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Evaluation of Dietary Compliance of Patients with Celiac Disease in Gaza Governorates

Submitted by

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Declaration

I certify that this entire thesis submitted for the degree of Master is the result of my own research, except where otherwise acknowledged, and that this thesis (or any part of the same) has not been submitted for a higher degree to any other university or institution.

Signed ----------

Nahla Abu Amer

Date: / / 2012

Dedication

I absolutely could not have made it through school without the love and support of my husband, my parents, my sisters, my son and my daughters.

I dedicate this work to

Those who have given me every opportunity of success.

Nahla Hamad Abu Amer

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ABSTRACT

Background: *Celiac disease is an inflammatory disorder of the small intestine, which is characterized by mucosa inflammation, villous atrophy and malabsorption.*

Aim: *To assess the dietary compliance to gluten free diet (GFD) status of registered celiac patients at Ard El Insan in the Gaza Strip, in order to improve the diet compliance among them.*

Methods: *The design of the study was descriptive, analytical, cross sectional one. The study included all patients who were diagnosed by either antibody test or intestinal biopsy from both sexes among all patients attending Ard El Insan clinic, according to the celiac disease care medical records in the year 2011. Data was collected through interviewed questionnaire completed by one hundred thirty five patients. The response rate among study population was 70%.*

Result: *The mean age was 26 years old, and 71% were female. The frequency of Celiac Disease in adults was 64%, and 39% of patients were from Gaza city, and 38% from the south. Medium level of education among patients constituted 46% against 20% with low level of education and 27% with high level. About 44% of patients were not working against 25% with occupation. Mean period of symptoms was 56 months before diagnosis, and mean duration of CD was 8 years. The median age of diagnosis was 21 years with a range from 1 to 64 years. Presenting symptoms included weight loss (86.7%), bloating (83.7%), abdominal pain (83%), diarrhea (79.3%), poor growth (75.6%), gases (71.9%), vomiting (45.9%), itchy skin (30.4%), constipation (25.2%), and lactose intolerance (20.7%). The final diagnosis was by gastroenterologist among 67% of patients against 27% by pediatrician. A serological test was performed to diagnose CD in 79% of the study population against 64% by intestinal biopsy. More than half of respondents (58%) reported strict adherence to a gluten-free diet, and 62% noted improved health. Almost the majority of study population (70%) didn't hear about CD before. Thirty-eight percent of the respondents didn't know if CD can be cured completely against 21% thought that CD cannot be cured completely. More than half of respondents didn't know the special logo of gluten-free food, and half of them reported lack in knowledge of determining if foods were free of gluten. Ard El Insan provided excellent information for 89% of respondents. The majority of study population (73%) avoided restaurants. Only 28% avoided going out. Eighty-seven of the respondents reported extreme difficulty in finding gluten free foods. When asked to select two items that would improve their quality of life, earlier diagnosis of celiac disease was selected by 85%, better dietary counseling by 39%, more gluten-free foods in the supermarkets by 37%, better labeling of gluten containing foods by 24%, and gluten- free choices on restaurant menus by 14%. The study showed that the more knowledgeable patients the more compliant they were (P-value = 0.044). Also there were a statistically significant differences in reference to compliance and the patients attitudes (P-value = 0.003).*

Conclusion: *In the Gaza strip, patients with celiac disease present at all ages with a variety of symptoms. Delay in diagnosis was common. More than half of respondents were compliant with a gluten-free diet. The study proved the importance of knowledge and attitudes to achieve compliance among respondents. A gluten-free food was difficult to obtain. The study recommends regular availability of GFD and to improve the case detection.*

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List of abbreviation

AGAs	Antigliadin Antibodies
AEI	Ard El Insan
CD	Celiac Disease
DM	Diabetes Mellitus
EMA	Endomysial Antibody
ESPGHAN	European Society for Pediatric Gastroenterology, Hepatology and Nutrition
GFD	Gluten Free Diet
GMU	Growth Monitoring Unit
MOH	Ministry of Health
NGOs	Non-Governmental Organization
NIH	National Institute of Health
PASSIA	Palestinian Academic Society for the Study of International Affairs
PCBS	Palestinian Central Bureau of Statistics
TTG	Tissue TransGlutaminase
WHO	World Health Organization

Chapter 1

1.1 Introduction

Celiac disease is an inflammatory disorder of the small intestine induced by prolamines of certain cereals, namely the gliadin of wheat, barley and rye, for example bread, semolina, pastry, pasta and many different items. The inflammation is associated with loss of villous height that leads to hypertrophy, and malabsorption (Warell et al, 2005). The classical nature of celiac disease is characterized by mucosa inflammation, villous atrophy, and crypt hyperplasia (Kliegman et al, 2007).

Prevalence of celiac disease is not definitely estimated because it has different clinical pictures and varieties in appearance of the disease itself, especially in patients who have mild symptoms of the disease or have no any symptoms. Due to the lack of medical awareness of CD, in addition the disease possibly occurs later in life, rates of detection remain poor. Studies in European countries showed that more than 1% of general population has CD (Amiriani et al, 2011). Prevalence of CD in the United States is found to be 1 out of every 120 (Biagi et al, 2010). Recent large screening studies on general population in developing areas of the world, (Southern Asia, Middle East, North, West and East Africa, South America) both in the general population and in the groups at risk appears to be a widespread public health problem (Cataldo and Montalto, 2007). In the Sahara population who are African descendants of Arab-Berber and live in great African Desert "Sahara" the highest records of CD were reported and appeared to be 5.6% (Cattassi, 2005). In Gaza Strip, the number of patients who are registered at Ard El Insan (AEI) have been estimated at 403 patients i.e. 0.03 % of the total population in Gaza Strip (Ard El-Insan, 2011).

The symptoms of CD can be vague and mimic many other conditions, and they vary so widely among patients, that there is no typical celiac symptoms, the amount of intestinal damage that has occurred and the length of time nutrient absorption has been abnormal seem to be the factors that determine the type and severity of symptoms experienced but, mainly the disease is characterized by diarrhea, stomatitis, malabsorption, a skin rash called dermatitis herpetiformis, osteopenia or osteoporosis (Green and Cellier, 2007).

The diagnosis of CD is based on three parameters (1) history and clinical presentation is compatible with CD (2) serological screening tests which include the measurement of IgA antibody to human tissue transglutaminase (TTG) for initial testing for CD and the measurement of IgA antibody to endomysium (EMA). (3) histological tests that are recommended for confirmation of the diagnosis of CD and they they require an intestinal biopsy in all cases to be obtained from the second or more distal part of the duodenum. There is a good evidence that villous atrophy is a characteristic histopathology feature of CD (Hill et al, 2005).

The only treatment for CD is a gluten free diet, which is defined as a diet that excludes wheat, rye, and barley, this means changing lifelong eating habits and adapting new gluten free lifestyle. So the compliance with the gluten free diet is the big challenge for celiac patients in order to avoid the complication of the disease and to improve their life (Cureton, 2006).

1.2 Research problem

CD is a common genetic disorder that affects people all over the world. It has been reported that the prevalence of celiac disease is 2% among adults (Lohi et al, 2007). The burden of celiac disease is highlighted through the last years, due the management of diagnosis and its huge complication, in addition to psychological and socioeconomic

effects. The only way to treat celiac patients is the gluten free diet, and many complications well appear if there is no compliance to the gluten for example malignancy (Norton et al, 2009). Compliance status among celiac patients in the Gaza strip are the main point of this study to be clarified in order to get the real situation, through studying the compliance of celiac patients in AEI.

1.3 Justification

Spread of CD has been increased by 1% of the general population in Europe (Amiriani et al, 2011). In the Gaza Strip, the numbers of celiac cases have been estimated at 403 patients (0.03%), but the prevalence of celiac disease in Gaza strip is under estimated. CD shows impaired health –related quality of life and requires a permanent strict gluten free diet. However, data concerning how the situation is experienced by celiac patients are limited (Usai et al, 2007). However, the impact of CD symptoms on health-related quality of life in CD is unclear. In AEI there is a gluten free diet program for celiac patients. So the compliance status among these celiac patients reflects the success of this program. Consequently, the compliance or non-compliance will contribute to the positive or negative impact on health. These reasons can be given to explain why compliance to GFD among celiac patients needs to be managed properly.

1.4 Aim of the study

To assess the dietary compliance to gluten free diet (GFD) status of registered celiac patients at AEI, and to identify barriers to compliance. Thus the study could help in promoting the adherence of celiac patients to GFD.

1.5 General Objectives

To evaluate compliance to gluten-free diet in celiac patients registered at Ard El Insan.

1.6 Specific objectives

1- To examine the relationship between patients' compliance to GFD and their knowledge and attitude.

2- To identify the compliant patients, and non- compliant patients.

3- To identify the main barriers to compliance, among the study population.

4- To study the effect of food regimen compliance on symptoms of the disease.

5- To examine variation in compliance rates among patients in reference to their Sociodemographic variables.

6- To provide recommendation to improve compliance.

1.7 Context of the study

1.7.1 Geography

Gaza strip is a small area on the south western part of Palestine lying on the eastern coast of the Mediterranean Sea. It is boarded by Egypt from the south, Negev desert from the east. Gaza Strip is 50 km long, from Beit-Hanon in the north to Rafah in the south. Its width ranges from 6 to 12 km from east to west with total surface area about 365 square kilometers. Gaza strip is composed of five governorates, North, Gaza city, Mid-Zone, Khanyounis and Rafah (PASSIA, 2009).

1.7.2 Demographic characteristics

The total Palestinian population in the world was estimated to be 11 millions, 4.1 millions in Palestinian territory, 1.6 million in the Gaza Strip (PCBS, 2010), which represent 39% of the total population of Palestinian territories, the second most density populated area

among Palestinian states. Refugees in Gaza Strip represent 1.1 million refugees which is 67.4% of the total population of Gaza strip (PCBS, 2010). The population pyramid has a wider bottom with 44.2% under 15 years in Gaza Strip.

1.7.3 Socioeconomic characteristics

According to the document of the PCBS (2010) the dependency ratio in Gaza strip is 87.4, the median age is 17.2, the crude birth rate is 37.1 births, the crude death rate is 4.0 per 1000 population and the fertility rate is 5.3 births in 2007. Over one half (57%) of households were living under the poverty line which is 3.18$ per person daily (PCBS, 2007).

1.7.4 Nongovernmental Health Organizations

In the Gaza strip the Ministry of health (MOH) is responsible for majority of provided services unlike the West Bank in which private sector and nongovernmental organizations (NGOs) constitute 60% of health services providers (Abu-Zaineh, 2009). This constitutes a heavy burden on the MOH facilities that undoubtedly affect the preparedness, quality, resources and staff availability in a nation with increased demands and growing needs. Therefore, the NGOs in the Gaza Strip can comprise a real support to the MOH and they can provide both qualitative and quantitative health services such as Ard El Insan (AEI) Palestinian benevolent association in which celiac disease patients receive health services, gluten free diet, counseling, follow up, investigations and social activities and support.

AEI was established in 1984 as an international organization and then turned to be Palestinian Non Governmental Organization in 1999. AEI is managed by a steering committee of local board of directors. AEI is a benevolent society that provides nutritional and health services to the most needy and marginalized children under five, their mothers and families. Two community health and nutrition rehabilitation Centers in Gaza and

Khanyounis city provide curative, preventive and educational health services to beneficiaries in these areas. In addition, each center conducts community-based programs targeting vulnerable areas in different locations such as refugee camps, villages, deprived and rural areas. Each operational centre comprises; a medical and nutritional assessment unit; a growth monitoring unit (GMU) which provides follow-up of severely and moderately malnourished children, and nutrition education; a special care unit for specific nutritional treatment such as nutritional anemia, celiac disease, and rickets; and a breastfeeding counseling unit, for mothers who present with breastfeeding difficulties. Over the years, AEI became a leading community health and nutrition services provider in the Gaza Strip. This has been achieved through adopting consistent technical intervention strategies in the following fields : medical intervention, nutrition therapy , counseling, health and nutrition awareness, psychological support, promote household food security, promotion of breast-feeding, emergency intervention, training, advocacy and exchange of information, as well as conducting research related to nutrition, community, and environmental health. A principle feature of AEI activities is to encourage community participation through local committees, support groups, volunteers and other services providers (The Palestinian NGOs Portal, 2011).

1.8 Operational definitions

Celiac disease

It is an immune-mediated enteropathy caused by permanent sensitivity to gluten in genetically susceptible individuals (Kliegman et al, 2007).

Compliance

The term compliance has been defined by WHO as "faithful adherence by the patient to prescribed instructions" (WHO, 2006). In medicine, compliance (also adherence, concordance, or capacitance) describes the degree to which a patient correctly follows

medical advice. Most commonly, it refers to medication or drug compliance (Wikipedia, 2011).

Malnutrition

A term used to refer to any condition in which the body does not receive enough nutrients for proper function. Malnutrition may range from mild to severe and life-threatening. It can be a result of starvation, in which a person has an inadequate intake of calories, or it may be related to a deficiency of one particular nutrient. Malnutrition can also occur because a person cannot properly digest or absorb nutrients from the food they consume, as may occur with certain medical conditions (William and Melissa, 2008).

Absorption

Absorption has diverse specific meanings. In the body, absorption is the process whereby a cell, tissue or organ takes up a substance. In the intestinal tract, absorption is the uptake of food (or other substances) from the digestive tract (Med terms dictionary, 2003).

Diarrhea

It is a familiar phenomenon with unusually frequent or unusually liquid bowel movements, excessive watery evacuations of fecal material, which is the opposite of constipation (WHO, 2011).

Gluten

A protein found in wheat or related grains and many foods that we eat. Gluten can be found in a large variety of foods including soups, salad dressings, processed foods and natural flavorings. Unidentified starch, binders and fillers in medications or vitamins can be unsuspected sources of gluten (William and Melissa, 2008).

Gluten free diet

A gluten-free diet is a diet that excludes the protein gluten, which is found in grains such as wheat, barley and rye **(**Mayo Clinic**,** 2010).

Malabsorption

It is the impaired absorption by the intestine of nutrients from food. Malabsorption can be specific and involves sugars, fats, protein, or vitamins. Alternatively, malabsorption can be general and nonspecific **(**William and Melissa, 2008).

Knowledge

It is an awareness, understanding, or information that has been obtained by experience or study that is either in a person's mind or processed by people generally (William and Melissa, 2008).

