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Unraveling the Complexity of the Gluten-Free Sugar-Free Diet: An Analysis of Parental Struggles in Providing Nutrition for Children with Special Needs

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ABSTRACT

This study aims to explore the level of parental knowledge regarding the Gluten-Free Sugar-Free (GFSF) diet and to identify the various challenges they face in its implementation for children with special needs. Using a quantitative survey approach, data were collected from 48 participating parents. Results showed that 50% of respondents had a high level of knowledge about the GFSF diet, 37.5% had moderate knowledge, and 12.5% had basic knowledge. No respondents had low knowledge. However, all respondents (100%) reported experiencing significant challenges in implementing the GFSF diet, including difficulties in accessing food ingredients, costs, and lack of practical knowledge. These findings indicate the need for more targeted interventions to support parents in overcoming these challenges, including improving the accessibility and affordability of GFSF products and providing educational programs tailored to their specific needs. This study provides important insights for developing effective strategies to support the health and well-being of children with special needs through the GFSF diet.

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Introduction

The Gluten-Free Sugar-Free (GFSF) diet is often considered beneficial for children with special needs, such as those with Autism Spectrum Disorger (ASD) or attention deficit hyperactivity disorder (ADHD). Gluten, a protein found in wheat, barley, and rye, and added sugars commonly found in processed foods can disproportionately affect these children. Foods containing gluten can form gluteomorphin, which may lead to behavioral disorders such as hyperactivity (Astuti et al., 2019). Some parents and researchers report that eliminating these substances can reduce symptoms like hyperactivity, attention deficits, and

irritability. Additionally, some studies indicate potential improvements in social interaction and communication among children with ASD following a GFSF diet.

Autism Spectrum Disorder (ASD) is a developmental disorder that manifests with various symptoms (Nurhidayah & Ramdhanie, 2021; Triana & Djayanti, 2024).The severity and symptoms of ASD in children vary (Camelia et al., 2019). ASD symptoms typically appear before the age of three, including communication difficulties, social withdrawal, and restricted, repetitive behaviors (Kauffman et al., 2017). Individuals with ASD also exhibit impairments in cognitive, motor, sensory perception, affect, or mood functions (Putri & Hapsari, 2019). Children with ASD inherently desire social interaction, but their sensory impairments often hinder their ability to engage socially (Baculu & Andri, 2019; Nyoman, 2019). This disorder can disrupt or interfere with signals from the ears, eyes, and other sensory organs (Iswari et al., 2019), leading to stigma and discrimination that they are isolated in their own world (Rukmasari & Ramadhani, 2019).

Children with autism require holistic intervention from an early age(Suprihartini et al., 2021). The prevalence of autism worldwide is currently 15-20 cases per 10,000 children or about 0.15-0.20% (Aditya, 2017). The rising prevalence of ASD and other neurological conditions in children has led parents to seek various dietary approaches to enhance the quality of life and functional capacity of their children. One widely discussed approach is the Gluten-Free Sugar-Free (GFSF) diet(Pramardika et al., 2019). This diet is claimed to reduce symptoms and improve the well-being of some children with special needs. This can be achieved by altering an individual's lifestyle to prevent the increase of sugar and gluten levels (Hasanah, 2024; Izzah et al., 2020; Kuszairi, 2017).

Diet and physical activity are contributing factors to the overweight conditions of children with ASD (Wijayanti & Mutalazimah, 2018). Food choices are crucial for children with ASD (Izzah et al., 2020; Kusumayanti & Nursanyoto, 2015). Gluten-containing foods should indeed be avoided by children with autism(Bagaskorowati & R. Sumantri, 2022). The GFSF diet, which focuses on consuming natural and minimally processed foods, not only eliminates gluten and sugar but also reduces the risk of exposure to food additives and preservatives commonly found in processed products. This cleaner diet can help alleviate the burden on the digestive and immune systems of children, who are often more vulnerable in this group. Efforts should be made to ensure optimal growth and development of children with autism through proper nutrition(Iswari et al., 2019). Foods like fresh fruits, vegetables, lean proteins, and gluten-free grains such as quinoa and rice, which are rich in nutrients, can support the overall growth and development of children. Moreover, reducing added sugars

supports better glycemic control, contributing to more consistent energy levels and stable moods.

