**ISSN- 0301-1216**
*Indian J. Prev. Soc. Med. Vol. 55, No. 4, 2024*

# Knowledge, Attitudes, and Practices of Caregivers on Dietary Adherence and Medical Food Usage: A Study on the Impact of Education

Garvita Kharbanda[1], Sirimavo Nair[2], Priyanshu Mathur[3]

## ABSTRACT

**Objective:** To assess the knowledge, attitudes and practices of caregivers in Rajasthan in relation to the dietary adherence and medical food usage of children living with Aminoacidopathies. **Subjects and Methods:** Questionnaires with multiple-choice questions were distributed to 44 caregivers of children between 6 months to 12 years attending the Centre of Rare diseases. The independent "t" test, Pearson's correlation and stepwise linear regression were used to assess the associations between the variables in question and $p \leq 0.05$ was accepted as statistically significant. **Results:** Of the 44 participants, 26.4 (60%) were between 20 and 40 years of age with a high school diploma or higher degree and had between 2 and 3 children. The mean knowledge score was 1.16, the mean attitude score was 2.39 and the mean practice score was 2.73. Major weaknesses were reported in Knowledge level of the caregivers. Dietary adherence was significantly higher among caregivers with higher education ($p<0.01$). There is a significant positive relationship between caregiver education levels and dietary adherence ($r=0.62$, $p<0.01$). In addition, knowledge, attitude and level of education were positively and significantly associated with practices ($p<0.005$). **Conclusions:** Our study showed that caregivers with higher education had good knowledge and practice in relation to the dietary adherence and medical food usage of preschool children. Caregivers with higher education had better knowledge and practices. These findings underscore the importance of education in improving caregiver practices and, consequently, patient outcomes.

**Keywords:** Caregivers, Knowledge, Attitudes, Practices, Dietary Adherence, Medical Food Usage, Education, Inherited Metabolic Disorders

## Introduction

Aminoacidopathies are a group of rare, inherited metabolic disorders that result from defective amino acid metabolism. Conditions such as Phenylketonuria (PKU), Maple Syrup Urine Disease (MSUD), and Homocystinuria (HCU) fall under this category, each leading to the accumulation of toxic aminoacids and their byproducts, causing a range of health issues if untreated. The primary treatment for these disorders is strict dietary management, which involves the restriction of certain amino acids and supplementation with specialized medical foods. Early intervention and dietary adherence are essential in mitigating the severe neurological, developmental, and metabolic consequences associated with these disorders.[1]

However, effective dietary management for aminoacidopathies presents unique challenges, particularly in resource-limited regions like Rajasthan, India. Access to medical foods, dietary supplements, and specialized health care is often constrained, placing the burden of care heavily on caregivers.

---

1. Research Scholar, Department of Foods and Nutrition, Faculty of Family and Community Sciences, The Maharaja Sayajirao University of Baroda, Vadodara, Gujarat; **Email:** garvita.k-fnphd@msubaroda.ac.in; Mobile 9672444484
2. Professor, Department of Foods and Nutrition, Faculty of Family and Community Sciences, The Maharaja Sayajirao University of Baroda, Vadodara, Gujarat. **Email:** sirinair@gmail.com; Mobile 9898608039
3. Associate Professor, In-Charge Nodal Centre for Rare Disease, JK Lone Hospital, SMS Medical College, Jaipur; **Email -** priyanshu82@gmail.com; Mobile- 9982451490

**Corresponding Address:** Garvita Kharbanda, Ph.D. Scholar, Department of Foods & Nutrition, Faculty of Family and Community Sciences, The Maharaja Sayajirao University of Gujarat, Vadodara, Gujarat, **Email: garvita.k-fnphd@msubaroda.ac.in**

| Submission | 30.10.2024 | Revision | 16.11.2024 | Accepted | 10.12.2024 | Printing | 31.12.2024 |
|---|---|---|---|---|---|---|---|

***Prior Publication*: Nil*; Source of Funding:* Nil; *Conflicts of Interest*: None, *Article #534/713***

As caregivers are primarily responsible for managing the child's dietary restrictions and monitoring their health, their knowledge, attitudes, and practices (KAP) play a crucial role in determining treatment success. A caregiver's ability to understand the dietary needs of their child and comply with prescribed dietary regimens is critical to ensuring metabolic control and preventing life-threatening complications.[2]