Intestinal Biopsy

A biopsy is a diagnostic procedure in which tissue or cells are removed from a part of the body and specially prepared for examination under a microscope. When the tissue involved is part of the small intestine, the procedure is called a small intestine biopsy (Beers et al, 2004).

Chapter 2: Literature review

2.1 Conceptual framework theoretical aspect

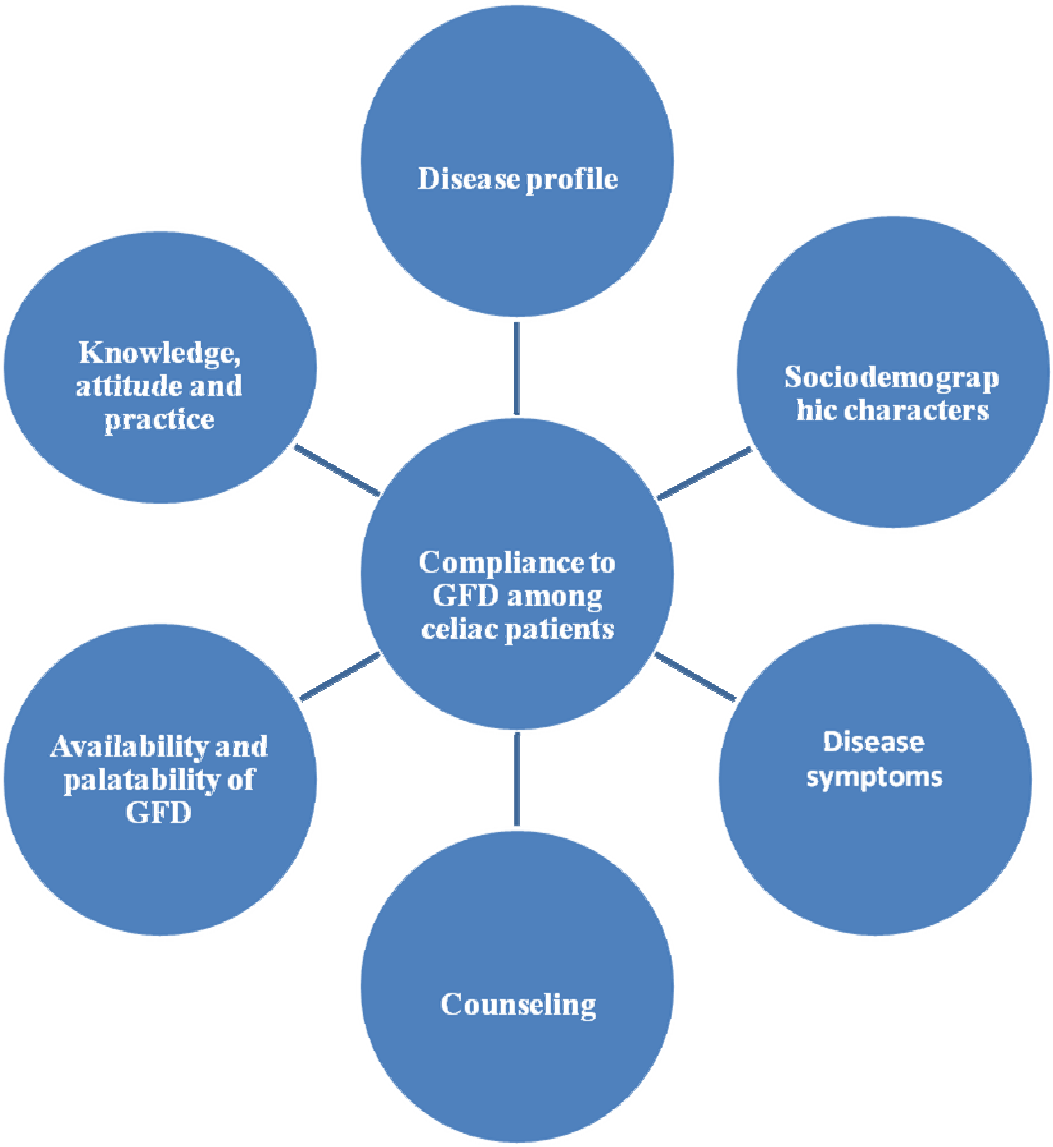
In this chapter the researcher presents the conceptual framework of the study, it's an academic trial to pick the part of patient's compliance with their gluten free diet. The researcher depicts the ideas extracted from the different compliance concepts, which have been incorporate into this connectional framework (Figure 2.1).

During study stages the researcher gave attention to the specialty and characteristics of the Palestinian community and its diversity with an effort to accommodate with properly.

Conceptual framework is a tool of presenting the ideas about how to classify and present the study data. It may help also in advising theoretical or analytical framework as a basis for the analysis and interpretation of data. It is not enough merely to collect facts and to describe them. It's known that many of researcher collect many facts, but then they have to organize and classify them into coherent pattern.

The study aims to identify and explain relevant relationships between the facts. In other words the researcher try to produce a concept or build a theoretical structure that can explain facts, and relationships between them. The importance of theory is to help the investigator summarize previous experience of others. Sometimes the formulation of a theory may indicate missing ideas or guide to additional data required.

Conceptual framework design



2.2 Dimensions of patient compliance with their gluten free diet

The diagram shows the main components that explain the factors that affect compliance among celiac patients. They include:

2.2.1 Personal Sociodemographic characters

These characters include: gender, age, locality, education, family size, occupation and income. Naturally there could be individual different compliance level in reference to the different personal factors, so it is important to study their factors in relation to the compliance with gluten free diet.

2.2.2 Knowledge and attitude

They are factors that reflect the compliance with the gluten free diet. It is important for celiac patients to know the special logo of gluten-free food, the main sources of gluten and hidden sources such as in medications. Patient thoughts and practices about the gluten free diet can provide a general picture about the compliance situation regarding the patients with gluten free diet, and are very important for early detection of complication or serious illness that affect the body(Mohsin, et al. 2005).

2.2.3 Disease profile

It means different aspects that related to the disease as Duration of the disease, the appearance of symptoms before diagnosis. As celiac patients suffer different types of symptoms that vary from sever to mild appearance of these pictures. So the disappearance of these symptoms may encourage patients to practice strict adherence to their GFD in order to get rid of these exhausting symptoms.

Also age of diagnosis, family history of patients, and the present of associated chronic diseases. All these factors may affect the compliance of the patients.

2.2.4 Provision of counseling and gluten free diet

The provision of counseling improves the performance of patients, make them gain greater control over their dietary habits, understand how unhelpful patterns of diet are negatively affecting their life, and learn new ways to deal with their dietary habits. In addition the provider's consultation can improve compliance of patients to their GFD.

2.2.5 Availability and palatability of GFD

According to the importance of GFD for every celiac patient, so the availability of GFD in grocery stores and supermarkets will help the celiac patients accomplish their adherence to the special regimen and make it easier.

2.3 Literature review

2.3.1 History

Most people think of CD as a modern day ailment, however in this research, it was found that the best place to start is the history of CD. In the beginning of humans, known as the Neolithic Period, humans were hunters, and primarily survived on fruits, nuts, and meat when available. During the Neolithic Period, humans evolved and began cultivating plants which quickly led to the agricultural revolution. It was during this time that CD was born where the grains enter their diet. Some the Neolithic man was introduced to a new diet which differed starkly from his previous diet (Stone, 2010). While some people were able to adapt to this new food diet, comprising cereals and animal protein, others developed food intolerances. This led to the birth of celiac disease. The earliest known record of this disease was when the Greek physician, Aretaeus of Cappadocia, wrote about 'the coeliac affection' in the second century A.D. He described the condition as, *"If the stomach is irretentive of the food and if it passes through undigested and crude, and nothing ascends into the body, we call such persons coeliacs"*. He termed the Greek word 'koiliakos' to

describe the people afflicted with the disorder, the word “koiliakos” derived from the Greek word for “abdomen”. Around seventeen centuries later, in the early 19th century Mr. Mathew Baillie published his observations on celiac disease which he cited as, 'chronic diarrhea disorder causing malnutrition and characterized by a gas-distended abdomen'. In 1888, Dr. Samuel Gee introduced dietary treatment as an effective intervention (Dowd et al., 1974). In 1924, a dietician therapy was introduced by Sidney Haas known as the "banana diet", another important maker in the history of CD was Dr. Willem Karel Dick, who excluded wheat, rye and oat from diet and noted an improvement in celiac patients. In 1954, Dr. Dicke, Charlotte Anderson, and a number of their colleagues, confirmed these findings, and describe the damage to the lining of the small intestine. In 1960 CD was clear and can be diagnosed with a biopsy of the small intestine. At the end of 1969 the diagnosis of CD is approved by a panel of experts of the European Society for Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN). IN 1980's it became increasingly clear that CD could be associated with other conditions, mostly autoimmune disorders. In 1990 new diagnostic guidelines were established by ESPGHAN. And CD was starting to be accepted as an autoimmune disease because of the association of a specific gene, either DQ2 or DQ8 (Guandalini, 2007).

2.3.2 Prevalence

Until the last decade, CD was considered to be a rare disease, but today it is known to be universally distributed, to involve all races, and it is one of the most commonly known genetic diseases, with a mean prevalence of 1%-2% in the general population, being clearly underestimated and under diagnosed worldwide (Rodrigo et al., 2011).

The prevalence of CD is difficult to be estimated because the disease has different clinical symptoms. Globally, CD prevalence is affecting more than one percent of the population in the Western world (Green and Cellier, 2007), 1 in 133 in the United States (Catassi and

Fasano, 2008), then increase to 1 out of every 120 in 2010 (Biagi et al., 2010) and 1% in Europe (Mustalahti and Catassi, 2010).

Regionally, a very high prevalence of CD in the Middle East region has recently been reported both in the general population and in at risk-group. These high frequencies are due to the wide consumption of wheat and barley. Prevalence of CD among low risk populations varies from 0.14% to 1.17% (Greco et al., 2010), 1%-1.3% in Turkey (Gursoy et al., 2005), 0.6%-0.96% in Iran (Akbari et al., 2006), 0.5% in Egypt (Abu-Zekry et al., 2008), 0.6% in Tunisia (Ben Hariz et al., 2007), and 0.12 in Israel (Israeli et al., 2010). Locally, in Gaza strip there are 403 celiac patients registered at AEI. Out of these cases there are 220 patients in the Gaza city center, and 183 ones in Khanyounis center (Ard El Insan, 2008).

2.3.3 Pathogenesis

CD is an autoimmune disease of many etiological factors. Pathogenesis of CD involves interactions between environmental, genetic, and immunologic factors (Herrera et al., 2009). CD is activated by proteins in the dietary cereal grains wheat, rye, and barley. As a consequence of the interaction of gluten peptides with the intestinal mucosa in genetically prepared patients with CD**,** gluten peptides, promote the production of tissue transglutaminase (TTG) which has been discovered to be the auto antigen against which the abnormal immune response is directed. This leads to the damage of the intestinal mucosa of individuals with active disease. This damage is manifested through the atrophy of the intestinal villi, accompanied with malabsorption of nutrients (Kagnoff, 2007). Genetic factors play a role in the pathogenesis of CD and this is evident from clinical observation of many cases of CD within families, and in monozygotic twins approaching 70% to 75% (karell et al., 2003). There is a 10-fold increased risk of CD in first degree relatives (i.e. parents, siblings or children) of someone with CD (Fasano et al., 2003).

2.3.4 Clinical manifestation

Symptoms of the disease are remarkably varied and depend on age, or there may be no obvious symptoms at all. Because there is no standard picture of a person with CD, some patients go from doctor to doctor for years, seeking a diagnosis for their illness.

CD has different pictures of clinical manifestation, which varies from typical CD and atypical CD. The best known symptoms of CD include sever chronic diarrhea with voluminous stools, vomiting, abdominal distention, and weight loss to the point of wasting, which is noted typically in younger children (Barker and Liu, 2008).

Atypical CD is usually seen in older children or adolescents, who often haven't sufficient signs of malabsorption (Bottaro et al., 2004). The main of clinical features of extra intestinal CD include dermatitis herpetiformis (Collin and Reunala, 2003), iron deficiency (Bottaro et al., 2004), neurological problems (Zelnik et al., 2004), infertility in women, osteopenia and osteoporosis (leffler et al., 2003).

2.3.5 Diagnosis

Blood tests

Diagnosis of celiac disease is usually first suggested by the presence of different antibodies like anti-tissue transglutaminase antibodies (TTGA), anti-endomysial antibodies (EMA) , and antigliadin antibodies (AGAs) in subjects whom the diagnosis of celiac disease is entertained, such as those with malabsorption and vitamin or mineral deficiencies, osteoporosis/osteopenia, infertility or other clinical symptoms. It can also be used to screen individuals considered to be at high risk for celiac disease, such as those with diabetes type 1 or first-degree relatives of an affected individual (Catassi and Fasano,2008).

Intestinal Biopsy

The diagnosis of CD is confirmed by establishing a biopsy of the small intestine by upper intestinal endoscopy. Histology will show some degree of villous atrophy and crypt hyperplasia. The histological biopsy remains the golden mandatory standard for diagnosis of celiac disease (Mandal et al., 2007).

2.3.6 Complication

If CD left untreated, complication may develop**.** Some of these problems can occur because of the small intestine's inability to digest food and absorb nutrients properly. Other problems may develop from damage to the intestinal lining that may or may not cause noticeable symptoms. Osteoporosis is the worse complication because celiac patients have difficulty to absorb calcium and vitamin D, which helps bone to develop and gain strength (Stenson et al., 2005). Another complication of the disease is infertility due to hormonal imbalance resulting from the disease. CD might lead to intestinal cancer if the disease remains untreated overtime. There are other diseases that might arise with the CD, like thyroid diseases, high risk of developing Diabetes, Lupus, and Rheumatoid Arthritis (Buckley et al., 2007).

2.3.7 Treatment

The clear treatment for celiac disease is total lifelong avoidance of gluten, found in wheat, rye and barley. Consultation with a dietician for strict gluten-free diet education is essential in the treatment and follow-up of celiac disease. Treatment includes also looking for and treating the complication of the disease such as iron deficiency anemia, folates deficiency, fat-soluble vitamins deficiency A, D, E and K (Collin et al., 2007).

2.3.8 Management of celiac disease

2.3.8.1 Short term Management

Dietary treatment

The only treatment for CD is a strict, lifelong GFD. Education regarding a GFD from a dietitian with experience in CD is considered an essential part of patient management (Raymond et al., 2006). Patients need to be confident identifying sources of gluten in foods and interpreting food labels and ingredient lists. The role of the dietitian will subsequently extend to the nutritional adequacy of the patients GFD.

