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Effectiveness of a Community-Based Health Literacy Program on Caregiver Awareness and Adherence to Home Management Among Children with Phenylketonuria

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ABSTRACT: **Background**: Implementing community-based health literacy programs is essential to enhance caregivers' awareness and adherence to home management practices, thereby supporting improved health outcomes among children with phenylketonuria (PKU).

Aim: This study aimed to evaluate the effectiveness of a community-based health literacy program on caregiver awareness and adherence to home management practices among

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children with PKU. Methods: A quasi-experimental research design was utilized. The study was conducted through community health centers and follow-up clinics affiliated with the Genetics Clinic of Assiut University Children's Hospital, Assiut Governorate, Egypt. A purposive sample of 50 caregivers of children diagnosed with PKU was recruited and randomly assigned to study and control groups. Three tools were used for data collection: a structured interview questionnaire, a caregiver awareness assessment questionnaire, and a home management adherence scale. The intervention group participated in a structured community-based health literacy program, whereas the control group received routine health education and follow-up care.

Results: At baseline, no statistically significant differences were observed between the study and control groups regarding demographic characteristics, caregiver awareness, or home management adherence, confirming baseline comparability. Following program implementation, caregivers in the study group demonstrated significantly higher awareness scores than those in the control group ($p \leq 0.001$). Significant improvements were also observed in dietary management, correct administration of metabolic formulas, regular blood phenylalanine monitoring, and follow-up attendance ($p \leq 0.001$). A strong positive correlation was identified between caregiver awareness and home management adherence ($r = 0.724$, $p = 0.001$). These improvements were sustained during the three-month follow-up.

Conclusion: The community-based health literacy program effectively improved caregiver awareness and adherence to home management practices among children with PKU.

1. INTRODUCTION

Phenylketonuria (PKU) is one of the most common inherited metabolic disorders and among the earliest diseases included in neonatal screening programs. It is classified as an inborn error of amino acid metabolism resulting from mutations in the phenylalanine hydroxylase (PAH) gene, which impair the normal metabolism of the amino acid phenylalanine (1). The PAH enzyme is responsible for converting phenylalanine into tyrosine with the aid of tetrahydrobiopterin (BH4) as a cofactor. Deficiency or dysfunction of this enzyme leads to the accumulation of phenylalanine and phenylketones in the blood and body tissues, causing toxic effects on the central nervous system and irreversible neurological impairment if untreated (2).

Elevated serum phenylalanine concentrations in the blood and brain can result in severe intellectual disability, developmental delay, seizures, behavioral disturbances, hyperactivity, tremors, autistic manifestations, anxiety, and aggressive behavior. Physical manifestations such as eczema and hypopigmentation of the skin, hair, and eyes may also occur. However, these complications can largely be prevented through early diagnosis and strict adherence to treatment protocols initiated soon after birth (3).

Worldwide, the prevalence of PKU differs significantly according to ethnicity and geographic location. The overall global prevalence is estimated to be approximately 1 in 23,930 live births. Higher incidence rates are reported among populations of European origin, ranging from 1 in 5,000 to 1 in 15,000 births, while the disease is relatively uncommon in Asian and African populations. Finland reports one of the lowest incidence rates worldwide, whereas Japan records approximately 1 case per 125,000 live births (4).

Newborn screening programs represent the cornerstone for early identification of PKU. Screening is usually performed between the third and seventh day after birth by obtaining a blood sample from the infant's heel to measure serum phenylalanine levels. Without early intervention, infants with PKU generally appear healthy at birth but gradually develop symptoms during the first months of life. By the age of one year, untreated children often exhibit significant developmental delay and severe cognitive impairment requiring lifelong supportive care (5).

In Egypt, implementation of PKU screening was delayed for several years. Before 2015, screening was conducted only in selected governorates with high rates of consanguineous marriages, revealing an estimated incidence of approximately 1 in 7,000

newborns (6). Since November 2015, the Egyptian Ministry of Health and Population has expanded PKU screening to all governorates through the national neonatal screening program, using the same filter paper system utilized for congenital hypothyroidism screening (7).

Phenylketonuria is categorized under hyperphenylalaninemia disorders according to blood phenylalanine levels. Classical PKU is characterized by serum phenylalanine concentrations exceeding 1,200 µmol/L, mild PKU ranges between 600 and 1,200 µmol/L, while non-PKU hyperphenylalaninemia ranges from 120 to 600 µmol/L (8). Proper classification is essential to determine treatment strategies and follow-up plans.

Dietary management remains the primary treatment approach for PKU. Treatment mainly depends on lifelong restriction of phenylalanine intake through adherence to a low-protein diet combined with phenylalanine-free amino acid supplements or glycomacropeptide-based formulas (9). Current dietary recommendations aim to maintain blood phenylalanine levels between 120 and 360 µmol/L while preserving normal tyrosine levels throughout life (2). Consequently, children with PKU must avoid or strictly limit high-protein foods such as meat, dairy products, eggs, nuts, legumes, and products containing aspartame. Regular blood monitoring is necessary to ensure metabolic control and adjust dietary therapy accordingly (10).

