

Socioeconomic Impacts of Gluten-Free Diet among Saudi Children with Celiac Disease

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Purpose: To determine the socio-economic impact of gluten free diet (GFD) on Saudi children and their families

Methods: A cross-sectional study was conducted in which an online questionnaire was sent to all families registered in the Saudi celiac patients support group. We included only children (age 18 years of age and younger) with biopsy-confirmed celiac disease (CD).

Results: A total of 113 children were included in the final analysis, the median age was 9.9 years; 62.8% were females. One hundred (88.5%) of the participating families reported that GFD food was not easily available in their areas, 17% of them reported that it was not available at all in their area. One hundred and six (93.8%) reported that the price of GFD food was very expensive and 70 (61.9%) families that the diet was heavily affecting their family budget. Significant social difficulties were reported among the participating families and their children including interference with the child's interaction with other children (49.6%), the families' ability to attend social gatherings (60.2%), the families' ability to eat in restaurants (73.5%), and the families' ability to travel (58.4%).

Conclusion: There is significant negative socio-economic impact of GFD on children with CD & their families. Health care providers should be aware of these psycho-social difficulties and be well trained to provide a proper education and psychological support for these patients and their families.

Key Words: Celiac disease, Diet, Gluten-free diet, Economics, Child, Saudi Arabia

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INTRODUCTION

Celiac disease (CD) is a chronic immune-mediated enteropathy caused by an immunological reaction to gluten, which subsequently causes small bowel villous atrophy and malabsorption. CD is primarily managed with a lifelong gluten free diet (GFD). Although GFD is very effective in treating CD and preventing complications, it has several limitations: it is not easily available in all places, it is expensive, and usually not palatable. In addition, it imposes a restrictive dietary life style. For all of these reasons, GFD causes significant socio-economic impact on children with CD and their families, which subsequently, affects their quality of life [1-5].

In Saudi Arabia, there are no large data about the prevalence of CD; however, several studies found a sero-prevalence rate between 1-4%, making Saudi Arabia one of the countries with a high prevalence rate of CD [6-8], furthermore, children less than 14 years of age account for 29% of the total number of the Saudi population (30.9 million) [9], with such high percentage of young population, high prevalence rate of CD among children is expected.

We have recently shown that Saudi children have relatively poor compliance to GFD compared to those from other countries [10]. Different factors contribute to this relatively poor compliance rate, including: limited availability of GFD products, their cost, and the limited financial support from the health sectors in supplying free GFD products [10].

Because there are no local data about the impact of GFD, we conducted this study to determine the socio-economic impact of GFD on Saudi children and their families.

MATERIALS AND METHODS

We conducted a cross-sectional study, in which an online questionnaire was sent to all families registered in the Saudi celiac patients support group (SCPSG), from the period of November 2013 till January 2014. The eligibility criteria included families with children 18 years of age and younger, with

biopsy-confirmed CD.

The questionnaire consisted of four sections: the first section inquired about the demographic data of the child and family, the second section was on diagnostic details, while the third section had questions about family knowledge about GFD, its effect on the child's symptoms and the compliance of the child. The data from the previous 3 sections was recently published elsewhere [10].

The fourth section of the questionnaire focused on examining the socio-economic impact of GFD on these children & their families in 4 domains: the effect on the child interaction with other children, the effect on the family's ability to attend social gatherings, the effect on the family's ability to eat in restaurants and the effect on the family's ability to travel.

The contents of the survey were reviewed by two senior pediatric gastroenterologists & pretested on a sample of patients to check its reliability & feasibility.

The study participants were divided into 3 groups: group 1 included children 1-6 years, group 2, 7-12 years, and group 3, 13-18 years. We hypothesized that the social impact would be different among these different age groups in some aspects. For instance, preschoolers stayed usually at home under the direct supervision by their families compared to the elementary school group who attends school unsupervised by their families, and the third group is the adolescents, that typically are unaccompanied in their social activities.

Statistical analysis

The three groups were compared for continuous variables by one way ANOVA and subsequent post hoc Tukey test, and for categorical variables by chi squared test (or its alternative Fisher exact test if any cell counts less than 5). A *p*-value of <0.05 was considered as significant. Economic impact of GFD was explored by calculating proportions for the economic variables like pricing of GFD in the market and its impact on the family budget. Statistical analysis was conducted in IBM SPSS Statistics ver. 21.0 (IBM Co., Armonk, NY, USA).

