Yerevan)

"Diagnostic tests were quite expensive, especially if you do not have health insurance, I think people of average or lower financial status in our country cannot afford to go to pass all that diagnostic tests, moreover to keep a gluten-free diet"

(Young aged, early diagnosed, Yerevan)

4.7 Theme 7. Suggestions for the future

4.7.1 Raising Awareness

When participants spoke about their wishes and what they can suggest to change in our country, most of them mentioned the need to raise awareness among our citizens about celiac disease and the GF diet. There were cases when respondents had worries about their future in our country, like how they will get married with this disease, and everything came from the negative attitude of our society to the people with celiac disease and low level of awareness of the disease in the society.

"There is a need to raise the awareness of our society about the problem, so that they don't give a negative reaction to patients like us. Waiting staff in the cafes do not lie that there is no gluten in the product, but in reality, they do not know. In a word, we need to talk a lot on this topic, to make our problem audible, that people know that there is a demand for gluten-free products, that there are people with this problem, to change something in our country."

(Middle aged, early diagnosed, Armavir)

"For example, I always think about my personal life, how I should get married in the conditions of our society, they will criticize me and say I am sick. I have many fears about this issue because many people have no idea about it. I want people's awareness about the disease and diet raised."

(Young aged, early diagnosed, Yerevan)

"In Armenia, I want people to be aware of the disease and have at least one of our local food brands produce gluten-free cookies or chocolate. The price should be a little affordable. Then we would not feel so discriminated."

(Young aged, early diagnosed, Yerevan)

4.7.2 Experience sharing

Besides the need to raise awareness among our society members, many participants have mentioned the need to create a celiac disease association or some online platform where all patients diagnosed with celiac disease can communicate, get new information about the disease, GF diet, share experiences and get psychological support from each other.

"We should create an online platform, where people share their experience with the disease and that will be a psychological support for us, or if one of us has found a new gluten-free food in our stores, would share it on that platform so that everyone knows about it."

(Young aged, early diagnosed, Yerevan)

"If a celiac disease association is opened in Armenia, even if we meet once a year, there will be an exchange of experience; the information will definitely help new patients."

(Young aged, newly diagnosed, Yerevan)

5. Discussion

This study investigated the psychological impact of CD diagnosis on patients' quality of life in Armenia. The collected data resulted in the following main themes: symptoms, difficulties in getting the diagnosis, GF diet, emotional health, relationships, and financial issues.

When answering the first research question: "What was the psychosocial impact of CD diagnosis on patient's quality of life in Armenia?", the answers were mainly showing the negative effect of the CD diagnosis on patient's quality of life. The participant's journey started from their symptoms, which most commonly were nausea, abdominal pain, bloating, diarrhea, and constipation. All these symptoms affected respondents' life in many spheres; they created obstacles to studying, working, socializing, and maintaining good relationships

with family members and friends. A related study done in India demonstrated a decreased quality of life and lower physical health composite score among CD patients who had symptoms like diarrhea, fatigue, and abdominal pain. The study found that patients with CD had decreased daily activities and limited work-related activities⁴⁰.

The negative impact of the symptoms of CD on a patient's everyday life was even higher in Armenia because of delayed diagnosis for the majority of patients. For one of the study participants, it took up to seven years to get her diagnosis, and the main reason for this was the low awareness of the disease among health care providers. Another study done in 2018 in the Netherlands among general practitioners showed a decreased detection rate of CD by general practitioners⁴¹.

The majority of participants spoke about the difficulties of keeping a GF diet, and it was dependent on many factors. The most common factors were lack of availability of GF food in many public places, high cost, also lack of knowledge about GF food among café workers, and labeling issues. A survey done in Greece trying to find out the challenges of keeping a GF diet showed similar findings that the main difficulties in adhering to the GF diet were connected with limited availability of GF food, high cost, and problems with GF meals at restaurants⁴². Another study done in Norway in 2020 showed accessibility of the gluten-free foods in the public places and availability of gluten-free menu in the cafes and restaurants⁴³.

Another common problem that affected patients' strict adherence to the GF diet was a misconception of the disease and diet. The participants first mentioned the lack of information about the dietary restrictions that they get from their doctors. They were told that they should avoid food containing only wheat, barley, and rye; they did not get information about hidden sources of gluten, tips for reading food labeling's, also about cross-contamination of the food. This created a misperception of the disease; they even thought

that the diet was temporary, not for the whole life. The lack of knowledge among participants had serious health effects on them, because they continued to eat gluten even when keeping the diet and their symptoms were not completely gone. A study done in England showed that a detailed explanation of the disease and a GF diet in plain language and frequent follow-ups by dietitian or gastroenterologist were associated with better compliance to a GF diet and patient satisfaction⁴⁴.