Despite advances in dietary therapy and specialized formulas, maintaining strict adherence to home management remains challenging for many families. Limited availability and high costs of low-protein foods, together with inadequate health literacy, insufficient disease-related awareness, and limited access to educational resources, contribute to poor metabolic control in many affected children (11). Therefore, family caregivers play a crucial role in managing the child's condition, as they are primarily responsible for meal preparation, formula administration, dietary monitoring, blood phenylalanine follow-up, and adherence to prescribed treatment plans.

Phenylketonuria continues to represent a significant health burden among Egyptian children, particularly in Upper Egypt where consanguineous marriage remains common, increasing the risk of hereditary and metabolic disorders. Delayed diagnosis and previously limited neonatal screening services contributed to increased incidence and complications of PKU in Egypt (6). Although national screening programs have improved early detection, many caregivers continue to face challenges related to understanding disease management requirements and maintaining adherence to home-based care practices.

Effective management of PKU depends largely on caregivers' awareness, health literacy, and commitment to lifelong home management. Inadequate awareness and poor adherence to dietary restrictions, formula administration, blood phenylalanine monitoring, and follow-up visits may result in poor metabolic control and increased risk of neurological complications. Therefore, enhancing caregivers' health literacy has become a priority in improving long-term outcomes among children with PKU.

Community-based health literacy programs provide an opportunity to empower caregivers with the knowledge, skills, and confidence necessary to manage PKU effectively within their home environment. Such programs may improve caregivers' awareness, strengthen adherence to home management practices, promote family engagement in care, and contribute to better health outcomes for affected children. Accordingly, evaluating the effectiveness of community-based health literacy programs is essential to support evidence-based community health nursing practice and sustainable health development.

Aim of the Study

The aim of this study is to evaluate the effectiveness of a community-based health literacy program on improving caregiver awareness and adherence to home management among children with phenylketonuria.

Specific Objectives

- Determine the effect of the community-based health literacy program on caregivers' awareness regarding phenylketonuria and its management.
- Assess the effect of the community-based health literacy program on caregivers' adherence to home management practices for children with phenylketonuria.
- Evaluate the effect of the community-based health literacy program on adherence to dietary management, formula administration, regular phenylalanine monitoring, and follow-up attendance among children with phenylketonuria.

Research Hypotheses

- Caregivers who receive the community-based health literacy program will demonstrate significantly higher awareness regarding phenylketonuria and its management after the intervention compared with their pre-intervention scores.
- Caregivers who participate in the community-based health literacy program will demonstrate significantly improved adherence to home management practices after implementation of the program compared with those receiving routine care.
- Children whose caregivers participate in the community-based health literacy program will demonstrate significantly improved adherence to dietary management and follow-up recommendations compared with children in the control group.

2. MATERIALS AND METHODS

2.1 Study Material

Research Design

A quasi-experimental research design was utilized to evaluate the effectiveness of a community-based health literacy program on caregiver awareness and adherence to home management among children with phenylketonuria (PKU).

Setting

The study was conducted through community health centers and follow-up clinics affiliated with the Genetics Clinic of Assiut University Children's Hospital, Assiut Governorate, Egypt. These settings were selected because they provide follow-up care, dietary counseling, laboratory investigations, genetic counseling services, and health education for children diagnosed with phenylketonuria and their families from different districts of Assiut Governorate.

Subjects

A purposive sample of 50 family caregivers accompanying their children diagnosed with phenylketonuria was included in the study. In addition, 50 children diagnosed with phenylketonuria were included in the study.

Inclusion Criteria:

- Children diagnosed with phenylketonuria.
- Children aged from birth to 18 years.
- Family caregivers responsible for the child's daily care and home management.
- Caregivers willing to participate in the study.
- Caregivers able to attend community-based educational sessions.

Exclusion Criteria:

- Children diagnosed with severe chronic illnesses in addition to phenylketonuria.
- Caregivers who refused participation in the study.
- Caregivers who were unable to complete the educational program or follow-up assessments.

Sample Size:

The subjects were randomly assigned into two groups:

Study Group

Family caregivers who participated in the community-based health literacy program.

Control Group

Family caregivers who received routine health education and follow-up services only.

Each caregiver was assigned a number, and allocation was performed using sealed opaque envelopes prepared in advance by an independent person not involved in the study implementation. Caregivers who selected envelopes labeled "A" were assigned to the study group, while those who selected envelopes labeled "B" were assigned to the control group. Allocation concealment

was maintained throughout the assignment process to minimize selection bias and ensure equal distribution between both groups.

Pre-intervention, immediate post-intervention, and three-month follow-up assessments were conducted to determine the effectiveness of the community-based health literacy program on caregivers' awareness and adherence to home management practices among children with phenylketonuria.

2.2 Sample Collection

The study tools were developed by the researcher after an extensive review of relevant national and international literature related to phenylketonuria, health literacy, caregiver awareness, home management adherence, and community-based educational interventions.

Tool I: Structured Interview Questionnaire Sheet

This tool was designed to collect baseline data related to children with phenylketonuria and their family caregivers. It consisted of two parts:

Part (A): Characteristics and Medical History of Children with Phenylketonuria

This part included:

Child's age.

Gender.

Birth order.

Duration since diagnosis.

Age at diagnosis.

Method of disease detection.

Frequency of follow-up visits.

