



CELIAC DISEASE IN AQABA: LACK OF AWARENESS, FINANCIAL PROBLEMS, AND SOLUTIONS

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ABSTRACT: *The present study aims to increase awareness about celiac disease in Aqaba in Jordan. There is one charity in Aqaba, Al- Haya Charity, takes care of these children. According to this charity about there are around 120 children who are suffering this disease in Aqaba. Their key problems are lack of awareness about celiac disease, the deficiency and high prices of gluten free products, moreover; the high prices of medical tests and checkups. Rosary Sisters' School tried to help by T.O.P, Team of Pioneers, interviewed around 17 of these patients in order to investigate their problems and difficulties they faced to be come over. Results showed that lack of awareness came in the first rank of problems; in the second rank were financial obstacles and finally the social point of views about celiac disease patients. Therefore, this research is published to shed lights on this disease in Aqaba.*

KEYWORDS: Celiac Disease, Lack of Awareness, Gluten Free Diet, Malabsorption

JELCODES: I12, Z19, P36, H1

INTRODUCTION

The prevalence of celiac disease (CD) has increased dramatically over the last five decades. As a result, different kinds of experimental or descriptive studies have been conducted examining different Pathological cases, as well as exploring the relationships between social, economic, psychological factors and celiac disease (CD), and searching for therapeutic solutions. In spite of tremendous number of studies, experiments and vast research, many questions about celiac disease (CD) have not been answered yet. The dilemma may need a gargantuan work and an immense research which may take a long period of time to find a potent effective remedy for it.

There are two controversial issues that may have a direct and influential effect on the horns of (CD) dilemma. The first one is that (CD) is greatly under-diagnosed. For example, Kostopoulou (et.al, 2009) stated that "celiac disease has been characterized as the most under-diagnosed common chronic condition in the UK today." The second is the most important issue for this project is the lack of awareness about (CD). There are many healthy adults, teenagers, or children may have celiac disease (CD), or may suffer from a pathological condition that may be related to celiac (CD) disease but they are not aware of it, which is the key problem in Aqaba. This project directed by ELO, English Language Olympics, 2018 has chosen this problem to be solved initially in Aqaba.



The Problem of the Project

This project aims to find practical solutions for the lack of awareness about (CD) in Aqaba which is located 336.22 km south of Amman, the capital city of Jordan. As mentioned before, many individuals may have (CD) or endure some ailments related to (CD) without being aware of it. The lack of awareness of (CD) may come as a result of the difficulty of diagnosing or misdiagnosing because the symptoms of (CD) are atypical and nonspecific. In other words, (CD) may share the same symptoms with other gastrointestinal diseases such as diarrhea, abdominal bloating and pain, vomiting, pale, fatigue, or constipation. Leonardi (et.al, 2010) identified (CD) as a silent disease that patients may have no symptoms of malabsorption at all till adulthood.

Therefore, the main purpose of this project is to open doors for Jordanians to know more about (CD) in order to have a better healthy life. For the time being, our targeted patient group is children in Aqaba as the first step for our project.

LITERATURE REVIEW

Celiac disease is a chronic, genetic, autoimmune, intolerance to gluten, a collective component of proteins contained in wheat, barley, and rye. In another word, it is a digestive disorder takes place in the small intestine. The intestinal villi linings are "small fingerlike projections which will be destroyed by antibodies triggered by gluten. This damage and atrophy of the tissue of the villi lining causes inflammation leads to malabsorption of food nutrients and the loss of water and solids.

Many studies and experiments have been conducted to investigate (CD) since the final years of the 20th century: some studies tried to find statistics about the prevalence of (CD) in many different countries. For instance, in 1999 MD MRCP (et.al) motioned that "In most of Europe the prevalence of celiac disease (gluten enteropathy) is somewhere between 0.05 and 0.2% of the general population" Recently, Ludvigsson (et.al, 2015) studied factors which might lead to the prevalence of (CD). This study indicated that "first-degree relatives and patients with Type 1 diabetes" were the most important factors for the prevalence of the disease.

The oldest and largest celiac disease charity in the world in the UK claimed that only 24% of those have celiac disease are medically diagnosed; which means there are around 500 0000 people in the UK who are currently undiagnosed. This charity led a 2- year campaign, which began in May 2015, to increase awareness and reduce the delay in diagnosis.

In 2017, Eyad Altamimi has discussed and shed a light to the situation of celiac disease (CD) in south of Jordan. He explained that thirty- five children had celiac disease during the study period and their treatment required to follow gluten- free diet. The main problem they have been facing is not only the shortage of gluten free products, but also and high prices of these products, in addition the lack of awareness about this disease in Jordan. He stated

The true prevalence of the disease in our area of the world is underestimated due to the lack of awareness of the atypical presentation of the disease. A previous study from Jordan reported an incidence of celiac disease of 1 in 2,800 live births, with estimated point prevalence of 7:100,000. Another study estimated the serological prevalence of



celiac disease in Jordanian school children to be 1:124 (0.8%; 95% confidence interval, 0.5% to 1.3%).

