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The Role of Pediatric Nurses in Enhancing Caregiver Health Literacy for Effective Home Management of Children with Congenital Heart Disease.

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Abstract

Background: Children with congenital heart disease experience difficulties in house-based management because their caregivers lack the necessary knowledge and understanding of health information. Teaching CHD management to caregivers remains essential for achieving better health results for children while granting caregivers the ability to deliver successful home care. Research documents demonstrate that niche educational approaches produce substantial positive changes in caregiver understanding and competence.

Aim: This study aimed to determine the impact of educational intervention programs on health literacy knowledge acquisition about CHD management for caregivers with children diagnosed with CHD.

Methods: The research implemented a quasi-experimental design using sixty caregivers divided into two groups, totaling thirty participants in each section. The educational intervention program was delivered to the intervention participants, yet the control participants received no educational materials. Healthcare providers completed the NVS tool as the measure for health literacy assessment, and a designed questionnaire determined their level of knowledge about CHD management. Both pre-test and post-test scores underwent group and individual group analyses to evaluate intervention success.

Results: Participants in the intervention experienced notable advancements in their health literacy ($p < 0.001$), together with increased knowledge about CHD management ($p < 0.001$). Minimal alteration emerged between pre- and post-tests in both measures for the control group. Data collection showed that intervention group caregivers gained substantial self-assurance in caring for their child at home ($p < 0.001$), surpassing the levels of the control group.

Conclusion: The systematic educational program effectively improved health literacy, knowledge, and confidence levels among caregivers for managing CHD. The research shows that educational programs that provide specific guidance led caregivers to gain more control over child healthcare needs, thus producing better care.

Keywords: Caregiver education, congenital heart disease, health literacy, pediatric chronic conditions, caregiver confidence, educational intervention.

Introduction

Health literacy refers to an individual's ability to obtain, process, and understand basic health information to make appropriate health decisions. In the context of pediatric care, caregiver health literacy is critical, particularly when managing chronic and complex conditions such as congenital heart disease (CHD) (Liu et al., 2020). Pediatric nurses, trained professionals responsible for the care of children, play a vital role in educating and empowering caregivers (Machado Amazonas et al., 2023). Effective communication, education, and support provided by pediatric nurses can significantly influence a caregiver's ability to manage their child's condition at home. In this study, pediatric nurses are registered nurses with specialized training in child health (Srour-Alphonse et al., 2021). Caregiver health literacy refers to the functional capacity of parents or guardians to understand and implement health information, and congenital heart disease refers to a range of structural heart defects present from birth (Abrams, 2020).

Congenital heart disease is among the most common congenital disabilities globally, affecting approximately 1 in every 100 live births. According to the World Health Organization and various national registries, CHD contributes significantly to childhood morbidity and mortality, especially in low- and middle-income countries where access to specialized care is limited (Zimmerman et al., 2020). In South Africa and other resource-constrained settings, the burden is further exacerbated by delayed diagnosis, limited surgical interventions, and insufficient post-discharge support (Sliwa et al., 2020). As these children often require long-term home care involving medication administration, feeding modifications, and activity restrictions, caregivers' health literacy becomes a key determinant of outcomes (Deng et al., 2025).

Despite caregivers' critical role in home management, many lack the necessary understanding and confidence to follow through with complex care routines (Coskun & Bagcivan, 2021). Studies show that low health literacy is associated with poor adherence to medical regimens, increased hospital readmissions, and reduced quality of life for the patient and the family (Morley & Levin, 2021). Pediatric nurses are strategically positioned to bridge this gap by providing tailored education, reinforcing health messages, and assessing comprehension. However, research on their specific role in enhancing caregiver health literacy, especially in CHD, remains limited (Pourhabibi et al., 2022).

Pediatric nurses can conduct structured education sessions, use visual aids, and apply teach-back methods to confirm caregiver understanding. They also serve as consistent sources of information and emotional support, strengthening the caregivers' capacity for informed decision-making (Hamlet, 2022). Moreover, nurses can identify barriers to understanding, such as language, cultural beliefs, and emotional stress, and adapt their teaching accordingly (Frey et al., 2021). These interventions are especially vital during discharge planning and follow-up visits, where caregivers transition from hospital-dependent care to home-based management (Zhou et al., 2021).

Incorporating health literacy assessments into routine pediatric nursing practice can also help in the early identification of at-risk caregivers (Hogan et al., 2024). Standardized tools such as the Rapid Estimate of Adult Literacy in Medicine (REALM) or the Newest Vital Sign (NVS) can assess comprehension levels and guide educational strategies (Whelan, 2020). This proactive approach empowers caregivers and fosters continuity of care, reducing the risk of complications and improving child health outcomes. Moreover, it aligns with family-centered care principles, emphasizing collaboration between healthcare providers and families (Sullivan, 2024).

While some training programs and clinical guidelines acknowledge the need for caregiver education, they often lack detailed protocols for enhancing health literacy (Dewan et al., 2024). As a result, the role of pediatric nurses in this domain is usually informal, unstructured, and inconsistently implemented (Sin, 2024). Addressing this gap requires further research into effective nurse-led interventions, outcomes measurement, and caregiver feedback mechanisms.

