

Original Research Article

Knowledge and practice among mothers of children with autism spectrum disorder on gluten free casein free diet in a tertiary medical centre of Bangladesh

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ABSTRACT

The gluten-free casein-free (GFCF) diet helps reduce hyperactivity and improve learning, cognitive function, and communication in children with autism spectrum disorder (ASD). Poor adherence and knowledge can lead to improper application, resulting in persistent health issues and hyperactive behavior. This study aimed to address these gaps. A descriptive cross-sectional study was conducted among 50 mothers of children with ASD on GFCF diet from August 2024 to January 2025 by purposive sampling technique. Descriptive statistics and Chi-square test were used to explore the knowledge and practices of the mothers and to identify factors affecting them using the statistical software. During the six-month study with a 100% response, 50 mothers of children with ASD (ages 18–35+) were interviewed. A significant association was found between mothers' knowledge levels and GFCF diet practices ($p < 0.001$). The study concludes that most mothers had medium knowledge and practice levels, highlighting the need for improved awareness to enhance dietary practices. Mothers' moderate knowledge of the GFCF diet highlights the need for improved practices to address maladaptive behaviors. Future guidelines should consider enablers and barriers, as adherence remains incomplete (only GF or CF). A qualitative approach is recommended.

Keywords: Autism spectrum disorders, GFCF diet, Mother's knowledge and practice

INTRODUCTION

According to the World Health Organization (WHO), autism spectrum disorder (ASD), or autism, represents a diverse group of conditions associated with difficulties in the development of the brain.¹ ASD is characterized by difficulty in communication, sensory anomalies, stereotypic and repetitive behaviors, and varying degrees of intellectual disabilities.² WHO also predicts cases of autism will occur in 1 in 160 children worldwide. The prevalence of ASDs has increased since Leo Kanner was first illustrated in 1943 and continues to rise.³ The gluten free and casein free diet (GFCF) is a nutritional intervention that is being utilized in aiding children with autism.⁴ It is founded on the principle of eliminating foods

that contain gluten (wheat, barley, and rye) and casein (cow's milk) products from an individual's daily diet. Research has shown that gluten and casein, scientifically referred to as gliadomorphins and casomorphins, are strong psychosis inducing proteins.⁵

There are many reasons that families of young children newly diagnosed with ASD choose the GFCF diet. Above all, the diet is easily accessible. It can be implemented at home and be used concurrently with other interventions.⁶ Insufficient knowledge of the GFCF diet has an impact on providing improper food for children. This is in accordance with the study which shows that a good level of mother's knowledge is in line with the implementation of a gluten-free diet and casein correctly and vice versa.^{7,8}

Improper GFCF diet practice causes health problems in autistic children such as decreased bone density.⁹ Therefore, proper knowledge regarding the GFCF diet is important for parents. According to the study social support increases someone to search information through internet sites, and facilitate consumers for a healthy diet. Therefore, lack of social support from the surrounding environment can influence parents to seek information regarding the GFCF diet.⁹ The GFCF diet is a popular intervention for children with ASD. Elimination diets are commonly used in the ASD community, in which half of families of children with ASD have tried them in an effort to improve their child's functioning or behavior.¹⁰

In addition, in Bangladesh, rare studies have been found on this issue, although the neurological problem especially autism is increasing daily. Moreover, the literature mentioned above did not reveal the details on the GFCF diet knowledge and practice of the study areas. In this case, this study tries to cover up the gaps by conducting the study in the central region of Bangladesh, which is also known for its model education area in Bangladesh. The information gained from this study would be utilized for health promotion, adoption of legislation and appropriate tools to increase knowledge and practices on GFCF diet that decrease the problematic feature of neurological disorder in Bangladesh.

METHODS

Study design

A cross-sectional study was conducted from a vast number of patients with neurodevelopment disorder attending the out-patient department of Institute of Pediatric

Neurodisorder and Autism, BSMMU, Dhaka from August 2024 to January 2025. The research subjects were taken purposively with subject criteria, namely: mothers of 3-15 years-old-children of ASD with hyperactivity, and the mother who already visited doctor or health care providers for their child's ASD treatment purpose. Based on the inclusion criteria, 50 mothers were obtained for this study. Respondents were recruited without prior invitation via a purposive sampling method to examine knowledge and practice of mothers on GFCF diet in children with ASD. On the other hand, mothers who couldn't practice GFCF diet were excluded from our study.