The completion and return of the questionnaire

was considered as consent. All responses were anonymous.

The study protocol was approved by the institutional research board at King Khalid University Hospital, King Saud University (KSU) (IRB no. 13/3903).

RESULTS

Participants' characteristics

A total of 120 families completed the questionnaires; 113 (94.2%) of the included children had a biopsy-confirmed diagnosis of CD and therefore included in the analysis, of which 62.8% of them were females. Median age of the involved children was 9.9 years, median age at symptom onset was 5.5 years and the median age at diagnosis was 7 years.

Group 1 (preschool children) was composed of 21 (18.6%) children, group 2 (elementary school children) 67 (59.3%), and group 3 (high school children/adolescents) included 25 (22.1%) participants.

The details of the participants' characteristics are summarised in Table 1.

Social impact of GFD

Eleven (9.7%) of the participating families reported significant changes in the family diet after diagnosing their child with CD, while 43 (38.1%) re-

ported partial changes, and 59 (52.2%) families reported no change.

There was a significant social impact of GFD on the affected children and their families in different domains as follows; 49.6% of the families reported that GFD has an effect on their child interaction with other children, 60.2% reported an effect on the family's ability to attend social gatherings, 73.5% reported an effect on the family's ability to eat in restaurants; and 58.4% reported an effect on the family's ability to travel. The three age groups demonstrated similar social impact (Table 2). Seventy six percent of the involved families reported that the school staff did not understand their children's problem.

Economic impact of GFD

One hundred and six (93.8%) of the participating families reported that the price of the GFD is very expensive. Two thirds of the participating families spent an average of 500-2,000 Saudi Riyals per month (133-533 US dollars) for GFD purchasing. Seventy (61.9%) of the families reported that GFD was heavily affecting their family budget. Details of the economic variables are depicted in Table 3.

Table 1. Baseline Characteristics of the Involved Children

Parameter	Age group in years			All cases (n=113)	p-value
	1-6.9 (n=21)	7-12.9 (n=67)	13-18 (n=25)		
Age at diagnosis (yr)	3.4±2.2	6.5±2.6	11.4±3.4	7.04±3.8	<0.001*
Gender					0.691
Female	13 (61.9)	44 (65.7)	14 (56.0)	71 (62.8)	
Male	8 (38.1)	23 (34.3)	11 (44.0)	42 (37.2)	
Family history in the 1st/2nd					0.899
Yes	7 (33.3)	19 (28.4)	7 (28.0)	33 (29.2)	
No	14 (66.7)	48 (71.6)	18 (72.0)	80 (70.8)	
Insulin dependent diabetes mellitus					0.874
Yes	5 (23.8)	19 (28.4)	6 (24.0)	30 (26.5)	
No	16 (76.2)	48 (71.6)	19 (76.0)	83 (73.5)	
Adherence					0.134
Strict	15 (71.4)	42 (62.7)	11 (44.0)	68 (60.2)	
Partial/poor	6 (28.6)	25 (37.3)	14 (56.0)	45 (39.8)	

Values are presented as mean±standard deviation or number (%).

*Statistically significant.

Table 2. The Social Impacts of Gluten Free Diet on Children with Celiac Disease and Their Families

Variable	All cases (n=113)	Age group in years			p-value
		1-6.9 (n=21)	7-12.9 (n=67)	13-18 (n=25)	
Impact on interaction with other children					0.377
Strongly disagree	9 (8.0)	1 (4.8)	8 (11.9)	0	
Disagree	48 (42.5)	8 (38.1)	25 (37.3)	15 (60.0)	
Agree	29 (25.7)	6 (28.6)	17 (25.4)	6 (24.0)	
Strongly agree	27 (23.9)	6 (28.6)	17 (25.4)	4 (16.0)	
Impact on attending social gatherings					0.782
Strongly disagree	8 (7.1)	1 (4.8)	7 (10.4)	0	
Disagree	37 (32.7)	6 (28.6)	21 (31.3)	10 (40.0)	
Agree	40 (35.4)	9 (42.9)	23 (34.3)	8 (32.0)	
Strongly agree	28 (24.8)	5 (23.8)	16 (23.9)	7 (28.0)	
Impact on ability to eat in restaurants					0.828
Strongly disagree	5 (4.4)	1 (4.8)	4 (6.0)	0	
Disagree	25 (22.1)	3 (14.3)	15 (22.4)	7 (28.0)	
Agree	42 (37.2)	8 (38.1)	26 (38.8)	8 (32.0)	
Strongly agree	41 (36.3)	9 (42.9)	22 (32.8)	10 (40.0)	
Impact on ability to travel					0.936
Strongly disagree	6 (5.3)	1 (4.8)	4 (6.0)	1 (4.0)	
Disagree	41 (36.3)	6 (28.6)	24 (35.8)	11 (44.0)	
Agree	34 (30.1)	7 (33.3)	19 (28.4)	8 (32.0)	
Strongly agree	32 (28.3)	7 (33.3)	20 (29.9)	5 (20.0)	