When presenting the challenges of keeping a GF diet, most of the participants mentioned how time-consuming had become their preparations to go out or to go to some events because now it requires more planning skills and time from them to get prepared for that events. The respondents mentioned that before going somewhere, they should buy or prepare their GF bread, chocolate, and cake; to take with them to avoid eating food containing gluten. In a similar study done in Brazil in 2018, the results showed that 65.7% of participants take some GF food from home when going to different social events⁴⁵.

Another barrier to strict adherence to the GF diet was cross-contamination. All participants thought that it was a huge problem in Armenia, because there was no separate café or restaurant in Armenia with a GF food menu. It is an issue in many countries; the study done in Brazil to test for gluten in naturally gluten-free foods found that gluten contamination was above the FDA settled threshold, above 20 ppm^{46,2}.

Getting the diagnosis of celiac disease mostly was very stressful and emotionally hard to accept for the participants. Some of them felt even depressed that they could not eat their favorite food. Some had thoughts that they could not complete daily needed calories with the GF food and would remain hungry. A study done in Sweden found out that some of the participants felt angry and sad when they heard about their diagnosis. When they understood that they could not eat their beloved bread and pasta, it was overwhelming for them; also, some of them mentioned about the disgusting taste of a GF alternatives⁴⁷.

On the other hand, there were cases when people felt better after knowing about the diagnosis because it was accepted as a solution for getting free from the variety of symptoms that they had before it. The diagnosis of CD made the participants excessively visible in situations where they did not wish to get visible and forced them to speak about their disease and gastrointestinal symptoms with people they did not want. A study done in Sweden to investigate difficulties encountered by CD patients in their everyday life found out that unwanted visibility was a real problem for participants. They have felt the fixation of their colleagues and friends on their symptoms and diet, which was unpleasant. Also, they have felt uncomfortable eating with people whom they did not know well enough to disclose their diagnosis⁴⁸.

The majority of participants have mentioned that the disease affected their psychological well-being, and they had many worries about their future after knowing about it. There was a case when a patient was so overwhelmed due to the diagnosis that she was thinking about committing suicide. Some of the participants said that the disease created difficulties in self-presentation in a new environment and communication with new people. Some of the participants have mentioned that they cope with the stress that disease caused by reading about famous people's life who had CD too. A literature review conducted in 2015 showed that CD patients are more prone to anxiety and depression than the general population, first of all, because of the disease itself and difficulties with coping with the diet, also many comorbidities that most of the CD patients have, including fatigue, unsatisfactory sexual life, poor sleep, functional dyspepsia, all of which could affect the quality of patient's life⁴⁹.

Most of the patients had the feeling of being different and isolated from their surroundings after the diagnosis. Because of the lack of GF food for them, the participants have avoided many social events. Some strange comments by other people, even by waiters, about their diet and disease caused even more stress and feeling of stigmatization. The participants felt

upset and isolated when someone ate one of their favorite foods, which contains gluten, and this could be another reason for avoiding social interactions. Also, fear of eating something not safe for them and harming themselves was another issue that made respondents reluctant to participate in many events. A study done in Sweden among 43 participants showed that people felt isolated in situations when they could not have the same food as their surroundings in gatherings with friends and during coffee breaks. The feeling was present even at home when eating with family members⁴⁸. In another study done in Sweden, the participants mentioned that the GF diet caused them to feel like an outsider every time when they should eat out of home⁴⁷.

Lack of understanding and support from their family members and friends was another big issue for participants. Some of them mentioned that their family members did not believe that such a diagnosis existed and thought that it was only the result of the participant's fantasy. There was even a case when a family member said that the participant started to keep a GF diet to be trendy. Another participant took her meal to the workplace, and her colleagues made inappropriate comments. They said that she gave more seriousness to the disease than needed. All these comments hurt the participants and made their compliance with the GF diet more difficult. In some cases, the participants avoided some family gatherings because of the gluten-containing food that would be there. Another study done in the United States in 2015 showed that patients with gluten intolerance were more likely to avoid family celebrations and family members' support was one of the most crucial aspects in facilitating adherence to a GF diet⁵⁰.

There were participants that mentioned that after the diagnosis, they got huge support from their family members and relatives, which really helped them to overcome the stress caused by the disease. The family members of the participants have prepared GF food for them or found some stores where GF food was available. They have mentioned that their friends,

when planning some gatherings every time took into account the fact that they have a problem with gluten, and there was some choice for them without gluten. Also, one of the participants mentioned that attitude toward your disease firstly comes from how educated your surroundings are; it affects their level of understanding. A literature review conducted in 2015 found that family members' involvement in CD management had a crucial role in better adherence to a GF diet and diagnosis acceptance by patients. CD patients' quality of life has improved when their family members have shared some responsibilities for their GF food preparation and diet adherence⁵¹.

