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The First Assessment of Celiac Disease Knowledge among Kuwaiti Nutritionists through a Validated KAP Model

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Abstract Registered dietitians /nutritionists play a crucial role in the management of celiac disease (CD). The present study aims to evaluate the knowledge of nutritionists working with CD patients in Kuwait, which has lately been witnessing increased incidence of this disease. A convenient cross-sectional sample of 156 nutritionists from both genders, different age groups, educational levels and experience working in different hospitals and health centers in Kuwait was recruited. To assess their knowledge and practice, a self-administered validated questionnaire was used. Descriptive data analyses were performed using SPSS program. Results of 141 respondents (90% response rate) indicated that nutritionists holding university degrees had highly significant ($P \le 0.01$) higher mean knowledge scores about CD than those holding a diploma degree (9.9 \pm 1.3 and 9.3 \pm 1.3 vs 8.7 \pm 1.4, out of 14 respectively). It also indicated that gender, geographic area and/or experience had no significant effects (P > 0.05) on the overall mean knowledge scores of the respondents albeit males had higher, though non-significant (P>0.05) mean scores than females in some geographic areas. The age of nutritionists had no effect on their knowledge scores despite the longer experience older ones have. The results also indicated that although most nutritionists seem to be well aware of the causes (99.3 %), treatment (98.6%), diagnosis (61%) and complications (78.7%) associated with CD, the majority of them confused it with wheat allergy (78% vs. 22%; $P \le 0.01$). Nutritionists' knowledge about "Unsafe Ingredients" in the celiac diet information card" was successfully answered by only 6.4% of the participants, whereas 81.6% of them were not sure (p < 0.05). Results of the study emphasize the need for continued-structured education programs for the Kuwaiti nutritionists working with CD patients in all areas related to CD.

Keywords: celiac disease, Kuwait, nutritionists, knowledge

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1. Introduction

Celiac Disease (CD), a worldwide health problem, is an autoimmune disease of gluten intolerance that causes inflammation of the intestines, it is triggered by consumption of wheat and some other prolamin-containing cereals and their products. Worldwide, the prevalence level of CD ranges between 0.5-1% among general populations while it is higher among individuals with diabetes, autoimmune disorders, Down Syndrome or those having relatives with CD [1,2]. Epidemiological studies show that its prevalence is underestimated in the Middle East and North Africa (MENA) [3] where its prevalence among healthy populations is estimated to range between 0.8 and 2.67%, [4,5]. Younes et al. [6] reported that Arab populations have a distinctive susceptibility to CD genetic profile compared to other ethnic groups. Except children information on the prevalence of CD among general healthy populations are scarce in most Arab countries [7],

yet it is estimated to be 2.2% and 1.86% in Saudi Arabia and in United Arab Emirates respectively [8,9]. In Kuwait, there are no up-to-date information on the epidemiology of CD although unofficial reports claim increased incidence among the general public which prompted the Kuwaiti government to take the initiative of producing gluten-free flour and bread in the state-owned mill and bakeries and distribute them for free.

Treatment of CD is Gluten-Free Diet (GFD) under the close supervision and guidance by specialized nutritionists and cooperation of the patients. However, since most patients lack the skills and knowledge to manage their conditions [10] adequate knowledge, experience and education of the supervising nutritionist are of paramount importance for the success of the treatment program. If patients have to follow a GFD without the health professional's (nutritionist) guidance, they could be at risk of experiencing several nutritional deficiencies [11] such as obesity and hyperlipidemia and other clinical or subclinical complications due to consumption of fat-rich foods or unbalanced intake of several nutrients. This is

true for those who believe that consuming a list of prohibited food items is enough for the treatment of the disease symptoms without any further supervision or evaluation of the disease progression [12] hence the necessity of involving an experienced nutritionist in the treatment protocol [13] in cooperation with medical doctors as Rahmoune et al. [14] emphasized the role of young doctors in introducing GFD to child patients.