Values are presented as number (%).

Table 3. Economic Impact of GFD on Family Budget (n=113)

Variable	Value
Pricing of GFD in the market	
Very expensive	106 (93.8)
Reasonable price	7 (6.2)
Monthly expenses for GFD (SR)	
100-500	19 (16.8)
501-1,000	48 (42.5)
1,001-2,000	36 (31.9)
More than 2,000	10 (8.8)
Effects GFD expenses on family budget	
Heavily affecting the budget	70 (61.9)
Reasonably affecting the budget	32 (28.3)
No effect on the budget	11 (9.7)

Values are presented as number (%).

GFD: gluten free diet.

*1 US dollar=3.75 SR.

DISCUSSION

We recently have shown that the compliance to GFD among Saudi children is relatively poor (62%) compared to other parts of the world [10]. As there are no local data looking for the socio-economic im-

part of GFD on celiac patients, we aimed, in the present study, to examine the socio-economic impact of GFD on Saudi children with CD and their families.

Though strict GFD is very effective in managing CD and preventing its complications; however, it is very restrictive and might impose significant psycho-social and economic impact on celiac patients as shown by studies from different parts of the world [3,5,11]. Rashid et al. [3] reported that 63% of the involved children in their study felt that they are left out of social activities, 54% reported avoiding eating at restaurants and 15% reported avoiding travel. We found similar results in our sample, in which more than half of the participating families reported significant negative impact of GFD on their social life activities in most of the measured domains; family's ability to attend social gathering, dining out and to travel. The negative impact was observed more on the ability of the families to dinning out and to travel, this is expected as most of the restaurants in the country do not serve gluten free meals, and if they do, the prices are very expensive. We did not find a

difference between the three age groups in regards to the social impact, which indicate that the negative impact are universally distributed among the children regardless of the age. Previous studies found more impact on the adolescents' age groups with less school integration and lower self-esteem [12].

Almost two third of the families felt that the school staff did not understand their children problem. Therefore, more awareness campaigns targeting the school staff are needed to enhance their knowledge about CD and its dietary burden on CD children as they spend a large part of their day at schools.

The heavy burden of the prices of GFD is reported worldwide, and it has been found to be one of the major factors affecting the compliance to GFD [13,14]. Because adherence to strict GFD is a life-long issue, the economic impact will continue to be a challenge for these families, if the GFD prices are not reduced overtime.

In Italy, CD is considered a "social disease" for which free distribution of GFD is provided by the government [5]. In Saudi Arabia at present, free prescription of GFD products is only supplied through the military hospitals. We believe that providing financial support through the government and expanding the free prescription for GFD products will help in reducing the economic burden on these families and subsequently will help in improving the adherence rate to GFD and the quality of life of these patients. The role of health care professionals (physicians and dieticians) along with SCPSG is important in raising this issue to the governmental authorities.

Our study is not without limitations, as the involved families in our study are limited to those registered in the support group, this may impose some population bias, and therefore the results may not be representative for all the families with CD in the country.

Our study showed significant negative socio-economic impacts of GFD on Saudi children and their families. Health care providers should be aware of these psycho-social difficulties and should be well

trained to provide a proper education and psychological support for these patients and their families.

Furthermore, the health care professionals and the celiac support group should work with the governmental authorities to ensure the presence of easily available and affordable GFD; this will help in reducing the psycho-social burdens, which will be reflected subsequently on improving the quality of life of those children and their families.

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