Data collection procedure

Two females' expert clinical psychologists who diagnosed the hyperactivity of children with ASD by the DSM-5 manual besides along with the principal investigator of the study area were conducted the interview. To calculate the anthropometric pattern, the body weight was measured using a platform beam scale. The subjects stand still over the center of the platform with body weight evenly distributed between both feet with light indoor clothing. Weight was recorded to the nearest 0.1 kg. Z-score weight-for-age (WAZ) was classified by WHO.¹¹

RESULTS

Demographic and socio-economic pattern of respondent

Table 1 shows the descriptive analysis of socio-demographic factors of the respondents. Around 54% of participants were between the ages of 26-35 and more than half (60%) came from a single family, 44% of them were from urban area.

Table 1: Respondents demographic and socio-economic profile (n=50).

Variables	N (%)	Variables	n (%)
Mother's age in years		Mother's occupation	
15-25	8 (16)	Housewife	42 (84)
26-35	27 (54)	Service holder	8 (16)
35 and above	15 (30)	Father's occupation	
Father's age in years		Day labor	2 (4)
26-35	12 (24)	Service holder	23 (46)
35 and above	38 (76)	Business	16 (32)
Mother's education		Foreigner	9 (18)
Illiterate	1 (2)	Residence	
Below SSC	8 (16)	Urban	22 (44)
SSC-HSC	20 (40)	Semi urban	17 (34)
Graduation	8 (16)	Rural	11 (22)
Above graduation	13 (26)	Family type	
Father's education		Single	30(60)
Below primary	3 (6)	Joint	20 (40)
Below SSC	7 (14)	Household income (social class)	
SSC-HSC	15 (30)	Below 12500 (lower)	3 (6)
Graduation	13 (26)	12500-21500 (middle)	9 (18)
Above graduation	12 (24)	Above 21500 (upper)	38 (76)

Continued.

Variables	N (%)	Variables	n (%)
Demographic and anthropometric pattern of children with ASD (n=50)			
Age of child in years		Mode of delivery	
3-5	24 (48)	Normal	5 (10)
6-10	24 (48)	Caesarean	45 (90)
11-15	2 (4)	Nutritional status of children	
Child's gender		Mild malnourished	9 (18)
Male	43 (86)	Moderate	4 (8)
Female	7 (14)	Severe under nutrition	2 (4)
Child's religion		Normal	25 (50)
Islam	50 (100)	Obesity	10 (20)

Mother's level of knowledge about GFCF diet

When assessing the participants' knowledge regarding, how did the participants learn or know about the GFCF diet. More than half 54% reported "doctor" remaining 46% learned about it from dietitian, relative and internet (Table 2). When asked about name of the alternative food of GFCF, rice, rich and corn, rich and nut milk, rice and coconut milk were 76.2%, 2.4%, 16.7%, 4.8% said respectively.

Table 2: Level of knowledge about GFCF diet.

Variables	Frequency (%)
Hearing about GFCF diet	
Yes	42 (84)
No	8 (16)
Alternative food of GFCF? (42)	
Rice	32 (76.2)
Rich and corn	1 (2.4)
Rich and nut milk	7 (16.7)
Rice and coconut milk	2 (4.8)
Has any mother benefited from using GFCF diet? (42)	
Yes	15 (35.7)
Do not know	27 (64.3)
Which problems were decreased? (yes=15)	
Hyperactivity decreased	14 (93.3)
Decrease allergic problem	1 (6.7)
Did you consult a health care professional? (42)	
Yes	11 (26.2)
No	31 (73.8)
Necessity of others knowing about GFCF diet	
Yes	41 (97.6)
Do not know	1 (2.4)
Mother's knowledge level on GFCF diet (50)	
No knowledge	8 (16)
Poor	19 (38)
Medium	18 (36)
Good	5 (10)

Mother's level of practice on GFCF diet

To ascertain maternal practice on GFCF diet, about three quarters (72%) mothers practice GFCF diet on their

children with ASD besides 17% followed completely and majority 83% completed only one of GFCF diet but not both together (GF or CF not both GFCF) (Table 3).

Table 3: Practice level of GFCF diet.

Variables	Frequency (%)
Did you apply GFCF diet on your children with ASD?	
Yes	36 (72)
No	14 (28)
If answer is yes, completely or not completely? (yes=36)	
Completely	6 (16.7)
Not completely	30 (83.3)
Noticed any improve in your child since starting the diet?	
Yes	29 (80.6)
Do not understand	7 (19.4)
Which type of improves? (yes=29)	
Hyper	21 (72.4)
Hyper and allergic reaction	3 (10.3)
Digestion related	1 (3.4)
Speech related	2 (6.9)
Hyper and speech related	2 (6.9)
Recommend others the practice of GFCF diet? (n=36)	
Yes	36 (72)
Do not know	14 (28)
Practice level on GFCF diet (50)	
No practice	14 (28)
Poor	8 (16)
Medium	21 (42)
Sufficient	7 (14)

Association between knowledge and practice on GFCF diet

The Chi-square test reveals that there was a strongly significant association between knowledge level about GFCF diet and diet practices ($p < 0.001$). On the other hand, there was no significant association between knowledge level and demographic and socio-economic factors of the respondents (Table 4).