The patients have also experienced financial difficulties after the diagnosis, connected with the price of the GF products. Also, some of them mentioned that the diagnostic tests were expensive too. Participants said that their food became ten times more expensive than it was before the diagnosis, and there were situations when participants did not buy the product because of the price. They said that it is psychologically very hard to acknowledge that you have no other choice and also cannot allow yourself to buy some particular food because of the price. Some of them said that all the money they earned was going only for their food; also, some felt guilty in front of their family members that they spent so much money buying GF food. Also, the participants mentioned that in our country, not everyone could keep the GF diet because the products are not accessible even to middle-class people. A study done in Saudi Arabia showed that 90% of CD patients faced difficulties in keeping a GF diet because of the high cost of GF food. Financial issues affected their psychological well-being and quality of life⁵².

Also, answering to second research question on what could be done to mitigate the effect of CD diagnosis on patient's quality of life, the majority of participants mentioned about, first of all, launching some programs or trainings that will help to increase their community's knowledge about the disease and the GF diet. Also, raising awareness among Armenian

residents, market workers, and cafe/restaurant workers was considered important so that when they meet a customer with special needs, they keep themselves from making strange comments or giving wrong products instead of GF ones. Also, there were suggestions that one of our local food brands starts producing GF chocolate and cakes. It will make CD patient's life easier, and prices would be affordable compared to the imported food. Some of them suggested creating an online platform for experience sharing, psychological support for each other, and also sharing new GF products that each of the patients will find in the Armenian stores. A study done in 2018 in Spain showed that most of the participants mentioned the need to raise public awareness about the problem, which will help the patients to cope with the disease⁵³. Another study done in Jordan found that lunching educational program among CD patients' parents improved patients' adherence to GF diet⁵⁴.

One of the study's strengths was that this was the first study done in Armenia about CD and its effects on patients' quality of life. Also, all the interviews were conducted face-to-face, which allowed direct interaction between the investigator and participants and contributed to receiving more detailed data from the respondents. Another strength of the study was that data saturation was reached. During the data collection stage, a researcher diary was kept to address the researcher's reflexivity, which included the researcher's own thoughts and assumptions. The diary was used in the data analysis stage, which increased the study finding's accuracy and credibility. Besides the researcher diary, after each interview, the member checking technique was applied to enhance the trustworthiness of the findings and validity of the qualitative study.

One of the limitations of this study was that the study population included only women with CD, therefore the study findings cannot necessarily be applicable to male population with CD. Also, the study setting included only Yerevan city and Armavir marz, and the situation in the remaining marzes might be different. Hence, the study findings could not be

extrapolated to CD patients living in other marzes. The oldest age of the participants was 43 years old, meaning that there were no elderly people included in the study, possibly because of the sampling method applied (personal contacts, snow-ball), so the findings are limited for a specific age group, including only young and middle aged women. Another limitation was that the study participants were only CD patients, the study did not include other stakeholders: family members, workers of markets and restaurants, food producers, and policy makers, as their perspectives towards the problem may differ from the CD patients' perspective. Finally, the data was collected using only in-depth interviews, but if it was combined with observations in the stores or KAP surveys among food service workers, it could enrich the study with stronger evidence of the accessibility/availability of GF food.

6. Conclusion

After getting the diagnosis, CD patients should keep a lifelong GF diet, which creates many problems in different life spheres. This study findings suggested that CD patients faced a variety of problems in keeping a GF diet in Armenia. The disease created many difficulties in patients' life, and dealing with them required a complex approach. The participants experienced many psychological issues connected with the diagnosis; they have felt isolated, stigmatized, and depressed. The findings suggested that although there were some choices of GF food in Armenia, these were expensive, not accessible for all patients and not available in all stores. The disease had a huge psychological burden, and healthcare workers should be aware of it and take into account the psychosocial consequences of the disease in the management of these patients.

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Table 1. Qualitative interview themes and subthemes

Symptoms	Impact on activities
Concentration	Avoiding social activities
Energy	Holidays
Gastrointestinal	Other social activities
Pain	Planning ahead
Weight	Time
Gluten-free diet	Traveling
Acceptability of gluten-free food	Work
Cross-contamination	Relationships
Eating outside of the home	Lack of understanding
Food choice	Support
Food shopping	Trust
Risk	Financial issues
Emotional health	Cost of gluten-free food
Concerns and worries	
Feelings	
Isolation and exclusion	
Unwanted visibility	

Source: Crocker H, Jenkinson C, Peters M. Quality of life in coeliac disease: qualitative interviews to develop candidate items for the Coeliac Disease Assessment Questionnaire. *Patient Relat Outcome Meas.* 2018; Volume 9:211-220. doi:10.2147/prom.s149238