Data Collection

To find practical and adequate solutions for a specific problem, searching for and collecting data is the first step to be done. Consequently, TOP Team, a group of seven students at Rosary Sisters' School in Aqaba, has been looking for information and facts about (CD) in Jordan. Many medical centers have been visited to meet specialist physicians to know more about this disease and get closer to its situation in Jordan. In order to achieve this, TOP Team visited Al Safa Medical Clinic in Aqaba to meet Dr. Mohammad Al Bitar where the team members were introduced to the required information to start reading and searching previous studies in order to launch the first milestone of the project. This visit was mentioned on website of the clinic and its page on Facebook which has many followers. See note (1).

On Saturday, 17th March, TOP Team visited Al Haya charity in Aqaba to meet CD patients who were diagnosed with CD more than five years ago. The team met 8 patients aged between 7 and 48-years old. A quarter of them were males while three quarters were females. All the patients seemed to have at least three of the following symptoms: abdominal bloating and pain, vomiting, pale, fatigue, or constipation. Some of the patients have been suffering from other diseases such as osteoporosis and swelling of lymph nodes.

There was a 17 - year old patient who was diagnosed with autism when he was 7 years old. Recently, he was advised to follow gluten- free diet by his doctors. His mom mentioned that after following this diet, his symptoms gradually improved.

Regarding their regular medical checkup, most of them visit Hashim Hospital in Aqaba. Some of them didn't have a checkup again since the first time they were diagnosed because of the high cost of the test.

Solutions

As a result of TOP team search, it is founded that many children and their families are burdened with (CD) socially and financially in Aqaba. TOP Team has offered some social, financial and technological solutions for the problems of (CD).

Community Service and Social Solutions

The team has conducted " Not Alone "campaign which aims to render assistance and support to children who suffer from (CD) in Jordan.

By naming the campaign "Not Alone", children and their families may be unburdened psychologically. On the one hand, this name may give children the sensation of power and hope to cope with (CD), on the other hand, arouse their intrinsic motivation to get over it. Raising the intrinsic motivation of getting over any disease may increase chances of effective responses to its treatment. Because of the integrated relationship between psychological and social factors keeping in mind that (CD) patients are individuals in a society, and their positive or negative attitudes toward their society may affect their responses to therapy, comes the importance of the social dimensions of the project.



Regarding to the local community's lack of awareness about (CD), the team has visited many social organizations, charities and restaurants in Aqaba to work hand in hand standing with and supporting (CD) patients. TOP Team has agreed with Life Charity for Celiac Patients to hold a seminar at Rosary Sisters' School in Aqaba on March, 12th. The purpose of this seminar is to introduce (CD) for the local community in order to solve the problem of lack of awareness about the condition. A brochure about (CD) has been prepared and distributed by the TOP team.

Keeping in mind that (CD) patients have their own rights as a part of the whole community to live a normal life, many procedures and much more effort should be made. To achieve this, the team has introduced the idea of gluten free food menus in restaurants for the first time in Aqaba. T.O.P team visited Cala Café to propose the idea of gluten free menus. Thankfully, they agreed after knowing about this group of patients to help them by preparing gluten free menus and meals.

Sociotechnological Solutions

As no one can deny the effect of the internet in our daily life, a website has been designed by the team for the local community about (CD). This website may help many patients and their families to know more about (CD).

Financial Solutions

After having an empty sack of our visits to many banks and organizations to get financial fund to support Al Haya charity and making a last-ditch effort to finish on time, TOP Team has chosen the 31st March as Gluten for Non gluten Bazaar Day. Rosary Sisters' School (R.S.S.) is going to host this bazaar annually. The revenue of the bazaar is going to be sent to Al Haya charity. On 31st March, Gluten for Non gluten Bazaar was held at (R.S.S.), TOP Team sold many gluten products such as cakes, pastries, cookies and pies for students at the school. The earnings were around 300 J.D. TOP Team bought a computer to furnish Al Haya charity because it needs one urgently to save patients records and documentations.

CONCLUSION

T.O.P team endeavored prodigious efforts to increase the awareness of celiac disease in Aqaba. TOP team has taken first steps to achieve some of their goals of spreading awareness and help out those children who are suffering (CD). They are going to venture the voyage to accomplish what they have set out.

Notes

T.O.P team is a group of 7 students from Rosary Sisters' School in Aqaba guided by their teachers Dr. Sumaya Abed Alqaer and SherihanBaidas



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