The competence of nutritionists and health workers including doctors is usually evaluated by validated surveys and skilled interviews. In a study by Geiger et al. [15] conducted to measure Registered Dietitian Nutritionists' (RDNs) self-reported CD knowledge, it was shown that RDNs had moderate to high levels of knowledge for the related knowledge topics. The study concluded that RDNs may need more reinforcement on the identification and treatment of nutritional deficiencies of CD management.

The aim of this work is to assess the general knowledge of Kuwaiti nutritionists towards CD and evaluate their qualifications and identify their points of weakness to help plan for their continued education and capacity building.

2. Materials and Methods

2.1. Study Design

A cross-sectional design using a convenient sample of 156 volunteer nutritionists was conducted to assess the knowledge of CD nutritionists in Kuwait via a self-administered Knowledge Attitude Practice (KAP) model questionnaire. The tool consists of two sections; the first section is composed of demographic characterization of participants as presented in Table 1 and the other is about dietetic practices in approaching CD patients consisting of 14 questions as indicated in Table 2 - Table 4. The term nutritionist signifies those who had formal training in human nutrition and usually hold a diploma, BS, MS or Ph.D degree in human nutrition since no dietitian registration is required for their practice in Kuwait.

Ta	ble	1. I	Demograp	hic c	haracteristics	of	nutrit	ionists	(n=1	41)
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Demographic Data	N (%)		
Age			
22-31y	89 (63.1)		
32-41y	41 (29.1)		
≥ 42y	11 (7.8)		
Gender			
Males	10 (7.1)		
Females	131 (92.9)		
Education			
Diploma	60 (42.6)		
BSc. Degree	70 (49.6)		
Graduate studies	11 (7.8)		
Geographic Area			
Capital city	69 (48.9)		
Hawalli	13 (9.2)		
Mubarak Alkabir	27 (19.1)		
Al-Farwaniya	10 (7.1)		
Al-Ahmadi	15 (10.6)		
Al-Jahra	7 (5.0)		
Years of Experience			
>5 years	72 ()		
3-4 years	22 ()		
1-2 years	47 ()		

2.2. Study Sample and Human Participants

A convenient sample of 156 volunteer nutritionists was selected after the approval of their respective hospitals or health centers was obtained. Asigned consent form was obtained from each participant. Approval of the Institutional Review Board (IRB) was obtained from each participating hospital. All participants were contacted and explained the purpose of the study, its nature, methodology and confidentiality.

2.3. Evaluation of Nutritionists Knowledge about CD

To assess the knowledge of nutritionists, an adapted KAP study questionnaire [16] was translated forward and backwards into Arabic. The English versions of the questions are listed in Table 2 - Table 4. The tool was then revised by an expert panel of nutritionists. Modifications were made as necessary to suit culture and the norms of Kuwaiti society. For clarity and comprehensiveness, a pilot study that involved 15 nutritionists was conducted to test the reliability of the tool. The questionnaire was divided into two sections: the first section comprised basic demographic information, including age, gender, education level and living area. The second section included questions on 4 major domains of knowledge including: causes, complications, diagnosis and nutritional management of CD. There were multiple answers to each one of the questions included in each of the four domains, including some incorrect answers and the choice of don't know". Data was analyzed qualitatively by calculating the percentage of participants who answered that they were aware of each characteristic known to be associated with CD. Additionally, questions related to knowledge and attitude were grouped to generate overall scores. The overall knowledge scores were grouped according to age, gender, geographic area and experience of nutritionist. Correct answers were given a score of one (1), incorrect answers zero (0) and "unsure" or "I don't know" half a score (0.5). The average score of each answer for each question within each group of nutritionists was calculated. The maximum general score was 14 i.e. the total number of questions correctly answered.

2.4. Statistical Analysis

Statistical analyses were performed using SPSS version 20.0 software [17]. Categorical variables were summarized by descriptive statistics, including total numbers and percentages. Significance was analyzed using a Chi-Square test. Continuous variables were summarized by the mean and standard deviation (SD), with significant differences between two categories analyzed using the Mann-Whitney U-test. A p-value of less than 0.05 was considered statistically significant.