Presence of family history of PKU.

Degree of parental consanguinity.

Previous hospitalization.

Presence of disease-related complications.

Current health condition.

Part (B): Demographic Characteristics of Family Caregivers

This part included:

Caregiver's age.

Gender.

Educational level.

Occupation.

Marital status.

Residence.

Relationship to the child.

Family income.

Source of information regarding PKU.

Tool II: Caregiver Awareness Assessment Questionnaire

This tool was developed to assess caregivers' awareness regarding phenylketonuria and its management before and after implementation of the community-based health literacy program.

The questionnaire consisted of multiple-choice and closed-ended questions covering the following domains:

Definition and causes of PKU.

Genetic inheritance and risk factors.

Signs and symptoms of PKU.

Importance of newborn screening and early diagnosis.

Dietary management and low-phenylalanine diet.

Phenylalanine-free formula administration.

Blood phenylalanine monitoring.

Potential complications of poor disease control.

Follow-up requirements.

Available healthcare and community support services.

Scoring System

Each correct answer was scored one point and each incorrect or unknown answer received zero.

The total awareness score was categorized as follows:

Good awareness: ≥75%.

Fair awareness: 50%–<75%.

Poor awareness: <50%.

Tool III: Home Management Adherence Scale

This tool was developed to assess caregivers' adherence to home management practices before and after implementation of the community-based health literacy program it was developed by the researchers based on the literatures (3, 5,7).

The scale included the following domains:

Adherence to prescribed low-phenylalanine diet.

Regular administration of prescribed metabolic formula.

Monitoring and recording dietary intake.

Attendance at scheduled follow-up visits.

Compliance with blood phenylalanine testing.

Home monitoring of child health status.

Management of illness episodes.

Communication with healthcare providers.

Seeking medical advice when needed.

Maintaining treatment recommendations at home.

Scoring System

Responses were rated using a three-point Likert scale:

Always = 2

Sometimes = 1

Never = 0

The total adherence score was categorized as:

High adherence: ≥75%.

Moderate adherence: 50%–<75%.

Low adherence: <50%.

Validity and Reliability

Content validity of the study tools was assessed by a panel of five experts in community health nursing, paediatric nursing, paediatrics, and medical genetics.

The experts evaluated the tools regarding:

Clarity.

Relevance.

Comprehensiveness.

Applicability.

Consistency with study objectives.

Necessary modifications were carried out according to experts' recommendations before implementation of the study.

Reliability of the study tools was tested using Cronbach's alpha coefficient to determine internal consistency. Reliability testing was conducted for: Caregiver Awareness Assessment Questionnaire. Home Management Adherence Scale.

The obtained reliability coefficients demonstrated satisfactory internal consistency and reliability for data collection.

2.3 Extraction Procedure

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2.4 Analytical Methods

A pilot study was conducted on 10% of the total study sample (5 caregivers) before beginning the actual fieldwork to assess:

Feasibility of the study.

Applicability and clarity of the tools.

Simplicity of the questions.

Time required to complete the tools.

Necessary modifications were made based on the pilot study findings. Participants included in the pilot study were excluded from the main study sample.

Field Work

The fieldwork of the current study was carried out over a period of six months, starting from January 2025 until the end of June 2025, through community health centers and follow-up clinics affiliated with the Assiut Genetic Counseling Center, Assiut Governorate, Egypt.

The researcher attended the selected settings two days weekly from 9:00 a.m. to 1:00 p.m. according to caregivers' attendance schedules and community health education sessions.

Data collection was conducted at three phases:

Phase I: Assessment Phase

This phase was conducted to assess the baseline status of caregivers' awareness regarding phenylketonuria and their adherence to home management practices before implementation of the community-based health literacy program.

The following procedures were carried out during this phase:

An official approval letter to conduct the study was obtained from the Dean of the Faculty of Nursing and submitted to the directors of the selected settings after clarification of the purpose and nature of the study.

The researcher attended the selected community health centers and follow-up clinics regularly according to the predetermined schedule to identify eligible children diagnosed with PKU and their family caregivers.

Family caregivers accompanying children with PKU were approached individually during follow-up visits and community health education sessions.

The researcher introduced herself to caregivers and explained:

- Purpose of the study.
- Importance of participation.
- Expected benefits of the community-based health literacy program.

Written informed consent was obtained from caregivers willing to participate in the study.

Caregivers and children who fulfilled the inclusion criteria were selected for participation.

Subjects were randomly assigned into: Study and Control groups.

Baseline assessment was conducted for both groups using the study tools.

Data collection during the assessment phase included:

- Demographic characteristics of caregivers.
- Personal and medical data of children with PKU.
- Assessment of caregivers' awareness regarding PKU and its management.
- Assessment of caregivers' adherence to home management practices.
- Assessment of dietary management and follow-up compliance.

The average time needed to complete the assessment tools ranged between 20–30 minutes for each caregiver.

Phase II: Implementation Phase

- Based on findings obtained from the assessment phase and review of current related literature, the community-based health literacy program was developed and implemented for caregivers in the study group.
- This phase lasted approximately four months.
- The implementation phase included the following steps:
- The health literacy program was prepared by the researcher using simple Arabic language appropriate to caregivers' educational and cultural backgrounds.
- An illustrated educational booklet was developed and distributed to caregivers in the study group to reinforce understanding and facilitate home management.