Table 2. Demographic characteristics of the study participants

Characteristic	Categories	Number
Age	Below 30 years	11
	30 years and over	3
Gender	Female	14
	Male	0
Years passed since the diagnosis	Less than one year	4
	One year or more	10
Residence	Yerevan	12
	Armavir city	2
Education	High school/college	2
	Bachelor	5
	Master	7
Marital status	Single (incl. engaged)	12
	Married	2

Table 3. Identified themes and subthemes

Themes	Symptoms	Difficulties of getting the diagnosis	Gluten-free diet	Emotional health	Relationships	Financial issues	Suggestions for the future
Subthemes			Difficulties of keeping a gluten-free diet	Unwanted visibility	Lack of understanding		Awareness raising
			Misconception of the disease	Feelings			
			Eating outside home	Concerns and worries	Support		Experience sharing
			Cross-contamination	Isolation and exclusion			

Appendix 1. Study guide

Psychosocial impact of Celiac disease diagnosis on patient's quality of life in Armenia: A Qualitative Research Study

Interview guide

Interviewee ID _____

Date: dd/mm/yyyy
format

Start time: (hh:mm) 24 hour

Place:

Good afternoon and thank you for agreeing to participate in this study. My name is Lilit; I am a Master of Public Health graduate student at the Turpanjian College of Health Sciences at the American University of Armenia. As already mentioned when discussing informed consent form, I conduct a study to explore the psychosocial impact of Celiac disease diagnosis on patients' quality of life in Armenia and understand which life fields are more suffered by the disease. I want to ask you to share your thoughts and opinions. If you do not mind, I will record our conversation.

1. What were the most common symptoms that worried you before the diagnosis?
 - ✓ How has it affected your life?
 - ✓ What did you associate those symptoms with before getting the diagnosis?

2. Can you tell me how much time did you spend and which procedures did you undergo to get your diagnosis?
 - ✓ Was it stressful? Why? How was your stress expressed?
 - ✓ How expensive do you think were the diagnostic tests?

3. What was the impact of the celiac disease diagnosis on your life?
 - ✓ Which life fields were affected more? And how was it expressed?
 - ✓ Can you please tell me about your preparations (actions) when you are invited to some event?

- ✓ Have you ever taken any home-prepared food with you when going out for some entertainment?
4. What difficulties do you face when keeping a gluten-free diet?
- ✓ What information have you been told by your doctor about your dietary needs besides eliminating all gluten-containing foods?
 - ✓ What kind of information have you got from your doctor after getting the diagnosis regarding where you can buy the special food?
 - ✓ What type of gluten-free food could you find in your local markets?
 - ✓ What kind of food do you prefer to eat in the restaurants/cafes?
 - ✓ What do you know about cross-contamination?
 - ✓ What do you know about food labeling, and do you read them before buying the products?
5. Has the disease influenced your psychological well-being? If yes, how?
- ✓ What do you do to overcome it?
6. How have your friends and family reacted to your diagnosis?
- ✓ How have they supported you? What have they done?
 - ✓ How was your family member's diet changed since your diagnosis?
 - ✓ How have your friends reacted when you took something to eat with you to their house or café?
7. What financial difficulties have you faced after your diagnosis?
- ✓ From where have you bought your food?
 - ✓ What experience do you have in ordering gluten-free products from other countries?

- ✓ How has the price of gluten-free products affected your choice of buying them?
- ✓ What do you know about the vitamins and supplements that some CD patients need to take on by daily basis?

8. Is there anything else concerning the influence of the disease on your life that we did not talk about? Would you like to add something?

Thank you for your participation!

End time: (hh:mm) 24 hour format

**Ցելիակիա հիվանդության ախտորոշման հոգեւոցիալական ազդեցությունը
հիվանդների կյանքի որակի վրա Հայաստանում**

Որակական հետազոտություն

Հարցազրույցի ուղեցույց

Հարցվողի ՏՀ՝ _____

Ամսաթիվ՝ _____/_____/_____ (օր/ամիս/տարեթիվ)

Մեկնարկի ժամը՝ ____:____ (24 ժամյա ձևաչափ)

Վայրը՝ _____

Բարի օր և շնորհակալություն: Որ համաձայնեցիք մասնակցել այս հետազոտությանը: Իմ անունը Լիլիթ է: Ես Հայաստանի ամերիկյան համալսարանի Թրփանձեան առողջապահական գիտությունների քոլեջի Հանրային առողջապահության մագիստրատուրայի ավարտական կուրսի ուսանող եմ: Ինչպես կարդացել եք տեղեկացված համաձայնության ձևում, ես իրականացնում եմ հետազոտություն՝ ուսումնասիրելու ցելիակիա հիվանդության ախտորոշման հոգեբանական ազդեցությունը հիվանդների կյանքի որակի վրա Հայաստանում և հասկանալու, թե կյանքի ո՞ր ոլորտներն են ավելի շատ տուժում հիվանդությունից: Ես ուզում եմ խնդրել Ձեզ՝ կիսվել ինձ հետ Ձեր մտքերով և կարծիքներով: Եթե դեմ չեք, ես կձայնագրեմ մեր խոսակցությունը:

