Research

The factors obstaculating adherence to the gluten free diet in the youth bands: an observational study

Citation: Vallese S., Vallana V., Musso B., Bergesio G., Rinaldi B., Strocco A. "The factors obstaculating adherence to the gluten free diet in the youth bands: an observational study" (2023) *infermieristica journal* 2(3): 131-137. DOI: 10.36253/if-2096

Received: March 29, 2023

Revised: October 3, 2023

Just accepted online: October 16, 2023

Published: October 31, 2023

Data Availability Statement: All relevant data are within the paper and its Supporting Information files. This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record.

Competing Interests: The Author(s) declare(s) no conflict of interest.

Silvia Vallese[1], Vittoria Vallana[1], Benedetta Musso[1], Giorgio Bergesio [2], Bartolomeo Rinaldi[2], Andrea Strocco[3]

[1]RN Cardiology Ward, Cardinal Massaia Hospital, Asti, Italy
[2]RN Lecturer at Nursing Course Degree, University of Turin, Office of Asti, Italy
[3]MD, Anesthesia and Intensive Care resident - University of Piemonte Orientale, Novara, Italy

Abstract

Introduction. Celiac Disease (CD) affects the small intestine and it's characterized by a high sensitivity to gluten. Among the main signs and symptoms, there are typical or intestinal ones such as abdominal pain, abdominal swelling, diarrhea, weight loss, atrophy of the intestinal villi. At the moment, the only effective therapy is to follow a gluten-free diet during a long-life. The aim of the study is to investigate the difficulties of adherence to gluten free diet (GFD) in young people with CD.

Materials and methods. A questionnaire was administered to the population under study (15-30 years), between 9 July 2022 and 29 August 2022. The interviewees answered 28 questions: 5 concerning the socio-demographic variable, 23 concerning the difficulties of adherence to the GFD.

Results. Two hundred and twenty-seven people answered the questionnaire. Among them, a low percentage was sent to the attention of a dietician or psychologist. 78.8% prepare their own meal independently. 78.4% believe they know the foods allowed and 93% say they strictly follow the diet.

Discussion. Following the GF diet is a challenge for most young people with CD. Restaurants offering GF meals are limited and this could be a reason for opting out leisure and socializing, or in the worst-case scenario, the person with CD is forced not to join the GFD. The risk of contamination that can involve fear, isolation, embarrassment in asking questions, is another factor to consider.

Conclusion. Adherence difficulties begins with the CD diagnosis and continue with the entry of patients into the "gluten-free" world. The main problem in related to the social setting of young people, who wants to live without complications due to shortage of places with gluten free (GF) food. In future studies, the literature may address difficulties with adherence, rather than quality of life and

CD-related behavior. It's necessary to improve the attention on GF world to decrease discomfort about medical conditions.

Keywords: Celiac Disease, Gluten Free Foods, Gluten Free Diet, Adherence Difficulties

Introduction

Celiac disease (CD) is a chronic immune mediated enteropathy which affects small intestine and it's characterized by an high sensitivity to gluten. This lead to systemic clinical manifestations and affects who is genetically predisposed[1]. The immunogenic component of gluten is the gliadin that, in genetically predisposed people, triggers an innate cell mediated immune reaction. It leads to atrophy and flattening of intestinal villi. This molecule is present in various cereals, such as barley, wheat, rye, spelt and kamut[2].

CD can occur in different ways: paucisintomatic (subclinical) or, in typical forms, with severe intestinal disorders (abdominal pain, diarrhea, swelling and weight loss). Atypical or extra-intestinal forms exist and they can cause delayed growth of children, anemia, osteoporosis, non-specific abdominal disorders, ataxia, neuropathy, alopecia areata, psoriasis and dermatitis herpetiformis[3,4].

Nowadays, subclinical and atypical cases are respectively 30% and 40-60%[5,6].

CD seems to have a familiar component: in fact, its frequency increases in close relatives (5%), up to 20% of cases among brothers, parents and children. Immunogenetics assumes a correlation with DQ2 or DQ8 heterodimer (genes on the surface) codified by HLA (Human Leukocyte Antigens) system of II class[5].