Dietary management of aminoacidopathies requires precise control of amino acid intake to prevent the accumulation of toxic substances. For example, in PKU, the amino acid phenylalanine must be restricted because the enzyme phenylalanine hydroxylase is deficient or absent, leading to elevated phenylalanine levels that can result in irreversible neurological damage if not managed properly.[3] The existing body of literature highlights the critical role of care giver KAP in managing rare metabolic disorders. Studies on PKU, for instance, have demonstrated that caregivers with higher levels of knowledge and positive attitudes toward the importance of diet are more likely to adhere to dietary guidelines and achieve better metabolic control.[4] Rovelli et al.[5] emphasized the importance of caregiver education in improving adherence, suggesting that targeted interventions aimed at increasing caregiver knowledge can lead to better outcomes for children with aminoacidopathies.

Similarly, in MSUD, there is a defect in the enzymes responsible for breaking down branched-chain amino acids, such as leucine, isoleucine, and valine. An accumulation of these amino acids can cause metabolic crises, including severe neurological impairment and death.[6] In Homocystinuria, excess homocysteine accumulates due to defects in methionine metabolism, leading to vascular and neurological complications.[8]

The successful management of these disorders relies heavily on strict adherence to a low-protein diet and the use of medical foods, which are specially formulated to provide the necessary nutrition without the harmful amino acids. These medical foods are essential for growth and development in children with aminoacidopathies but are often expensive, difficult to access, and require careful preparation. For care givers, particularly in rural or under-resourced areas, these challenges are compounded by limited access to healthcare professionals trained in metabolic disorders and dietary counseling. Additionally, economic barriers can make it difficult for families to afford these specialized foods, leading to poor dietary adherence and an increased risk of metabolic crises.[4]

Caregivers are integral to the successful management of children with amino-acidopathies, as they are responsible for ensuring that dietary restrictions are followed and medical foods are administered correctly. Research has shown that caregiver knowledge of metabolic disorders significantly influences dietary adherence and treatment outcomes.[5] Without a comprehensive understanding of the disorder, care givers may struggle to maintain the child's diet, resulting in metabolic imbalances that can lead to serious health complications.

Caregiver attitudes towards dietary management also play an important role in determining compliance. A caregiver who perceives the dietary restrictions as overly burden some or difficult to implement may be less likely to adhere to the prescribed regimen, leading to poorer metabolic control.[6] In contrast, caregivers who understand the importance of dietary adherence and are motivated to follow the regimen tend to exhibit better compliance, resulting in improved outcomes for the child.[8] Positive attitudes toward dietary management are often influenced by caregiver education, social support, and access to healthcare resources.[9]

In addition to knowledge and attitudes, caregiver practices, such as meal planning, administering medical foods, and monitoring the child's health, is essential for effective management. Caregivers with higher levels of education may be better equipped to understand and implement complex dietary plans, while those with limited education or resources may face greater challenges in maintaining strict dietary adherence.[10] A lack of practical skills in food preparation and difficulty in accessing appropriate medical food scan further hinder adherence.[11]

However, the challenges faced by caregivers in resource-limited settings have not been as extensively explored. In regions like Rajasthan, where access to healthcare resources, specialized metabolic foods, and trained professionals may be limited, caregivers face additional barriers that can negatively impact dietary adherence. Socioeconomic factors,

educational background, and access to information all play a role in shaping caregiver practices and, by extension, treatment outcomes.[12]

Understanding the specific challenges faced by caregivers in such settings is essential for developing effective interventions aimed at improving dietary adherence. By assessing caregiver KAP in relation to the dietary management of aminoacidopathies, this study aims to identify gaps in knowledge, areas where attitudes can be improved, and practices that may need reinforcement. The findings of this study can help inform the development of educational programs and support systems tailored to the unique needs of caregivers in resource-limited regions, ultimately improving patient outcomes.