Medical treatment

Once an individual is diagnosed with CD, the attending medical practitioner should give additional recommendations regarding tests for related conditions and screening of family members.

Patients' support

Information on CD and the GFD is available to those diagnosed with CD through each state Coeliac Society. Associate membership is also available to dietitians. Ongoing support is provided in the form of resources, regular publications, phone support, shopping tours, cooking demonstrations, information sessions and social events. A letter from a registered medical practitioner indicating a medical need for a GFD is required to join The Coeliac Society.

2.3.8.2 Long Term Management

It is expected that histology, serology and symptoms will improve on a strict GFD (Green and Jabri, 2003). Repeated endoscopy and bowel biopsy is recommended 12 – 24 months post diagnosis to confirm dietary compliance and bowel repair (Haines et al., 2008). A follow up consultation with an experienced dietitian to thoroughly assess understanding and compliance with the GFD is important.

Effective management of CD requires intense family cooperation as well as concerted national efforts to provide these patients easy access to gluten free diets. The evolution of Celiac Societies and widespread dissemination of knowledge through all available media will greatly help in management of patients with this chronic disease.

Successful management of CD requires a team approach, including the person with CD and his or her family, physician, dietitian, and celiac support group; an individualized approach; understanding of quality of life issues; use of evidence-based, current information and resources; and regular follow-up to monitor compliance, nutritional status, and additional information and support (Case, 2005).

2.3.9 Compliance

2.3.9.1 Definition

In medicine, compliance (also adherence, concordance, or capacitance) describes the degree to which a patient correctly follows medical advice. Most commonly, it refers to medication or drug compliance (Wikipedia, 2011). In many studies the word "adherence" is preferred by many health care providers, because "compliance" suggests that the patient is passively following the doctor's orders. Patients should not be passive: a treatment plan must be based on a therapeutic alliance or contract between the physician and the patient (Osterberg, and Blaschke, 2005). The term compliance has been defined by WHO as "faithful adherence by the patient to prescribed instructions" (WHO, 2006).

2.3.9.2 How to measure compliance

Good dietary compliance will reduce the risk of further complications and associated health care costs and improve quality of life in patients with CD (Case, 2005).

Even today, patients self reports can simply and effectively measure adherence. There are direct and indirect methods available for measuring adherence. Each method has

advantages and disadvantages, and there is no method considered as the gold standard (Osterberg and Blaschke, 2005). In celiac disease the Intestinal biopsy and antibody test are examples of direct methods for measuring adherence. Indirect methods for measuring adherence include asking the patient about different aspects according to the gluten free diet, by using questionnaire and assessment of the clinical symptoms. These methods are easy to use, but asking the patients can be susceptible to misrepresentation and tends to result overestimating the patients adherence (Osterberg and Blaschke, 2005).

Many articles wrote about evaluating the compliance to the gluten free diet, in Athens University a study was conducted on celiac children to investigate the compliance with a GFD and the impact of CD and GFD on the lifestyle of patients and their families, by using special questionnaire. The conclusion was that the Children with CD have low compliance with the GFD. Better education about the disease, the availability of GF products, and appropriate food labeling could improve compliance and quality of life (Roma et al., 2010).

Chauhan and et al stated a study to assess dietary compliance to Gluten Free Diet (GFD), by using self administered questionnaire for group of children who were diagnosed as celiac disease. In this study noncompliance to gluten free dietary regimen is seen in 18 % of cases. Dietary noncompliance is more common in the adolescent age group, in joint families and those who have more number of siblings. Dietary restrictions have impact on child's social activities and thus psychosocial parameters (PSC score) are better in the dietary compliant group (Chauhan et al., 2010).

Another study is to evaluate the effect of gluten-free diet adherence on health-related quality of life in adult coeliac disease patients. This study also used a questionnaire; the results confirm the burden of coeliac disease on health-related quality of life. Moreover,

these data show that health-related quality of life in coeliac disease is impaired by poor compliance (Usai et al., 2007).

The Brazilian Celiac Association evaluate the compliance of its patient to gluten free diet by using structured questionnaire, 69.4% were classified as compliant patients whereas 29.5% were classified as noncompliant. The proportion of patients aged 21 or older who consume gluten frequently or without any restriction is larger (17.7%) than those who were younger than 21 years (9.9%) (Sdepanian et al., 2001).

In a study for evaluation the diagnosis and dietary compliance in Canadian children less than 16 years, it was reported that 10% to 20% had major disruption in life style. Twenty three percent felt angry all or most of the time about following a gluten free diet. Only 15% avoided travel, and during travel 83%brought routinely gluten free food with them. More than half of the families avoided restaurants and for 28% it was extremely difficult to locate stores with gluten free food. within the same context, 27% reported extreme difficulty in finding gluten free food or determining if the food was free of gluten (Mohsin, 2005).

Compliance to gluten-free diet for patients with screen-detected celiac disease, and patients with symptom-detected celiac disease was associated with improved quality of life (Mustalahti et al., 2002).

2.3.9.3 Knowledge and attitude

When a patient begins to eat gluten-free, there is often much concern and confusion as to which foods are allowed and which are not. The food of Patients with celiac disease should be gluten free, but it should be normal and contain moderate cholesterol, low fat, low salt, moderate protein, high fiber, and different kinds of vitamins and minerals required for good nutrient balance. To improve the gluten free diet, the patient should have food rich in grains, seeds like beans, rice, and bran that are good sources of protein,

amino acids, carbohydrates, calcium, and iron (Thompson et al., 2005). So People with celiac disease must read all food labels to ensure the gluten-free status of a food item to avoid cross contamination of foods. Shopping for gluten free food becomes easier once the patient has some experience, and more grocery stores now allocate space gluten free product.

In the Gaza strip, it is difficult to find grocery stores and supermarkets that provide gluten free products. Though all celiac patients receive gluten free flour from Ard El Insan Palestinian benevolent association clinic and can prepare it at home (Ard El Insan, 2011). Furthermore, generally there is a greater need for health care professionals who are knowledgeable about celiac disease and the gluten free diet. Expert dietitians are responsible for nutrition assessment, treatment of nutritional deficiencies, and education of patients with celiac disease and to everyone who prepares food for the celiac patients. Sharing literature about the gluten free diet with the household members, patient relatives, friends, children caregivers, and children classmates is necessary in the school (Case, 2005).

Patients who understand the long-term consequences of celiac disease will make informed choices in managing their disease. Dietitians provide the tools that patients need to successfully understand the diet and integrate it into every aspect of their lives, leading to overall improvements in the physical and emotional challenges of the disease.

Accredited Practicing Dietitians and other health professionals play a critical role in the management of those with CD. Initial education regarding the GFD and ongoing support and assessment of long term nutritional adequacy and compliance is essential.

The physician must clearly communicate, with a positive attitude, an overview of CD and strongly emphasize the importance of a GFD for life. It is essential that patients be referred immediately to a dietitian who is specialized in celiac disease for complete nutrition

assessment, diet education, meal planning, and assistance with the adaptation to the challenging new gluten-free lifestyle (Case, 2005). A dietitian with such expertise can educate patients about the complexities of the gluten-free diet; sources of hidden gluten; balanced meal planning; label reading; shopping for foods; dining out and traveling, benefits of exercise and relaxation; appropriate vitamin and mineral supplementation; and credible resources and support groups. Patients need to learn to integrate the gluten-free diet into their school or work schedules, as well as family life (Barton et al., 2007). Another important role of the dietitian is to educate family members who can support the patient when they face the challenges of the gluten-free diet. Family members must understand the importance of taking precautionary measures to prevent cross-contamination of foods. Gluten-free foods must be stored and prepared separately, cooking and serving utensils must be cleaned carefully prior to use, and a separate toaster must be purchased for the person with celiac disease. Collectively, these practices support the patient's adherence to the gluten-free diet.

Several visits should be scheduled with a dietitian because follow-up is necessary to assess knowledge, competence and compliance, as well as to provide reinforcement (See and Murray, 2006). Without such support the result will be confusion, frustration, and insufficient knowledge regarding celiac disease and gluten-free diet (Dennis and Case, 2004). Patients should be encouraged to join a celiac disease support group because patients who are active members are usually more knowledgeable and adherent to their diet (Kupper, 2005). Ongoing support, education, and attention to changing nutritional needs are critical factors in the patient's successful adaptation to this new diet and lifestyle.

2.3.9.4 Counseling and education

Some people with celiac disease cheat and eat gluten, and others make mistakes and eat gluten by accident, and how ever some can successfully stick to the diet. One thing is sure: Following a gluten-free diet is extremely challenging. Celiac patients are allowed a wide variety of foods – but they can't contain wheat, barley, or rye (or any derivatives of these grains). Even microscopic amounts must be avoided in order to protect intestines and reduce risk of serious complication (Duggan et al., 2008). Half of the truth is what the patient knows about gluten free diet, which is the Gluten, comes from wheat, barley, and rye, and they need to stay away from them. For example no bread, no pasta, no cakes, no cookies… but this is the half of the challenge because gluten is not just in the obvious places. It can be hidden in many products. Gluten makes soups and gravies thicker, and salad dressings creamier. It keeps yogurt and soft cheeses from getting runny and dried spices from clumping in their little jars. It can be in the molds that give chocolates their shape. It keeps candy bars from sticking to the factory conveyor belt. It can be hidden in the natural flavoring, modified food starch, and textured vegetable protein which added to food products. It's also in chewy candies. It's the filler in pills and tablets. It hides in lipsticks, toothpaste, and mouthwash (Lapid, 2009). According to this the celiac patient should have treatment plan that includes lifestyle counseling and nutrition education on the gluten-free diet. This counseling and health education is provided by gastroenterologists, nurses and registered dietitians through a community support group, and provides appropriate foods through the Department of Nutrition and Food Services (Addolorato et al., 2004).

The NIH Consensus Conference on Celiac Disease identified six key elements in the management of people with Celiac Disease (Canadian celiac association, 2009):

Consultation with a skilled dietitian, **E**ducation about the disease, **L**ifelong adherence to a gluten-free diet, **I**dentification and treatment of nutritional deficiencies, **A**ccess to an advocacy group, **C**ontinuous long-term follow up by a multidisciplinary team.

2.3.9.5 Barriers to compliance

Changes in dietary habits are difficult to maintain, and there are many barriers to continued compliance with a GFD.

Inadequate health literacy: That's means inadequate health information which is needed to make correct health decisions (Naal, 2011). This was obvious on study about Assessment of dietary compliance to Gluten Free Diet in Indian children with Celiac Disease, in which the Dietary compliance was higher in children with higher maternal education and in parents having better knowledge and understanding of disease (Chauhan and et al. 2010).

Poor communication: Patients will be more vulnerable to complication when there is a lack of interdisciplinary collaboration as seen in study about factors related to compliance with a GFD in patients with celiac disease, from the factors correlating with compliance with a gluten-free diet among White Caucasians' were: Coeliac Society membership, explanation by a physician, and regular dietetic follow-up. These factors were not identified amongst the South Asians, who were less likely to attend dietetic clinics, join the Coeliac Society (Butterworth and et al., 2004).

Financial constraints: Financial constraints that make it difficult for patients to get the gluten free foods, or even to have the cost of transportation to the medical center. In Gaza strip only AEI provides gluten free flour for celiac patients, and other gluten free products rarely found in one or two supermarkets in Gaza, and cost about three times their regular wheat-based counterparts. This is increases the burden that would likely have a negative impact on dietary compliance (Ladnier, 2008).

Emotional concerns: The daily dealing with chronic condition make the patients feel hopeless, which hinders their ability to retain instructions about caring for themselves. Children look at their parents for emotional cues and strategies for handling stressful events. For these reasons, it is important for parents to be positive, help their children to manage their gluten free diet. Also family members of celiac patient have the same responsibility. On analysis of individual PSC items, it was found that anger, irritability; behavioral problem, tiredness, decreasing school performance, unhappiness etc were higher in celiac patients (Chauhan et al., 2010).

Addolarto et al have shown that anxiety is present in celiac disease subjects as a reactive form which decreases with GFD; however depressive symptoms still persist in treated Patients (Addolorato et al., 2001). Ciacci et al in their study have also reported that anger is the predominant emotion which induced patients to transgress (Ciacci, 2002).

It is obvious on these different studies the need of these patients for psychological support when they are put on GFD.

Chapter 3: Methodology

This chapter presents the study methodology; demonstrates the study design, study population, eligibility criteria, place of the research, ethical consideration. In addition, it represents the instrument of the study, data collection process, data entry and analysis, and limitation of the study.

3.1 Study design

The design of this study is a descriptive, analytical, observational cross sectional design that focuses on patients affected with celiac disease, who were attending Ard El-Insan in Gaza strip.

This design was chosen because it is the best design to describe the relationship between diseases (or other health-related characteristics) and other variables of interest as exist in a defined population at one particular time (i.e. exposure and outcomes are both measured at the same time). The study described the compliance of patients of celiac disease with the gluten free diet, and detected the factors which might affect their compliance in a short time. Cross sectional studies are less expensive, enable the researcher to meet the study objectives in a short time, and study the causes and effects at the same point of time (Levin, 2006).

3.2 Study settings

The study was conducted at the two centers of Ard El-Insan clinic, in the Gaza strip and Khanyounis. Ard El-Insan is a Palestinian nongovernmental organization that provides nutritional and health services to beneficiaries in these areas. In addition, each center conducts a community-based program targeting vulnerable areas in different locations such as refugee camps, villages, deprived and rural areas. Celiac patients are one of their beneficiaries where they receive nutrition therapy, counseling, and psychological support.

3.3 Study population

Study population included all patients who were diagnosed by either antibody test or intestinal biopsy from both genders among all patients attending Ard El Insan clinic. According to the celiac disease care medical records in the year 2011, the patients' list included 193 patients. Parents of the diseased children (2-11 years old) (mothers or fathers) were interviewed, and patients above 11 years old were interviewed by the researcher to answer the questionnaire (Woolley et al., 2008).

3.4 Eligibility criteria

3.4.1 Inclusion criteria

- Patients who were diagnosed as celiac patients and eligible for follow up in Ard El Insan clinic, both genders males and females.
- Parents of celiac patients from 2-11 years old.