- Caregivers in the study group were divided into small groups consisting of approximately 10–15 caregivers according to attendance schedules and available facilities.
- The program consisted of approximately 7–10 educational sessions.
- Sessions were conducted two days weekly from 10:00 a.m. to 12:00 p.m.

Duration of each session ranged from 30–45 minutes depending on:

- Topic discussed.
- Caregivers' interaction.
- Questions and feedback.

At the beginning of the first session, orientation was conducted regarding:

- Program objectives.
- Importance of participation.
- Session schedule.
- Expected outcomes.
- Each session started with:
- Greeting participants.
- Reviewing previous content.
- Discussing caregivers' questions.
- Clarifying misunderstandings.
- Presenting objectives of the new session.

Educational sessions included information regarding:

- Definition and causes of PKU.
- Genetic inheritance and risk factors.
- Signs, symptoms, and complications.
- Importance of newborn screening and early diagnosis.
- Dietary management and low-phenylalanine diet.
- Formula preparation and administration.
- Importance of blood phenylalanine monitoring.
- Follow-up requirements.
- Available healthcare and community support services.

Practical sessions included training caregivers on:

- Preparing and administering prescribed metabolic formula.
- Selecting appropriate low-phenylalanine foods.
- Reading food labels.
- Recording dietary intake.
- Monitoring child health status at home.
- Managing illness episodes.
- Maintaining follow-up appointments.
- Communicating effectively with healthcare providers.

Different educational methods were utilized during implementation including:

- Interactive lectures.
- Group discussions.
- Brainstorming.

- Demonstration and re-demonstration.
- Question and answer sessions.
- Educational videos.
- PowerPoint presentations.
- Posters and illustrated pictures.
- Distribution of educational booklets.
- Continuous feedback and reinforcement.

These methods were selected to facilitate understanding, encourage participation, improve awareness, and enhance adherence to home management practices.

Continuous feedback and reinforcement were provided throughout all sessions.

The researcher maintained communication with caregivers during follow-up visits to answer questions and reinforce home management adherence.

The control group received routine health education and follow-up services available at the selected settings without participation in the community-based health literacy program.

Phase III: Evaluation Phase

This phase was conducted immediately after completion of the community-based health literacy program and again three months later during follow-up visits to evaluate the effectiveness of the intervention.

The following procedures were carried out:

- Caregivers in both study and control groups were reassessed using the same study tools utilized during the assessment phase.
- Caregivers' awareness regarding PKU and its management was re-evaluated.
- Caregivers' adherence to home management practices was reassessed.
- Evaluation focused on determining improvement in:
- Caregiver awareness.
- Dietary adherence.
- Formula administration.
- Follow-up attendance.
- Home management adherence.

Comparisons between pre-program, post-program, and follow-up findings were conducted for both study and control groups to determine the effectiveness of the community-based health literacy program.

Statistical analysis was performed to identify significant differences between both groups regarding caregiver awareness and adherence to home management practices following implementation of the intervention.

2.5 Statistical Analysis

Collected data were coded, tabulated, and analyzed using the Statistical Package for Social Sciences (SPSS) version 26.0.

The following statistical measures were used:

- Frequency and percentage distribution.
- Mean and standard deviation.
- Chi-square test.
- Paired t-test.
- Independent t-test.
- Pearson correlation coefficient.

- Statistical significance was considered at p-value ≤ 0.05.

3. RESULTS AND DISCUSSION

3.1. RESULTS

Table 1. Percentage Distribution of the Studied Caregivers According to Their Personal Characteristics (N=50)

Personal Characteristics	Study Group (n=25)		Control Group (n=25)		χ^2/Fisher	P-value
	No.	%	No.	%		
Caregiver Age (years) <25 years	7	28.0	4	16.0	1.049	0.306(NS)
≥25 years	18	72.0	21	84.0		
Mean ± SD	27.60±5.58		29.28±5.02			
Educational Level Illiterate	0	0.0	1	4.0	1.464	0.833(NS)
Primary	1	4.0	2	8.0		
Preparatory	6	24.0	5	20.0		
Secondary	13	52.0	12	48.0		
University or higher	5	20.0	5	20.0		
Occupation Working	9	36.0	8	32.0	1.089	0.765(NS)
Not working	16	64.0	17	68.0		
Residence Urban	9	36.0	7	28.0	0.368	0.544(NS)
Rural	16	64.0	18	72.0		

Table 1. shows that the mean age of caregivers was 27.60±5.58 years in the study group and 29.28±5.02 years in the control group. More than half of caregivers in both groups had secondary education. Nearly two-thirds were not working and lived in rural areas. No statistically significant differences were found between the study and control groups regarding demographic characteristics (p>0.05), indicating baseline homogeneity.