1. Որո՞նք էին ամենաարտահայտված ախտանիշները, որոնք անհանգստացնում էին Ձեզ՝ նախքան ախտորոշումը:
 - ✓ Ինչպե՞ս էին դրանք ազդում Ձեր առօրյայի վրա:
 - ✓ Ինչի՞ հետ էիք կապում այդ ախտանիշները՝ նախքան ախտորոշումը:
2. Կարո՞ղ եք ասել, թե որքան ժամանակ եք ծախսել և ի՞նչ հետազոտություններ եք անցել Ձեր ախտորոշումը ստանալու համար:
 - ✓ Այդ գործընթացը սթրեսայի՞ն էր: Ինչու՞,ինչպե՞ս էր դա արտահայտվում:
 - ✓ Ձեր կարծիքով, որքա՞ն թանկ արժեին ախտորոշիչ հետազոտությունները:

3. Ի՞նչ ազդեցություն է ունեցել ցելիակիա հիվանդության ախտորոշումը Ձեր կյանքի վրա:
 - ✓ Ձեր կյանքի ո՞ր ոլորտներն են ավելի շատ տուժել ախտորոշումից հետո: Իսկ ինչպե՞ս է դա արտահայտվում:
 - ✓ Խնդրում եմ, պատմեք, թե ինչպե՞ս եք նախապատրաստվում մասնակցելու որևէ միջոցառման, որին ք հրավիրված եք:
 - ✓ Երբևէ ժամանցի որևէ վայր այցելելիս Ձեզ հետ տարե՞լ էք տանը պատրաստված սնունդ:

4. Ի՞նչ դժվարությունների եք հանդիպում գլյուտեն չպարունակող սննդակարգի հետևելիս:
 - ✓ Ձեր սննդակարգի մասին ի՞նչ տեղեկատվություն է Ձեզ տվել Ձեր բժիշկը՝ բացի գլյուտեն պարունակող բոլոր մթերքները բացառելուց:
 - ✓ Ի՞նչ տեղեկատվություն եք ստացել Ձեր բժշկից այն մասին, թե որտեղի՞ց կարող եք գնել հատուկ սննդամթերքներ, որոնք չեն պարունակում գլյուտեն:
 - ✓ Ի՞նչ տեսակի գլյուտեն չպարունակող մթերքներ կարող եք գտնել Ձեր բնակավայրին մոտ գտնվող խանութներում:
 - ✓ Ինչպիսի՞ սնունդ եք նախընտրում ուտել ռեստորաններում կամ սրճարաններում:
 - ✓ Ի՞նչ գիտեք սննդամթերքների խաչաձեւ աղտոտման մասին:
 - ✓ Ի՞նչ գիտեք սննդամթերքի մակնշման մասին և կարդու՞մ եք, արդյոք, դրանք՝ նախքան մթերքը գնելը:

5. Հիվանդությունն ազդե՞լ է ձեր հոգեբանական վիճակի վրա: Եթե այո, ինչպե՞ս:
 - ✓ Ի՞նչ եք անում այդ ազդեցությունը հաղթահարելու համար:

6. Ինչպե՞ս են Ձեր ընտանիքի անդամներն ու ընկերներն արձագանքել Ձեր ախտորոշմանը:
 - ✓ Ինչպե՞ս են նրանք աջակցում Ձեզ: Ի՞նչ են անում:
 - ✓ Ինչպե՞ս է փոխվել Ձեր ընտանիքի անդամների սննդակարգը՝ Ձեր ախտորոշումից հետո:

- ✓ Ինչպե՞ս են արձագանքել Ձեր ընկերները, երբ դուք Ձեզ հետ ուտելու բան եք տարել իրենց տուն կամ սրճարան:
- 7. Ախտորոշումից հետո ի՞նչ ֆինանսական դժվարությունների եք հանդիպել:
 - ✓ Սովորաբար որտեղի՞ց եք գնում Ձեր սնունդը:
 - ✓ Այլ երկրներից գլուտեն չպարունակող մթերք պատվիրելու ի՞նչ փորձ ունեք:
 - ✓ Ինչպե՞ս է ազդել գլուտեն չպարունակող մթերքների գինը դրանք գնելու Ձեր որոշման վրա:
 - ✓ Ի՞նչ գիտեք վիտամինների և հավելումների մասին, որոնք ցելիակիա ունեցող որոշ հիվանդներ պետք է ամեն օր ընդունեն:
- 8. Կա՞ որևէ այլ բան, որը վերաբերում է հիվանդության ազդեցությանը Ձեր կյանքի վրա, որի մասին մենք չենք խոսել: Կցանկանայի՞ք ինչ-որ բան ավելացնել:

Շնորհակալություն Ձեր մասնակցության համար:

Ավարտի ժամը՝ ____: ____ (24 ժամյա ձևաչափ)

Appendix 2 Demographic questionnaire

Interviewee ID _____

1. How old are you?
_____ (completed years)

1. Please indicate your gender?
 - 1) Female
 - 2) Male
 - 3) Prefer not to say
 - 4) Other

2. How many years have passed since the diagnosis of CD? _____

3. Where do you live?
 - 1) City/town
 - 2) Village

4. Please, indicate the highest level of education you have received.
 - 1) Less than high school (less than 12 years)
 - 2) High school completed
 - 3) College
 - 4) Bachelor degree
 - 5) Master degree
 - 6) Post-graduate degree

5. What is your marital status?
 - 1) Married
 - 2) Separated/Divorced
 - 3) Widowed
 - 4) Single
 - 5) Engaged

Thank you.

Ժողովրդագրական հարցաթերթիկ

Հարցվողի ՏՀ՝ _____

1. Քանի՞ տարեկան եք: _____ (լրացած տարիներ)

2. Նշեք խնդրեմ, Ձեր սեռը:
 - 1) Իգական
 - 2) Արական
 - 4) Այլ _____

3. Քանի՞ տարի է անցել ցելիակիայի Ձեր ախտորոշումից: _____ տարի

4. Ի՞նչ տիպի է Ձեր բնակավայրը:
 - 1) Քաղաքային
 - 2) Գյուղական

5. Խնդրում եմ՝ նշեք Ձեր ամենաբարձր կրթությունը, որ Դուք ստացել եք:
 - 1) Ավագ դպրոցից պակաս (12 տարուց պակաս)
 - 2) Ավագ դպրոց
 - 3) Քոլեջ
 - 4) Բակալավրիատ
 - 5) Մագիստրատուրա
 - 6) Ասպիրանտուրա

6. Ինչպիսի՞ն է Ձեր ամուսնական կարգավիճակը:
 - 1) Ամուսնացած
 - 2) Բաժանված/Ամուսնալուծված
 - 3) Այրի
 - 4) Միայնակ
 - 5) Նշանված

Շնորհակալություն:

Appendix 3 Demographic data collection form

Participant ID	Age (years)	Gender	Years since the diagnosis	Residence (urban/rural)	Education	Marital status

Appendix 4. Consent form

American University of Armenia Turpanjian College of Health Sciences

Institutional Review Board #1

Informed consent form for participants

Psychosocial impact of Celiac disease diagnosis on patient's quality of life in Armenia:

A qualitative research study

Hello, my name is Lilit Hovhannisyan; I am a Master of Public Health graduate student at the Turpanjian College of Health Sciences at the American University of Armenia. As part of my thesis project, I conduct a study to understand the psychosocial impact of Celiac disease diagnosis on patients' quality of life in Armenia. Interviews with about 15 participants are planned within the framework of the research. I am inviting you to participate in this interview for this project because you are diagnosed with celiac disease, and I would like to know the impact of the disease on your quality of life. Your participation in this study will be limited to this interview. The interview will take a maximum of 60 minutes. During the interview, there will be questions regarding your experiences of diagnosis and its psychosocial impact on you. In this study, your participation is voluntary. You can stop the interview at any point or refuse to answer any question. You will not get any financial reward for your participation in the study, but your participation will help to better understand the difficulties that face the patients with Celiac disease in Armenia. There are no identified risks associated with your participation in this interview.

I will ask your permission to use audio recording and note-taking during the interview to avoid missing important information. All information you provide will stay confidential, and will be used for research purposes only. The identifiable data and the recordings will be destroyed after the study. Your name will not be written next to the information you provide. In the final report, only the summary of data from all interviews will be presented.

If you have any questions regarding the study, you can contact Dr. Anahit Demirchyan to the principal investigator of this study (374- 60)612562. Suppose you feel you have not been treated fairly or think you have been hurt by joining the study; in that case, you can contact Ms. Varduhi Hayrumyan, the Human Participant Protections administrator of the Institutional Review Board of the American University of Armenia (374-60) 612561.

Do you agree to participate? If yes, shall we continue? Do you agree to the recording? If YES, I will turn on the recorder when we start the interview. If NO, I will take notes during the interview, if you do not mind.