3.4.2. Exclusion criteria

- Patients who are not residents of the Gaza Strip.
- Patients from 2-11 years old who are accompanied by others rather than their parents.
- Patients whom the diagnostic tests of CD were not included in their files.

3.5 Data collection

Data collection was carried out via patient's document revision for the first section of the questionnaire, and then it was validated by the interviewed questionnaire. The second section was carried out by the interviewed questionnaire to the patients, or their parents for children who are less than eleven years old. The questionnaire was collected by the researcher.

Study instrument

The questionnaire was designed and prepared to compile information relating to the objectives of the study, It was developed by the Canadian Celiac Association's and it was modified according to our situation by the researcher with the consultation of 10 experts in different fields.

The questionnaire consists of two parts: the first part is exploring information from the patient's medical file which includes: Sociodemographic characters, date of diagnosis, chemical and pathological tests that are considered as indicators for diagnosing and controlling the disease.

The second is part is exploring the information about knowledge, attitude, patient's history of the disease, dietary habits and compliance regarding to gluten free diet.

The questionnaire was used in Arabic language because it is the mother language for the participants, annex (6 and 7). The average time for filling the questionnaire was from 10 to 15 minutes. Total period of data collection was three months.

3.6 Compliance definition

The term compliance has been defined by WHO as "faithful adherence by the patient to prescribed instructions" (WHO, 2006). In this study compliance was discussed and measured according to the gluten free diet regimen plan, so the compliance can be measured by using a structured questionnaire, and every participant was asked about the gluten free diet regimen and comparing his response with the exact regimen plan for celiac patient followed at Ard El Insan clinic. If the participant regimen is compatible with the exact one, the participant will be considered as a compliant and if not, the patient will be considered as non- compliant.

The non- compliance will be studied in relation to different variables of the study.

3.7 Response rate

The list of patients included 193 participants. Two of patients were died, the telephones of ten of them were out of service, and eight of them believed that they are not celiac patients, and the remainder didn't response and most of them were dropouts. The net respondents were 135 patients with response rate of 72%.

3.8 Validity and reliability

Part of the instrument used for data collection in this study was professionally prepared by the Canadian Celiac Association in collaboration with the faculty of medicine of the University of Ottawa. Other contents were added by the researcher based on Gaza situation. The modified questionnaire was discussed with consultants and experts in health to assess the relevance, clarity and comprehensiveness of the used instrument. In order to validate the questionnaire in this study, the researcher sent it with a covering letter, title, and objectives of the study to 10 different experts including researchers, managers, PHC physicians, pharmacists, and specialist physicians (Annex 8). To increase validity in this research, the following was done:

- Systematic checking and follow up for the collected data.
- Data cleaning and checking.

Also, to ensure the high reliability of the instrument used in this study, the data collection was completed by the researcher herself, standardization of the tools, and unifying the implementation procedures that will be conducted through out the study.

3.9 Data entry and analysis

After data collection, questionnaires were overviewed. Then the data were entered and analyzed by using a statistical package of social science version 13 (SPSS). Data cleaning was performed to check entry errors. Data analysis was carried out as follows:

- Reviewing and checking the questionnaire.
- Defining and coding of data.
- Formation of frequency tables for the study variables.
- Cross tabulation of the results.
- Calculation scores of different variables.
- Statistical relationship between the dependant variable and the independent variables was tested by using Chi- Square.
- The level of Statistical significance was measured by using P- value for different variables. It was considered statistically significant when it is lower than 0.05.

3.10 Period of the study

The study was implemented immediately after the approval of the proposal from the deanship of graduate studies at Al-Quds university, ethical approval from Ard El Insan, and Helsinki approval, during the period from May 2011 to November 2011.

3.11 Administrative and ethical matters

- An official letter of approval to conduct the study was obtained from Helsinki committee (ethical committee in Gaza strip) (Annex 2).
- The study proposal was approved by the school of public health.
- An official letter was obtained from Ard El Insan Association to conduct the study in Ard El Insan clinic (Annex 3).
- Every participant in this study received complete explanation about the purpose of the study, instrument, period of interview, voluntary and optional participation, and confidentiality, and sign informed consent (Annex 4 and 5).

- All the ethical concepts were taken into consideration: respect of people, dignity, and privacy.

3.12 Pilot study

A pilot study was carried out on 30 subjects before starting the real data collection, selected by convenient sampling method to examine predictability, reliability, and validity of the study, and to identify any defects in the study design and areas of difficulties and ambiguity. After piloting process some changes and modification was done in the study tool according to the pilot study.

3.13 Limitation of the study

- The study included only the registered patients at Ard El Insan clinic as it is the only clinic that manages the celiac disease patients.
- Lack of educational resources especially updated journals and books about celiac disease.

Chapter 4 Results and discussion

4.1 Characteristics of the study population

Table 4.1: Distribution of the study population by socio-demographic characteristics.

Variables	Frequency	Percentage %
Age		
1-11 years	23	17
12-20 years	25	18.5
21 years and more	87	64.5
Total	135	100
Sex		
Male	39	28.9
Female	96	71.1
Total	135	100
Marital status		
Children below 18 years	42	31
Single	35	26
Married	56	41.5
Divorced	2	1.5
Total	135	100
Locality		
North Gaza	15	11.1
Gaza city	53	39.3
Mid-zone	16	11.9
South	51	37.8
Total	135	100
Years of education		
Children below 6 years	10	7
(0-6years) Low	27	20
(7-12years) Medium	62	46
(>13years) High	36	27
Total	135	100
Family members		
1-3	10	7.4
4-6	47	34.8
>7	78	57.8
Total	135	100
Occupation		
Children below 18 years	42	31
Working	34	25
Not working	59	44
Total	135	100
Income		
Less than1000 NIS	18	52.9
1000-2000 NIS	11	32.4
More than2000 NIS	5	14.7
Total	34	100

The study results showed that the highest age category was among the adult age group (21 years and more), represented by 64.4%, then followed by the age group (12-20years), represented by 18.5%, while the least percentage 17% was among the children age group as shown in figure (4.1.1). The study showed that CD was seen more among adults than children which was inconsistent study was done in the northeast of Spain on 4230 subjects who were included consecutively (1 to ≥80 years old), that showed that the prevalence of CD in childhood was five times higher than in adults. This difference may be due to environmental factors, latency of celiac disease in adulthood or misdiagnosis of CD in Gaza children due to the similarity of symptoms to many other diseases symptoms. (Marine et al., 2011).

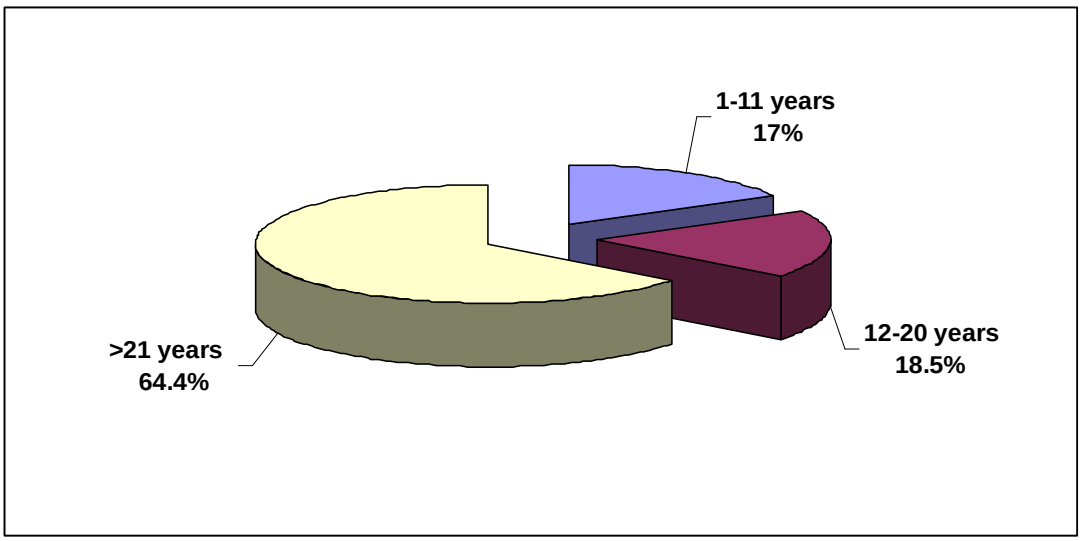


Figure 4.1.1: Percentage distribution of the study population by age

In this study, female subjects were more than males, nearly twice and half. Female represented 71.1% of the study population, while males represented 28.9% as shown in (figure 4.1.2). Female predominance in this study is consistent with many published studies, as an Italian study on a group of celiac patients, confirmed that CD is more predominant in female than male (Meqiomi, et al., 2008; Mohammed, et al., 2006).

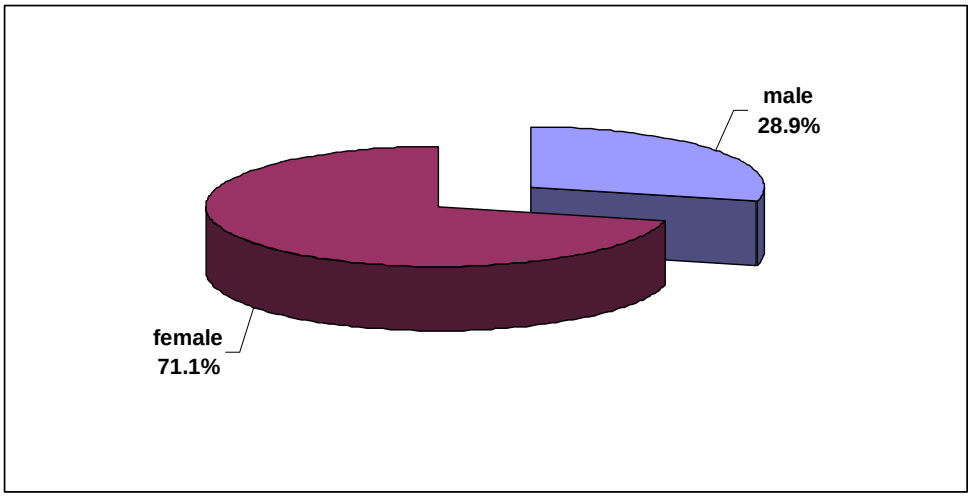


Figure 4.1.2: Percentage distribution of the study population by sex

Table 4.1 showed that the percentage of study population who were single was 26%, after the exception of children up to 18 years old. The married percentage was 41.5%.

The distribution of study population according to their localities was the highest in Gaza city (39.3%), followed by south region (37.8%), and then the lowest was in Mid-zone (11.9%) and north Gaza (11.1%) as demonstrated in figure (4.1.3). The prevalence rate of CD per area based on its population was 1:10.000 in Gaza city and south, 1:14.000 in mid-zone, and 1:20.000 in north Gaza.

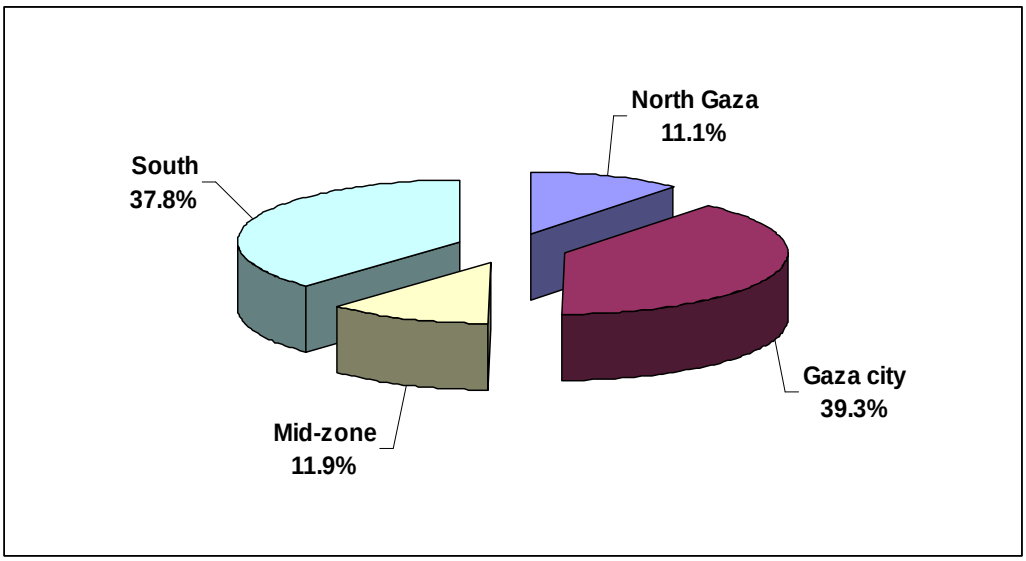


Figure 4.1.3: Percentage distribution of the study population by locality

Regarding the educational level, the researcher categorized the years of education into three groups. The children below the school age were excluded, the first group was the low level of 6 years of education which is represented by 20%, and the second group was the median level from 7-12 years of education, which was represented by 46%, and finally the third group was the higher level with more than 12 years of education, was represented by 27% as shown in table 4.1.

Concerning the occupation, 44% of the study population who were above 18 years old were unemployment, and only 25% were having an employment as shown in figure (4.1.4). These results were consistent with the new united nation Gaza blockade anniversary report that found unemployment there among the highest in the world (UNRWA, 2011), also studies conducted in Sudan showed that CD is more detected among moderate and low socioeconomic classes (Mohammed, et al., 2006). From those who were working, 52.9% their income was less than 1000 Nis, 32.4% was from 1000-2000 Nis, and 14.7% was more than 2000 Nis.

