

# Adherence to gluten free diet and problems faced by children with celiac disease and type 1 diabetes mellitus

Anjali Verma<sup>1</sup>, Shilpi Rani<sup>1</sup>, Surender Verma<sup>2</sup>, Alok Khanna<sup>1</sup>

<sup>1</sup>Pediatrics, PGIMS, Rohtak, Haryana, India, <sup>2</sup>General Surgery, PGIMS, Rohtak, Haryana, India

## ABSTRACT

**Introduction:** Celiac disease (CD) in children can be associated with Type 1 Diabetes Mellitus (T1DM) as both share autoimmune etiology. Mainstay of treatment in celiac disease is total avoidance of gluten in diet whereas treatment in child with both the diseases will be Insulin therapy, exercise along with gluten free diet (GFD). There is dearth of literature regarding adherence to GFD and barriers for children with both T1DM and CD. **Methods:** A questionnaire-based study was done at a tertiary care institute so as to compare the self-reported gluten adherence and the problems faced by children with dual diseases (T1DM and CD) and CD alone. Thirty children of age group 5-14 years each with Type 1 DM and CD (T1DMCD group) and celiac disease (CD group) were selected consecutively. A questionnaire was filled by asking questions from either children (above 8 years) or parents (below 8 years) and the results were compiled, compared and further analysed. **Results:** Baseline demographic parameters were comparable in both the groups. Gluten adherence was found to be worse in T1DMCD group as compared to CD group. Greater number of problems were experienced by children with both T1DM and CD as compared to children with CD alone ( $P < 0.05$ ). Financial burden more so in T1DMCD group, unawareness about disease and benefits of GFD, less availability and social isolation were found to be the most significant barriers to diet adherence. **Conclusion:** As these children face dual diseases, they should be made more aware regarding benefits of GFD. Such information is valuable to primary care physicians for better management and rehabilitation of children suffering from these chronic diseases.

**Keywords:** Autoimmune disorders, gluten adherence, gluten free diet

## Introduction

Celiac disease (CD) and Type 1 Diabetes Mellitus (T1DM) can be present separately or combined in some children as both are autoimmune diseases. The prevalence of CD is much higher (5-10%) in patients with T1DM when compared with general population.<sup>[1]</sup> Mainstay of treatment in celiac disease is total avoidance of gluten and additionally Insulin therapy and physical activity in concurrent occurrence of both the diseases. Strict adherence to Gluten free diet (GFD) leads to decreased symptoms, weight gain and less incidence of hypoglycemia thus

leading to better health outcomes in patients with both T1DM and CD.<sup>[2,3]</sup>

Previous literature is mainly on the quality of life (QoL) in children with T1DMCD and it was correlated with compliance to GFD.<sup>[4]</sup> Studies have also shown that initially QoL of celiac patients is affected by diet restriction but it improved after around 1 year of GFD, even if they were partly adherent.<sup>[5,6]</sup> Not much literature is there regarding adherence to GFD in children with both T1DM and CD especially in our local population.

Study of after effects of dietary changes imposed by both diseases is equally important which has been poorly evaluated till date. While health benefits from a GFD in children with T1DMCD have been described,<sup>[7]</sup> parents of these children have also reported significant challenges in managing both T1D and

**Address for correspondence:** Dr. Alok Khanna,  
8/8 FM, Medical Campus, PGIMS, Rohtak, Haryana, India.  
E-mail: khannavidushi45@gmail.com

Received: 04-02-2024

Revised: 10-04-2024

Accepted: 15-04-2024

Published: 18-10-2024

### Access this article online

#### Quick Response Code:



**Website:**  
<http://journals.lww.com/JFMPC>

**DOI:**  
10.4103/jfmprc.jfmprc\_186\_24

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

**For reprints contact:** WKHLRPMedknow\_reprints@wolterskluwer.com

**How to cite this article:** Verma A, Rani S, Verma S, Khanna A. Adherence to gluten free diet and problems faced by children with celiac disease and type 1 diabetes mellitus. J Family Med Prim Care 2024;13:4252-5.