Table 2. Nutritionists knowledge about causes and complications of CD (n=141)

Questions and their provided answering choices	Proportion of participants choosing each answer*	Significance of P-value **
CD is caused due to an immunological reaction to:		
Albumin	0	
Globulin	1 (0.7)	
Gluten, gliadin / prolamine	140(99.3)	0.000^{**}
CD is a food allergy:		
• Yes	110 (78)	0.01**
• No	31 (22)	0.01
The type of glycoprotein found in wheat mainly causes CD:		
Gliadin	74 (52.5)	
Lecithin	28 (19.8)	
Collagen	12 (8.5)	
Ceruloplasmin	8 (5.7)	
Do not know	19 (13.5)	0.000^{**}
Gluten is a type of carbohydrate that reacts with CD and gluten-sensitive patients:		
• True	60 (42.6)	0.09
• False	81 (57.4)	0.09
There are other diseases associated with CD.		
• True	111 (78.7)	
• False	30 (21.3)	0.000**
Diseases that can develop if CD is not treated:		
Cancer of the lymph nodes	15 (10.6)	
Osteoporosis	36 (25.5)	
Thyroid disease	14 (10)	
All of the above	69(49)	0.00**
Do not know	7 (4.9)	
CD can cause anemia:		
• True	115(81.6)	
• False	26 (18.4)	0.00**

^{*}Number and (%);**highly significant ($P \le 0.05$) according to Chi-Square test.

Table 3. Nutritionists knowledge about CD diagnosis (n=141)

Questions and their provided answering choices	Proportion of participants choosing each answer*	Significance of P-value **	
Screening/diagnosis techniques of CD			
• Yes	86 (61)	0.01**	
• No	55 (39)		
The most reliable test (100%) in CDdiagnosis:			
Antibody testing	58 (41.1)		
• Genetics	17 (12.1)	0.000**	
• Iris diagnosis	1 (0.7)		
• Biopsy of the twelve tissues	56 (39.7)		
• Do not know	9 (6.4)		

^{*}Number and (%);**highly significant ($P \le 0.01$) according to Chi-Square test.

Table 4. Nutritionists' knowledge of the nutritional management of CD (n=141).

Questions and their provided answering choices	Proportion of participants choosing each answer*	Significance of P-value **
Treatment approach of CD:	<u> </u>	
• Antibiotics	2 (1.4)	
Surgical operation	0	
Change in diet	139 (98.6)	
Radiation therapy	0	0.000**
CD patients should completely avoid the following:		
• Barley	1 (0.7)	
• Macaroni	0	
Crispy biscuits made with wheat flour	5 (3.6)	0.000**
• All of the above	135 (95.7)	0.000
Are dried potatoes, corn oil, sea salt, natural flavors, sucrose, fructose, spices, wheat flour, tomato		
paste, grapefruit, maltodextrin and citric acid unsafe ingredients in the celiac diet information card		
• True	9 (6.4)	
• False	17 (12)	0.000**
• Not sure	115 (81.6)	0.000
FDA guidelines of "Gluten Free" food labeling		
• 5 ppm	20(14.2)	
• 10ppm	22(15.6)	0.000**
• 20ppm	12(8.5)	0.000
• 0ppm	75(53.2)	
• Do not know	12(8.5)	

^{*}Number and (%);**highly significant (P \leq 0.01) according to Chi-Square test.

3. Results and Discussion

To our knowledge, this is the first study to assess the knowledge of Kuwaiti nutritionists as evaluated by a validated KAP model. The study has some limitations, including self-reported responses and limited prior studies addressing this subject which may affect the strength of our findings. However, although our study is descriptive, it would provide baseline data on current knowledge and practice of Kuwaiti nutritionists. Hence, it highlights the need for training programs aiming to improve dietary counseling in CD management.