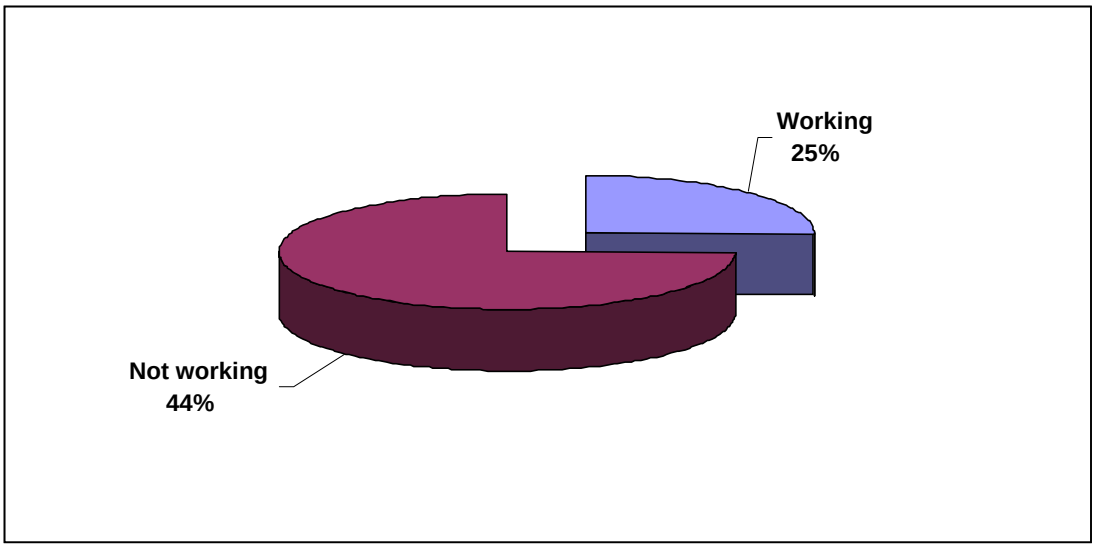


Figure 4.1.4: Percentage distribution of the study population by occupation

As showed in table (4.1), the highest percentage 57.8% had a family size more than 7 persons, followed by family size ranged from 4-6 persons represented by 34.8%, while the family size ranged from1-3 represented by 7.4%.

4.2 Disease profile of the study population

Table 4.2: Distribution of the study population according to the disease characteristics .

Variables	Frequency	Percentage %
Duration of CD		
1-5 years	67	50
6-40 years	68	50
Total	135	100
Family history		
Yes	24	17.8
No	111	82.2
Total	135	100
Period of symptoms before diagnosis by months		
1-24 months	71	52.6
25> months	63	46.7
Total	134	99.3
Associated chronic diseases		
Yes	23	83
No	112	17
Total	135	100
1- DM	8	5.9
2- Thyroid diseases	7	5.1
3- Others	8	5.9
Age of diagnosis		
1-21	70	51.9
22-64	65	48.1
Total	135	100
Diagnosed by		
Pediatrician	36	26.7
Gastroenterologist	90	66.7
Allergist	4	3
Endocrinology	5	3.7
Total	135	100
Type of test that confirm diagnosis		
Intestinal biopsy	86	63.7
Antibody test	107	79.3

Health profile includes duration of CD, family history, associated chronic disease, period of symptoms before diagnosis, age of diagnosis, physicians made the final diagnosis, and finally the type of the test that confirm diagnosis as shown in table (4.2).

Duration of the disease was divided into two groups, first group was from 1-5 years, which represented 50% of the study population, and the second group included those the duration of CD from 6-40 years, represented by 50% of study population as shown in table (4.2).

Regarding the family history, as shown in table 4.2 the majority of the study population had no family history, it was represented by 82.2%, and only 17.8% of the study population had family history of the disease. This positive family history results among the study population is more than the percentage in previous research study that extended on family members of an adult patients with CD that showed the overall family involvement was 11.8% (Rodrigo, et al., 2004).

Considering the association with chronic diseases, 17% of study population had associated with chronic diseases, while 83% did not (table 4.2). DM was represented by 5.9% of the study population and thyroid diseases was represented by 5.1%, these results is nearly the same in previous research study showed that the percentage of DM among celiac patients was 5.4% and thyroid diseases was also 5.4% (Collin, et al., 2011).

In table 4.2, the period of symptoms before the diagnosis of the disease was divided into two groups, the first group was from 1-24 months, represented by 52.6% of study population, and the second group was more than 25 months, represented by 46.7% of study population. CD has different pictures of clinical manifestation, which varies from typical CD and atypical CD. Medical awareness of these multiple presentation and diseases associated with CD is not good and often leads to delay in diagnosis (Green, 2001).

In this study the age of diagnosis ranged from 1 to 64 years old by median age of 21 years, more than 50% were diagnosed at age from one year to twenty one years old (51.9%) and 48.1% were diagnosed at age from 22 years and more as shown in table 4.2.

The study done by Mohsin Rashid, 2005 on all members of Canadian Celiac Association, showed that the median age of diagnosis was three years .This difference because the data that were analyzed was done only for the children younger than 16 years.

Physicians of final diagnosis in this study indicated that more than 66.7% of the study population consulted Gastroenterologist, 26.7% consulted Pediatrician, 3.7% consulted Endocrinology, and finally 3% consulted Allergist as shown in table 4.2.

A serological test was performed to diagnose celiac disease in 79.3% of those in this population; this percentage was relatively higher than previous research study which was70% (Mohsin, et al., 2005). The diagnosis of CD by intestinal biopsy was used by 63.7% of study population.

4.3 Symptoms of the disease among study population

Table 4.3: Distribution of study population according to their symptoms.

Variables	Frequency	Percentage %
Symptoms before diagnosis		
Diarrhea	107	79.3
Constipation	34	25.2
Bloating	113	83.7
Gas	97	71.9
Abdominal pain	112	83
Weight loss	117	86.7
Lactose intolerance	28	20.7
Vomiting	62	45.9
Itchy skin	41	30.4
Poor growth	102	75.6

Table 4.3 lists the clinical symptoms of CD of the study population reported before the diagnosis of CD. Weight loss was the most common symptom presenting in 86.7% of the

respondents. Other prominent gastrointestinal symptoms included bloating (83.7%), abdominal pain (83%), diarrhea (79.3%), poor growth (75.6%), gases (71.9%), vomiting (45.9%), itchy skin (30.4%), constipation (25.2%), and lactose intolerance (20.7%). Previous research study showed that the abdominal pain was the common symptom (Mohsin, et al. 2005). Another study in Tehran reported that CD was the most common cause of adult chronic non-bloody diarrhea, which is not consistent with the research results (shahbazkhani, et al., 2004b and Ciclitira, et al., 2001).

4.4 Disappearance of symptoms

Table 4.4: Distribution of study population according to disappearance of symptoms

Disappearance of symptoms after GFD	Frequency	Percentage %
Yes	59	47.4
No	76	52.6
Total	135	100
If no, check the possible cause		
Problems with adhering to a gluten-free diet	39	51.3
Unaware of hidden sources of gluten	17	22.3
Some other food allergy	12	15.8
Unknown cause	8	10.5

After starting GFD, 47.4% of the study population noted disappearance of symptoms, while 52.6% said that the symptoms were persistent (table 4.4). This result was not consistent with previous research study done in Canada, in which 89% of the respondents noted improvement in their health (Mohsin, et al. 2005). According to the possible causes of existence of symptoms were problems with adhering to GFD (51%), as problems with the availability and sensory acceptance of gluten-free food, insufficient social support. Unaware of hidden sources of gluten was (22.3%), some other food allergy (15.8%), and Unknown causes (10.5%) as shown in table 4.4.

4.5 Knowledge about disease

Table4.5: Distribution of study population according to their knowledge about the disease.

Variable	Frequency	Percentage %
1-Hearing about CD before		
Yes	41	30.4
No	94	69.6
Total	135	100
2-Celiac disease can be cured completely		
Yes	56	41.5
No	28	20.7
Don't know	51	37.8
Total	135	100
3-Thinking that celiac patients live normal life		
Yes	94	69.6
No	41	30.4
Total	135	100
4- Knowledge of the special logo of gluten free food		
Yes	58	43
No	77	57
Total	135	100
5- Knowledge about food containing gluten		
Yes	67	49.6
No	68	50.4
Total	135	100
6-Have counseling		
Yes	134	99.3
No	1	0.7
Total	135	100
7- Source of information		
Gastroenterologist	74	54.8
Dietitian/nutritionist	18	13.3
Ard El Insan	120	88.9
Health centers	8	5.9
Internet	26	19.3

Knowledge of patients was assessed by asking them about CD. They were asked if they heard about CD, if CD can be cured, also they were asked if they thought that celiac patients can live normal life, and about their knowledge of special logo of gluten free food, and about food containing gluten. Table 4.5 clarifies that the majority of study population

69.6% didn’t hear about CD before, while 30.4% heard about CD before. Nearly 41.5% thought that CD can be cured completely, while 37.8% of them didn’t know if CD can be cured, but the others thought that CD can't be cured. This may indicated their psychological state, and didn’t reflect the clinical meaning of this question. knowledge completely about the disease..

Nearly seventy percent of patients believed that celiac patients live normal life, and 30.4% didn’t believe that celiac patients live normal life. This is may be due to their negative feelings and the psychological status when they are interviewed. Fifty-seven percent of the study population didn’t know the special logo of gluten free food, while 43% knew it. About half of the study population 50.4% didn’t have enough knowledge about food containing gluten, while the other half 49.6% identified the gluten containing foods. This reflects the defect of education about gluten- containing food during counseling. The patients were asked if they had counseling about the disease and its treatment, most of them 99% had information about the disease from different sources. The main source of information was from AEI 88.9%, as all patients belonged to AEI, and all were informed that CD required lifelong adherence to a strict GFD. The other sources were from gastroenterologist 54.8%, internet 19.3%, dietitian 13.3%, and health centers 5.9%.

4.5.1 Knowledge level

Table 4.5.1: Distribution of study population according to their knowledge level.

Variable	Frequency	Percentage %
Knowledge level		
Low	61	45.2%
High	74	54.8%
Total	135	100

The five questions about knowledge were recoded into two categories: who answered less than two positive knowledge answers considered low knowledge level and who had more than two positive knowledge answers considered high knowledge level as shown in table 4.5.1. It was found that 54.8% of study population had high level of knowledge, while 45.2% of them had low level as shown in table 4.5.1.

4.6 Attitude and practices

Table 4.6: Distribution of study population according to their attitudes and practices.

Variable	Frequency	Percentage %
1-Avoid restaurants because of CD		
Yes	98	72.6
No	37	27.4
Total	135	100
2-Aviod going out because of CD		
Yes	38	28.1
No	97	71.9
Total	135	100
3-Difficulty to find gluten free diet		
Yes	118	87.4
No	17	12.6
Total	135	100
4-Difficulty to determine if food is gluten free		
Yes	65	48.1
No	70	51.9
Total	135	100
5- Eating gluten-containing food because you can not afford gluten-free food		
Yes	42	31.1
No	93	68.9
Total	135	100

The researcher clarified the attitudes and practices of respondents as shown in table 4.6. Restaurants were avoided in 72.6% and 27.4% hadn't any problem about going to restaurants. A study conducted in Canada by Mohsin (2005) determined that restaurants were avoided by 54% of celiac patients. This doesn't mean that all of seventy two percent didn't to restaurants due to the disease, because in our culture going to restaurants is avoided also due to economical and social causes.

Only 28.1% avoided going out or travelling, and 71.9% didn't have any troubles for going out or traveling. Also here the percentage of study population that avoided going out or traveling is higher than in the previous research study, which was 15% (Mohsin, et al., 2005).

The majority of study population 87.4% found it difficult to find GFD, as AEI is the only institution that provides gluten free food. In the Gaza Strip a few number of stores providing gluten free foods, which are not accessible for all patients.

Nearly 52% of study population didn't find any difficulty to determine if a food was gluten free, while 48.1% found it difficult to determine if a food was free of gluten or not. This is not consistent with Mohsin, et al.,(2005) study, in which 27% found a difficulty to determine if food was gluten free or not.

When the patients were asked if they have been eating gluten- containing food, because they didn't afford GFD, about 69% of the study population answered with no. Whilst 31% didn't afford GFD, so they ate foods containing gluten. This is may be a reasonable cause of non compliance.

4.6.1 Attitude and practices level

Table4.6.1: Distribution of study population according to attitude level.

Variable	Frequency	Percentage %
Attitude level		
Low	79	58.5%
High	56	41.5%
Total	135	100

The questions about attitude and practice were recoded the into two categories: ones who answered less than two positive attitude questions were considered low attitude level and

the ones who had more than two positive attitude answers considered high attitude level as shown in table 4.6.1.

It was found that 58.5% of study population had low level of attitude, while 41.5% of them had high level as shown in table 4.6.1.

4.7 Ways of improving lives

Table 4.7: Distribution of study population according to the ways of improving their lives.

Variable	Frequency	Percentage %
1-Earlier diagnosis of CD		
Yes	115	85.2
No	2o	14.8
Total	135	100
2-Better labeling of gluten containing foods		
Yes	32	23.7
No	103	76.3
Total	135	100
3-Gluten free choices on restaurant menus'		
Yes	19	14.1
No	116	85.9
Total	135	100
4-Better dietary counseling		
Yes	53	39.3
No	82	60.7
Total	135	100
5-More gluten free foods in the supermarkets		
Yes	50	37
No	85	63
Total	135	100

The participants were asked to select 2 items from the questionnaire that they felt would improve their quality of life. Early diagnosis was selected by 85.2% of the study population, better dietary counseling by 39.3% and more gluten free foods in the supermarkets by 37%. Better labeling of gluten containing foods was selected by 23.7% and gluten free choices on restaurant menus' by 14% as shown in table 4.7.

4.8 Description of GFD status among study population

Table 4.8: Distribution of study population according to their GFD status.

Variable	Frequency	Percentage %
Following GFD		
Yes	121	89.6
No	14	10.4
Total	135	100
Quality of improvement		
A lot	92	68.2
Moderately	32	23.7
A little	10	7.4
Not at all	1	0.7
Total	135	100
Description of the current diet		
Strictly gluten-free	78	57.8
Partially gluten-free	45	33.3
Not gluten free	12	8.9
Total	135	100
Difficulty to follow GFD		
Very difficult	53	39.3
Moderately difficult	50	37
Little difficult	19	14.1
Not difficult	13	9.6
Total	135	100

The majority 89.6% of the study population followed GFD, and only 10.4% didn't. (table 4.8). After starting the GFD, 68% noted a significant improvement in health, 23.7% a moderately improvement, and 7.4% noted a little improvement.

The study population was asked about the difficulty to follow GFD, 39.3% found it very difficult, 37% found it moderately difficult, 14% found it a little difficult. And nearly 10% found it not difficult at all.

When the participants were asked to describe their current diet, the food of 57.8% of them was strictly gluten -free, 33.3% was partially gluten- free, and nearly 9% was not gluten-free. This question was used to measure the compliance of study population, so it was

divided into two groups, those who were strictly compliant (57.8%), and those who were partially and not compliant (42.2%) as shown in Table 4.9.

4.9 Compliance status among study population

Table 4.9: Distribution of study population according to their compliance .

