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Assessing Parents Knowledge of Coeliac Disease: A Prospective Study of 70 Cases

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ABSTRACT

Background: Celiac disease is treated by following a strict gluten-free diet for life. Following this diet is practically difficult and the patient requires appropriate management.

Objective of the Study: To assess the knowledge of the parents of children being followed for celiac disease in order to answer the different questions asked by the parents, thus being able to help them better adhere to the gluten-free diet and improve their social life by providing them with the necessary information about the diet and the disease.

Patients and Methods: Prospective survey with a descriptive aim carried out among 70 parents of children followed in the pediatric gastroenterology and nutrition unit during a period of 6 months, from December 2021 to May 2022. The parents are questioned by a questionnaire divided into three parts and which was established in the therapeutic education sessions and also in the medical and dietetic consultations.

Results: The average age of our patients was 9.92+/- 7.10 with a predominance of the female sex (sex ratio = 0.82). More than half of the parents were illiterate. Good compliance with the gluten-free diet was found in most patients, especially in 63.38%. Non-compliance with the diet was explained by denial of the disease in 24.4%. More than half of the patients had dietary and medical consultations, with half of them following up every six months. Information on the disease and the diet was provided by health professionals in the majority of cases (88.73%). On the part of the questionnaire assessing the parents' knowledge of the disease 49.3% of the parents knew that the diet is for life; 32.39% of the parents knew that the disease is autoimmune, 59.15% knew the risk of cancer. 36.62% knew about the risk of infertility related to the disease and 32.39% were aware of the risk of delayed puberty. It was noted that 61.97% of the parents read the labels of the marketed products before consumption. 21.13% of the parents checked the presence of gluten in medicines.

Conclusion: Despite good compliance with the gluten-free diet noted in most patients, awareness and continuous therapeutic education of patients and their relatives on the disease and its management remain the essential weapons to ensure compliance with the gluten-free diet for life.

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Introduction

The management of celiac disease relies on strict and lifelong adherence to a gluten-free diet. However, the practical challenges associated with maintaining this diet underscore the necessity for tailored management strategies. Parental understanding of both the clinical and dietary aspects of celiac disease significantly impact adherence to the gluten-free diet. The enduring dietary restrictions imposed by the gluten-free regimen notably affect patients' quality of life. This emphasizes the importance of a comprehensive approach to celiac disease management, which encompasses not only medical considerations but also psychosocial and nutritional factors to improve diet adherence and enhance patient quality of life [1,2].

This study aims to comprehensively assess parental knowledge levels regarding celiac disease, with the primary objective of supporting parents in achieving better adherence to the challenging gluten-free diet; by improving their understanding of both the diet and the disease.

Patients and Methods

This prospective descriptive survey was conducted over a six-month period, spanning from December 2021 to May 2022, involving 70 parents of children under the care of the Pediatric Gastroenterology and Nutrition Unit. A structured questionnaire, administered during therapeutic education sessions and medical/dietary consultations, was divided into three sections. The first part collected socio-demographic information, while the second part aimed to assess parents' knowledge about the disease and

adherence to the gluten-free diet (GFD). The final section of the questionnaire targeted the impact of the disease on children's education and psychosocial aspects.

Data collected were analyzed using SPSS Statistics Version 23. The analysis proceeded in two steps: a descriptive phase where quantitative variables were expressed as means and standard deviations, and qualitative variables were expressed as frequency and percentage. Subsequently, an analysis was conducted to determine the relationships between variables, employing chi-square tests ($P < 0.05$ was considered significant).

Results

The study findings reveal a male predominance of 54.9%, with an average age of 9.9 years and a mean age at diagnosis of 47 months. The average disease duration was 6 years, with the majority of participants coming from a low socioeconomic background (56.3%). Consultation frequency varied, with 52% attending semi-annual visits, 35% annual visits, 11% quarterly appointments, and 2% having their first visit during the study period.

A high level of adherence to the gluten-free diet was observed in the majority of patients, particularly in 63.38% of cases. Non-adherence to the diet was attributed to denial of the disease in 24.4% of cases. Adherence to the gluten-free diet was assessed across various parameters (Table 1).

Table 1: Analysis of Adherence to the Gluten-Free Diet Across Various Parameters

		Good adherence n (%)	Poor adherence n (%)	p value
Duration of disease progression	< 1 Year 1-5 Years 5-10 Years > 10 Years	5,7% 17,1% 25,7% 15,7%	12,8% 5,7% 12,8% 5,7%	0,05
Parents' education level	Illiteracy primary education Secondary education University education	18,5% 22,8% 22,8% 0	11,4% 11,4% 10% 4,2%	0,17
Socio-economic level	High 1,4% Medium 42,2% Low 56,3%	1,4 % 24,2% 38,5%	0 18,5% 18,5%	0,48
Awareness of the genetic predisposition		49,3%	50,7%	0,09
Understanding of the gluten-free diet		23 %	78 %	0,37
Knowledge of the risk of infertility		37 %	63 %	0,07
Knowledge of the risk of carcinogenesis		60 %	40 %	0,02
Awareness of the risk of delayed puberty		33 %	67 %	0,2
Verification des etiquettes		62 %	38 %	0,01
Social impact		64,2 %	35,7%	0,001

Regarding parental education, primary education was the most common (33.8%), followed by illiteracy (29.5%), secondary education (14%), and university education (4.3%). There was no correlation between adherence and parental education level, with maximum adherence observed in parents with primary education (P=0.17).