CD diagnosis begins with the evaluation of clinical manifestations in response to a gluten free diet. Then, the presence of the specific autoantigen tissue transglutaminase (TG2) and anti-endomysial antibody (EMA) are searched. TG2 is very sensitive (95%) and cheap, which make it the most common test for the diagnosis and CD tracking. EMA is more specific and is used to confirm the diagnosis. Duodenal biopsy is still the standard test to confirm the diagnosis[7].

Literature data estimate a prevalence of celiac patients of about 1% both in Europe and USA, with an increase of diagnosis average age (30-40 years old) and a rate female/male of 3:1[7].

The increase of numbers of diagnosis is due to higher sensitivity of diagnostic tests and screening introduction. Various authors sustain that CD may be linked to the mediterrean diet, which lead to a gluten intake of about 20 g/die. Moreover, the quality of gluten is being studied because new industrial food variants may be involved in increasing of disease cases[8]. These theories don't find current evidence, so risk factors remain unknown[9].

Currently, the only effective treatment is a rigorously gluten free diet (GFD). After the diagnosis, patients are directed to the dietician for follow-up so that they can receive useful information for everyday life. To improve theurapeutic adherence to GFD is endorsed to participate actively to support groups or associations[9]. In fact, especially in young people, it can be difficult to follow a GFD. During childhood, parents choose what to eat for their children, while since adolescence people acquire freedom and choose themselves what to eat. This can represent one of the reasons of therapeutic non adherence[10]. From here one can deduce that a teenager may have a lot of problems to follow a GFD, because he spends more time with peers than with family.[8] Moreover, he can be stressed and feel various emotions, from the fear of possible contamination to rage and embarrassment, he can be afraid to make incorrect decisions about the feed or feel different than friends, peers, classmates or colleagues[11].

From several bibliographic searches, a lack of information about main obstacles and daily difficulties that a young celiac adult can come across, appears. It happens because adherence level is mainly studied, together with the behaviour resulted and not the real daily difficulties[12].

In literature, quality of life of celiac young people is explored, without an evaluation the possible causes that lead to a non-adherence to a GFD[12].

The objective of the study is to investigate the real difficulties to follow a GFD in a sample of celiac young people (15-30 years old).

Materials and methods

Between 9 July 2022 and 29 August 2022, a questionnaire (available upon request) was administered to a sample of 15-30 years old people with CD (n=227) to evaluate the adherence difficulties to GFD.

The tool was created by the analysis of 8 articles[12,13,14,15,16,17,18,19] and, subsequently setting to the reality of the study. 28 questions were planned, of which 5 to evaluate sociodemographic variables and 23 to evaluate the adherence difficulties to GFD. The form was administered online with Google Moduli®. The tool was shared on social media to reach the sufficient sample of convenience size to provide data to make inference on population. Each response received was received by email from the authors and reviewed, but never published to ensure privacy. The expected time to complete the form was about 3 minutes. Sample characteristics are resumed in Table 1.

Age (years)	%			
10-20	32			
21-30	55,5			
31-40	7			
41-50	5,4			
Gender	**Female (%)**	**Male (%)**		
	84,6	15,4		
Profession	**High school students (%)**	**University students (%)**	**Workers (%)**	
	20, 7	44,1	40,5	
Region of origin	**North Italy (%)**	**Centre Italy (%)**	**South Italy (%)**	
	52,42	26,43	21,15	
Age at diagnosis	**% <10 yo**	**% 11-20yo**	**% 21-30yo**	**% >30yo**
	40,09	33,92	21,59	4,41

Results

227 people with CD answered the questionnaire. Among them, 34 didn't meet the criteria of inclusion. So, a sample of 193 subjects was considered.

53,7% of surveyed people wasn't take in charge by a dietician or a nutritionist after diagnosis phase. Among 112 patients to whom advice has been requested, only 28% has received an evaluation by a nutritionist, while 26,4% by a dietician. For 91.6% of cases, a visit to a psychologist was not considered.

From the questionnaire, 62,1% of participants prepare meals themselves. Parents take care of their children diet in 73,6% of cases. A minority of the sample (8,4%) buy pre-packed GF meal.