Variable	Frequency	Percentage%
Compliance		
Strictly compliant	78	57.8
Partially or not compliant	57	42.2
Total	135	100

The 57.8% rate of strict dietary compliance to a gluten-free diet observed in this study, compared with the higher rates of 95% reported in Canadian survey study, 75% in Indian study, 73.5% in Italian study (Mohsin, et al., 2005; Chauhan, et al., 2010; Errichiello,et al.,2010). The variation of compliance rate differs due to difference in operation definition, selection of cut off points and is likely due to a combination of many factors. Some may be due to the poor economic situation caused by the siege which has affected all levels. AEI was one of the associations that were affected, as it is the only one that provides gluten free flour to patients. During the data collection there was a lack of gluten free flour that was provided by AEI to patients.

Inferential statistics

4.10 Compliance and Sociodemographic characters

Table 4.10: The relationship between compliance and Sociodemographic variables

Sociodemographic variables	Compliant		Non-compliant		P-value
	No	%	No	%	
Age					
1-11 years	16	69.6%	7	30.4%	0.194
12-20 years	11	44.0%	14	56.0%	
21 years and more	51	58.6%	36	41.4%	
Sex					
Male	25	64.1%	14	35.9%	0.343
Female	53	55.2%	43	44.8%	
Marital status					
Single	14	40%	21	60%	0.032
Married	38	68%	18	32%	
Divorced	1	50%	1	50%	
Locality					
North Gaza	8	53.3%	7	46.7%	0.786
Gaza city	30	56.3%	23	43.4%	
Mid-zone	8	50.0%	8	50.0%	
South	32	62.7%	19	37.3%	
Years of education					
(0-6years) Low	17	63%	10	37%	0.504
(7-12years) Medium	32	51.6%	30	48.4%	
(>13years) High	22	61%	14	39%	
Family members					
1-3	5	50.0%	5	50.0%	0.862
4-6	27	57.4%	20	42.6%	
>7	46	59.0%	32	41.0%	
Occupation					
Working	19	55.9%	15	44.1%	0.870
Not working	34	58%	25	42%	
Income					
<1000 NIS	8	44.4%	10	55.6%	0.086
1000-2000 NIS	6	54.5%	5	45.5%	
>2000 NIS	5	100.0%	0	0.0%	

Cross tabulation was used to determine the relationship between dependant variable (compliance), and independent variables (domains from the questionnaire) (table 4.10).

The results showed that the compliance rate was better 69.6% among the first age group (1-11 yr) as compared to middle age group 44.0%, and the adult age group 58.6%, but the difference did not reach the statistical significance (P-value 0.19). The results agreed with previous studies showing that the compliance was higher among children (Mohsin et al, 2005), and decreased among adolescents (Chauhan et al., 2010).

Regarding the gender it was indicated that the compliance among males represented by 64.1% was higher than females (55.2%), but the difference did not reach the statistical significance (P-value 0.34). The results were contrary to these of a study done on 204 celiac patients in southern Italy; it showed that there was no difference in compliance between males and females (Errichiello, et al., 2010).

Concerning the marital status the results showed that married patients were more compliant (68%) than single or divorced groups, with statistically significant (P-value 0.32). High compliance rate among married persons may be due to the presence of partner's care beside psychological and physical support to accomplish the compliance.

Regarding the locality of the study population, the compliance was higher among south population 62.7% than in Gaza city 56.3%, north Gaza 53.3%, and mid-zone 50.0%. The results did not reach the statistical significance (P-value 0.79).

Also the results showed that the compliance was 63% among low years of education, and was 51.6% among the medium years of education, while it was 61% among high years of education. This difference did not reach the statistical significance (P-value 0.50).

According to the family members the results showed that compliance among the group in which the family members was more than seven persons 59.0% was higher than the middle group 57.4%, which consists of 4-6 persons, and first group 50.0%, that consists of 1-3 persons. This difference did not reach the statistical significance (P-value 0.86).

Regarding the occupation, it was found that the compliance among workers was56% which was lower than the compliance among non workers.

Among those who were working, the compliance was higher among participants, whose their income was higher than 2000 Nis (100%), and 54.5% among persons, in which their income was from 1000-2000 Nis. The lowest compliance was among those who were their income less than 100 Nis (44.4%), but this difference did not reach the statistical significance (P-value 0.09).

4.11 Compliance and disease profile

Table 4.11: The relationship between compliance and disease profile.

Disease profile	Compliant		Non-compliant		P-value
	No	%	No	%	
Duration of CD					
1-5 years	38	58.5%	27	41.5%	0.859
6-40 years	37	56.9%	28	43.1%	
Family history					
Yes	13	54.2%	11	45.8%	0.693
No	65	58.6%	46	41.4%	
Period of symptoms before diagnosis by months					
1-24 m	40	56.3%	31	43.7%	0.386
More than 25 m	38	60.3%	25	39.7%	
Associated chronic diseases					
Yes	15	65.2%	8	34.8%	0.428
No	63	56.3%	49	43.8%	
Age of diagnosis					
1-21	37	52.9%	33	47.1%	0.230
22-64	41	63.1%	24	36.9%	
Physicians of final diagnosis					
Pediatrician	21	58.3%	15	41.7%	0.762
Gastroenterologist	51	56.7%	39	43.3%	
Allergist	2	50.0%	2	50.0%	
Endocrinology	4	80.0%	1	20.0%	
Type of test that confirm diagnosis					
Intestinal biopsy	48	55.8%	38	44.2%	0.541
Antibody test	62	57.9%	45	42.1%d	

A cross tabulation was done to study the relationship between compliance and disease related variables, including duration of the disease, family history, period of symptoms,

associated chronic diseases, age of diagnosis, physicians of final diagnosis, and type of the test that confirm the disease (Table 4.11).

The results showed that the compliance rate was slightly higher (58.5%) among participants, in whom their duration of the disease was from 1-5 years, but it did not reach the statistical significance (P-value 0.86).

Among patients who had not positive family history of the disease, 58.6% of them had been compliant; this was higher than among patients who had positive family history (54.2%). This difference did not reach the statistical significance (P-value 0.69).

According to the period of symptoms before diagnosis, the compliance among patients who was their period more than 25 months was higher than (60.3%) the other group (56.3%). This indicates that compliance rate increased as the duration of symptoms before diagnosis increased, that means ones who suffered more were the more compliant. The difference did not reach the statistical significance (P-value 0.39).

The compliance rate was higher (65.2%) among patients associated with chronic diseases than those who were not associated with chronic diseases (56.3%), but it did not reach the statistical significance (P-value 0.43).

The results showed that patients who were diagnosed at age period from 22-64 years old were more compliant (63.1%) than those who were diagnosed at age period from 1-22 years old, but this difference did not reach the statistical significance (P-value=0.23).

According to the physicians of final diagnosis, the results showed that the patients, who were diagnosed by endocrinology, were the most compliant (80.0%). The patients who were diagnosed by pediatrician were 58.3%, by gastroenterologist were 56.7%, and by allergist were 50.0%. This difference did not reach the statistical significance (P-value 0.76).

Concerning the type of test that confirm diagnosis, the patient who were diagnosed by antibody test were more compliant (57.9%) than those who were diagnosed by intestinal biopsy (55.8%), but it did not reach the statistical significance (P-value 0.54).

4.12 Compliance and knowledge

Table 4. 12: The relationships between compliance and knowledge about the disease.

knowledge	Compliant		Non-compliant		P-value
	No	%	No	%	
Hearing about CD before					
Yes	25	61.0%	16	39.0%	0.619
No	53	56.4%	41	43.6%	
Celiac disease can be cured completely					
Yes	33	58.9%	23	41.1%	0.633
No	14	50.0%	14	50.0%	
Don't know	31	60.8%	20	39.2%	
Thinking that celiac patients live normal life					
Yes	58	61.7%	36	38.3%	0.162
No	20	48.8%	21	51.2%	
Knowledge of the special logo of gluten free food					
Yes	39	67.2%	19	32.8%	0.053
No	39	50.6%	38	49.4%	
Knowledge about food containing gluten					
Yes	45	67.2%	22	32.8%	0.028
No	33	48.5%	35	51.5%	

A cross tabulation was done to study the relationship between compliance and knowledge of patients about the disease (Table 4.12). The results showed that the compliance among people who were hearing about CD before was higher than (61.0%) those who didn't (56.4%), but this difference did not reach the statistical significant (P-value=0.62).

The results showed that there weren't statistically significance differences (P-value=0.63), among the three groups when they were asked about the curability of the disease. The higher compliance rate was 60.8% among those who didn't know if CD can be cured completely, followed by those who knew that CD can be cured (58.9%), then those who thought that CD cannot be cured (50.0%).

The results showed that 61.7% of patients, who thought that celiac patients live normal life, were compliant, while 48.85% of patients who thought that celiac patient don't live normal life were compliant. This indicates that the compliance decreases among patients who had not a true knowledge about CD. These differences among three groups did not reach the statistically significance (P-value=0.16).

The results showed that there were statistically significant variations in reference to recognition of special logo of gluten free food (P-value=0.05). The compliance among those who knew the logo (67.2%) was higher than among those who didn't (50.6%).

According to the recognition of gluten-containing foods, the results showed that there were statistically significance variations (P-value=0.02). The compliance among those who recognized the gluten-containing foods (67.2%) was higher than among those who didn't (48.5%).

4.13 Compliance and knowledge level

Table 4.13: The relationship between compliance and level of knowledge about the disease.

Knowledge level	Compliant		Non-compliant		P-value
	No	%	No	%	
Low	30	52.6%	27	47.4%	0.210
High	47	63.5%	27	36.5%	

It was found that the compliance among those who had high level of knowledge (63.5%) was higher than those who had low level of knowledge (52.6%), but this difference did not reach the statistical significance (P-value=0.16). This indicates that the more the patients have knowledge about the disease the more they are compliant.

An in-dependent t-test was used to compare the means of the two groups of compliance in reference to the knowledge (Table 4.14).

Table 4.14: Differences in compliance status according to knowledge.

Compliance	Knowledge			P-value
	N	Mean	SD	
Strictly compliant	78	2.86	1.078	0.044
Partially or not compliant	57	2.47	1.104	

The results showed that there were statistically significant variations in reference to knowledge and compliance (P-value=0.04). These results were consistent with Indian study which indicated that compliance was higher in children with higher maternal education; in parents having better knowledge and understanding of the disease (Chauhan, et al., 2010). Another study was done on Brazilian celiac patients indicated that the more the patients know and understand about the disease, the better able they are to comply with the diet (Sdepanian, 2001).

4.15 Compliance and attitude

Table 4.15: The relationship between compliance and attitude, practice regarding GFD.

Attitude	Compliant		Non-compliant		P-value
	No	%	No	%	
Avoid restaurants because of CD					
Yes	59	60.2%	39	39.8%	0.353
No	19	51.4%	18	48.6%	
Avoid going out or travelling because of CD					
Yes	20	52.6%	18	47.4%	0.449
No	58	59.8%	39	40.2%	
Difficulty to find gluten free diet in stores					
Yes	74	57.4%	55	42.6%	0.652
No	4	66.7%	2	33.3%	
Eating gluten-containing food if gluten-free food cannot be found					
Yes	11	26.2%	31	73.8%	0.000
No	67	72.0%	26	28.0%	
Difficulty to determine if foods were gluten-free from reading their labels					
Yes	33	50.8%	32	49.2%	0.112
No	45	64.3%	25	35.7%	

A cross tabulation was used to study the relationship between compliance and attitude regarding GFD among patients (Table 4.15). The results showed that the compliance among those who avoided restaurants was 60.2%, while 51.4% of those who didn't avoid restaurants were compliant, but these differences did not reach the statistically significance (P-value=0.35).

The results showed the compliance among those who did not avoid travelling or going out was 59.8%, which was higher than those who avoid restaurants or going out (52.6%). These differences weren't statistically significance (P-value=0.44).

It was found that the compliance rate among those who didn't find difficulty to find gluten free foods was higher than those who found difficulty (57.4%). These differences didn't reach the statistically significance (P-value=0.65).

There were statistically significant differences between patients who didn't eat gluten-containing food if gluten-free food cannot be found and those who did (P-value=0.00).

The results showed that there weren't statistically significance differences (P-value=0.11), among the two groups when they were asked about the difficulty to determine if foods were gluten-free from reading their labels. The highest compliance rate was 64.3% among those who didn't find difficulty to determine if foods were gluten-free.

4.16 Compliance and attitude level

Table 4.16: the relationship between compliance and attitude level.

Attitude level	Compliant		Non-compliant		P-value
	No	%	No	%	
Low	39	49%%	40	51%	0.055
High	39	69.6%	17	30.4%	

It was found that the compliance among those who had high level of attitude (69.6%) was higher than those who had low level of attitude (53.5%), but this difference did not reach the statistical significance (P-value=0.06).

An in-dependent t-test was used to compare the means of the two groups of compliance in reference to attitude (Table 4.17).

Table 4.17: Differences in compliance status according to attitude.

Compliance	**Attitude**			**P-value**
	N	**Mean**	**SD**	
Strictly compliant	78	3.070	1.009	0.003
Partially or not compliant	57	2.525	0.976	

The results showed that there were statistically significance variations in reference to attitude and compliance (P-value=0.00). that means that patients with positive attitude were more compliant than others.

Chapter 5

Conclusion and recommendations

5.1 Conclusions

Celiac disease is a chronic disease with a permanent intolerance to a protein called gluten, which causes damage to the small bowel mucosa. Compliance with a GFD is a continuous challenge for celiac patients to prevent the complications that will occur later. The purpose of this study was to assess the compliance status and related factors among celiac patients in the Gaza strip.

CD was predominant among females, also more than half of them were 21 years old or more. Nearly half of them were single, and the largest percentage of them was from Gaza city and from the southern areas. Family size with more than 7 members was more than the half of study population. Most of the study population were of medium level of education, and they were not working. The majority of patient who were working, their income was less than 1000 Nis.

The larger component of study population didn't have family history nor associated chronic diseases. More than half of study population, their period of symptoms before diagnosis was from one month to 24 months, and the age of diagnosis was from 1-21 years old. The final diagnosis was mainly done by a gastroenterologist through antibody test.

Weight loss, bloating, abdominal pain, diarrhea, poor growth and gases were predominant symptoms of CD amongst patients. Ard El Insan was the most frequent source of information.

According to the knowledge regarding CD the majority of patients didn't hear about CD before. Most of patients thought that celiac patients live a normal life, and nearly more than one third of them thought that CD can be cured completely. Celiac patients had

inadequate knowledge about CD, more than half of patients didn't know the special logo of CD, and nearly half of them didn’t know the foods containing gluten.