Given the crucial role that caregivers play in managing aminoacidopathies, this study seeks to evaluate the KAP of caregivers in Rajasthan with regard to dietary adherence and the use of medical foods. The objectives are to [a] understand the level of education and [b] to understand the impact of education on KAP. By identifying the factors that influence caregiver knowledge, attitudes, and practices, this research aims to provide valuable insights into the barriers faced by caregivers and the support they require managing these complex metabolic disorders effectively. Furthermore, the study will explore the relationship between caregiver education levels and dietary adherence, with the goal of determining whether educational interventions can improve outcomes for children with aminoacidopathies.

Specifically, this study will examine the extent to which caregiver education, knowledge of the disorder, and attitudes toward dietary management influence the practices of meal planning, medical food administration, and monitoring of metabolic health. The study will employ statistical analyses to assess these relationships and identify areas where intervention scan be targeted to improve adherence.

By highlighting the critical role of caregiver KAP in the management of Aminoacidopathies, this research underscores the importance of education and support in achieving successful dietary adherence. The findings from this study can inform future policy and program development, with the ultimate aim of improving health outcomes for children living with rare metabolic disorders in resource-limited settings.

## Subjects and Methods

This was a cross-sectional study conducted using self-administered questionnaire on a sample of 44 caregivers from Rajasthan. The study took place at the Centre of Rare Disease, Jaipur, Rajasthan. The inclusion criterion was being a caregiver for a child with amino acid disorder (between 6 months to 12 years of age). A total of 60 caregivers were enrolled in the study, out of which only 44 caregivers consented to participate for the study. The questionnaire used for the study was developed and written both in English and Hindi. It included questions based on assessing the knowledge, attitudes and practices of caregivers towards the dietary adherence, medical food us age of the children as well as some demographic questions. The questionnaire was piloted before the start of the study. Some questions were then reworded to improve clarity. The responses were then rated based on the scoring. A KAP (Knowledge, Attitudes, and Practices) questionnaire was administered to participating caregivers to assess their understanding and management of dietary adherence and medical food usage for children diagnosed with in born Errors of Metabolism (IEMs). The questionnaire consisted of General questions based on Gender, Diagnosis of the child, education level and three key sections: ***Knowledge, Attitudes,*** and ***Practices.*** In the knowledge section, caregivers' general understanding of dietary restrictions and their specific knowledge of medical food usage were evaluated, highlighting the importance of proper nutrition in managing aminoacidopathies. Attitudes were assessed based on caregivers' perceptions of these verities of their child's condition and their beliefs regarding the effectiveness of dietary interventions. This section aimed to gauge caregivers' emotional engagement and motivation to adhere to dietary management. Practices were evaluated by focusing on caregivers' behaviors in managing their child's condition, such as adherence to dietary plans, consistent use of medical foods, regular medical check-ups, medication adherence, and preparedness for metabolic crises. Responses to the questionnaire were recorded using ordinal scales to measure the quality of caregivers' knowledge, attitudes, and practices. Dietary adherence, medical food usage, engagement with health care specialist, crisis preparedness was measured on a

scale from 1 (*Always*) to 4 (*Never*). Knowledge, Attitude and Practices were rated on a four-point scale—1 (*Poor)*, 2 (*Fair)*, 3 (*Good)*, and 4 (*Excellent)*—based on the number of correct answers.

These structured scales provided a clear way to evaluate caregiver performance and identify areas for potential improvement in their management of IEMs. Data were analyzed using descriptive statistics to summarize caregiver demographics and KAP scores. Frequencies, means, and standard deviations were calculated for continuous variables, while categorical variables were expressed as percentages. Pearson correlation coefficients were computed to examine the relationships between education levels and KAP variables. The key area of focus was the correlation between caregiver education levels and dietary adherence. In addition, independent t-tests were performed to assess differences in KAP scores between groups based on education levels. Stepwise line a regression was used to evaluate the predictive power of education, knowledge, and attitudes on dietary adherence.