- Demographic characteristics of the selected sample of nutritionists. A total of 141 completed questionnaires were returned i.e.90% response rate. Descriptive data and demographic characteristics of the studied sample are presented in Table 1. Majority of participants were female (93%) and aged between 22 - 31 years (63%), with 51% of nutritionists had an experience of more than 5 years.

-Nutritionists' knowledge about the causes and complications of CD. Table 2 shows the nutritionists' knowledge about causes and the associated complications of CD. The majority of the nutritionists in our sample (99.3%) were able to correctly identify the major cause of CD ($P \le 0.01$). However, a significantly high percentage (78% vs. 22%) of respondents confused CD with wheat allergy ($P \le 0.01$). The main dissimilarity between both conditions is that wheat allergy is an IgE-mediated reaction to the ω-5 fraction of gliadin found only in wheat [18] while CD is caused by an immune response to all prolamins (wheat gliadin, barley hordein, rye secalin and oat avenin). Therefore, unlike CD patients, people with a wheat allergy do not have to avoid oats, rye and barley containing foods. However, a significantly $(P \le 0.01)$ high percentage (52.5%) of nutritionists were aware of the CD cause "Gliadin" compared to "Lecithin", "Collagen", and "Ceruloplasmin" (19.8%, 8.5 % and 5.7%, respectively). The answer indicates that the majority of participants acquired a high level of knowledge regarding the main cause of CD. However, of the 141 nutritionists, those who chose "False" for the statement "Gluten is a type of carbohydrate that reacts with patients with celiac and gluten-sensitive patients" constituted high but not significant ($P \ge 0.05$) percentage (57.4%) than those who chose "True" (42.6%). Table 2 also shows the nutritionists' knowledge about complications of CD. The percentage of nutritionists who correctly answered the question "whether CD is associated with other diseases or not" was significantly higher (78.7%) than those who did not (21.3%) ($P \le 0.01$). CD is linked to many diseases and health conditions such as malignancies [19], ecchymosis and petechia (lack of vitamin K), osteoporosis [20], anemia [21] secondary hyperparathyroidism, osteomalacia and hemorrhage (due to malabsorption of vitamin K) [22], in addition to infertility and spontaneous and recurrent abortions [23]. Approximately 49% of the participants were aware of all possible CD- associated diseases and complications, similarly, the percentage of participants who correctly identified a single disease/complication including osteoporosis, cancer of the lymph nodes, thyroid disease were (25.5%, 10.6% and 10%, respectively; $P \le 0.01$). However, only 4.9% of the participants were

not aware of any of these diseases and complications. CD patients are highly susceptible to the development of malignancy with 8-10% risk rate. The disease is also highly associated with lymphoproliferative malignancy, Osteoporosis [19] hyperparathyroidism and hypocalcemia [20] which could develop in CD patients due to malabsorption of calcium and or vitamin D. Also, CD patients show a 3-fold increased risk of non-Hodgkin's lymphoma [24] and other types of malignancies [19]. They also should be monitored for common complications, including neurologic complaints and the development of other autoimmune diseases, especially of the thyroid and liver [25,26]. Our findings indicate that the respondents acquired a good level of knowledge when it comes to the types of diseases that may accompany CD. Likewise, a highly significant percentage (81.6%) of nutritionists recognized that CD can cause anemia ($P \le 0.01$), which indicates that most of them know the relationship between CD and anemia. Anemia is a common hematological disorder of CD which is not resolved by iron therapy [20] and results from the malabsorption of iron, folic acid and vitamin B_{12} or loss of the gastrointestinal blood in patients with total villous atrophy [27].