78,4% of young adults believe to be very familiar with foods to eat daily. The prevalence of going out to eat with friends is on one or two times a week (43,6%), even if 70,5% of the interviewed declares that the choice of premises with GF option is limited. As regards GFD adherence, 93% affirms to follow it strictly because it carries wellness, even if it is considered a diet which requires a constant effort. 51,5% of the sample asks information about food content without embarrassment while eating outside, instead 41,4% feels ashamed and remaining 7% a priori doesn't ask question because it feels uncomfortable (Table 4). 86,8% of the interviewed reads carefully food labels (Table 2), but 63,9% affirms that the labels are often not easy to understand (Table 3). As regards lunch outdoor (canteen, office, breaks), 77,3% declares to feel more confident to have GF food or snacks.

Table 2. Sample attention to gluten presence (n=227)

You don't control if there are GF meals because you're not interested	1,3 % (3)
Others (parent, relatives) do it for you	11.90 % (27)
You always read the labels	86,80% (197)

Table 3. Perception on dietary advice clarity

Sometimes, they are incomprehensible	3,10% (7)
They're not always easy to read	63,90% (145)
They're easy to read	33,0% (75)

Table 4. Description of dietary habits outside of the family context

You don't ask information because you feel embarrassed	3,10% (7)
You feel embarrassed with your friends to ask information on food, but you do it	63,90% (145)
You ask information on how food in prepared, without embarrassment	33,00% (75)

Discussion

Various aspects influence GFD in young adults affected by CD and through this study it was possible to assess obstacles after diagnosis. Generally, impulsiveness that characterizes most young people causes almost immediately rebelliousness towards GFD[20]. Over time, if no interventions are carried out, this ostility turns into isolation, embarrassment, rage and feeling of diversity from peers[21]. This leads to a low problem-solving skills and to find compensation strategies that often don't coincide with clinical needs[22]. At first, it's diriment that the person is stimulated to plan, organize, prepare independently meals and take it with him if necessary. It's fundamental to always remember that, as demonstrated by interviewed, most of the sample substains to know which food they can eat, but literature has repeatedly demonstrated that patient mastery about their feed does not always reflect reality[21].

From questionnaire results, that the offer of places offering gluten-free food is still limited and, for young adults who going out - as declared - 1-2 times a week, it can be a reason of cancellation of outings with friends or, at worst, to oblige the person to adapt and to eat food with gluten. Even if data about intentional consumption of gluten is irrelevant and almost all of the respondents sustains to follow a strictly diet, eating out home represents a critical factor both for precedent reasons and of possible unintentional contamination of food in GF premises.22 This last problem begins a problem which explains the reason why there are few places where a person affected by CD could have a GF meal. In fact, contamination risk, the taste of gluten-free foods and the high cost of

raw materials can be considered limitations for restaurant managers, and they have to face when they decide to offer a GF choice (school canteen included).23

This means that the person, as demonstrated by analyzed data, feels safer to prepare independently his meal, bearing a burden even in moments of conviviality and entertainment. It's necessary to try to imagine these difficulties during a travel where language and logistic difficulties are added.

Even if, as a Canadian study affirms33, concern after diagnosis, symptoms related to gluten intake, and the need to gain weight after a gluten diet lead the person to a condition where he's obliged to follow a GFD, analysed limits impose a reflection on possible lack of adherence to a therapy, especially in a young population. Teenagers fall into the most risk category as regards the difficulty in adhering to a diet and emotional support is fundamental to prevent this risk. Some factors, such as familiar context and parents' instruction level, may influence behavior of young people and this makes the family very important. In fact, different studies aim to better understand the pathology both to parents and others family components: their role is important to support them and to help them feel less isolated, faciliting social life aspects seen like a big obstacle from celiac people.24-27

After the diagnosis, there are few individuals to whom a dietician/nutritionist consultant is recommended and this data is alarming when it comes to psychological support. In literature, the need to attend a specialist visit after diagnosis is demonstrated: this because a healthcare professional could evaluate a possible risk of non adherence and intervene early29. The professional nutrition expert could implement a path of therapeutic education on GFD, while a psychological support allows to face daily life20,28 and to improve adherence, even in the long term.29, 30

From the survey, in most cases, parents prepare meals for their children, so it's important to involve families in the support path outlined. It's fundamental that families are aware of tax deductions applicable (DM 4 may, 2006, Italy) to GF food and are addressed to a common food style for all the component. To avoid difference in home environment is surely a decisive factor on a psychological level, since the acceptance of their condition has deep roots in the family.24 A strictly gluten free diet may lead to nutritional imbalances because GF products contain less fiber. Another risk is to try to compensate dietary restrictions by introducing high-calorie foods with high sugar content, fats or high protein foods (eggs, meat, snacks), leading to an increase in weight.31

Conclusion

GFD adherence difficulties begins with the CD diagnosis and eith the nursing care. The main problem is related to the social setting of young people, who wants to live without complications due to shortage of places with GF food. Literature should investigate about adherence difficulties, instead of quality of life and behaviour CD related. It's necessary to improve the attention on GF world to decrease discomfort about medical conditions.