CD simultaneously including financial concerns and impact on mental/emotional health.<sup>[8]</sup> Unique or elevated barriers in adherence to a GFD for children with T1DMCD, compared to those with CD alone, have not been previously described. Knowledge of primary care physicians about adherence as well as barriers in these groups will help in better management at a primary level.

Hence this study was done to assess self-reported adherence to GFD and analyse day to day experiences or problems faced by children with dual diseases for maintaining a gluten free lifestyle.

## Material and Methods

A cross sectional study was conducted by enrolling patients from Pediatric Endocrinology Clinic in a Tertiary care teaching hospital over a period of one year i.e. from November 2022 to October 2023. Patient were enrolled after written informed consent from parents/legal guardians and ethical clearance was obtained from institutional ethics committee. A convenient sample size of 30 children each from Type 1 Diabetes Mellitus and Celiac disease (T1DMCD group) and celiac disease (CD group) were selected consecutively, thus a total of 60 children of age group 5- 14 years were enrolled in the study.

Demographic details in form of age, sex, residence, source of family income, socioeconomic status using Modified Kuppaswamy scale were noted. Details about age of onset, symptoms and other associated comorbidities in both the group were noted. Participants underwent a baseline assessment including anthropometric measurements and diet pattern. Last value of HbA1C in T1DMCD group and IgA TTG values in both the groups were also recorded. Adherence to gluten free diet was assessed by self-reporting by the parents of these children. Day to day experiences and problems faced by these children were assessed by questionnaire which had both closed as well as open ended questions. It was filled by a post graduate resident who asked those questions in their own language. The questionnaire used was evaluated by a team for interpretation and understanding and was validated before the study. The statistical analyses were performed by using SPSS 22.0 software package. Value of  $P < 0.05$  was accepted as statistically significant.

## Results

Total sixty patients were enrolled, out of which thirty patients were in each group. Maximum children were females in both the groups and belonged to rural background. Only 20% were symptomatic for celiac disease in T1DMCD group. Last tTg IgA was positive in 53.3% of patients with both the disease where it was positive in few (1.6%) patients with celiac disease. tTg IgA levels of more than or equal to 20 U/ml was taken as positive. Baseline demographic parameters like age, sex, background, socioeconomic status as well as anthropometric measurements were comparable in both the groups [Table 1].

**Table 1: Showing baseline demographic parameters in both the groups**

Parameter	T1DMCD (Group A)	CD (Group B)	P
Mean age (Years)	8±2.6 years	7±3.4 years	0.11
Sex [n (%)]			0.21
Male	14 (46.7%)	11 (36.7%)	
Female	16 (53.3%)	19 (63.3%)	
Background [n (%)]			0.61
Urban	12 (40%)	13 (43.3%)	
Rural	18 (60%)	17 (56.7%)	
Socioeconomic status [n (%)]			0.51
Lower	7 (23.3%)	8 (26.7%)	
Upper lower	9 (30%)	10 (33.3%)	
Lower middle	11 (36.7%)	10 (33.3%)	
Upper middle	3 (10%)	2 (6.7%)	
Time since CD diagnosis (Years)	2±1.6 years	2±2.8 years	0.38
Symptomatic for celiac disease [n (%)]			0.005
Yes	6 (20%)	30 (100%)	
No	24 (80%)	0 (0%)	
Mean HbA1c (%)	9.5±1.8%	-	-
Last tTg IgA [n (%)]			0.002
Positive	16 (53.3%)	5 (1.7%)	
Negative	14 (46.7%)	25 (83.3%)	

Gluten adherence was found to be worse in T1DMCD group as compared to CD group which was statistically significant. Greater number of difficulties were experienced by children with both T1DM and CD as compared to children with CD alone ( $P < 0.05$ ). Maximum difficulties were experienced in areas like school (67%), home with siblings (43%) and eating outside (23%). Three patients in CD and one in T1DMCD group only did not report any difficulties related to the GFD. Around one third in both the groups were aware about health benefits of GFD. Only 6 (20%) in T1DMCD group were aware about health benefits of millets which are gluten free and can help in better control of hyperglycemia [Table 2].