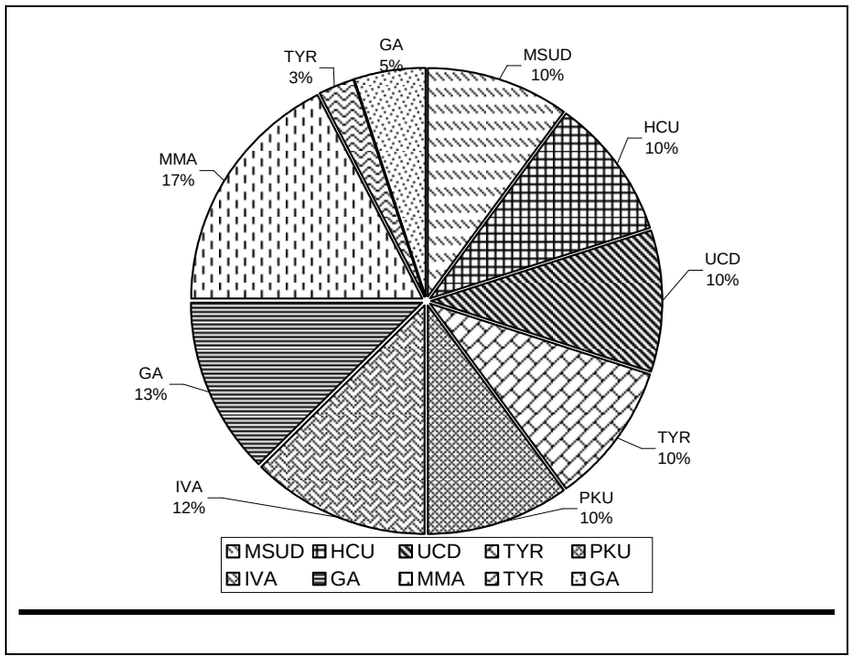

A significance level of $p \leq 0.05$ was considered statistically significant for all analyses. All analyses were conducted using SPSS version 26.0 (IBM Corp., Armonk, NY, USA). Results were presented with appropriate graphical and tabular summaries, highlighting key findings and their implications for care giver practices and patient outcomes.

**Results**

Out of total subject (n=44), 44 completed the study. These results mentioned are of surviving 44 who are considered as Population cohort (PC) or Universal sample. All 44 questionnaires were completed and thereby giving a response rate of 100%. Out of 44 subjects with Amino acid disorders, Methylmalonic Acidemia (MMA) being the most prevalent at 17.5%. Both Glutaric Acidemia (GA) and Isovaleric Acidemia (IVA) each represent 12.5%, while Tyrosinemia (TYR) accounts for 15% combined across two segments. Homocystinuria (HCU), Maple Syrup Urine Disease (MSUD), Urea Cycle Disorder (UCD), and Phenylketonuria (PKU) each make up 10% of the cases. Among the caregiver subjects**,** 52.5% are females and 47.5% males. 37.5% of the caregivers hold high school diplomas, 30% with graduate degrees, and 30% with postgraduate qualifications and above. A majority 72.5% are parents, with guardians making up 27.5%, highlighting a diverse and capable support system for managing these disorders effectively.

**Knowledge:** The aim was to capture the operational knowledge level of the caregivers based on their regular practices. Knowledge was assessed in two categories: general knowledge about the disorder and specific knowledge regarding dietary management and medical food usage. Our observation was, the scores pertaining to general knowledge were, 35% of the caregivers had excellent general knowledge while 50% had good and fair knowledge. 75% of those with a higher degree demonstrate excellent specific knowledge of dietary restrictions and the importance of adherence. The overall mean knowledge score was 1.16 out of 4 point scale. Mothers had significantly better overall knowledge scores than fathers and other caregivers ($p<0.001$). In addition, participants with a university educational level or higher had significantly better overall knowledge scores than less educated participants ($p<0.003$). Additionally, mothers of children aged 7 months to 4years had significantly better knowledge about dietary management ($p=0.000$).