Table 5: Association between knowledge and practice on GFCF diet.

Level of knowledge about GFCF diet	Apply GFCF diet on children with ASD		Total	Chi-squared statistics	
	Yes	No		χ^2 (df)	P value
No knowledge	0	8	8	25.068 (3)	0.000, p<0.001
Poor	16	3	19		
Medium	15	3	18		
Good	5	0	5		
Total	36	14	50		

DISCUSSION

This study explores the relationship between maternal knowledge and the practice of a GFCF diet for children with ASD in Bangladesh, comparing findings to prior research. It also evaluates the diet's impact on ASD symptoms and provides insights into dietary practices, socio-demographics, and knowledge dissemination.

The findings indicate that 54% of mothers were aged 26–35 years, with 76% belonging to the upper social class based on household income (>21,500 BDT, approximately 179 USD). High-income levels were critical, as prior research highlights that the costs associated with caring for children with autism are substantial due to the extensive medical and therapeutic needs.¹²

Most mothers in the study had medium education levels (SSC-HSC). While higher education is generally associated with better knowledge, respondents with high school-level education appeared adequately informed through healthcare providers and educators. This aligns with findings that parenting quality is more crucial than education level in managing children with ASD.¹³

Eighty-four percent of mothers were housewives, a trend consistent with the impact of parenting demands for children with ASD on maternal employment. Mothers prioritized caregiving, which is particularly essential for the precise and regular implementation of the GFCF diet.¹⁴

The study revealed that 48% of children with ASD were aged 6–10 years, with 86% being boys, consistent with existing literature suggesting a higher prevalence of autism among boys due to genetic factors associated with the X chromosome.^{15,16} Nutritional status, as measured by weight-for-age (WAZ), was reported as normal in most children, corroborating findings from studies conducted in Dhaka.¹⁷

The majority (54%) of mothers first learned about the GFCF diet from doctors during their child's ASD diagnosis. Other sources included child development therapists (21%) and dietitians, relatives, or the internet (25%). Comparatively, studies in Canada found cookbooks, the internet, and print media to be major sources of knowledge.¹⁸ This disparity highlights the role of doctors as key informants in the Bangladeshi context,

underlining the importance of structured and accessible healthcare communication.¹⁹

The study reported that most mothers demonstrated poor to moderate knowledge levels regarding the GFCF diet. This aligns with Mutianingrum's findings, which emphasized that better maternal knowledge correlates with accurate implementation of the diet, while inadequate knowledge may result in health issues such as reduced bone density in children with ASD.^{20,21}

Dietary practices were encouraging, with 72% of mothers implementing the GFCF diet for their children—a higher prevalence than the 50% reported in the United States.²² However, only 17% adhered to a complete GFCF diet, with most focusing on either gluten-free or casein-free practices. Limited knowledge of specific foods to avoid and low confidence in implementing the diet were identified as barriers, as noted in previous studies.²³

Impact of the GFCF diet

Children in the study had been on the GFCF diet for periods ranging from one month to over a year, with 39% following it for more than a year. Positive changes were observed in 80% of children, including improvements in hyperactivity (72.4%), allergic reactions (10.3%), digestion (3.4%), speech (6.9%), and hyper-speech behaviors (6.9%). These findings are consistent with prior research, which noted improvements in language, communication, motor coordination, social integration, and repetitive behavior among children on the GFCF diet.

To address gaps in knowledge and practices, the study recommends dietary education and training for parents, involving nutritionists or dietitians. Learning materials, such as videos, leaflets, and pocket guides, could facilitate understanding and practical implementation. Collaboration with autism schools and stakeholders could provide comprehensive support and ensure effective dissemination of information on how to select and prepare GFCF foods.

Limitations

The limitations of the study were as follows: the study was conducted on a limited number of participants; the study lacks a control group of children who are not following the GFCF diet, making it difficult to attribute observed

improvements solely to dietary changes; differences in how long children adhered to the diet and variations in dietary restrictions make it challenging to determine the long-term effectiveness of the GFCF diet; the study does not fully address the affordability and availability of GFCF foods, which could impact adherence rates, particularly among lower-income families; and while maternal knowledge was assessed, the study did not explore in depth the specific factors influencing knowledge acquisition or how different sources of information impact dietary adherence.

CONCLUSION

The study underscores that while most mothers of children with ASD demonstrate a moderate understanding and practice of the GFCF diet, there is a clear demand for more structured guidance and support. Despite their educational background and prior engagement with healthcare providers, the need for a well-defined GFCF dietary guideline remains evident. This highlights a critical opportunity to enhance awareness and promote better dietary practices to address both nutritional needs and maladaptive behaviors in children with ASD. The findings of this study provide a valuable foundation for the development and implementation of tailored GFCF diet guidelines, which could significantly improve the quality of life for children with ASD and their families.