- Assessment of nutritionists' knowledge about the diagnosis of CD. Among nutritionists, a percentage of 61% was knowledgeable about the techniques used for the screening and diagnosis of CD, whereas 39% of them had no idea about these techniques. Participants were also asked about the most reliable test for diagnosing CD. The highest percentage of participants (41.1%) significantly $(P \le 0.01)$ chose the answer "antibody testing" compared to 39.7% who answered "Biopsy of the twelve tissues "and 12.1% checked the choice "Genetics". On the other hand, the lowest percentage of participants (0.7%) checked the answer "Diagnosis of the iris". Only 6.4% had no idea about the most reliable test for diagnosing CD. CD is characterized by varying degrees of atrophy of the intestinal mucosa, with reduced height, or complete disappearance of the villi [29]. This may explain the controversial answers of participants.

- Assessment of nutritionists' knowledge about the management of the CD. Dietary modifications and GFD approach constitute the only available current treatment for CD. Information on GFD and dietary adherence is crucial and should be provided in collaboration with a dietitian [30]. In this context, almost all nutritionists (98.6%) in our sample were able to identify the best treatment approach of CD indicating their high level of knowledge about CD treatment. In contrast, only 1.4% of respondents in our sample were not able to correctly identify the best treatment approach of CD and considered "Antibiotics" as the best treatment method, which indicates grave lack of basic knowledge of the way CD is managed (Table 4). The gluten-free diet is the only proven treatment for CD as it results in improving the symptoms and complications that accompany the disease [31].

The present study also examined the nutritionists' knowledge about foods that should be avoided by CD patients and their ability to read and interpret food labels. Almost all nutritionists in our study (95.7%) were able to correctly classify three (3) listed food/grains and cereal foods including barley, macaroni and crispy biscuits made

with wheat flour as items that should be avoided by CD patients. However, only 3.6% of participants considered only "Crispy biscuits made with wheat flour" as an item that should be avoided $(P \le 0.01)$ (Table 4). All forms of wheat and wheat milling products and byproducts must be avoided by CD patients including wheat bran, wheat starch, wheat germ, emmer wheat, einkorn wheat, farina, semolina, durum wheat, graham flour, spelt wheat, faro, gluten, wheat bread, gliadin and cracked wheat [30]. In addition to some locally-consumed products like Burghul, Couscous, Maftool, Farikah, Middle eastern sweets and pastries etc...... Avoidance of all these food items by CD patients is a must [32]. A very high percentage of nutritionists in our sample successfully and correctly identified food items that should be avoided by CD patients. This indicates that most of our selected sample of Kuwaiti nutritionists have a high level of knowledge when it comes to food products that should be avoided by CD patients. Although all grain products contain prolamins (including rice), only the prolamins in wheat, rye and barley are confirmed to cause the immunological reactions to CD [33]. Thus, the rice should not be avoided in the CD diet. Accordingly, the proportion of respondents (80%) in our sample who were able to classify rice correctly was significantly higher than those ($\sim 20\%$) who did not ($P \le 0.01$).

The maximum gluten level allowed in food to be labeled gluten-free is "20 ppm" [26]. Significant ($P \le 0.01$) percentage of participants(83%) did not correctly identify the maximum gluten level allowed in food labeling as compared to only (8.5%) of those who accurately did ($P \le 0.01$). This indicates that most participants lack the knowledge about nutrition labeling according to FDA.

Knowledge of about the ability of the selected sample of Kuwaitinutritionists to identify unsafe ingredients in a food label was also examined. Respondents who were not sure about the correct information regarding unsafe components in a food label represented the highest significant ($P \le 0.05$) proportion of the sample (81.6%) ($P \le 0.05$). Only 6.4% of the participants were not able to correctly identify whether a food product provides unsafe ingredients or not from a provided food label.

The ingredients that usually appear on the labels of food products that contain or may contain gluten are whole - grain cereals, flour, modified starch, starch, fiber, thickeners, semolina, protein, vegetable protein, hydrolyzed protein, malt, malt extract, yeast or yeast extract, spices and aromas [34]. Most nutritionists were not sure about the list of ingredients that should be avoided indicating their lack of knowledge when it comes to the unsafe ingredients and food chemistry. Again this could have grave consequences on patients who resort to these nutritionists for advice.