Recent research on the GFSF diet, particularly for children with special needs like autism, yields varied findings. Some parental reports suggest behavioral improvements in their children after adopting the GFSF diet. Additionally, some studies note improvements in digestive function and energy levels following the diet. Other research finds that children on a GFSF diet often experience reduced anxiety symptoms and improved concentration, indicating the potential benefits of this diet in managing neurological conditions.

Parents of children with special needs play a crucial role in implementing the Gluten-Free Sugar-Free (GFSF) diet (Dewi & Yullyana, 2019). A mother's compliance in applying the GFCF diet is vital, encompassing her attitudes and actions in implementing the diet for ASD children, thereby reducing autism symptoms(Nurhidayah & Ramdhanie, 2021). As primary caregivers, they are responsible for ensuring that every meal prepared meets the specific dietary standards. This process often requires meticulous attention, ensuring that no food contains gluten or sugar. This adds to their workload, which they might not have anticipated when they began implementing this diet.

Furthermore, parents need to invest significant time and energy in planning and preparing daily meals. A mother's knowledge is a determinant of the success in implementing this diet (Handayani & Kurniawan, 2019; Nurhidayah & Ramdhanie, 2021). Finding suitable food items for a GFSF diet can be challenging (Shadrina et al., 2019). Mothers must conduct thorough research to understand safe food ingredients and avoid potential cross-contamination. This often involves learning about new products and cooking methods, which can be time-consuming and labor-intensive. They also need to ensure their children receive adequate nutrition while adhering to dietary restrictions, adding complexity to their tasks. This is necessary because children with ASD have absorption issues with nutritional intake (Sine & Picauly, 2018).

Additionally, parents often face resource-related challenges. The cost of GFSF-compliant food items can be higher than conventional foods, and not all families have easy access to these products. They might need to seek special suppliers or purchase items from specific stores that are not always easily accessible or affordable. Adequate food consumption in terms of quality and quantity is crucial for good nutrition (Dewi & Yullyana, 2019). Given these challenges, adequate support and understanding from the community and health professionals are essential to help them manage the diet effectively.

The purpose of this study is to explore and analyze the level of parental knowledge about the Gluten-Free Sugar-Free (GFSF) Diet and to identify the various challenges they face in implementing this diet for children with special needs. This study aims to understand how well parents grasp the concept and benefits of the GFSF diet and uncover the challenges that encompass practical, emotional, and financial aspects in its implementation. Through this research, comprehensive insights into the support and resources needed by parents to successfully implement the GFSF diet can be obtained, ultimately contributing positively to the health and well-being of children with special needs.

Method

This study employed a quantitative research design with a survey approach. The objective of this research was to explore the level of parental knowledge and the obstacles they faced in implementing the Gluten-Free Sugar-Free (GFSF) Diet for children with special needs. The sample of this study consisted of parents of children with special needs who were either currently applying or planning to apply the GFSF diet. The sample size used was 49 parents. The sample was selected purposively to ensure that participants had direct experience with the implementation of the GFSF diet for their children.

The instrument used in this study was a structured questionnaire specifically designed to measure two main aspects: 1) Parental Knowledge: This part of the questionnaire included questions about parents' understanding of the GFSF diet concept, its benefits, and other related information; 2) Challenges Faced: This section included questions regarding the various obstacles parents encounter in implementing the GFSF diet, such as difficulties in finding gluten- and sugar-free food ingredients, additional costs incurred, and resistance from children to the diet.

Data were collected through the distribution of the questionnaire to the selected sample. The questionnaire was distributed both online and directly to participants who were willing to participate in this study. Before filling out the questionnaire, participants were given explanation of the research objectives and provided with written consent to participate. The data obtained from the questionnaires were analyzed using descriptive analysis with the assistance of JASP software. This analysis aimed to provide an overview of the level of parental knowledge about the GFSF diet and to identify the challenges they face in its implementation. Descriptive statistics such as frequency, percentage, mean, and standard deviation were used to analyze the data.

This research was conducted following ethical research principles. Participants were provided with sufficient information about the research objectives, and their data confidentiality was ensured. Participants were also given the freedom to withdraw from the study at any time without any consequences.