References

1. Fok CY, Holland KS, Gil-Zaragozano E, Paul SP. The role of nurses and dietitians in managing paediatric coeliac disease. Br J Nurs. 2016;25(8):449– 55.
2. Robinson BL, Davis SC, Vess J, Lebel J. Primary care Management of celiac disease. Nurse Pract. 2015;40(2):28–34.
3. Hujoel IA, Reilly NR, Rubio-Tapia A. Celiac Disease: Clinical Features and Diagnosis. Gastroenterol Clin North Am [Internet]. 2019;48(1):19–37.
4. Dominguez Castro P, Harkin G, Hussey M, Christopher B, Kiat C, Liong Chin J, et al. Changes in Presentation of Celiac Disease in Ireland From the 1960s to 2015. Clin Gastroenterol Hepatol [Internet]. 2017;15(6):864-871.e3.
5. Volta U, Caio G, Giancola F, Rhoden KJ, Ruggeri E, Boschetti E, Stanghellini V, De Giorgio R. Features and Progression of Potential Celiac Disease in Adults. Clin Gastroenterol Hepatol. 2016;14(5):686-93.e1.
6. Volta U, Caio G, Stanghellini V, De Giorgio R. The changing clinical profile of celiac disease: A 15-year experience (1998-2012) in an Italian referral center. BMC Gastroenterol. 2014;14(1):1–8.
7. Ben Houmich T, Admou B. Celiac disease: Understandings in diagnostic, nutritional, and medicinal aspects. International Journal of Immunopatholo-gy and Pharmacology. 2021;35.
8. Arnone, Jacqueline MSN, RN; Fitzsimons, Virginia EdD, RNC, FAAN. Ado-lescents With Celiac Disease. A Literature Review of the Impact Develop-mental Tasks Have on Adherence With a Gluten-Free Diet. Gastroenterolo-gy Nursing 35(4):p 248-254, luglio/agosto 2012..
9. Lebwohl B, Rubio-Tapia A. Epidemiology, Presentation, and Diagnosis of Celiac Disease. Gastroenterology. 2021 Jan;160(1):63-75.
10. Al-Toma A, Volta U, Auricchio R, Castillejo G, Sanders DS, Cellier C, et al. European Society for the Study of Coeliac Disease (ESsCD) guideline for coeliac disease and other gluten-related disorders. United Eur Gastroenterol J. 2019;7(5):583–613.
11. Caio G, Volta U, Sapone A, Leffler DA, De Giorgio R, Catassi C, et al. Celiac disease: A comprehensive current review. BMC Med. 2019;17(1).
12. Meyer S, Rosenblum S. Daily experiences and challenges among children and adolescents with celiac disease: Focus group results. J Pediatr Gas-troenterol Nutr. 2018;66(1):58–63.
13. Silvester JA, Weiten D, Graff LA, Walker JR, Duerksen DR. Living gluten-free: Adherence, knowledge, lifestyle adaptations and feelings towards a gluten- free diet. J Hum Nutr Diet. 2016;29(3):374–82.
14. Biagi F, Andrealli A, Bianchi PI, Marchese A, Klersy C, Corazza GR. A gluten- free diet score to evaluate dietary compliance in patients with coe-liac disease. Br J Nutr. 2009;102(6):882–7.
15. Leffler DA, Dennis M, Edwards George JB, Jamma S, Magge S, Cook EF, et al. A Simple Validated Gluten-Free Diet Adherence Survey for Adults With Celiac Disease. Clin Gastroenterol Hepatol. 2009;7(5):530-536.e2.
16. Black JL, Orfila C. Impact of coeliac disease on dietary habits and quality of life. J Hum Nutr Diet. 2011;24(6):582–7.
17. Lins MTC, Tassitano RM, Brandt KG, Antunes MMDC, Silva GAP Da. Translation, cultural adaptation, and validation of the celiac disease DUX (CDDUX). J Pediatr (Rio J). 2015;91(5):448–54.
18. Fueyo-Díaz R, Gascón-Santos S, Asensio-Martínez Á, Sánchez-Calavera MA, Magallón-Botaya R. Transcultural adaptation and validation of the Ce-liac Dietary Adherence Test. A simple questionnaire to measure adherence to a gluten-free diet. Rev Esp Enferm Dig. 2016;108(3):138–44.
19. Wessels MMS, te Lintelo M, Vriezinga SL, Putter H, Hopman EG, Mearin ML. Assessment of dietary compliance in celiac children using a standard-ized dietary interview. Clin Nutr. 2018;37(3):1000–4.
20. Biagi F, Bianchi PI, Marchese A, Trotta L, Vattiato C, Balduzzi D, et al. A score that verifies adherence to a gluten-free diet: A cross-sectional, multi-centre validation in real clinical life. Br J Nutr. 2012;108(10):1884–8.
21. Anca I, Stănescu-Popp A, Arama V, Et al."diagnostic impact al dietei fără gluten din perspectiva pacientului [Celiac disease: diagnostic criteria and impact of gluten free diet--patients' perspective]. Rev Med Chir Soc Med Nat Iasi. 2008 Apr-Jun;112(2):351-5. Romanian.
22. Edwards George JB, Leffler DA, Dennis MD, Franko DL, Blom-Hoffman J, Kelly CP. Psychological correlates of gluten-free diet adherence in adults with celiac disease. J Clin Gastroenterol. 2009;43(4):301–6.
23. Rodrigo L, Pérez-Martinez I, Lauret-Braña E, Suárez-González A. Descrip-tive study of the different tools used to evaluate the adherence to a gluten-free diet in celiac disease patients. Nutrients. 2018;10(11).
24. Estévez V, Ayala J, Vespa C, Araya M. The gluten-free basic food bas-ket: A problem of availability, cost and nutritional composition. Eur J Clin Nutr. 2016;70(10):1215–7.
25. Dowd AJ, Tamminen KA, Jung ME, Case S, Mcewan D, Beauchamp MR. Motives for adherence to a gluten-free diet: A qualitative investiga-tion involving adults with coeliac disease. J Hum Nutr Diet. 2014;27(6):542–9.
26. Panzer RM, Dennis M, Kelly CP, Weir D, Leichtner A, Leffler DA. Navi-gating the gluten-free diet in college. J Pediatr Gastroenterol Nutr. 2012;55(6):740– 4.
27. Moayyedi P, Andrews CN, MacQueen G, Korownyk C, Marsiglio M, Graff L, Kvern B, Lazarescu A, Liu L,