More than one half of celiac patients had low attitude level, in which the majority of patients avoided restaurants, and had difficulty to find gluten free foods.

More than half of patients were compliant with a gluten-free diet, the majority of them were males, and from children. The majority of compliant patients were married and from south. More than half of patients were not working, with family size more than seven members. Higher compliance rates were amongst patients with chronic diseases, those who had long period of symptoms and those who were diagnosed at age 22 years old or more.

The results showed that knowledge and attitude have an important effect related to compliance. The compliance was higher among patients with high level of knowledge and attitude.

5.2 Recommendations

1- Increase medical awareness of different presentations of CD, diagnosis, and treatment among health care professionals in different health care centers specially in primary health care centers in the Gaza strip.

2- Efforts must be done by policy makers in order to:

* Offer appropriate diagnostic methods.

* Offer screening programs of risky individuals.

* Development of health programs to provide care and psychological support for celiac patients.

3- Providing educational programs about the disease and gluten-free diet to encourage optimal dietary compliance among celiac patients.

4- Enhance traders and the owners of stores via the Ministry of Economy to secure gluten-free foods in their stores.

Chapter: 6

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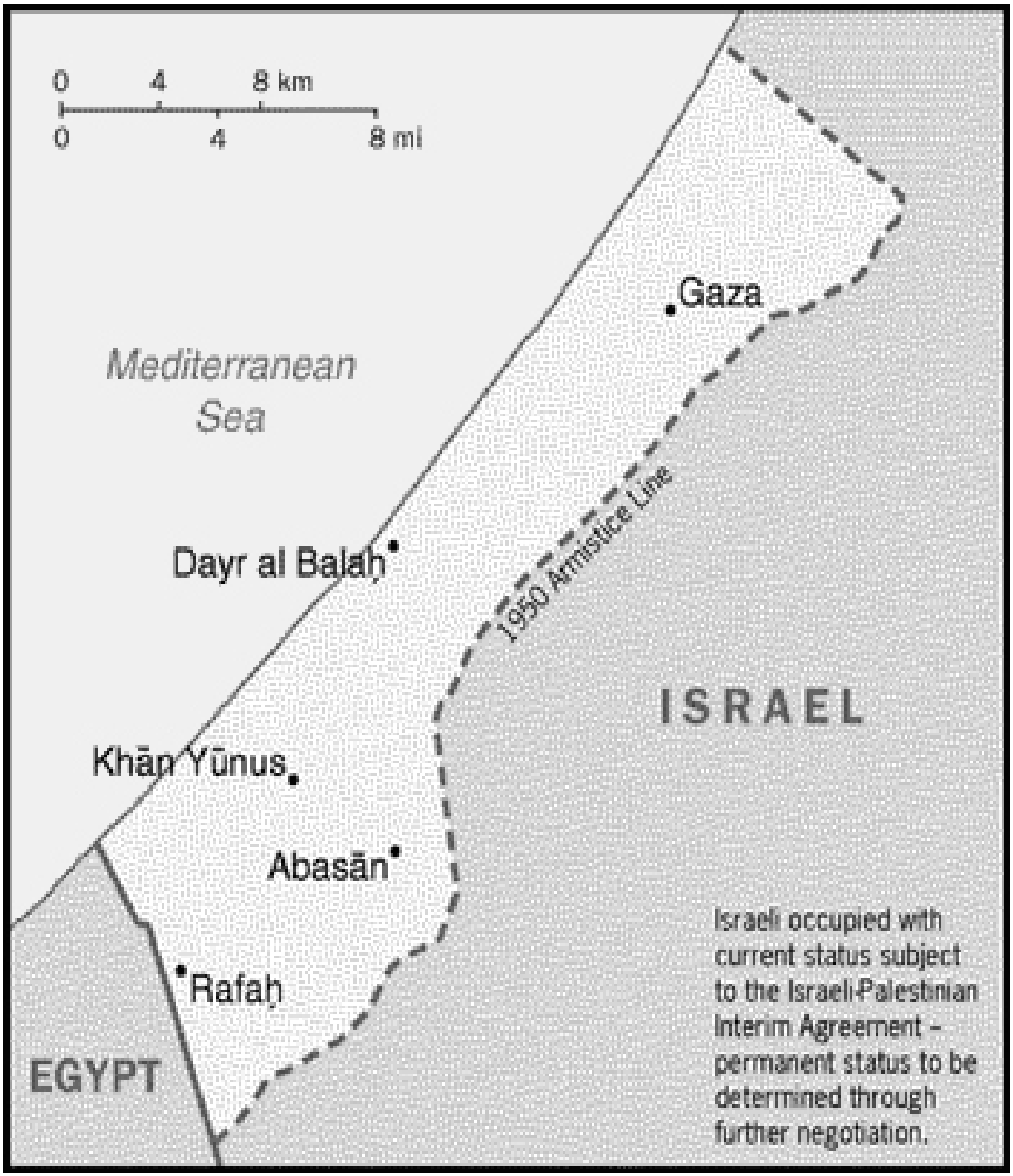
Annexes

Annex 1

Map of Gaza strip



Annex 2

Palestinian National Authority
Ministry of Health
Helsinki Committee

السلطة الوطنية الفلسطينية
وزارة الصحة
لجنة هلسنكي

التاريخ : 07/03/2011

Name: **Nahla Abu Amer**

الاسم: نهلة أبو عامر

I would like to inform you that the committee has discussed your application about:

" Evaluation of Dietary compliance of patients with Celiac disease –Gaza governorates."

نفيدكم علماً بأن اللجنة قد ناقشت مقترح دراستكم حول:-

"تقييم الالتزام الغذائي لمرضى السيلياك في محافظات غزة"

In its meeting on March 2011 and decided the Following:-

To approve the above mention research study.

و ذلك في جلستها المنعقدة لشهر 3 2011

و قد قررت ما يلي:-

الموافقة على البحث المذكور عاليه.

Signature
توقيع

Member
عضو

Member
عضو

Chairperson

Conditions:-

- Valid for 2 years from the date of approval to start.
- It is necessary to notify the committee in any change in the admitted study protocol.
- The committee appreciate receiving one copy of your final research when it is completed.

Annex 3

Al-Quds University

Jerusalem

School of Public Health

جـامـعـة الـقـدس

القدس

كلية الصحة العامة

التاريخ: 2011/6/25

حضرة الدكتور عدنان الوحيدي المحترم

مدير عام جمعية أرض الإنسان

تحية طيبة وبعد،،،

الموضوع: مساعدة الطالبة نهلة أبو عامر

تقوم الطالبة المذكورة أعلاه بإجراء بحث بعنوان:

"Evaluation of Dietary Compliance of Patients with Celiac Disease-Gaza Governorates"

كمتطلب للحصول على درجة الماجستير في الصحة العامة–مسار علم الأوبئة. و عليه نرجو التكرم للإيعاز لمن ترونه مناسب لتسهيل مهمة الطالبة في جمع البيانات اللازمة من مراكز جمعيتكم الموقرة.

علماً بأن المعلومات ستكون متوفرة لدى الباحثة و الجامعة فقط.

و اقبلوا فائق التحية و الاحترام،،،

د. بسام أبو حمد

منسق عام برامج الصحة العامة

نسخة:

- الملف

جمعية أرض الإنسان الفلسطينية الخيرية
وارد
الرقم / 306/2011
التاريخ / 30/6/2011
التوقيع /

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Annex 4

المشارك / و المشاركة ..... المحترم /ة

أقوم بدراسة حول تقييم مدى التزام مرضى الداء الزلاقي بالغذاء الخالي من الجلوتين في محافظات قطاع غزة والتي تهدف إلى تحسين أوضاعهم الصحية والخدمات المقدمة لهم . مع العلم أن هذه الدراسة هي متطلب للحصول على درجة الماجستير في الصحة العامة من جامعة القدس – أبو ديس .

أتطلع لمشاركتكم في إتمام هذه الدراسة غير الممولة من أي جهة ولن يترتب على مشاركتكم فيها أي التزامات أكثر من الوقت اللازم لتعبئة الاستبيان.

وأود إعلامكم أنه في حال موافقتكم على تعبئة الاستبيان من حقكم عدم الإجابة على أي سؤال لا تريدون الإجابة عنه وستكون جميع المعلومات سرية ولن يذكر فيها اسم أي مريض لان الاهتمام موجه فقط للناحية البحثية.

شاكري لكم حسن تعاونك

الباحثة

نهلة حماد أبو عامر

0599793267

nahlansg@hotmail.com

Annex 5

Explanatory letter

Dear participant

Thank you for your participation in this research, you have were selected because you met the selection criteria of participation.

This study is carried out as a part of the requirements for the Master degree in public health /epidemiology at Al Quds University-Palestine.

This study aims to assess the compliance status to gluten-free diet among celiac patients in Gaza governorates.

Your participation is voluntary, and you have the right to withdraw at any time during data collection. Your answers will be kept confidential and only it is requested from you to answer the questionnaire. You need not more than 15 minutes of your time.

Researcher: Nahla Abu Amer

Annex 6

Questionnaire For Evaluation of Dietary compliance of Patients with Celiac Disease

Serial number: ---------

A – General information

1-Age: -------

2-Sex: Male ( ) Female ( )

3-Marital status: Single ( ) Married ( ) Divorced ( ) Widowed ( )

4-Address: North ( ) Gaza ( ) Mid-zone ( ) Khanyounis ( ) Rafah ( )

5- Number of education years: ( )

6- Occupation: Work ( ) Don't work ( )

*If yes please state your job. ----------.

7- Income per month: <1000 shekel ( ) 1000-2000 shekel ( ) >2000 shekel ( )

8- Number of family members: ( )

B- Celiac disease sector

9- Did you hear about celiac disease before?

Yes ( ) No ( )

10-Duration of celiac disease: ( )

11-Do any of your family members have celiac disease? Yes ( ) No ( )

12-Do you have any chronic diseases? Yes ( ) No ( )

13-Please indicate if any doctor had told you that you are a celiac patient. Yes ( ) No ( )

14- At what age you have been diagnosed as celiac patient? ----------.

15- Was your diagnosis confirmed by any of the following tests?

Intestinal biopsy Yes ( ) No ( )

Antibody test Yes ( ) No ( )

16- For how long do you have celiac disease symptoms before diagnosis? _____ months.

17- Please Check Whether or not you have been suffering from the following conditions before diagnosis as celiac disease patient, and whether or not you have fully recovered from these conditions after following the GFD?

	Before		Now	
Condition	No	Yes	No	Yes
a) Diarrhea				
b) Constipation				
c) Bloating				
d) Gas				
e) Abdominal pain				
f) Vomiting				
g) Lactose intolerance				
h) Weight loss				
I) Itchy skin				
J) Poor growth				

18- If you have not fully recovered from the symptoms checked in question 17, please check whether you feel that any of your continuing symptoms may be due to:

a) Problems with adhering to a GFD	
b) Unaware of hidden sources of gluten	
c) Some other food allergies	
d) Unknown cause	

19- a) Who had been suspecting your problem as a celiac disease?

a) Physician ( ) b) Health worker ( ) c) Nurse ( ) d) Paramedical person ( )

b) What type of doctor made your final diagnosis of celiac disease?

a) Pediatrician ( ) b) Gastroenterologist ( ) c) Allergist ( ) d) Endocrinologist ( )

20- a) When you were diagnosed as a celiac disease patient, did somebody advice you to follow a gluten-free diet for life? Yes ( ) No ( )

b) If yes, were you referred to a nutritionist/dietitian? Yes ( ) No ( )

21- a) Did you follow a gluten-free diet? Yes ( ) No ( )

b) If yes, how much did your health improve when you went onto GFD?

A lot ( ) Moderately ( ) A little ( ) Not at all ( )

22- How difficult has it been for you to follow a gluten-free diet?

Very difficultly ( ) Moderately difficult ( ) A little difficult ( ) not difficult ( )

23- How would you describe your present diet?

Strictly gluten-free ( ) Partially gluten-free ( ) Not gluten-free ( )

24- a) Do you have any symptoms if you accidentally consume gluten-containing foods?

Yes ( ) No ( )

b) If yes, please check for all symptoms you experience.

Diarrhea	
Constipation	
Bloating/gas	
Stomach/abdominal discomfort	
Nausea/vomiting	
Itchy skin	

25- Please indicate: whether you have received any information about celiac disease and its treatment from the following sources, and the quality of information received. Please check for the best answer for each source.

	Received		Quality of information				
	Yes	No	Poor	Fair	Good	Very good	Excellent
a) Gastroenterologist							
b) Dietitian/nutritionist							
c) Ard El Insan							
d) health centers							
e) Internet							

26- Do you think that celiac patients live a normal life?

Yes ( ) No ( ) Don't know ( )

27- Do you think that celiac disease is:

Curable ( ) Not curable ( ) Don't know ( )

28- Do you avoid restaurants because of celiac disease? Yes ( ) No ( )

29- Do you avoid going out because of celiac disease? Yes ( ) No ( )

30- Do you bring with you gluten-free food when you travel Yes ( ) No ( )

31- Were you not invited out for meals because of celiac disease? Yes ( ) No ( )

32- Do you find it difficult to find gluten-free food in the stores? Yes ( ) No ( )

33- Do you find it difficult to get gluten-free food? Yes ( ) No ( )

34- Do you eat gluten-containing food because you can not afford gluten-free food?

Yes ( ) No ( )

35- Do you find it difficult to determine if foods were gluten-free from reading their labels? Yes ( ) No ( )

36- Please indicate any types of these foods contain wheat gluten?

Pasta ( ) Bread ( ) Egg ( ) Corn ( ) Pastry ( ) Milk ( ) Rice ( )

Vegetables ( ) Canned foods ( ) Couscous ( ) Semolina ( ) Fruits ( ) Chocolate ( )

37- Do you know the special logo of gluten free food?

Yes ( ) No ( )

38- From the following list, Please identify two items that you believe would better contribute improving the lives of individuals with celiac disease..

a) Earlier diagnosis of celiac disease.
b) Better labelling of gluten-containing ingredients in foods.
c) Gluten-free choices on restaurant menus.
d) Better dietary counselling, especially for newly diagnosed celiac patients.
e) More gluten-free foods in the grocery stores.
f) Others; please specify.

YOUR PARTICIPATION IN THIS SURVEY IS GREATLY APPRECIATED.