Findings and Discussion

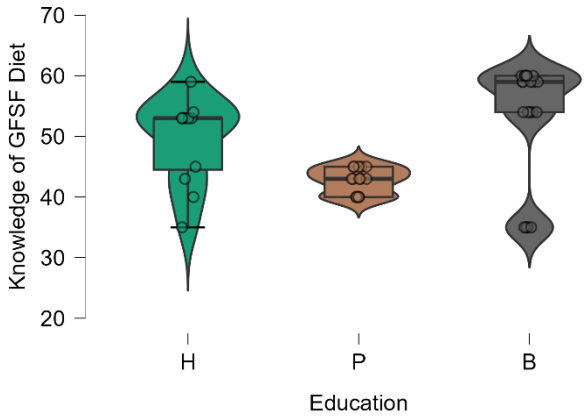
This study involved 48 respondents who provided valuable information about their understanding of the GFSF diet. To give a clear picture of parental understanding, the following table presents the frequency distribution of respondents' knowledge levels.

Table 1: Frequencies for GFSF Diet Knowledge Categories

Categories of Knowledge about the GFSF Diet		Frequency	Percent	Valid Percent	Cumulative Percent
46 - 60	High	24	50.000	50.000	50.000
36 - 45	Moderate	18	37.500	37.500	87.500
26 - 35	Basic	6	12.500	12.500	100.000
15 - 25	Low	0			
	Missing	0	0.000		
	Total	48	100.000		

Table 1 shows the frequency distribution of parents' knowledge levels regarding the Gluten-Free Sugar-Free (GFSF) diet for children with special needs. Out of 48 respondents, 24 parents (50%) had high knowledge about the GFSF diet. Meanwhile, 18 parents (37.5%) had moderate knowledge, and 6 parents (12.5%) had basic knowledge. No respondents had low knowledge or missing data, resulting in a cumulative percentage of 100%. This distribution indicates that the majority of parents have a good understanding of the GFSF diet, with half of the respondents in the high knowledge category, followed by a significant number with moderate knowledge.

Understanding parents' knowledge about the Gluten-Free Sugar-Free (GFSF) diet is crucial, especially in the context of children with special needs, such as those diagnosed with autism, as good understanding can support children's health and well-being (Zerbini et al. 2024). To evaluate how well this knowledge is among parents with various educational levels, the following graph shows the distribution of GFSF diet knowledge levels.



Graph 1: GFSF Diet Knowledge Levels by Parental Education

The violin plot in Graph 1 shows the distribution of GFSF diet knowledge levels among parents with different educational levels: high school/equivalent, diploma/bachelor's degree, and postgraduate. The knowledge distribution can be classified into four categories: low (15-25), basic (26-35), moderate (36-45), and high (46-60). In the group of parents with high school/equivalent education, the GFSF diet knowledge distribution shows significant variation, with values ranging from approximately 30 to 60. Most respondents in this group fall into the high category (46-60) with a median value of around 50, indicating that most parents with high school/equivalent education have high knowledge about the GFSF diet.

For the group of parents with diploma/bachelor's degrees, the distribution of GFSF diet knowledge also varies but is more centered around lower ranges. Knowledge values range from approximately 20 to 70, with a median around 40. Most respondents in this group fall into the moderate category (36-45), with some in the basic (26-35) and high (46-60) categories. This indicates that knowledge about the GFSF diet among parents with diploma/bachelor's degrees is lower compared to the high school/equivalent group.

The group of parents with postgraduate education shows the most focused distribution of GFSF diet knowledge, with a narrow range of values between approximately 40 and 55. The median value for this group is around 45, placing most respondents in the moderate (36-45) and high (46-60) categories. This indicates that knowledge about the GFSF diet among parents with postgraduate education tends to be uniform and relatively higher compared to the diploma/bachelor's group but lower compared to the high school/equivalent group.

