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IMPACT OF EDUCATIONAL INTERVENTION ON CAREGIVER KNOWLEDGE REGARDING CHILD CARE WITH INHERITED HEMOLYTIC ANEMIA

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Abstract

Background: Hemolytic anemia is widespread in Pakistan (2-5% prevalence), primarily due to glucose-6-phosphate dehydrogenase deficiency. Caregiver knowledge is crucial for improving the quality of life of affected children. Educating and supporting caregivers is essential for optimizing care.

Objective: This study aimed to evaluate the impact of an educational intervention on caregiver knowledge regarding child care with inherited hemolytic anemia.

Methods: An experimental design was conducted at children hospital Lahore, involving caregivers of children diagnosed with inherited hemolytic anemia. The educational intervention comprised structured sessions focusing on understanding the disease, its management, and strategies to enhance the quality of life for affected children. A two group's base study was conducted using standardized measures to gauge caregiver knowledge regarding the disease.

Results: The research revealed that a substantial proportion of mothers were between the ages of 29 and 38, had completed secondary education. Furthermore, a significant number of affected children were in the 1-3 age range, mostly boys. There was a notable difference in mean scores of maternal knowledge between the control group (8.78±2.254) and the intervention group (10.83±1.669).

Conclusion: Educational interventions empower caregivers to support children with inherited hemolytic anemia, enhancing management and quality of life outcomes. These initiatives are vital in chronic disease management, necessitating further research to investigate their long-term impacts and sustainability across diverse healthcare settings.

Keywords: Educational Intervention, Caregiver Knowledge, Inherited Hemolytic Anemia

Introduction: Anemia remains prevalent globally, affecting over 25% of the population. Of those affected, especially women and children under 7, more than 50% suffer from iron deficiency anemia (IDA)(1). Anemia affects about 43% of children under 5 worldwide and contributes to approximately 591,000 perinatal deaths annually. Half of all anemia cases are due to iron deficiency, though the proportion varies by population. Factors including hemoglobin production issues, insufficient precursors like Glucose-6-phosphate dehydrogenase (G6PD) deficiency, lead damage to erythrocytes, and blood loss also contribute to anemia (2).

Inherited hemolytic anemia results from genetic mutations causing premature destruction of red blood cells. Normally lasting around 120 days, red blood cells have a shortened lifespan in this condition, leading to symptoms like fatigue, shortness of breath, and jaundice (3). Various types of inherited hemolytic anemia, like sickle cell anemia, thalassemia, and hereditary spherocytosis, have distinct genetic causes and clinical presentations. Despite differences, they all result in anemia due to premature red blood cell destruction (4).

Hereditary anemias (HAs) are a diverse group of disorders with complex genotype-phenotype correlations. Recent years have seen significant progress in understanding their genetic basis and pathophysiology. Over 70 genes related to red blood cell physiology have been identified as causative of Has (5).

In 2010, approximately 312,000 children were diagnosed with anemia. The condition stems from a genetic mutation in the β-chain of the hemoglobin gene, where glutamic acid is replaced by valine in the hemoglobin protein (6)

G6PD deficiency, the most common disease affecting children's quality of life, stems from a genetic mutation in the G6PD gene, leading to a shortage of the G6PD enzyme crucial for red blood cell protection. Approximately 400 million people worldwide carry the defective gene, with prevalence high in Africa, Asia, Mediterranean countries, and Latin America. A recent meta-analysis reported a global prevalence of 4.5%, with Pakistan showing an incidence of 1.8% (7).

Overlooking locally published non-indexed papers, the analysis missed an incidence rate of 2% to 4% in Pakistani males, notably with an 8% incidence among Pathans (8). Two national studies found 26% and 30% of hospital admissions for 1624 and 6454 babies, respectively, needed neonatal jaundice evaluation. Major contributors included low birth weight, ABO or Rh incompatibility, sepsis, with 8% of jaundiced babies having G6PD deficiency (9).

Genetic testing for G6PD deficiency is crucial as it identifies carriers of the mutation, especially in populations with high prevalence, enabling improved management and prevention of potential complications (10).Genetic testing diagnoses G6PD deficiency in those with symptoms or reactions to triggers causing hemolysis, allowing for timely interventions to prevent complications. (11).

Genetic testing offers vital insights for family planning by assessing the risk of passing G6PD deficiency to offspring, enabling informed decisions regarding reproductive options like pre-implantation genetic diagnosis or prenatal testing (10).

Genetic testing facilitates population-level strategies for managing G6PD deficiency by pinpointing high-prevalence regions or communities, allowing targeted public health interventions such as education, genetic counseling, and screening programs. (12). Neonatal screening for G6PD deficiency raises awareness among parents and caretakers, leading to early treatment access and reduced mortality and morbidity. (13).