Barriers faced by children with both diseases were increased financial burden, poor availability followed by unawareness about importance of GFD and where as social isolation and poor availability were main concerns for children with celiac disease alone [Figure 1].

## Discussion

This study was done to compare gluten adherence and associated barriers between children with both the diseases and with celiac disease alone. Previous studies on the impact of GFD on various outcomes especially quality of life in patients with T1DM and CD have paved the way for more research on this topic.<sup>[2,4,9]</sup> Bakker *et al.* pointed out social fear in adult patients suffering from both the disease thus causing negative impact on QoL.<sup>[10]</sup>

There is lower adherence to GFD in patients with both the disease despite the fact that GFD is helpful in controlling diabetes also. For patients with dual diseases, previous studies suggest

**Table 2: Showing comparison of gluten adherence in both the groups**

Parameter	T1DMCD (Group A) n (%)	CD (Group B) n (%)	P
Gluten adherence			0.02
1. Fully adherent to gluten	10 (33.3%)	17 (56.7%)	
2. Somewhat	13 (43.3%)	9 (30%)	
3. Not adherent	7 (23.3%)	4 (13.3%)	
Difficulties faced in gluten adherence			0.03
1. Very difficult	12 (4%)	8 (26.7%)	
2. Somewhat difficult	17 (56.7%)	19 (63.3%)	
3. Not difficult	1 (3.3%)	3 (10%)	
Knowledge about			0.34
1. Benefits of GFD	10 (33.3%)	11 (36.7%)	
2. Millets as gluten free	10 (33.3%)	21 (70%)	
3. Millet-based products in market	6 (20%)	17 (56.7%)	
Difficulties face in various areas			0.03
1. School	12 (40%)	6 (20%)	
2. Home	18 (60%)	7 (23.3%)	
3. Outside eating	24 (80%)	14 (46.7%)	
4. Parties/Friends' houses	9 (30%)	7 (23.3%)	
5. Trips/camps	10 (33.3%)	8 (26.7%)	

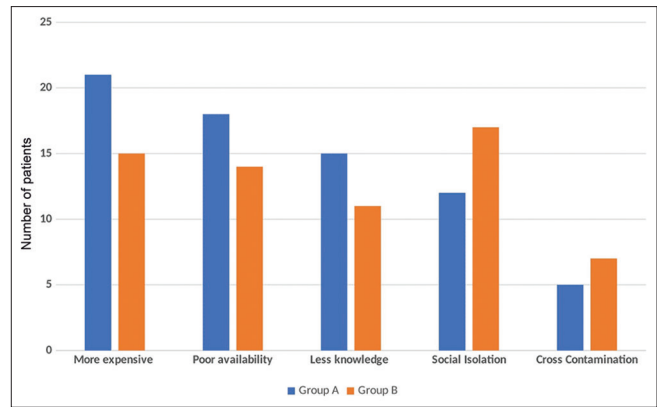
n=Number of patients

that gluten adherence is variable to a great extent i.e. from 25% to 69%.<sup>[11,12]</sup> Adherence in both the groups is in the range which was previously reported however it was much less in T1DMCD group. These results differ from a similar study which showed that adherence in both the groups is almost same. This was due to increased support in T1DMCD group in that study with frequent follow up as compared to CD group.<sup>[13]</sup>