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REFERENCES

1. World Health Organization. Autism. 2023. Available at: <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>. Accessed on 22 May 2024.
2. Lord C, Brugha TS, Charman T, Cusack J, Dumas G, Frazier T, et al. Autism spectrum disorder. Nat Rev Dis Primers. 2020;6(1):5.
3. Ratajczak HV. Theoretical aspects of autism: causes-a review. J Immunotoxicol. 2011;8:68-79.
4. White JF. Intestinal pathophysiology in autism. Exp Biol Med. 2003;228:639-49.
5. Lindström LH, Nyberg F, Terenius L, Bauer K, Besev G, Gunne LM, et al. CSF and plasma beta-casomorphin-like opioid peptides in postpartum psychosis. Am J Psychiatry. 1984;141(9):1059-66.
6. Green VA, Pituch KA, Itchon J, Choi A, O'Reilly M, Sigafos J. Internet survey of treatments used by parents of children with autism. Res Dev Disabil. 2006;27(1):70-84.
7. Cornish E. Gluten and casein free diets in autism: a study of the effects on food choice and nutrition. J Hum Nutr Diet. 2002;15(4):261-9.
8. Mutianingrum A, Herini ES. Relationship between mother's knowledge level with gluten-free, casein-free diet and nutritional status in autistic children. Gadjah Mada University. 2013. Available at: <https://repository.ugm.ac.id/122269/>. Accessed on 12 January 2025.
9. Hurwitz S. The Gluten-Free, Casein-Free Diet and Autism: Limited Return on Family Investment. J Early Interv. 2013;35(1):3-19.
10. McKinley CJ, Wright PJ. Informational social support and online health information seeking: Examining the association between factors contributing to healthy eating behavior. Comp Hum Behav. 2014;37:107-16.
11. World Health Organization. Child Growth Standards: Length/height-for-age, Weight-for-age, Weight-for-length, Weight-for-height and Body Mass Index-for-age: Methods and Development. 2006. Available at: <https://www.who.int/publications/i/item/924154693>. Accessed on 12 January 2025.
12. Mujiyanti DM. Level of Mother's Knowledge and Consumption Pattern in Children with Autism in Bogor. 2011. Available at: <http://repository.ipb.ac.id/handle/123456789/53466>. Accessed on 12 January 2025.
13. Yalastyarini EA, Permatasari C. Level of Mother's Knowledge and Mother's Compliance in Implementing GFCF (Gluten Free Casein Free) Diet Therapy in Children with Autism at the Mutiara Kasih Foundation, Trenggalek. J Nurs Pract. 2017;1(1):9-16.
14. Martiani M, Herini ES, Purba M. Parental knowledge and attitudes in relation to consumption patterns and nutritional status of autistic children. J Gizi Klin Indones. 2012;8(3):135.
15. Woods AG, Mahdavi E, Ryan JP. Treating clients with Asperger's syndrome and autism. Child Adolesc Psychiatry Ment Health. 2013;7(1):32.
16. Rahmah J, Diani N, Rachmawati K. Parental compliance on gluten free and casein free diets with the behavior of autism children. World J Nurs. 2023;3(2):16-25.
17. Akhter S, Shefa J, Hasan MM. Nutritional Status of Children with Neurodevelopment Disorders from a Tertiary Medical Center of Bangladesh. BIRDEM Med J. 2018;8(2):118-25.
18. Silvester JA, Weiten D, Graff LA, Walker JR, Duerksen DR. Is it gluten-free? Relationship between self-reported gluten-free diet adherence and knowledge of gluten content of foods. Nutrition. 2016;32(7-8):777-83.
19. Notoatmodjo S. Health research methodology. 2nd Edition. Jakarta Publishers; 2018.

20. Mutianingrum A, Herini ES. Relationship between mother's knowledge level with gluten-free, casein-free diet and nutritional status in autistic children. Gadjah Mada University. 2013. Available at: <https://repository.ugm.ac.id/122269/>. Accessed on 12 January 2025.
21. Hurwitz S. The Gluten-Free, Casein-Free Diet and Autism: Limited Return on Family Investment. *Journal of Early Intervention*, 2013;35(1):3-19.
22. Smith T, Antolovich M. Parental perceptions of supplemental interventions received by young children with autism in intensive behavior analytic treatment. *Behav Interv.* 2000;15:83-97.
23. Artino AR. Academic self-efficacy: from educational theory to instructional practice. *Perspectives Med Educ.* 2012;1(2):76-85.

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