G6PD deficiency, a form of inherited hemolytic anemia, can greatly affect a child's life, necessitating continuous medical care like transfusions and specialized treatment. Caregivers play a crucial role in managing medical needs and enhancing the child's well-being and quality of life. (14). Caregiver understanding of hemolytic anemia greatly influences a child's quality of life. It enables early complication detection, adherence to treatment plans, and addresses emotional and social needs. Well-informed and involved caregivers foster a sense of normalcy and support, easing the challenges of living with a chronic condition for the child (15).

Exploring caregivers' knowledge of children with hemolytic anemia offers insights into their experiences and areas needing support and education. Enhancing caregiver understanding can improve children's quality of life and ensure optimal care and support (16). Well-informed caregivers understand hemolytic anemia's impact, identify early complications like jaundice and fatigue, and seek timely medical care. They also address the child's vulnerabilities, implementing preventive measures to reduce infection risks and other health issues. (17)

Well-informed caregivers ensure children with hemolytic anemia receive timely and accurate medication doses to manage symptoms and prevent complications (18). Caregivers of children with hemolytic anemia oversee medication responses and adverse effects, while ensuring dietary needs are met by planning and monitoring meals, and reporting any issues to the healthcare team. (19).

Caregivers knowledgeable about hemolytic anemia offer emotional support to both the child and their family by explaining the condition in age-appropriate language, providing reassurance, and helping them cope with the challenges of living with a chronic illness (20). Caregivers informed about hemolytic anemia advocate for their child's healthcare needs, communicating effectively with providers, asking questions, providing feedback, and facilitating access to the latest treatments and research. (21).

The Enhancing caregiver knowledge regarding this disease will order to support the health and well-being of both children and their families (22). Children's quality of life is crucial for societal investment and their present well-being, a topic studied for decades with various approaches yet rarely discussed collectively in relation to children. (23). The effective management of G6PD deficiency anemia depends on caregiver knowledge about hemolysis triggers, impacting affected children's health and hospitalization frequency. Hemolytic anemia, prevalent in Pakistan, especially G6PD deficiency, poses a burden on families due to triggers like certain foods and medications.

Hypothesis

Ho: There is no impact of educational intervention on caregiver knowledge regarding child care with inherited hemolytic anemia

HA: There is impact of educational intervention on caregiver knowledge regarding child care with inherited hemolytic anemia

Materials and Methods: A randomized controlled study design assessed the impact of an educational intervention on caregiver knowledge and children's quality of life regarding G6PD disease. The independent variable was the educational intervention, while dependent variables included caregiver knowledge and children's quality of life. Caregiver knowledge encompassed understanding of G6PD disease, its causative factors, symptoms, complications, treatment modalities, and dietary restrictions. The study, conducted at Lahore Children Hospital over 9 months, recruited 46 participants through simple random sampling. Inclusion criteria comprised caregivers of children with inherited hemolytic anemia, while exclusion criteria included caregivers without affected children, limited language proficiency, unwillingness or inability to participate, severe cognitive impairment, psychiatric conditions, or children with other significant health conditions. Data collection involved administering validated questionnaires and followed ethical guidelines. Data analysis employed SPSS version 20.0, computing means, standard deviations, frequencies, and percentages, with normality tests, paired t-tests, and independent t-tests applied for significance determination ($p < 0.05$).

Results

Table No 1: Demographic variables of the study participants

Demographic Variables		n	%
Mother Age	18 - 28	21	45.7
	29- 38	25	54.3
Mothers' education	Illiterate	16	34.8
	Primary	13	28.3
	Secondary	17	37.0
Mothers' occupation	Housewife	17	37.0
	Working	29	63.0
Residence	Urban	26	56.5
	Rural	20	43.5
Positive kin relationship between the couples	Yes	15	32.6
	No	31	67.4
Positive family history for G6PD deficiency	Yes	12	26.1
	No	34	73.9
Child age in Year	1-3 Years	28	60.9
	4- 7 Years	14	30.4

	8-10 Years	4	8.7
Child Gender	Male	24	52.2
	Female	22	47.8
Valid Blood Transfusion Frequency	Weekly	14	30.4
	Monthly	17	37.0
	Bimonthly	15	32.6

Analyzed by frequency (n) and percentage (%)

The paragraph provides a detailed overview of the demographic characteristics of the study participants, encompassing mothers' age distribution (45.7% aged 18-28 and 54.3% aged 29-38), educational backgrounds (34.8% illiterate, 28.3% primary education, and 37.0% secondary education), and occupations (37.0% housewives, 63.0% working). Additionally, participants are categorized by residence (56.5% urban, 43.5% rural), kin relationships (32.6% positive, 67.4% negative), and family history of G6PD deficiency (26.1% positive, 73.9% negative). Children's ages range from 1-3 years (60.9%), 4-7 years (30.4%), and 8-10 years (8.7%), with an almost equal gender split (52.2% male, 47.8% female). Valid blood transfusion frequencies vary weekly (30.4%), monthly (37.0%), and bimonthly (32.6%), providing a comprehensive depiction of the study population's diverse characteristics.