The distribution of parents' socio-economic levels was as follows: 1.4% had a high level, 42.2% had a medium level, and 56.3% had a low level. There was no difference observed in adherence to the gluten-free diet between the adherent and non-adherent groups (P= 0,48).

Regarding sources of information, healthcare professionals were the primary source for parents, accounting for 88.7% of respondents, emphasizing the crucial role of medical guidance. Internet also played a significant role, contributing 22.5% of information, while support groups were relevant for 15.4% of participants. Books were used by 4.2%, and 1.4% did not specify a specific information source, highlighting the various channels used by parents to learn more about celiac disease.

We found that adherence was highest among individuals aged 6 to 12 years and declined after the age of 18. Furthermore, disease duration had an impact on adherence, with the highest levels observed after 5 to 10 years of disease. However, adherence in relation to the duration of disease progression did not show a significant difference between the two group, those adherent and non-adherent to the gluten-free diet (P-value = 0.05).

Regarding knowledge about the gluten-free diet, 50.7% of parents understood its lifelong necessity, with no significant difference in diet adherence between adherents and non-adherents (P=0.37). Additionally, 77.4% of parents were aware of the genetic predisposition, with no significant difference between the two groups (P=0.092). Parents' knowledge about the risk of infertility

represented 37%, carcinogenesis (60%), and puberty issues (33%). In the group of patients whose parents were aware of the risk of carcinogenesis, a high level of adherence to the gluten-free diet was observed compared to parents who were not aware of this risk (P=0.02) with also a high adherence rate in the group of parents who knew the necessity of checking food product labels before consumption (P=0.01).

The impact was primarily on social life (46%) followed by schooling (30%). The social impact was high in the adherent patient group compared to the non-adherent group (P = 0.001).

Discussion

The management of celiac disease heavily relies on strict adherence to a gluten-free diet, which presents practical challenges necessitating tailored approaches. Parental comprehension of both the clinical and dietary aspects of the disease significantly influence adherence to the gluten-free diet and is crucial for effective management of celiac disease [2,3]. In our study, we observed a satisfactory adherence rate of 63.3%, while non-adherence to the diet was reported in 36.62% of cases. Among the reasons cited for non-adherence, 40.8% of participants mentioned difficulties in following the diet at school, while denial of the disease was observed in 59.2% of cases. Adherence to the gluten-free diet was particularly noted among children aged 1 to 10 years, which may be explained by the strict supervision of parents in this age group. We did not observe a difference in adherence to the gluten-free diet based on parents' educational level, with maximum adherence observed among children whose parents did not exceed primary education level (34%). Our results were similar to those of Anu Garg's study involving 134 children aimed at exploring factors influencing adherence to a gluten-free diet. In their study, 65.67% of participants were strictly adherent to the diet. Better adherence was observed in the age group of 2 to 9 years, and no correlation was found between mothers' cultural level and adherence to the gluten-free diet.

The study conducted by Anson, involving parents of 43 children with celiac disease, highlighted that parents of compliant children feel adequately informed about future complications, thus reinforcing their vigilance regarding diet adherence [4]. Our findings regarding parental knowledge of future risks revealed significant correlations between knowledge of cancer risk and diet adherence, with a P-value of 0.01. Anson also described that mothers' education level was predominantly primary, showing no correlation between adherence and maternal education level, similar to what was observed in our study [4].

Children following a gluten-free diet often experience feelings of isolation due to strict dietary rules, leading to social exclusion. Family isolation results in changes in marital dynamics and socialization patterns, exclusion from family celebrations, modifications in vacation destinations, and alterations in the nature and frequency of social interactions to accommodate the gluten-free lifestyle. Additionally, limitations in dining options and the loss of spontaneity while dining out are negatively perceived [5-8]. Our study observed a significant social impact in 46% of cases; the analysis of adherence to the gluten-free diet considering social impact, in both adherent and non-adherent groups, revealed statistical significance (significant P-value = 0.001). To address this, therapeutic education activities involving groups of children and their parents were conducted to mitigate social isolation and promote effective communication and learning through shared experiences. Additionally, psychological support was provided to offer emotional and mental support to children facing this challenging situation.

Children should receive support from school health teams, health facilities and support groups. The availability of appetising, affordable and socially acceptable gluten-free foods, as well as improved food labelling, can increase compliance with the gluten-free diet [1,9-14].

In the study conducted by Nour Amin Elsahoryi titled "Educational Intervention Improved Parental Knowledge, Attitudes, and Adherence of Patients with Celiac Disease to Gluten-Free Diet," the findings revealed that parents with inadequate or moderate knowledge predominantly relied on the internet or social media for information (55.6% and 44.4% respectively). Conversely, those with good knowledge preferred seeking information from the gastroenterologist clinic (66.7%) and were less inclined to use the internet or social media as a source of information [1]. These findings contrast with those of our study, where healthcare professionals were the primary source of information (88.7%), followed by the internet (22.5%). These differences underscore the importance of the role of healthcare professionals in raising awareness and providing information to parents, which can have a significant impact on adherence to the gluten-free diet, as evidenced by our adherence rate of 64%.

Conclusion

Despite most patients demonstrating good adherence to the gluten-free diet, awareness and therapeutic education remain crucial for ensuring continuous adherence to this lifelong dietary regimen. Our findings underscore the importance of understanding disease complications in promoting better diet adherence. Therefore, regular therapeutic education sessions led by gastroenterologists and dietetic teams are necessary to raise awareness and knowledge levels among patients with celiac disease and their families, aiding in maintaining strict adherence to the gluten-free diet for life.

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