**Percentage distribution of diagnosis among patients**




**Attitudes:** The overall mean attitude score was 2.39 out of 4 point scales. A majority (85%) of caregivers with higher education exhibited positive attitudes toward strict dietary adherence, perceiving it as critical to avoiding metabolic crises. In contrary, 40% of caregivers with high school education displayed a more lenient attitude, expressing difficulty in maintaining strict dietary practices due to limited nutritional knowledge, complexity of the Dietary Management, Economic Constraints, Time and Resource limitation, Family and Social Support and Health Literacy barriers. The more educated participants had a significantly better appreciation of the importance of dietary adherence ($p=0.035$). Regular engagement with healthcare specialists was a critical factor in dietary adherence to have a deeper understanding on the population perspective. Caregivers who reported "always" attending specialist consultations had higher dietary adherence and better knowledge scores. 45% of caregivers reported always attending specialist consultations, and this group had higher adherence and crisis preparedness scores compared to those who consulted specialists "rarely" or "never" ($p<0.05$).

**Practices:** Caregivers with a higher level of education also had a better understanding and higher usage of medical foods, with 70% reporting consistent medical food usage. This contrasted with only 50% of caregivers with lower education levels who were able to use medical foods consistently ($p<0.05$). The study further analyzed the readiness of the parental population in order to gather information on the family support. Caregivers with high family support were more likely to adhere to dietary recommendations and seek regular check-ups ($p<0.05$). Only 42.5% of caregivers reported being prepared to handle metabolic crises, with preparedness being significantly higher among those with better education ($p<0.01$). Families with high levels of crisis preparedness were also more likely to adhere to dietary restrictions. 60% of caregivers with higher degree were knowledgeable about emergency protocols, compared to only 30% of high school graduates ($p<0.05$).

This gap indicates a need for improved education on crisis management. The overall mean practice score was 2.73 out of 4 point scales. The education level of the caregiver had a significant effect on their practices (p=0.017). Participants who did not complete a high school education had lower mean practice scores than those with a higher education. The mean dietary adherence score for the entire sample was 2.5, indicating moderate adherence. However, adherence was significantly higher among caregivers with higher education, with those holding a college degree scoring an average of 3.0, compared to 1.5 among high school graduates (p<0.01).

## Factors associated with good practices

Education, attitude and knowledge were positively and significantly related to the practices of the caregivers regarding the dietary adherence and medical food usage of children with Amino acid disorders. Having a university degree or higher and having a positive attitude had the strongest association with dietary adherence (r=0.62, p<0.01). Family support correlated with regular check-ups (r=0.52, p<0.05). Specialist consultation is correlated with higher dietary adherence and crisis preparedness (r=0.49, p<0.05). Crisis preparedness has a positive correlation with education level (r=0.47, p<0.01). Additionally, a chi-square test indicated a significant association between family support and regular check-ups ($\chi^2$=12.34, p<0.05), as well as specialist consultations and knowledge of emergency protocols ($\chi^2$=14.76, p<0.01).

**Table-1:** Socio-demographic profile of the caregivers (N=44)

| Category | Subcategory | No. | % |
|---|---|---|---|
| **Gender of Caregiver** | Male | 21 | 47.5 |
| | Female | 23 | 52.5 |
| **Relationship** | Father | 14 | 32.5 |
| | Mother | 18 | 40.0 |
| | Guardian | 12 | 27.5 |
| **Education** | High School | 13 | 30.0 |
| | Graduate | 16 | 37.5 |
| | Postgraduate | 13 | 30.0 |
| **Residence Area** | Rural | 28 | 62.5 |
| | Urban | 16 | 37.5 |
| **Socio-economic Status** | High | 19 | 42.5 |
| | Middle | 19 | 42.5 |
| | Low | 7 | 15.0 |
| **Occupation** | Engineer | 11 | 25.0 |
| | Doctor | 3 | 7.5 |
| | Teacher | 12 | 27.5 |
| | Others | 18 | 40.0 |
| **Family Support** | High | 20 | 45.0 |
| | Moderate | 12 | 27.5 |
| | Low | 5 | 11.0 |
| **Regular Check-ups** | Always | 20 | 45.0 |
| | Sometimes | 9 | 20.0 |
| | Often | 15 | 35.0 |
| | Never | 0 | 0.0 |
| **Specialist Consultations** | Always | 29 | 65.0 |
| | Sometimes | 10 | 22.5 |
| | Never | 6 | 13.0 |
| **Crisis Preparedness** | Yes | 19 | 42.5 |
| | No | 25 | 57.5 |
| **Emergency Protocol Knowledge** | Yes | 19 | 42.5 |
| | No | 25 | 57.5 |