Annex 7

Questionnaire (Arabic version)

الرقم التسلسلي:---------

القسم الأول: معلومات عامه حول المريض

1- العمر: **----------**

2- الجنس:

ذكر( ) أنثى ( )

3- الحالة الاجتماعية:

أعزب ( ) متزوج ( ) مطلق ( ) أرمل ( )

4- مكان الإقامة:

الشمال ( ) غزة ( ) الوسطى ( ) الجنوب ( )

5- عدد سنوات التعليم:

6- هل لديك وظيفة ؟

نعم ( ) لا ( )

*** إذا كانت الإجابة نعم حدد الوظيفة**

7- الدخل الشهري:

< 1000 شيقل ( ) 1000-2000 شيقل ( ) 2000شيقل ( )

8- عدد أفراد الأسرة:

القسم الثاني: معلومات حول المرض

9- هل سمعت عن مرض حساسية جلوتين القمح (الداء الزلاقي) قبل الآن ؟

نعم ( ) لا ( )

10- مدة المرض :

11- هل يوجد أحد من أفراد العائلة يعاني من هذا المرض؟

نعم ( ) لا ( )

12- هل تعاني من أي أمراض مزمنة؟

نعم ( ) لا ( )

13- هل أخبرك أي طبيب أنك تعاني من مرض حساسية جلوتين القمح؟

نعم ( ) لا ( )

14- كم كان عمرك عندما شخصت كمريض حساسية القمح؟

15- هل تم التأكد من التشخيص بإحدى الطرق الآتية:

* عينة من الأمعاء بواسطة منظار: نعم ( ) لا ( )

* تحليل دم : نعم ( ) لا ( )

16- ما هي مدة ظهور أعراض المرض قبل تشخيصك كمريض حساسية القمح؟

17- الرجاء اختيار الأعراض التي كنت تعاني منها قبل تشخيصك كمريض حساسية جلوتين القمح ، ثم اختر الأعراض التي تعاني منها الآن بعد إتباع الغذاء الخالي من الجلوتين.

	قبل التشخيص		بعد العلاج	
الأعراض	**نعم**	**لا**	**نعم**	**لا**
1) إسهال				
2) إمساك				
3) نفخة				
4) غازات				
5) الم في البطن				
6) قيء				
7) فقدان الوزن				
8) حساسية حليب				
9) حكة الجلد				
10) ضعف في النمو				

18- إذا لم تشفى تماما من الأعراض التي ذكرت في سؤال 17 الرجاء أن تختار من الجدول الأسباب التي تشعر بأنها هي السبب في ذلك:

مشاكل بالالتزام بالطعام الخالي من الجلوتين	
عدم العلم بالمصادر المخفية للجلوتين	
بعض الأنواع من حساسية الطعام	
أسباب غير معروفة	

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19 - ا) الرجاء اختيار من أول من توقع انك مريض حساسية جلوتين القمح:

طبيب ( ) موظف صحة ( ) ممرض ( ) موظف مهن طبية ( )

ب) أي نوع من الأخصائيين أجرى تشخيصك النهائي كمريض حساسية جلوتين القمح؟

أخصائي أطفال ( ) باطنه ( ) حساسية ( ) غدد ( )

20- أ) عندما شخصت كمريض حساسية جلوتين القمح هل نصحك شخص ما بإتباع غذاء خال من الجلوتين؟

نعم ( ) لا ( )

ب) إذا كانت الإجابة نعم هل حولت إلى أخصائي تغذية؟

نعم ( ) لا ( )

21- أ) هل تتناول غذاء خاليا من الجلوتين ؟

نعم ( ) لا ( )

ب) إذا كانت الإجابة نعم . ما مدى تحسن حالتك الصحية بعد إتباعك الغذاء الخالي من الجلوتين؟

جيد جدا ( ) متوسط ( ) قليلا ( ) لم اتحسن ( )

22- إلى أي مدى كانت الصعوبة في إتباع الغذاء الخالي من الجلوتين؟

صعب جدا ( ) متوسط الصعبة ( ) قليل الصعوبة ( ) ليس صعبا ( )

23- كيف توصف غذائك الحالي؟

خال من الجلوتين تماما ( ) خال من الجلوتين جزئيا ( ) ليس خاليا من الجلوتين ( )

24- أ) هل تظهر عندك أي أعراض إذا أكلت أطعمة تحتوي على الجلوتين

نعم ( ) لا ( ) لم أجرب ( )

ب) إذا كانت الإجابة نعم الرجاء اختيار الأعراض التي تظهر لديك:

أ- إسهال	
ب- إمساك	
ت- نفخة	
ث- غازات	
ج- ألم في البطن	
ح- قيء	
خ- حكة جلد	

25- الرجاء تحديد إذا كنت قد تلقيت أي معلومات عن مرض حساسية جلوتين القمح و طرق علاجه من احد المصادر المذكورة في الجدول، ومن ثم تحديد نوعية هذه المعلومات

			جودة المعلومات				
المصدر	نعم	لا	رديء	متوسط	جيد	جيد جدا	ممتاز
أ- أخصائي باطنه							
ب- أخصائي تغذية							
ت-أرض الإنسان							
ث- مراكز صحية							
ج-الشبكة الدولية للمعلومات							

26- هل تعتقد أن مريض حساسية جلوتين القمح يعيش حياة طبيعية؟

نعم ( ) لا ( )

27- هل تعتقد أن مرض حساسية جلوتين القمح يمكن أن يشفى تماما؟

نعم ( ) لا ( ) لا أعرف ( )

28- هل تتجنب الذهاب إلى المطاعم بسبب هذا المرض؟

نعم ( ) لا ( )

29- هل تتجنب الخروج بسبب هذا المرض؟

نعم ( ) لا ( )

30- هل تأخذ معك غذاءك الخالي من الجلوتين عند السفر؟

نعم ( ) لا ( )

31- هل سبق أنك لم تدع إلى غذاء أو وجبات غذائية بسبب مرضك ؟

نعم ( ) لا ( )

32- هل تجد صعوبة في إيجاد طعام خال من الجلوتين في البقالات ؟

نعم ( ) لا ( )

33- هل تجد صعوبة في الحصول على غذاء خال من الجلوتين؟

نعم ( ) لا ( )

34- هل تأكل طعاما يحتوي على جلوتين لأنك لا تستطيع الحصول على الطعام الخالي من الجلوتين؟

نعم ( ) لا ( )

35- هل تجد صعوبة في تحديد ما إذا كان الطعام يحتوي على الجلوتين من خلال قراءة البيانات الخاصة به؟

نعم ( ) لا ( )

36- يرجى تحديد أي من الأطعمة التالية يحتوي على جلوتين القمح ؟

المعكرونه ( ) الخبز ( ) البيض ( ) الذرة ( ) المعجنات ( ) الحليب ( )
الأغذية المعلبة ( ) المفتول ( ) السميد ( ) الفواكه ( ) الأرز ( ) الشوكولاته ( )
الخضروات ( )

37- هل تعرف الشعار الخاص بالمواد الخالية من الجلوتين؟

نعم ( ) لا ( )

38- من القائمة المدرجة الرجاء اختيار النتيجتين اللتين تعتقد أنهما تساهمان في تحسين حياة الأشخاص المصابين بداء حساسية جلوتين القمح؟

أ- التشخيص المبكر للمرض

ب- تحديد الأطعمة المحتوية على جلوتين

ت- توفير خيارات لأطعمة خالية من الجلوتين في المطاعم

ث- توعية وإرشاد حول التغذية خاصة للأشخاص حديثي التشخيص

ج- توفر أطعمة خالية من الجلوتين في البقالات

د- خيارات أخرى

Annex 8

Names of experts

- **Dr. Bassam Hamad.**
- **Dr. Riyad Zanoon.**
- **Dr. Adnan Al-Wahaidi.**
- **Dr. Samir Esmael.**
- **Dr. Mohammed Al-Raee.**
- **Dr. Yousef Abu Safieh.**
- **Dr. Abd El- Fattah.**
- **Dr. Salah Al-Nagah.**
- **Dr. Raja Baraka.**
- **Mrs. Etidal Ai Khateeb**.

Annex 9

ملخص الدراسة

يعتبر مرض الداء الزلاقي خللا إكلينيكيا يصيب الأمعاء الدقيقة للإنسان مؤديا للعديد من الأعراض المرضية، أهمها التهاب الغشاء المبطن للأمعاء و تدمير الخملات المسؤولة عن الامتصاص مما يؤدي لسوء الامتصاص. و هدف هذه الدراسة هو تقييم مدى التزام مرضى الداء الزلاقي المسجلين في جمعية أرض الإنسان بالنظام الغذائي الخالي من الجلوتين ضمن البرنامج الخاص بهذا المرض .

الأهداف الخاصة للدراسة

- اختبار العلاقة بين التزام المرضى بالعلاج و مدى معرفتهم بالمرض.
- التعرف على المرضى الملتزمين بالعلاج و غير الملتزمين.
- التعرف على عوائق الالتزام بالعلاج عند المرضى.
- دراسة مدى تأثير الالتزام بالعلاج على الأعراض الخاصة بالمرض.
- دراسة مستوى الالتزام و علاقته بالمتغيرات الاجتماعية و الديموغرافية.
- تقديم توصيات من أجل تحسين التزام المرضى بالعلاج.

منهجية الدراسة

لقد استخدم في هذا البحث الدراسة الصفية المقطعية التحليلية في جمعية ارض الإنسان بفرعيها في مدينتي غزة وخان يونس، و قد شملت الدراسة كل المرضى المسجلين في جمعية ارض الإنسان ضمن برنامج الداء الزلاقي المشخصين بفحص طبي مثبت، و كان إجمالي عددهم 193 مريضا، و كانت نسبة الاستجابة 70%. و تم جمع البيانات باستخدام استبانه تم تعبئتها من قبل المريض أو أهل المريض لمن تقل أعمارهم عن سن الحادية عشر بعد أن تم فحصها من قبل محكمين، بالإضافة إلى إجراء دراسة تجريبية قبل البدء بالبحث. و قد تم تحليل الاستبانة من قبل الباحث باستخدام البرنامج الإحصائي SPSS version 13 .

نتائج الدراسة

أظهرت النتائج أن متوسط أعمار المرضى كان 26 سنة، وكانت نسبة الإناث 71%. كما أوضحت الدراسة أن نسبة الداء الزلاقي لدى البالغين كانت 64%، وكان 39% من المرضى من مدينة غزة بينما كان 38% من الجنوب. وقد شكل مستوى التعليم المتوسط لدى المرضى 46 % مقابل 20% من ذوي المستوى المنخفض من التعليم و 27 % كانوا ذوي مستوى تعليمي عالٍ. كما أوضحت الدراسة ما يقارب أربع أربعون بالمائة من المرضى لا يعملون مقابل 25% لديهم عمل. و أظهرت الدراسة أن متوسط مدة ظهور الأعراض قبل التشخيص 56 شهرا، ومتوسط مدة المرض كانت 8 سنوات و متوسط العمر عند التشخيص كان 21 سنة بمدى يتراوح ما بين السنة إلى أربع وستين سنة. و من الأعراض التي ظهرت في الدراسة فقدان الوزن بنسبة 86.7%، النفخة بنسبة 83.7%، ألم في البطن بنسبة 83%، إسهال بنسبة 79.3%، ضعف في النمو بنسبة 75.6%، غازات في البطن بنسبة 71.9%، قيء بنسبة 45.9%، حكة جلد بنسبة 30.4%، إمساك بنسبة 25.2% و حساسية حليب بنسبة 20.7%.

لقد تم التشخيص النهائي عن طريق أخصائي باطنه لدى 67% من المرضى مقابل 27% بواسطة أخصائي طب أطفال. و تم تشخيص المرضى بواسطة تحليل الدم في 79% من الحالات مقابل 64% بواسطة المنظار المعوي. أكثر من نصف المرضى 58% كانوا ملتزمين بالغذاء الخالي من الجلوتين و 62% منهم لاحظوا تحسناً في صحتهم. لقد أوضحت الدراسة أن أغلبية المرضى (70%) لم يسمعوا عن المرض قبل إصابتهم و 38% منهم ليس لديهم خلفية عن إمكانية الشفاء نهائيا مقابل 21% اعتقدوا العكس. أكثر من نصف المرضى لم يعرفوا الشعار الخاص بالغذاء الخالي من الجلوتين وقد سجلوا نقصاً في مدى معرفتهم وتحديدهم للأغذية الخالية من الجلوتين.

وفيما يخص المعلومات الخاصة بالمرض وعلاجه فقد كانت أرض الإنسان المصدر الأكبر الذي يقدم المعلومات الممتازة ل 89% من المرضى. بالنسبة لسلوك المرضى تجاه هذا المرض فقد كان أغلبهم (73%) يتجنبون المطاعم و 28% فقط يتجنبون الزيارات والخروج. لقد سجل 87% من المرضى صعوبة قصوى في الحصول وإيجاد الطعام الخالي من الجلوتين. و عندما طلب من المرضى اختيار طريقتين لتحسين حياتهم، كان التشخيص المبكر للمرض قد اختير بواسطة 85% من المرضى والتوعية والإرشاد بواسطة 39%، توفر الأطعمة الخالية من الجلوتين في البقالات بواسطة 87%، الملصقات الواضحة للأغذية المحتوية على الجلوتين بواسطة 24% و توفر الأطعمة الخالية من الجلوتين في المطاعم بواسطة 14%.

لقد أوضحت الدراسة أنه كلما ازدادت معرفة المرضى تحسن التزامهم (بدلالة إحصائية 0.04).

الاستنتاج

يستنتج من الدراسة أن مرض الداء الزلاقي موجود في قطاع غزة ويصيب كل الأعمار وبأعراض مختلفة. التأخر في التشخيص كان واضحاً وكان أكثر من نصف المرضى ملتزمين بنظامهم الغذائي. أثبتت الدراسة أهمية المعرفة للوصول إلى الالتزام بالعلاج عند المرضى. كما بينت الدراسة مدى صعوبة الحصول على الغذاء الخالي من الجلوتين. توصي الدراسة بضرورة توفير الغذاء الخالي من الجلوتين بشكل منتظم و تامين برامج توعية حول المرض وعلاجه لتشجيع المرضى على الالتزام، و تحسين الوعي الطبي لدى المتخصصين حول المرض وطرق تشخيصه وعلاجه في جميع المراكز الصحية وخاصة مراكز الرعاية الأولية.