Low adherence in our study could be due to lesser perceived benefit of GFD in children with T1DMCD as usually most of them are asymptomatic for celiac disease. Silent celiac disease is known to be detected in patients with T1DM on routine screening.<sup>[14]</sup> CD-DIET study by Mahmud *et al.* has also reported high rates of asymptomatic celiac disease in patients with T1DM and one diagnosed significant anxiety was noticed in managing both diseases despite good efforts.<sup>[7]</sup> In another study done in adults with celiac disease, it was found that long-term and strict adherence was detected in patients with classical symptoms at diagnosis, which were found in very few patients in our T1DMCD group.<sup>[15]</sup>

Parents may not notice significant improvement in health and symptoms in asymptomatic children with celiac disease whereas strict adherence to GFD may adversely affect their family finances and will lead to social isolation. Even on GFD, children with both the diseases still have to face health issues due to T1DM.<sup>[13]</sup>

Our data specifically showed that a lot of difficulties were being experienced in coping with both the disease (T1DM and celiac) than CD alone. Additional financial burden due to expensive GFD, less availability of food options, poor sensitisation regarding GFD with more focus on Insulin therapy alone were found to be the most significant barriers to diet adherence which

**Figure 1: Showing barriers in maintaining adherence to GFD in both the groups**

were similar to that reported in previous studies.<sup>[13,16]</sup> However, in children with celiac disease the main barrier was social isolation followed by expensive GFD which became the main predictors of compliance to GFD.<sup>[16,17]</sup> The major barrier shared between both the groups was cost but it more affected more children with both the diseases. As there are limited number of options of gluten free diet in patients with associated T1DM as GFD containing rice is having high glycemic index, so families have to search for other gluten free options which ultimately increase the cost.<sup>[13]</sup> Many children in T1DMCD group were 'somewhat gluten adherent' in comparison to CD group where maximum was 'fully adherent' because family members of different age groups find it difficult to understand and follow the complex setting of diabetes and celiac meal planning.

Children with dual diseases face a significant number of challenges at restaurants or eating outside due to lack of availability of low glycemic gluten free foods. A systematic review done by Mozzillo has also showed that shifting to GFD can lead to higher post prandial glucose levels.<sup>[18]</sup> Unawareness regarding low glycemic gluten free options and understanding of benefits of GFD is also an important reason of non-adherence. Millets can be a good option for children having both the diseases because of their nutritional value, low glycemic index and gluten free mature and are used to make various food items worldwide. However, very few parents/children were aware about the gluten free nature of millets and their benefits. They were not aware of the food products available in the market made from millets which can be options for such children thus improving their mental health and quality of life.<sup>[18-20]</sup> The limitation of our study was its small sample size. Additionally, adherence was self-reported which could vary from actual adherence, moreover it was not supported by recent serological test in many participants.

## Conclusion

Adherence to Gluten free diet was found to be poor in patients with both T1DM and celiac disease when compared with celiac disease alone. As these children face dual diseases, equal attention should be given on adherence to GFD along with Insulin therapy

and physical activity. \ Larger studies with more sample size may be helpful for addressing their concerns more effectively.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