Table 2: Knowledge Level among caregivers regarding inherited hemolytic anemia.

Variables	n	%	X	S.D
Poor Knowledge <50% or <8 score	39	84.8	5.04	2.675
Average Knowledge 50-70 % (8 to10)	5	10.9		
Good Knowledge >70% or >10	2	4.3		
Total	46	100.0		

Descriptive statistics mean (X) and standard deviation (S.D)

The data reveals participants' knowledge levels assessed through a scoring system. Among the 46 participants, 84.8% (39 individuals) exhibit Poor Knowledge (score <50% or <8), while 10.9% (5 individuals) demonstrate Average Knowledge (score 50-70%). Only 4.3% (2 individuals) display Good Knowledge (score >70%). This diverse distribution underscores the varying degrees of understanding within the studied population, with a majority exhibiting poor knowledge levels, as depicted in Table 2.

Table 03: Impact of educational interventional on caregiver knowledge level

Knowledge	Control Group	Interventional Group	Mean difference	P-value
	X+S.D	X+S.D		
Pre-test	6.04±2.722	4.78±1.783	±1.27	0.07
Post-test	8.78±2.954	10.83±1.669	±2.05	0.006

Analyzed by independent t test with a p less than 0.05

Table 04 compares caregiver knowledge levels between the Control Group and the Interventional Group, evaluating the impact of an educational intervention. Initial knowledge levels in the Control Group averaged 8.78 with a standard deviation of 2.954, whereas the Interventional Group, exposed to the educational intervention, displayed a higher average knowledge level of 10.83 with a standard deviation of 1.669. Analysis using an independent t-test ($p < 0.05$) revealed a statistically significant difference in knowledge levels between the two groups (p-value = 0.032), indicating a positive impact of the educational intervention on caregiver knowledge enhancement.

Discussion: The study finds that the majority of mothers (54.3%) are aged 29 to 38, with 37.0% having secondary education and 63% employed. Additionally, 56.5% reside in urban areas, 32.6% report positive kin relationships, and 26.1% have a positive family history of G6PD deficiency.

Children aged 1-3 years comprise 60.9% of participants, with 52.2% being boys, and 37.0% receiving monthly blood transfusions**.** Similarly the study of Hakeem, Mousa (24) find that out of the total thalassemia patients, 67.2% were boys with age between 8 and 18 years. The study of Al-Saqladi and Albanna (25) reveals that 8.8% of individuals received supportive blood transfusion therapy as part of their clinical treatment. Of these recipients, 63.4% were male, with an average age of 5 years. Additionally, half of the transfused children were aged ≤5 years old (25).

According to the report of Iglesias Vázquez, Valera (26) anemia remains a mild or moderate concern for public health across many countries in Latin America and the Caribbean (LAC), particularly among children. In certain nations, it presents as a severe public health issue. While the average prevalence of anemia among children in LAC countries is 28.56%, this figure masks significant variations, with rates as low as 3.5% in Ecuador and 4% in Costa Rica, contrasting sharply with 70% in Haiti (26).

The study outlines significant demographic and clinical features: many mothers aged 29 to 38 with secondary education and employment, primarily 1-3-year-old children, predominantly boys, with a notable portion receiving monthly blood transfusions. Contrastingly, previous studies highlight thalassemia prevalence among boys aged 8-18 and substantial blood transfusion therapy among younger children. Another study reported that there was a notable contrast in anemia prevalence based on children's age, with preschoolers exhibiting a higher percentage of anemia compared to school-aged children. The period up to 5 years of age is characterized by rapid growth and elevated nutritional needs (27).

It highlights in the present study the distribution of participants based on their knowledge levels, ranging from poor to good, and discusses how these levels correspond to their quality of life scores. Among the participants, 84.8% demonstrated poor knowledge, scoring below 50%, a smaller proportion 10.9% showed average knowledge, with scores ranging from 50-70% and the minority 4.3% exhibited good knowledge, scoring above 70%. In contrast a research by Ramadan Korany, Sayed Ali (28) revealed that 72.5% of patients exhibited a satisfactory level of knowledge about thalassemia, while 27.5% had an unsatisfactory level. Regarding quality of life, 22.5% of patients reported a good level, whereas 77.5% indicated a poor level. However, there was no statistically significant relationship found between the overall knowledge level and the quality of life among thalassemia patients, as indicated by a p-value of 0.6 (28).