Paterson WG, Sidani S, Vanner S. Canadian Association of Gastroenterology Clinical Practice Guideline for the Man-agement of Irritable Bowel Syndrome (IBS). J Can Assoc Gastroenterol. 2019 Apr;2(1):6-29. Epub 2019 Jan 17.
28. Holbein CE, Carmody JK, Hommel KA. Topical Review: Adher-ence Interventions for Youth on Gluten-Free Diets. J Pediatr Psy-chol. 2018;43(4):392–401.
29. Czaja-Bulsa G, Bulsa M. Adherence to gluten-free diet in children with celi-ac disease. Nutrients. 2018;10(10):1–9.
30. Bacigalupe G, Plocha A. Celiac Is a Social Disease : Family Challenges and Strategies University of Massachusetts Boston. 2015;33(1):46–54.
31. Villafuerte-Galvez J, Vanga RR, Dennis M, Hansen J, Leffler DA, Kelly CP, et al. Factors governing long-term adherence to a gluten-free diet in adult patients with coeliac disease. Aliment Pharmacol Ther. 2015;42(6):753–60.
32. Almagro JR, Almagro DR, Ruiz CS, González JS, Martínez AH. The Expe-rience of Living with a Gluten-Free Diet: An Integrative Review. Gastroen-terol Nurs. 2018;41(3):189–200.
33. Rodrigues M, Yonaminez GH, Satiro CA. Rate and determinants of non- adherence to a gluten-free diet and nutritional status assessment in children and adolescents with celiac disease in a tertiary Brazilian referral center: A cross-sectional and retrospective study. BMC Gastroenterol. 2018;18(1):1–8.