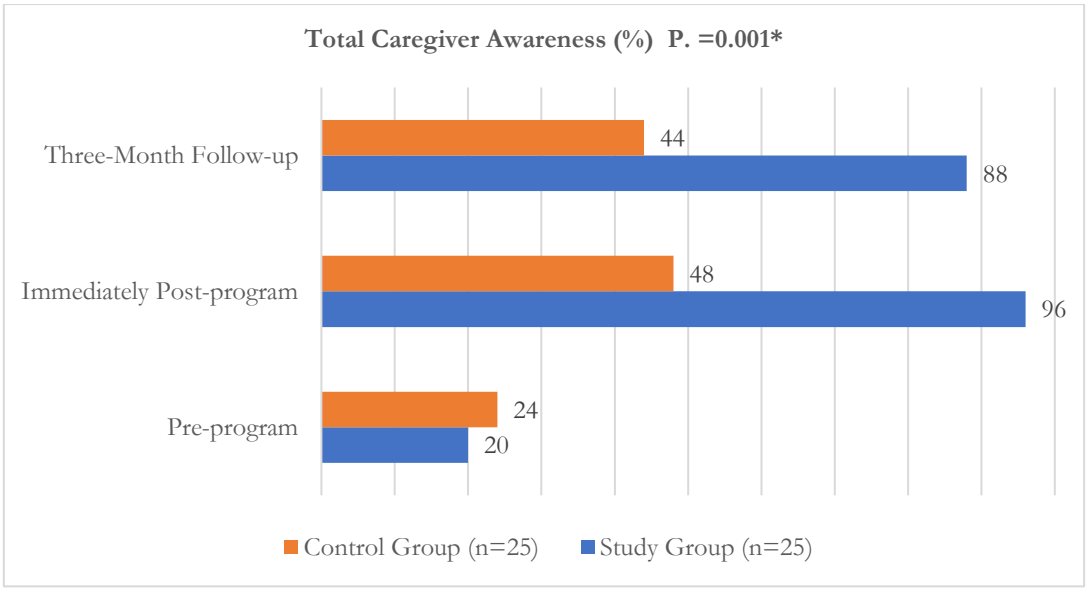


Figure 1. Total Caregiver Awareness Regarding Phenylketonuria Before, After, and at Follow-up (N=50)

Figure 1. illustrates caregivers' awareness regarding phenylketonuria before and after implementation of the community-based health literacy program. Before the intervention, there was no statistically significant difference between the study and control groups. Following implementation, 96% of caregivers in the study group achieved adequate awareness compared with 48% in the control group. At follow-up, 88% of caregivers in the study group maintained adequate awareness compared with 44% in the control group, with a highly statistically significant difference (p=0.001).

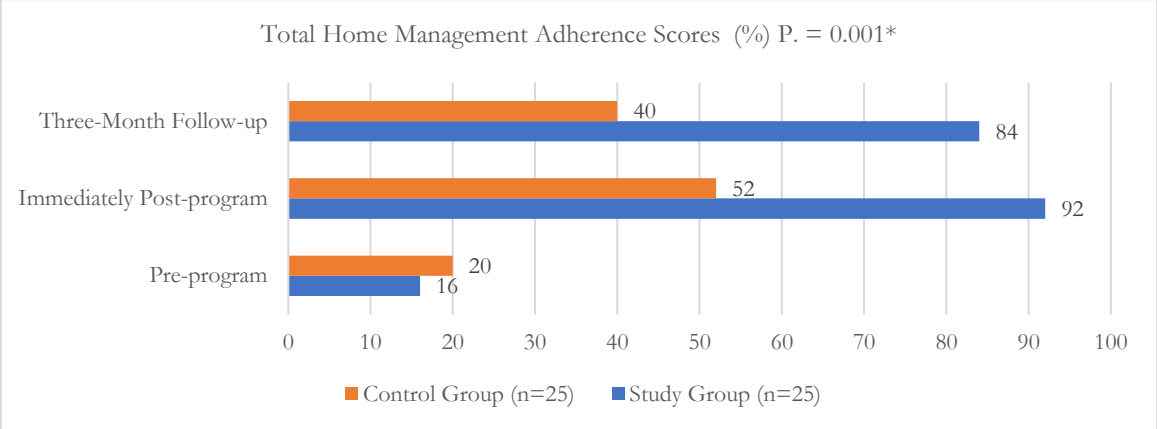


Figure 2. Total Home Management Adherence Scores Before, After, and at Follow-up (N=50)

Figure 2. demonstrates home management adherence among caregivers before and after the intervention. No statistically significant difference was observed before implementation. However, after the program, 92% of caregivers in the study group demonstrated high adherence compared with 52% in the control group. At follow-up, 84% of caregivers in the study group maintained high adherence compared with 40% in the control group, indicating a highly statistically significant improvement (p=0.001).

Table 2. Relationship Between Caregivers' Personal Characteristics and Total Awareness Scores After Program Implementation (N=50)

Personal Characteristics	χ^2	P-value
Age	1.852	0.174
Educational level	9.203	0.027*
Occupation	3.144	0.076
Residence	0.250	0.617
Previous training course	8.466	0.004**

Table 2. indicates that caregivers' awareness was significantly associated with educational level (p=0.027) and previous attendance of training courses related to phenylketonuria (p=0.004). No statistically significant relationships were found between awareness scores and caregivers' age, occupation, or residence.