Additionally, Essawy, El Sharkawy (29) investigation found that the majority of children diagnosed with sickle cell anemia experienced either poor (66%) or neutral (23%) quality of life. Conversely, only a small percentage reported having a good quality of life. The study identified that children's poor quality of life was associated with procrastination (delaying to perform any task), pain experiences, and limited physical activities. Similarly the study by Ramadan Korany, Sayed Ali (28) they found that how families manage things and the quality of life of their children with thalassemia are connected in a positive way.

The study evaluates the impact of an educational intervention on caregiver knowledge levels, comparing the Control and Interventional Groups. The Control Group began with an average knowledge level of 8.78, while the Interventional Group, exposed to the intervention, demonstrated a higher average knowledge level of 10.83 ($p < 0.05$). These results indicate a positive influence of the educational intervention on caregiver knowledge levels. Similarly, Vaghela (16) found that 95% of participants had insufficient understanding about iron deficiency anemia and prevention during the pre-test phase. Significant knowledge disparities existed between the pre-test and post-test phases among adolescent girls ($p < 0.05$). Furthermore, no significant correlation was identified between knowledge levels regarding iron deficiency anemia, its prevention, and socio-demographic or clinical variables, with a p-value exceeding 0.05 (16).

Meena and Yashaswinideepak found a notable increase in post-test knowledge scores (average score: 22.55, 62.63%) compared to pre-test scores (average score: 13.85, 38.47%), indicating the structured teaching program effectively enhanced adolescent girls' understanding of iron deficiency anemia. Furthermore, a significant mean difference of 8.7 between pre-test and post-test knowledge scores emphasizes the intervention's effectiveness (30). Conversely, in the research conducted by al

Abedi, Al-Hadrawy (31), most of the participating mothers demonstrated insufficient knowledge, favorable attitudes, and improper practices regarding glucose-6-phosphate dehydrogenase deficiency. The study revealed a statistical correlation between mothers' understanding of glucose-6-phosphate dehydrogenase deficiency and certain demographic factors, including age, educational attainment, and occupational status (31).

Likewise, Ragab Mahmoud, Ahmed (32) study revealed that over fifty percent of mothers exhibited inadequate overall knowledge scores and reported practices concerning the care of children with favism. Mothers' understanding and reported practices concerning favism were deemed insufficient. Therefore, implementing awareness campaigns and health education initiatives targeted at favism could enhance mothers' understanding of the condition and facilitate the effective prevention of associated triggering factors (32).

The impact of educational interventions on knowledge levels and practices related to various health conditions. Specifically, the studies explore the effectiveness of educational programs in improving understanding and promoting appropriate actions concerning conditions such as iron deficiency anemia, glucose-6-phosphate dehydrogenase deficiency, and favism among caregivers and specific demographic groups (33).

These studies collectively highlight the significance of targeted educational initiatives in enhancing awareness, improving knowledge levels, and fostering positive practices related to healthcare (34). They underscore the importance of tailored interventions to address specific health concerns and demographic characteristics within populations, ultimately aiming to promote better health outcomes and preventive measures (35).

According to Garzon, Cacciato (36) Iron deficiency anemia, G6PD deficiency, and favism are health conditions that can have significant impacts on individuals' health if not properly managed. Educational interventions play a crucial role in raising awareness, enhancing knowledge levels, and fostering positive practices related to these conditions (36).

So according to the report of Skolmowska, Głąbska (37) tailored educational initiatives are particularly important because they can address the specific needs and concerns of different demographic groups within populations. For example, caregivers may require specialized information and training to recognize symptoms, manage treatment, and prevent complications related to these health conditions in their dependents (37).

Furthermore, targeted interventions can help overcome barriers to healthcare access and utilization, especially among marginalized or underserved populations. By providing culturally sensitive and linguistically appropriate educational materials and programs, healthcare providers can effectively reach and engage diverse communities in discussions about health promotion and disease prevention (38).

According to Essawy, El Sharkawy (29) found that sickle cell anemia significantly impacts children's quality of life. The study revealed that over two-thirds of the children examined had poor quality of life, while less than a quarter had a neutral quality of life. A small percentage of the children studied reported having a good quality of life. (29).

Conclusion: The study uncovered some important findings. It noted that many mothers, mainly aged 29 to 38 years, have completed secondary school and hold jobs. Additionally, a significant number of affected children fall within the 1-3 years age range, with boys being the majority. A considerable portion of these children require monthly blood transfusions, indicating the severity of their health issues. Moreover, the study highlights the crucial role of education in helping people understand and manage health conditions like iron deficiency anemia, G6PD deficiency, and favism. Understanding these conditions is essential for better management and prevention. The study's insights into the demographics of those affected provide valuable information on how to tailor interventions effectively.

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