Overall, this graph indicates that education level influences the variation and distribution of GFSF diet knowledge among parents. The high school/equivalent group shows greater variation in their knowledge, with most in the high category. The diploma/bachelor's group shows lower knowledge, with most in the moderate category. Meanwhile, the

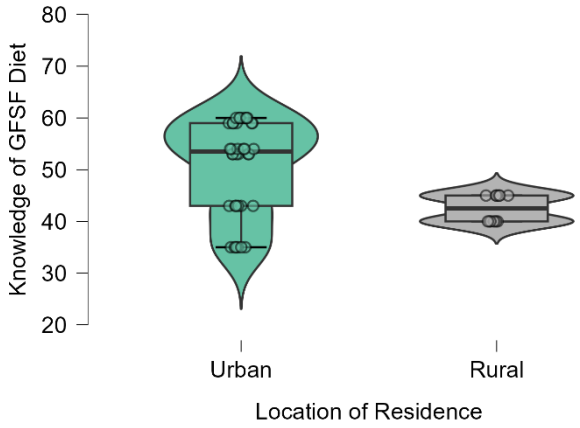
postgraduate group has more uniform knowledge, with most in the moderate and high categories. To complement understanding of the factors affecting knowledge about this diet, the following graph shows the distribution of GFSF diet knowledge levels among parents with different employment statuses.

Graph 2: GFSF Diet Knowledge Levels by Parental Employment Status

The violin plot in Graph 2 shows the distribution of GFSF diet knowledge levels among parents with different employment statuses: unemployed, full-time employed, retired, and others. This knowledge distribution shows significant variation among these groups. In the group of unemployed parents, the GFSF diet knowledge distribution is relatively narrow, with values ranging from approximately 30 to 50. The median value is around 40, indicating that most respondents in this group have moderate knowledge (36-45) about the GFSF diet. Parents in this group might have more time to access information and learn from available sources.

The group of full-time employed parents shows a more varied distribution of GFSF diet knowledge, with values ranging from approximately 35 to 55. The median value is around 45, placing most respondents in the moderate to high categories (46-60). Parents in this group might be aware of the benefits of the GFSF diet, but time and energy constraints to access deeper information might affect their knowledge levels. The retired group has a broader distribution of knowledge, with values ranging from approximately 30 to 60. The median value is around 50, indicating that most retired respondents have high knowledge about the GFSF diet. Parents in this group might have more time to seek information and implement new practices, as well as more life experience to understand the importance of specific diets.

The group of parents categorized as "Others" shows the most varied distribution, with values ranging from approximately 25 to 60. The median value is around 45, placing most respondents in the moderate to high categories. These findings indicate that employment status influences the level of parental knowledge about the GFSF diet.



Graph 3: GFSF Diet Knowledge Levels by Parental Residence

The violin plot in Graph 3 shows the distribution of GFSF diet knowledge levels among parents based on their place of residence: urban and rural. In the group of parents living in urban areas, the GFSF diet knowledge distribution shows significant variation, with values ranging from approximately 30 to 70. The median value is around 50, indicating that most respondents in this group have high knowledge about the GFSF diet. This distribution shows that urban parents tend to have better access to information about the GFSF diet, possibly due to the availability of more and easily accessible information resources.

For the group of parents living in rural areas, the distribution of GFSF diet knowledge is narrower, with values ranging from approximately 40 to 60. The median value is around 45, placing most respondents in the moderate to high categories. This narrower variation indicates that knowledge about the GFSF diet in rural areas tends to be more homogeneous, although slightly lower compared to the urban group.

Albert Bandura's Social Learning Theory emphasizes that individuals learn through observation, imitation, and modelling (Bandura, 2021). In this context, parents with high knowledge about the GFSF diet likely acquired information through various sources, such as healthcare professionals, scientific literature, or support communities. This knowledge is then internalized and applied in their children's daily diet. An individual's knowledge and beliefs about health influence their health actions. Research shows that 50% of respondents have high knowledge about the GFSF diet, reflecting their belief in the benefits of this diet for their children's health. They may believe that the GFSF diet can reduce autism symptoms or

improve their children's quality of life, motivating them to seek and apply information about the diet. Despite high knowledge about the benefits of the GFSF diet, implementing it is not easy and faces significant obstacles, as shown by the findings in Table 2.