Table 3. Percentage Distribution of the Studied Children According to Their Personal Characteristics (N=50)

Personal Characteristics	Study Group (n=25)		Control Group (n=25)		χ^2	P-value
	No.	%	No.	%		
Birth–<6 months	6	24.0	9	36.0		
6 months–<1 year	11	44.0	5	20.0	3.324	0.190(NS)
1–2 years	8	32.0	11	44.0		
Mean age ± SD	10.80±5.97		10.00±6.41			
Male	13	52.0	14	56.0	0.080	0.777(NS)

Personal Characteristics	Study Group (n=25)		Control Group (n=25)		χ^2	P-value
Female	12	48.0	11	44.0		

Table 3. reveals that the mean age of children was 10.80±5.97 months in the study group and 10.00±6.41 months in the control group. More than half of children in both groups were males. No statistically significant differences were observed between both groups regarding age or gender (p>0.05).

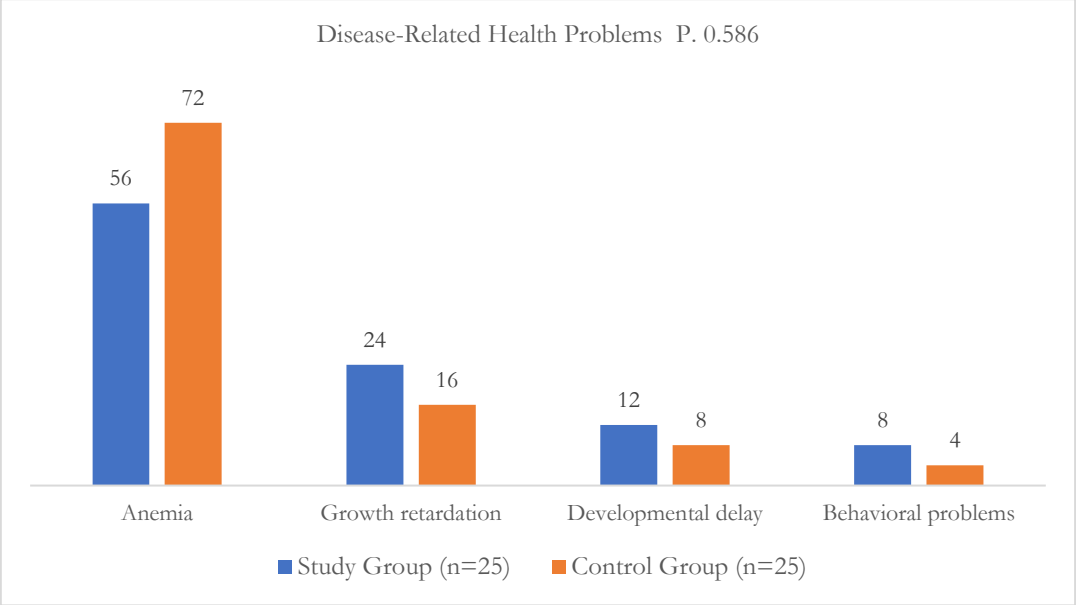


Figure 3. Percentage Distribution of Children According to Disease-Related Health Problems (N=50)

Figure 3. demonstrates that anemia was the most commonly reported health problem among children in both groups, affecting 56% of the study group and 72% of the control group. No statistically significant differences were found between both groups regarding disease-related health problems (p=0.586).

Table 4. Home Management Adherence Outcomes After Implementation of the Community-Based Health Literacy Program (N=50)

Outcome	Study Group (n=25)	Control Group (n=25)	χ^2	P-value
Adherence to low-Phe diet	22 (88.0)	11 (44.0)	11.284	0.001**
Correct formula administration	23 (92.0)	13 (52.0)	10.758	0.001**
Follow-up attendance	24 (96.0)	15 (60.0)	9.694	0.001**
Compliance with blood monitoring	21 (84.0)	10 (40.0)	10.101	0.001**
Overall high adherence	23 (92.0)	12 (48.0)	12.457	0.001**

Table 4. illustrates the effect of the community-based health literacy program on caregivers' adherence to home management. Caregivers in the study group demonstrated significantly higher adherence to dietary management, formula administration, follow-up attendance, and blood monitoring schedules than those in the control group. Overall adherence reached 92% in the study group compared with 48% in the control group, with a highly statistically significant difference (p=0.001).

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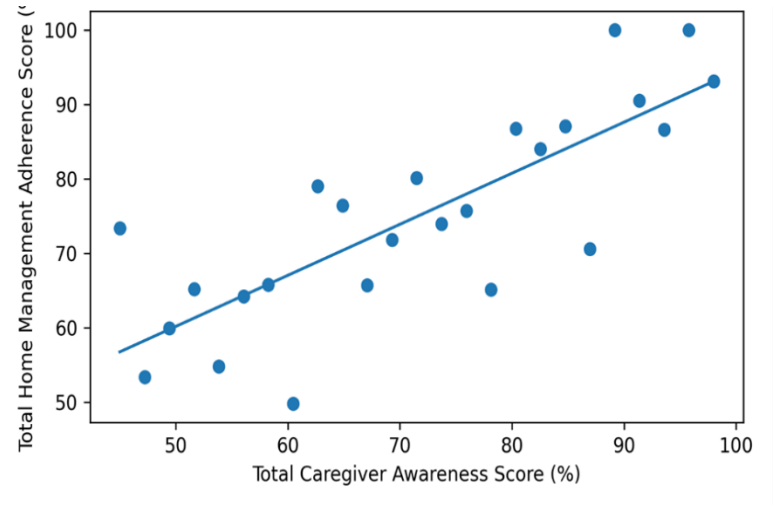