**Table- 2:** Comparison between groups

| Parameter | Comparison | Group -1 Mean ± SD | Group-2 Mean ± SD | 't' value | 'p' value | Significance |
|---|---|---|---|---|---|---|
| **Knowledge** | Mothers vs. Fathers/ Other Caregivers | 2.1 ± 0.5 | 1.5 ± 0.4 | 4.23 | < 0.001 | Highly Significant |
| | University Education vs. Less Educated | 1.8 ± 0.6 | 0.9 ± 0.5 | 5.67 | < 0.003 | Highly Significant |
| | Mothers of 7m-4y Children vs. Others | 3.0 ± 0.3 | 2.0 ± 0.5 | 6.45 | 0 | Highly Significant |
| **Attitude** | Higher Education vs. School Education | 3.2 ± 0.4 | 2.5 ± 0.5 | 3.12 | 0.035 | Significant |
| | Always Attend Consultations vs. Rarely/ Never | 2.8 ± 0.6 | 1.5 ± 0.4 | 2.89 | < 0.05 | Significant |
| **Practices** | Higher Education vs. Lower Education | 3.1 ± 0.5 | 2.1 ± 0.4 | 3.45 | < 0.05 | Significant |
| | Crisis Preparedness: Higher Degree vs. High School / Graduates | 3.5 ± 0.4 | 2.0 ± 0.6 | 4.01 | < 0.01 | Highly Significant |
| | Dietary Adherence: College Degree vs. High School Graduates | 3.0 ± 0.5 | 1.5 ± 0.4 | 5.13 | < 0.01 | Highly Significant |

## Discussion

The findings of this study underscore the critical role of caregiver education, support systems, and health care engagement in the management of children with amino acid disorders. A population cohort of 44 subjects with completed questionnaires enabled a comprehensive analysis of caregivers' knowledge, attitudes, and practices (KAP), particularly in relation to dietary management and crisis preparedness, which are paramount for these rare metabolic conditions. The results highlight a clear association between caregiver education levels and overall knowledge regarding amino acid disorders, particularly with regard to dietary management and the role of medical foods. Caregivers with university-level education or higher demonstrated superior knowledge of both general aspects of the disorders and the specific nuances of medical food usage. This disparity suggests that a caregiver's educational background significantly influences their ability to comprehend the metabolic complexities and management protocols involved. Notably, the superior knowledge observed among mothers of younger children (aged 7 months to 4 years) suggests an increased engagement with day-to-day care in this age group. The relationship between education and knowledge under scores the need for targeted educational interventions, particularly for caregivers with lower educational backgrounds, who may benefit from enhanced resources to improve their understanding of the strict dietary requirements, associated with amino acid disorders. The importance of this knowledge is magnified by the role that dietary management plays in preventing metabolic decompensation in disorders such as MMA, GA, and TYR. The study's findings on caregiver attitudes toward dietary adherence reflect the influence of education and engagement with healthcare professionals. Higher education levels were associated with more positive attitudes toward strict dietary practices, which are essential for mitigating the risk of metabolic crises. Caregivers with university-level education exhibited a strong commitment to maintaining dietary restrictions, perceiving them as critical to the child's metabolic stability. In contrast, caregivers with high school education or lower exhibited more lenient attitudes toward dietary adherence, often citing difficulties in maintaining the strict regimen required. This divergence suggests that attitudes are strongly shaped by a caregiver's understanding of the long-term implications of poor dietary control, emphasizing the need for tailored interventions that address both educational and psychological barriers to strict adherence. The

study also highlights the importance of regular specialist consultations in shaping positive attitudes toward dietary adherence.