Հայաստանի ամերիկյան համալսարան Թրփանճեան առողջապահական գիտությունների ֆակուլտետ

Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև

Ցելիակիա հիվանդության ախտորոշման հոգեւոցիալական ազդեցությունը Հայաստանում հիվանդների կյանքի որակի վրա. Որակական հետազոտություն

Բարև Ձեզ, իմ անունը Լիլիթ Հովհաննիսյան է: Ես Հայաստանի ամերիկյան համալսարանի Առողջապահական գիտությունների ֆակուլտետի ավարտական կուրսի ուսանողուհի եմ: Իմ մագիստրոսական թեզի շրջանակներում ես իրականացնում եմ մի հետազոտություն, որի նպատակն է ուսումնասիրել ցելիակիա հիվանդության ախտորոշման հոգեւոցիալական ազդեցությունը հիվանդների կյանքի որակի վրա Հայաստանում: Հետազոտության շրջանակում նախատեսվում են հարցազրույցներ մոտ 15 մասնակիցների հետ: Ես Ձեզ հրավիրում եմ մասնակցելու այս հարցազրույցին, քանի որ դուք ախտորոշվել եք ցելիակիա հիվանդությամբ և ես կցանկանայի իմանալ տվյալ ախտորոշման ազդեցությունը Ձեր կյանքի որակի վրա: Ձեր մասնակցությունն այս հետազոտությանը կսահմանափակվի այս հարցազրույցով: Հարցազրույցը կտևի ամենաշատը 60 րոպե: Հարցազրույցի ընթացքում ես Ձեզ հարցեր կտամ հիվանդության վերաբերյալ Ձեր փորձի և Ձեզ վրա հիվանդության թողած հոգեւոցիալական հետևանքների մասին: Այս հետազոտությանը Ձեր մասնակցությունը լիովին կամավոր է: Դուք կարող եք հրաժարվել պատասխանել հարցերից ցանկացածին կամ ընդհատել հարցազրույցը ցանկացած պահի: Հետազոտությանը մասնակցելը Ձեզ չի բերի որևէ ֆինանսական օգուտ, սակայն կօգնի ավելի լավ հասկանալ այն դժվարությունները, որոնց բախվում են ցելիակիայով հիվանդները Հայաստանում: Ձեր մասնակցությունը այս հարցազրույցին Ձեզ որևէ վնաս չի պատճառի:

Ձեր համաձայնությամբ ես կձայնագրեմ մեր հարցազրույցը կամ գրառումներ կանեմ, որպեսզի բաց չթողեմ Ձեր կողմից տրամադրված որևէ կարևոր տեղեկություն: Ձեր տրամադրած ամբողջ տեղեկատվությունը կմնա գաղտնի և կօգտագործվի միայն հետազոտության նպատակներով: Հետազոտության ավարտից հետո Ձեզ նույնականացնող տվյալները և ձայնագրությունները կոչնչացվեն: Ձեր անունը չի գրվի Ձեր տրամադրած տեղեկությունների կողքին, իսկ հետազոտության վերջնական զեկույցը կներառի միայն բոլոր հարցազրույցների համախառն արդյունքները:

Հետազոտության հետ կապված հարցեր ունենալու դեպքում կարող եք
զանգահարել Անահիտ Դեմիրճյանին՝ այս հետազոտության գլխավոր
հետազոտողին՝ հետևյալ հեռախոսահամարով՝ (374 60) 612562: Եթե կարծում եք,
որ Ձեր նկատմամբ արդարացի չեն վարվել կամ Ձեզ վիրավորել են, ապա կարող
եք զանգահարել Հայաստաի ամերիկյան համալսարանի գիտահետազոտական
էթիկայի հանձնաժողովի համակարգող՝ Վարդուհի Հայրումյանին՝ (374 60)
612561:

Դու համաձայն ե՞ս ք մասնակցել: Եթե՝ այո, կարող ե՞ս ք շարունակել: Դուք
համաձայն ե՞ք, որ ես ձայնագրեմ մեր զրույցը: Եթե՝ այո, ես կմիացնեմ
ձայնագրիչը, երբ մենք սկսենք հարցազրույցը: Եթե՝ ոչ, ես գրառումներ կանեմ:

Diagram 1. Wheat consumption and production in different parts of the world

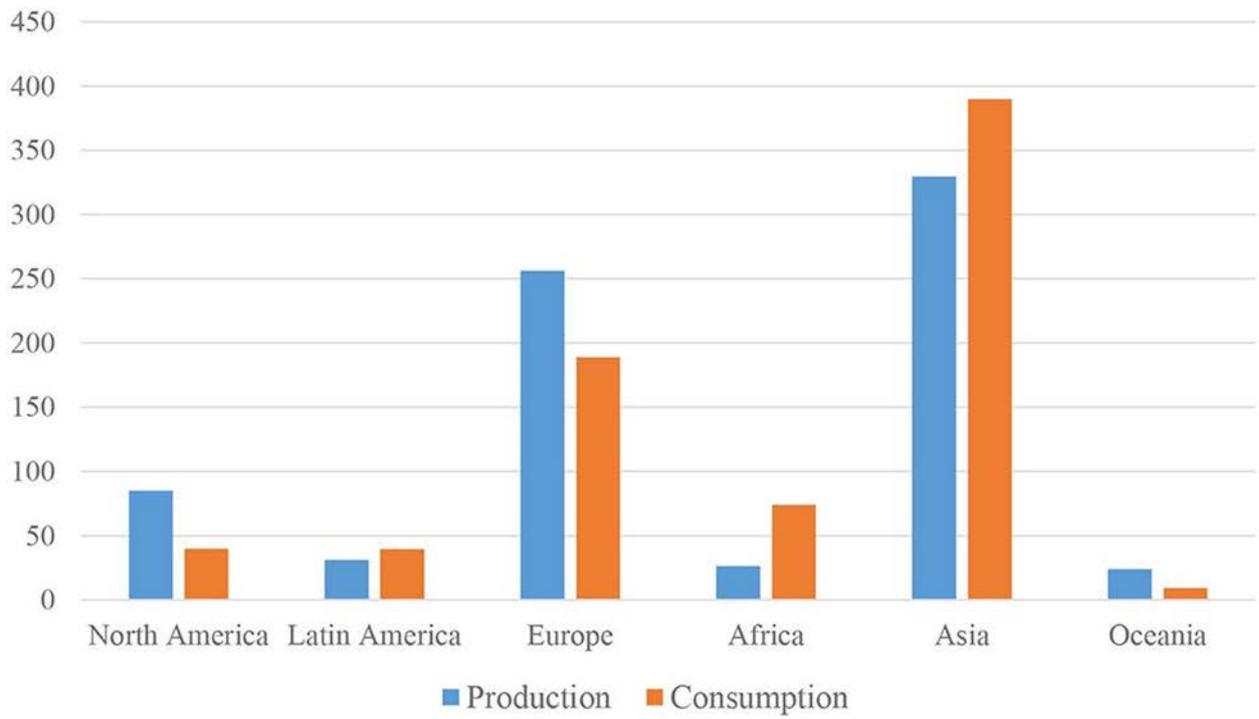
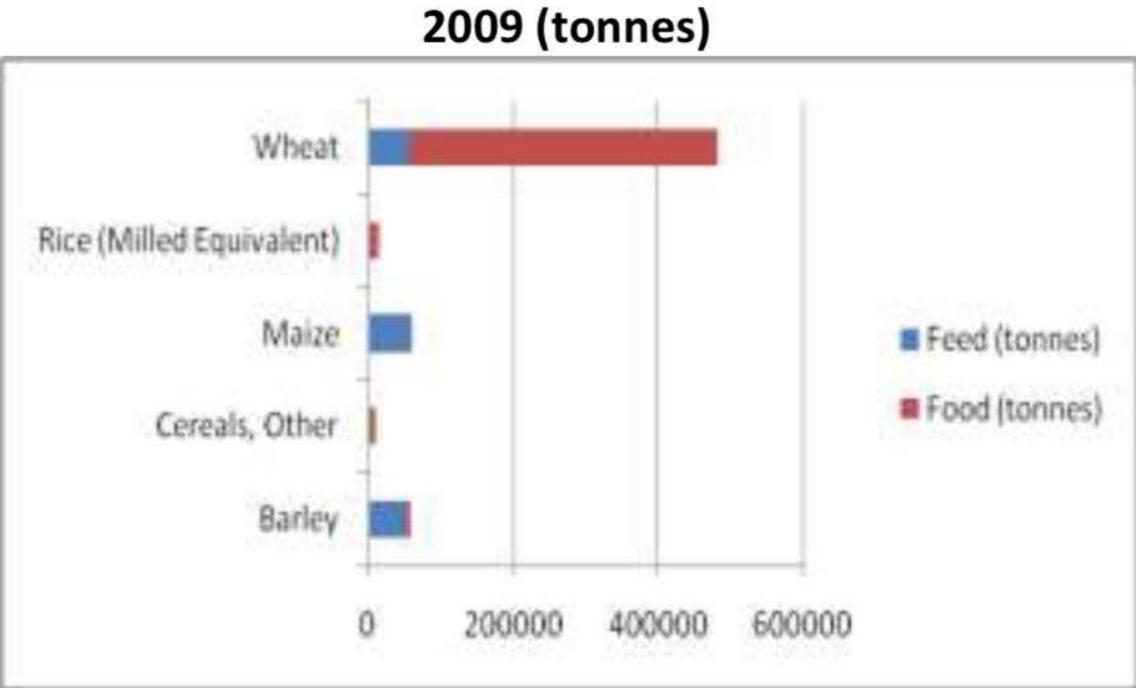


Diagram 2. Volume of cereals used for feed and food in Armenia



List of Appropriate Journals

B.M.C. Nutrition

American Journal of Gastroenterology

The American Journal of Clinical Nutrition

Psychology and Health

Food review International