Figure 4. Correlation between caregivers' awareness scores and home management adherence scores

Figure 4. demonstrates a positive correlation between caregivers' awareness scores and home management adherence scores following implementation of the community-based health literacy program, indicating that higher awareness levels were associated with better adherence to recommended home management practices for children with phenylketonuria ($r = 0.724$, $p = 0.001$)

3.2 Discussion

Phenylketonuria (PKU) is a lifelong inherited metabolic disorder that requires continuous home-based management and strict adherence to dietary restrictions to prevent serious neurological complications. Since caregivers are primarily responsible for implementing treatment recommendations within the home environment, improving their health literacy and disease-related awareness is essential for successful disease management (12). Therefore, evaluating the effectiveness of community-based health literacy programs is important to enhance caregiver awareness and promote adherence to home management practices among children with PKU.

The present study revealed that caregivers in both the study and control groups had comparable demographic characteristics. The mean age of caregivers was 27.60±5.58 years in the study group and 29.28±5.02 years in the control group. More than half of caregivers had secondary education, nearly two-thirds were not working, and the majority resided in rural areas. No statistically significant differences were observed between both groups, confirming baseline homogeneity.

From an interpretative perspective, these findings reflect the demographic profile commonly observed among caregivers of children with chronic disorders in Upper Egypt, where caregiving responsibilities are often undertaken by young mothers residing in rural communities. From the researcher's viewpoint, the similarity between groups strengthens the internal validity of the study and reduces the possibility that demographic factors influenced the observed outcomes.

These findings are consistent with Aslan and Karataş (13), who reported similar demographic characteristics among caregivers of children with inherited metabolic disorders and most caregivers were non-working mothers with secondary education levels and rural residence. Conversely, Lubina et al. (14) reported higher educational attainment and employment rates among caregivers, reflecting socioeconomic differences across populations.

The present study demonstrated a substantial improvement in caregiver awareness following implementation of the community-based health literacy program. Before the intervention, there was no statistically significant difference between the study and control groups. Following implementation, majority of caregivers in the study group achieved adequate awareness compared with the control group. Furthermore, majority of caregivers in the study group maintained adequate awareness during follow-up compared with the control group, with a highly statistically significant difference ($p = 0.001$).

These findings indicate that the community-based health literacy program effectively enhanced caregivers' understanding of PKU, including disease characteristics, dietary management, blood monitoring requirements, and prevention of complications.

The sustained improvement observed during follow-up suggests that caregivers retained the information provided and were able to apply it in daily child care activities.

From the researcher's perspective, the use of simple educational materials, group discussions, practical examples, and continuous reinforcement contributed significantly to improving caregivers' awareness and long-term retention of information.

These findings agree with Gökmen-Ozel et al. (15), who reported significant improvements in caregivers' disease-related knowledge following structured educational interventions. In contrast, Brumm et al. (16.) reported that improvements in caregiver knowledge gradually declined over time without ongoing reinforcement and support.

The current study also demonstrated significant improvement in home management adherence among caregivers who participated in the health literacy program. After implementation, majority of caregivers in the study group demonstrated high adherence to recommended home management practices compared with the control group. Significant improvements were observed in adherence to low-phenylalanine dietary recommendations, proper formula administration, attendance at follow-up appointments, and compliance with blood monitoring schedules ($p = 0.001$).

These findings suggest that increasing caregiver awareness positively influenced caregiving behaviours and promoted effective implementation of treatment recommendations within the home environment. Improved understanding of disease management requirements appears to have translated into better adherence to daily care activities.

From the researcher's viewpoint, the observed improvement highlights the importance of community-based educational approaches that empower caregivers with practical knowledge and skills required for long-term disease management.

These findings are consistent with MacDonald et al. (10), who reported that caregiver education significantly improved dietary adherence and treatment compliance among children with PKU. Similarly, Chew et al. (17) found that caregivers who participated in structured educational programs demonstrated greater adherence to home management recommendations than those receiving routine care alone. However, Gupta et al. (18) reported less pronounced improvements in adherence, attributing this to limited family support and socioeconomic barriers.

The present study further revealed that caregivers' awareness was significantly associated with educational level and previous attendance of training programs. Caregivers with higher educational attainment and previous exposure to training demonstrated significantly better awareness scores than their counterparts ($p < 0.05$).

This finding may be explained by the greater ability of educated caregivers to understand health information, interpret educational materials, and implement recommended practices effectively. Previous training experiences may also enhance confidence and facilitate knowledge acquisition.

These findings are supported by Chew et al. (17), who reported that caregiver education level was a significant predictor of health literacy and disease-management knowledge. Likewise, MacDonald et al. (10) found that previous participation in educational activities was associated with improved caregiver understanding and treatment adherence.

Regarding children's characteristics, no statistically significant differences were found between the study and control groups concerning age or gender. More than half of the children in both groups were males, and the average age was approximately ten months. Such comparability supports the validity of the intervention outcomes and indicates that differences observed after the intervention were unlikely to be influenced by demographic variations.