-Assessment of nutritionists' knowledge overall scores about CD according to their demographic indicators. Table 5 shows the mean knowledge scores of a nutritionist about their demographic characteristics. Results indicate that there are no significant differences $(P \ge 0.05)$ in mean knowledge scores of the respondents to their different age, gender, geographic area of their respective hospitals and/or experience. However, as expected, it was noticed that nutritionists holding university degrees (Graduate and Bachelor's) had significantly

 $(P \le 0.01)$ exhibited higher mean knowledge scores than those holding a diploma degree (9.9 \pm 1.3 and 9.3 \pm 1.3 vs. 8.7 ± 1.4 , respectively). When data was analyzed for gender within the hospital area, it appeared that the mean knowledge scores of male nutritionists were higher, though not significantly, than those of females, in some geographic areas. Other workers [35,36] reported similar results i.e. female nutritionists to have lower knowledge scores compared to males. This probably is because, due to social reasons, many females never receive education beyond community college levels which grant diplomas, thus confounding their scores with those of higher level of education. Furthermore, nutritionists in the age group of 42 years or older had higher, though not significantly, general knowledge scores than younger ones probably due to their long experience in the field rather than age per se.

Table 5. Mean overall knowledge scores* of nutritionists according to their demographic data**

Demographic Data	Knowledge Score Mean ± SD	P-value
Age		
22-31y (n=89)	9.1± 1.3	
32-41y (n=41)	9.0 ± 1.6	0.40
\geq 42y(n=11)	9.4 ± 1.5	
Gender		
M (n=10)	9.8 ± 0.5	0.08
F (n=131)	9.1±1.4	0.00
Education		
Diploma (n=60)	8.7 ± 1.4^{a}	
BSc. (n=70)	9.3± 1.3 ^b	0.00**
Graduate studies (n=11)	9.9± 1.3 ^b	
Geographic Area		
Capital city (n= 69)	9.0 ± 1.2	
Hawalli (n=13)	9.1 ± 1.1	
Mubarak Alkabir (n=27)	9.3 ± 2.0	
Al-Farwaniya (n=10)	9.1 ± 1.0	0.80
Al-Ahmadi (n=15)	8.8 ± 1.3	0.00
Al-Jahra (n=7)	9.1±1.3	
Experience		
>5 years (n= 72)	9.1 ± 1.5	
3-4 years (n= 22)	9.1 ± 1.0	0.06
1-2 years (n = 47)	9.0 ± 1.4	0.96

^{*} Out of 14 as maximum score. ** Highly significant ($P \le 0.01$) Non- Parametric tests: Independent -samples.

4. Conclusions

The present study revealed that although, in general, Kuwaiti nutritionists were informed in the major topics related to CD, many of them still lack the very basic knowledge about this disease which could jeopardize the wellbeing of their patients. Specifically, many of the nutritionists acquired a high level of knowledge about

^{**} Means in the same column within the same demographic criterion, with the same matching letters are not significantly different at the 5% level of probability ($P \le 0.01$) according to Chi-Square test.

causes and complications of CD, yet they still lack the knowledge of distinguishing between CD and wheat allergy. Furthermore, despite most of them enjoy a high level of knowledge when it comes to food products that should be avoided in CD, many lack the knowledge about the unsafe ingredients that should be avoided by CD patients. Likewise, some of them are not aware of many aspects of proper nutritional guidance for this disease. This emphasizes the need not only for continued education of these health workers but for intensive rehabilitation programs in the form of tailored courses in cereal chemistry and quality of foods. This should have a considerable positive impact on their knowledge and help them avoid making mistakes in the diagnosis, treatment and management of CD. Results of the study showed that nutritionists holding higher degrees are more knowledgeable about CD than those holding a diploma degree. However, gender might affect CD knowledge since male nutritionists had higher mean knowledge scores than females.

Statement of Competing Interest

No competing interest is involved in this work by any of the authors.

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