Caregivers who engaged consistently with healthcare specialists were more likely to understand the importance of adherence and demonstrate a commitment to managing the child's metabolic disorder. This aligns with existing literature that emphasizes the role of healthcare providers in reinforcing adherence behaviors in patients with chronic metabolic conditions. Dietary practices among caregivers varied significantly according to their educational background, with those holding higher education levels demonstrating superior adherence to dietary restrictions and medical food usage. This is a critical finding, given the role that dietary management plays in the long-term prognosis of children with amino acid disorders. The moderate adherence scores observed across the sample highlight the challenges faced by caregivers in maintaining strict dietary protocols, particularly in the context of conditions such as Homocystinuria and Urea Cycle Disorders, where even minor dietary deviation scan result insignificant metabolic disturbances. The higher adherence scores among caregivers with university-level education suggest that a deeper understanding of the disease mechanisms and dietary interventions contributes to more effective management practices. In contrast, caregivers with lower educational attainment were less likely to adhere to prescribed dietary regimens, indicating the need for targeted educational programs that enhance practical dietary management skills. The study also points to the critical role of family support and health care engagement in influencing caregiver practices. Caregivers who reported strong family support systems were more likely to adhere to dietary recommendations and seek regular medical check-ups. This finding is consistent with previous research that underscores the importance of a robust social support network in managing chronic metabolic conditions. Moreover, caregivers who engaged regularly with healthcare specialists exhibited higher levels of preparedness for metabolic crises, highlighting the importance of ongoing professional support in crisis management. Crisis preparedness emerged as a significant area of concern, with only a portion of caregivers reporting confidence in handling metabolic crises. This finding is particularly relevant given the acute metabolic in stability associated with amino acid disorders such as Maple Syrup Urine Disease (MSUD) and Phenylketonuria (PKU), where delayed intervention can result in irreversible neurological damage. Caregivers with higher education levels demonstrated superior crisis preparedness, particularly in their knowledge of emergency protocols and their ability to manage acute metabolic events. The correlation between education and crisis preparedness underscores the need for comprehensive crisis management training for caregivers, particularly those with lower educational backgrounds. Given the potential severity of metabolic crises in disorders like MMA and Urea Cycle Disorders, targeted educational interventions that focus on emergency preparedness and rapid response protocols could significantly improve outcomes for affected children.

The findings from this study provide several important insights into the current state of caregiver knowledge, attitudes, and practices in managing child healthcare. The limited knowledge observed inthis study, particularly around emergency protocol and crisis preparedness, underscores the need for more focused educational interventions. Caregivers in this study predominantly resided in rural areas, which may explain some of the observed knowledge deficiencies. Rural settings often face challenges such as limited access to information, healthcare services, and training programs. Future efforts should focus on bridging this knowledge gap, potentially through community-based training, telehealth services, and better dissemination of information through local healthcare systems. While caregivers displayed positive attitudes overall, the inconsistency in specialist consultations suggests that attitudinal barriers such as convenience, cost, or lack of awareness might be at play. Caregivers with higher socio-economic status may find it easier to maintain regular specialist visits, whereas those from middle and lower socio-economic backgrounds may encounter more barriers. Addressing these inequalities by improving access to healthcare, reducing costs, and increasing the availability of specialist consultations, especially in rural areas, could help elevate overall care standards. The high adherence to recommended practices is encouraging and reflects the caregivers' commitment to their roles. Given the complexities of managing a child's healthcare needs, particularly in areas related to dietary and medical food adherence, caregivers' strong performance in these are as points to effective routine management. However, sustaining this level of adherence may depend on consistent access to resources such as medical food,

medications, and regular check-ups. Policy efforts that support on going access to these resources in underserved communities are critical. The relatively balanced gender distribution highlights the importance of creating gender-neutral support systems for caregivers. While traditional care giving resources may focus on women, there's an increasing need to ensure that male caregivers receive equal access to education, support, and health care resources.

**Conclusion**

This study provides valuable in sights into the knowledge, attitudes, and practices of caregivers managing children with amino acid disorders, highlighting significant associations between education level, health care engagement, and adherence to dietary and medical management protocols. Caregivers with higher education levels demonstrated superior knowledge and adherence to dietary practices, particularly in the use of medical foods and crisis preparedness, underscoring the pivotal role of education in effective disease management.