The study additionally found that anaemia represented the most common health problem among children with PKU in both groups. This finding may be attributed to dietary restrictions and limited intake of natural protein sources, which may increase the risk of nutritional deficiencies if dietary management is not carefully monitored. These findings support the importance of regular nutritional assessment and continuous dietary counselling for affected children.

A positive correlation was identified between caregiver awareness scores and home management adherence scores following implementation of the program ($r = 0.724$, $p = 0.001$). This strong correlation indicates that increased awareness was associated with better adherence to recommended home management practices.

These findings are consistent with the study conducted by MacDonald et al. (10), which reported that improved caregiver knowledge was significantly associated with better dietary adherence and metabolic management among children with

phenylketonuria. Similarly, Chew et al. (17) found that caregivers with higher health literacy levels demonstrated superior compliance with home-based management recommendations and follow-up schedules for children with chronic conditions.

Conversely, the present findings differ from those reported by Gupta et al. (18), who found no significant association between caregiver knowledge and adherence behaviours, suggesting that financial constraints and family support played a greater role than awareness alone. Likewise, Sigalet et al. (19) and Khalil etal., (20) reported that demographic factors such as caregiver age, occupation, and family resources were stronger predictors of adherence than educational interventions or awareness levels.

From a clinical perspective, this finding emphasizes that enhancing caregiver awareness is a key determinant of successful disease management. Caregivers who understand the disease process, dietary requirements, and follow-up recommendations are more likely to implement treatment plans consistently and effectively.

Overall, the findings of the present study provide strong evidence that the community-based health literacy program successfully improved caregiver awareness and adherence to home management among children with phenylketonuria. The sustained improvements observed during follow-up support the value of incorporating structured community-based educational interventions into routine metabolic and paediatric health services to promote long-term disease control and improve health outcomes among affected children.

4. CONCLUSION

The findings of the present study demonstrated that the community-based health literacy program had a significant positive effect on improving caregivers' awareness regarding phenylketonuria and enhancing adherence to recommended home management practices among children with PKU. Caregivers who participated in the program showed significantly higher awareness levels and better adherence to dietary management, formula administration, follow-up attendance, and blood phenylalanine monitoring compared with those who received routine care. A strong positive correlation was observed between caregiver awareness and home management adherence, indicating that increased awareness contributes to improved caregiving behaviours. The findings highlight the importance of community-based health education interventions in empowering caregivers and promoting effective long-term management of children with phenylketonuria.

Recommendations

- Based on the findings of the present study, the following recommendations are proposed:
- Community-based health literacy programs should be integrated into routine services provided for caregivers of children with phenylketonuria to improve disease awareness and home management adherence.
- Continuous educational and counselling sessions should be provided through primary healthcare centres, family health units, and community health services to reinforce caregivers' knowledge and support long-term adherence.
- Standardized, culturally appropriate educational materials, including illustrated booklets, visual aids, and digital educational resources, should be developed and distributed to caregivers to facilitate understanding and home-based implementation of care recommendations.
- Regular community follow-up programs should be established to monitor caregivers' adherence to dietary restrictions, formula administration, and blood phenylalanine monitoring schedules.
- Health literacy initiatives should involve multidisciplinary collaboration among community health nurses, pediatricians, dietitians, and genetic counsellors to ensure comprehensive support for affected families.
- Periodic refresher educational programs should be conducted to maintain caregiver awareness and prevent decline in adherence behaviours over time.
- Community awareness campaigns should be implemented to increase public knowledge regarding phenylketonuria, newborn screening, genetic counselling, and the importance of early diagnosis and treatment.
- Further multicentre studies are recommended to evaluate the long-term impact of community-based health literacy interventions on caregiver outcomes, treatment adherence, and quality of life among children with phenylketonuria.

AUTHOR CONTRIBUTIONS

Lorem A. Ipsum: Conceptualization, Investigation.

Shaymaa S. Khalil: Main idea construction, Supervision, Critical revision for important intellectual content

Khawla S. Alsharif: Methodology, Laboratory Analysis.

Data Curation, Formal Analysis.

Hossam M. Nasser: Writing—Review & Editing.

Adel A. Abdelwahab; Ahmed I. Bazina& Ahmed M. Zarea: Writing—Review & Editing.

Sayeda M. Soliman &Doaa B. Akl; Data Curation, Formal Analysis.

CONFLICT OF INTEREST

The authors declare that they have no competing interests and no financial or personal relationships that could inappropriately influence or bias the content of this paper.

ETHICS STATEMENT

Approval to conduct the study was obtained from the Ethical Committee of the Faculty of Nursing. Official permission was obtained from responsible authorities of the selected settings. An informed consent was obtained from family caregivers after explanation of the purpose and procedures of the study. Confidentiality and anonymity of collected data were assured. Participants were informed about their right to refuse participation or withdraw from the study at any time without any consequences. The study followed ethical principles related to scientific research. No physical, psychological, social, or economic harm was expected during implementation of the study.

DATA AVAILABILITY STATEMENT

Data supporting the findings of this study are available from the corresponding author upon reasonable request.

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