## References

- Goh C, Banerjee K. Prevalence of coeliac disease in children and adolescents with type 1 diabetes mellitus in a clinic based population. *Postgrad Med J* 2007;83:132-6.
- Abid N, McGlone O, Cardwell C, McCallion W, Carson D. Clinical and metabolic effects of gluten free diet in children with type 1 diabetes and coeliac disease. *Pediatr Diabetes* 2011;12:322-5.
- Simmons JH, Foster NC, Riddlesworth TD, DuBose SN, Redondo MJ, Liu E, *et al.* Sex- and age-dependent effects of celiac disease on growth and weight gain in children with type 1 diabetes: Analysis of the type 1 diabetes exchange clinic registry. *Pediatr Diabetes* 2017;19:741-8.
- Nunes-Silva JG, Nunes VS, Schwartz RP, MLSS Trecco S, Evazian D, Correa-Giannella ML, *et al.* Impact of type 1 diabetes mellitus and celiac disease on nutrition and quality of life. *Nutr Diabetes* 2017;7:e239-9.
- Rubin RR, Peyrot M. Quality of life and diabetes. *Diabetes Metab Res Rev* 1999;15:205-18.
- Nachman F, Mauriño E, Vázquez H, Sfoglia C, Gonzalez A, Gonzalez V, *et al.* Quality of life in celiac disease patients: Prospective analysis on the importance of clinical severity at diagnosis and the impact of treatment. *Dig Liver Dis* 2009;41:15-25.
- Mahmud FH, Clarke ABM, Joachim KC, Assor E, McDonald C, Saibil F, *et al.* Screening and treatment outcomes in adults and children with type 1 diabetes and asymptomatic celiac disease: The CD-DIET study. *Diabetes Care* 2020;43:1553-6.
- Erickson K, Freeborn D, Roper SO, Mandleco B, Anderson A, Dyches T. Parent experiences raising young people with type 1 diabetes and celiac disease. *J Pediatr Nur* 2015;30:353-63.
- Mahmud FH, De Melo EN, Noordin K, Assor E, Sahota K, Davies-Shaw J, *et al.* The celiac disease and diabetes-dietary intervention and evaluation trial (CD-DIET) protocol: A randomised controlled study to evaluate treatment of asymptomatic coeliac disease in type 1 diabetes. *BMJ Open* 2015;5:e008097-7.
- Bakker SF, Pouwer F, Tushuizen ME, Hoogma RP, Mulder CJ, Simsek S. Compromised quality of life in patients with both type 1 diabetes mellitus and coeliac disease. *Diabetic Med* 2013;30:835-9.
- Saadah OI, Zacharin M, O'Callaghan A, Oliver MR, Catto-Smith AG. Effect of gluten-free diet and adherence on growth and diabetic control in diabetics with coeliac disease. *Arch Dis Child* 2004;89:871-6.
- Tsouka A, Mahmud FH, Marcon MA. Celiac disease alone and associated with type 1 diabetes mellitus. *J Pediatr Gastroenterol Nutr* 2015;61:297-302.
- Kakkar R, Fung A, Barker C, Foster A, Hursh BE. The experience of a gluten-free diet in children with type 1 diabetes and celiac disease. *J Can Assoc Gastroenterol* 2021;5:25-31.
- Pham-Short A, Donaghue KC, Ambler G, Phelan H, Twigg S, Craig ME. Screening for celiac disease in type 1 diabetes: A systematic review. *Pediatrics* 2015;136:e170-6.
- Schiepatti A, Maimaris S, Nicolardi ML, Alimenti E, Vernero M, Costetti M, *et al.* Determinants and trends of adherence to a gluten-free diet in adult celiac patients on a long-term follow-up (2000-2020). *Clin Gastroenterol Hepatol* 2022;20:e741-9.
- MacCulloch K, Rashid M. Factors affecting adherence to a gluten-free diet in children with celiac disease. *Paediatr Child Health* 2014;19:305-9.
- Garg A, Gupta R. Predictors of compliance to gluten-free diet in children with celiac disease. *Int Sch Res Notices* 2014;2014:248402. doi: 10.1155/2014/248402.
- Mozzillo E, Franceschi R, Di Candia F, Rosanio FM, Leonardi L, Fedi L, *et al.* The impact of gluten-free diet on growth, metabolic control and quality of life in youth with type 1 diabetes and celiac disease: A systematic review. *Diabetes Res Clin Pract* 2022;191:110032. doi: 10.1016/j.diabetes.2022.110032.
- Asrani P, Ali A, Tiwari K. Millets as an alternative diet for gluten-sensitive individuals: A critical review on nutritional components, sensitivities and popularity of wheat and millets among consumers. *Food Rev Int* 2022;1-30.
- Sabuz AA, Rana MR, Ahmed T, Molla MM, Islam N, Khan HH, *et al.* Health-promoting potential of millet: A review. *Separations* 2023;10:80.