Table 2: *Frequencies for Hambatan Diet GFSF*

GFSF Diet Challenge Category	Frequency	Percent	Valid Percent	Cumulative Percent
Very High Challenges	48	100.000	100.000	100.000
Missing	0	0.000		
Total	48	100.000		

Table 2 shows that all parents (100%) reported experiencing very high challenges in implementing the GFSF diet. No respondents reported challenges in other categories or no challenges at all. The valid percentage indicates that all collected data are valid, with no missing data. Therefore, the cumulative percentage also reaches 100%, indicating that every respondent experiences very high challenges in implementing this diet. These results suggest significant obstacles faced by parents in applying the GFSF diet for their children, which may include factors such as food availability, cost, and knowledge about the diet.

Table 3: Types of GFSF Diet Challenges

Types of GFSF Diet Challenges	Percent
Difficulty finding suitable GFSF products in local stores	50%
Feeling that product labels are often not informative enough about gluten, casein, and sugar content	62%
Feeling that the cost of GFSF products is too expensive compared to regular products	100%
Lack of clear and easily understandable information about the benefits of the GFSF diet	37%
Uncertainty about which information about the GFSF diet can be trusted	50%
Often confused about which components to avoid in the GFSF diet	37%
Feeling that there are not enough resources or professional assistance available to help implement the GFSF diet	62%
Feeling that the general public does not understand the needs of special diets like the GFSF diet	50%
Difficulty explaining to others why their child needs to follow the GFSF diet	62%
Feeling isolated due to a lack of support from family or friends regarding this diet choice	50%
Preparing GFSF meals feels very time-consuming	50%
Feeling that there is not enough variety in GFSF foods that can be given to their child	50%
Concerned that the GFSF diet may not meet their child’s overall nutritional needs	62%
Worried about the long-term effects of the GFSF diet on their child’s health	50%

Types of GFSF Diet Challenges	Percent
Feeling stressed because they always have to be vigilant about what their child eats	50%

Table 3 reveals the various challenges parents face in implementing the Gluten-Free Sugar-Free (GFSF) diet for their children. One of the biggest challenges is the cost, considered too high compared to regular products, reported by 100% of respondents. Additionally, 62% of parents feel that GFSF products are often too expensive, product labels are not informative enough about gluten, casein, and sugar content, and they lack resources or professional assistance to help implement the diet. Concerns about the long-term effects of the GFSF diet and meeting their child's nutritional needs are also major worries for 62% of respondents. Meanwhile, 50% of parents have difficulty finding suitable products in local stores, are uncertain about the reliability of available information, are confused about which components to avoid, and feel isolated due to a lack of support from family or friends. Other significant challenges include explaining the need for the diet to others and feeling stressed about constantly monitoring their child's diet, also reported by 50% of respondents. Additionally, 37% of parents express a lack of clear information about the diet's benefits and confusion about which components to avoid. This study shows that while the GFSF diet can be very beneficial, the practical and emotional challenges faced by parents need more attention to ensure effective implementation and support their children's well-being.

Accessibility (availability of products) and affordability (reasonable prices) are key factors in adopting a healthy diet (Gorgitano & Sodano, 2019). The GFSF diet may be difficult to implement due to limited access to gluten- and sugar-free products and higher costs compared to regular products. These barriers can make it difficult for parents to consistently implement the diet. Additionally, individual perceptions of barriers and benefits influence their decision to adopt health actions. The very high challenges in implementing the GFSF diet may reflect parents' perceptions of difficulties and their inability to manage the diet effectively(Demirkesen & Ozkaya, 2022). Furthermore, if parents do not see immediate or long-term benefits of the GFSF diet, they may be less motivated to overcome these barriers.

Conclusion and Recommendations

This study reveals that the majority of parents have moderate to high knowledge about the Gluten-Free Sugar-Free (GFSF) diet for children with special needs, with 50% of respondents having high knowledge and 37.5% having moderate knowledge. Despite this, all respondents reported very high challenges in implementing this diet. These challenges

include difficulties in accessing gluten- and sugar-free food ingredients, higher costs, and a lack of practical knowledge to manage the GFSF diet effectively. These findings indicate significant obstacles faced by parents in their efforts to improve the health and well-being of their children through the GFSF diet. Based on the findings of this study, it is important to enhance the accessibility and affordability of GFSF products and provide comprehensive educational programs and social support for parents. Assistance from health professionals such as nutritionists and doctors is also crucial to provide specific guidance and help overcome the challenges in implementing the GFSF diet.

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