The results further emphasize the importance of regular specialist consultations, which were positively associated with improved adherence and crisis management, demonstrating that health care provider engagement is critical for maintaining optimal care. Moreover, strong family and social support systems were found to enhance caregiver practices, suggesting that interventions aimed at fostering supportive environments could improve outcomes for children with these rare metabolic conditions. While the study identifies important predictors of successful management, it also reveals gaps in knowledge, adherence, and crisis preparedness among caregivers with lower educational back grounds, indicating the need for targeted educational programs and support structures. The findings underscore the necessity for multi-disciplinary care approaches, accessible educational resources, and policy interventions to reduce barriers to effective disease management; particularly for families with limited access to healthcare and educational resources.

In conclusion, this study contributes to the growing body of literature on the management of in born errors of metabolism by care givers, offering evidence-based recommendations for improving knowledge dissemination, health care engagement, and adherence to dietary protocols. By addressing these key factors, health care systems can enhance the quality of life and long-term outcomes for children affected by amino acid disorders.

## References

1. Lim SY, et al. "Exploring the Barriers and Motivators to Dietary Adherence among Caregivers of Patients with Amino Acid Metabolism Disorders." Nutrients, 2022, 14 (12), 2535.
2. MacDonald A, Smith TA, de Silva S, Alam V, & van Loon JMT. "The personal burden for caregivers of children with phenylketonuria: A cross-sectional study investigating time burden and costs in the UK." Journal of Inherited Metabolic Disease, 2019, 42 (1), 165-174.
3. Vockley et al., 2014. "Phenylalanine Hydroxylase Deficiency: Diagnosis and Management Guideline." Genetics in Medicine, 16(2), 188-200.Wilcox, G. Lysine restriction and the use of medical foods in the management of Inborn Errors of metabolism. Molecular Genetics and Metabolism, 2012, 107 (1-2), 1-6.
4. Yagudina R, Kulikov A, Serpik V, Protsenko M, & Kopeyka K. "Factors Affecting Adherence to a Low Phenylalanine Diet in Patients with Phenylketonuria: A Systematic Review." Frontiers in Pediatrics, 2020, 8,
5. Rovelli V, Dicintio A & Cazzorla C. "Unmet needs in phenylketonuria: An exploratory Italian survey among patients and caregivers." Current Medical Research and Opinion, 2014, 40(1), 1-10.
6. Strauss KA, et al. "Maple Syrup Urine Disease and Brain Development: Principles of Management and Formula Design." Molecular Genetics and Metabolism, 99(Supplement 2010, (1), S86-S93.
7. Skovby F, Gaustadnes M, & Mudd SH. A revisit to the natural history of homocystinuria due to cystathionine β-synthase deficiency. Molecular Genetics and Metabolism, 2010, 99 (1), 1-10.

8. Firman SJ, Ramachandran R, & Whelan K. Knowledge, perceptions, and behaviours regarding dietary management of adults living with phenylketonuria: A nationwide questionnaire survey. Journal of Human Nutrition and Dietetics, 2022, 35(4), 488–497.
9. Van Wegberg AMJ, MacDonald A, et al. The complete European guidelines on phenylketonuria: Diagnosis and treatment. Orphanet Journal of Rare Diseases, 2017, 12, 162.
10. Rondanelli M, Porta F, Gasparri C, Razza C, Tartara A, & Perna S. A food pyramid for adult patients with phenylketonuria and a systematic review on the current evidences regarding the optimal dietary treatment of adult patients with PKU. Clinical Nutrition, 2023, 42 (5), 732–763.
11. Peng Y, Huang Q, Yu Y, Zhu L., & Yuan H. Knowledge, attitude, and practice toward nutrition support and management among hemodialysis patients. BMC Nephrology, 2021, 22 (1), 123.
12. Lim JY, Ali NM, Rajikan R, et al.. Need analysis of a dietary application among caregivers of patients with amino acid metabolism disorders (AAMDs): A mixed-method approach. Journal of Pediatric Biochemistry, 2021, 11(2), 102-110.

**Citation:** Kharbanda G, Nair S, Mathur P. Knowledge, Attitudes, and Practices of Caregivers on Dietary Adherence and Medical Food Usage: A Study on the Impact of Education. Indian J Prev Soc Med, 2024; 55 (4): **338-347.**