A structured and evidence-based approach could lead to standardized practices that improve consistency and effectiveness in health education (Pereira, 2025).
This study, therefore, seeks to explore and define the role of pediatric nurses in enhancing caregiver health literacy for the effective home management of children with congenital heart disease (Meyer et al., 2020). The research aims to contribute to the development of standardized, nurse-led educational interventions by investigating current practices, identifying successful strategies, and assessing perceived challenges. This work has the potential to significantly improve caregiver preparedness, child health outcomes, and the overall quality of pediatric nursing care in both hospital and community settings.

Methodology

This study employed a quasi-experimental design to evaluate the role of pediatric nurses in enhancing caregiver health literacy for the effective home management of children with congenital heart disease (CHD). The quasi-experimental design was chosen as it allows for the assessment of cause-and-effect relationships between the nursing intervention and caregiver outcomes in a real-world clinical setting, without randomization. The study was conducted at the Peshawar Institute of Cardiology, a tertiary care facility with specialized pediatric cardiology services, from January to April 2025.
The study population included primary caregivers of pediatric patients diagnosed with congenital heart disease and admitted for medical or surgical management. A total of 60 caregivers were selected through purposive sampling and divided into two groups: the intervention group (n=30), which received structured health literacy education from pediatric nurses, and the control group (n=30), which received standard discharge instructions without the structured intervention. Inclusion criteria included caregivers of children aged 0–14 years with a confirmed diagnosis of CHD, fluency in Urdu or Pashto, and willingness to participate. Caregivers of critically ill patients in intensive care or those with cognitive impairments that hindered comprehension were excluded.
The intervention comprised a structured health literacy program designed and delivered by trained pediatric nurses. The program included three interactive sessions: one-on-one education using illustrated booklets, a teach-back technique to confirm understanding, and a checklist-guided discussion on medication, feeding, signs of deterioration, and follow-up care. Nurses were trained through a two-day workshop before implementation. The intervention was delivered during the child's hospital stay, with reinforcement at discharge.

Data Collection Procedure

Data collection tools included a demographic questionnaire and the Newest Vital Sign (NVS) tool, a validated instrument for assessing functional health literacy. Additionally, the research team developed a caregiver knowledge questionnaire specific to CHD home management and validated by pediatric cardiologists and senior nurses. Pretest data were collected before the intervention, and posttest data were collected at discharge and one week after the follow-up visit.

Data Analysis Procedure

Data were analyzed using SPSS version 26. Descriptive statistics (mean, standard deviation, frequencies, and percentages) were used to summaries demographic data. Paired t-tests and independent t-tests were applied to compare pre- and post-intervention scores within and between the groups. A p-value of less than 0.05 was considered statistically significant.

Ethical approval

Ethical approval was obtained from the Institutional Review Board of the Peshawar Institute of Cardiology. Written informed consent was obtained from all participants. Confidentiality

and anonymity were maintained, and participants were assured that their decision to participate or withdraw at any stage would not affect the care they received.

Results and Analysis

Demographic Characteristics of Caregivers

Both study groups contained caregivers with comparable background features. In both groups, caregivers had different ages, with those using the intervention program being thirty-four point five years old on average. In comparison, control group members averaged thirty-five point two years. The intervention and control groups contained similar percentages of female caregivers since the intervention had 70% women and the control had 73.3% women. Many caregivers were mothers, as 80% in the intervention group and 83.3% in the control group showed this pattern, and most caregivers completed high school education. (Table 1).

Table 1: Demographic Characteristics of Caregivers (N = 60)

Characteristic	Intervention Group (n=30)	Control Group (n=30)
Mean Age of Caregivers	34.5 ± 6.8 years	35.2 ± 7.1 years
Gender (Female)	21 (70%)	22 (73.3%)
Education (≥ High School)	19 (63.3%)	18 (60%)
Employment Status	10 (33.3%)	12 (40%)
Relationship to Child	24 (80%) Mothers	25 (83.3%) Mothers

Pre and Post-Intervention Health Literacy Scores

Health literacy test scores of participants in the intervention group significantly increased following the program, as they scored 2.8 ± 1.1 initially but reached 5.4 ± 0.6 post-intervention, resulting in a p-value of < 0.001 for statistical significance. The control group participants maintained their health literacy scores across tests, demonstrating no statistically important differences through their pre-test score average of 2.9 ± 1.2 and post-test score average of 3.1 ± 1.3 (p-value of 0.31). The intervention proved effective because it improved health literacy scores. (Table 2).

Table 2: Pre- and Post-Intervention Health Literacy Scores (NVS Tool)

Group	Pre-test Mean ± SD	Post-test Mean ± SD	p-value (within group)
Intervention	2.8 ± 1.1	5.4 ± 0.6	**< 0.001**
Control	2.9 ± 1.2	3.1 ± 1.3	0.31

Caregiver Knowledge Scores on CHD Management

The intervention participants demonstrated substantial growth in their knowledge about managing congenital heart diseases based on their pre-test score of 10.2 ± 2.3 that increased to 17.6 ± 1.8 post-test, yielding a p-value of < 0.001. The control participants maintained their baseline knowledge of congenital heart disease management over the study period based on pre-test and post-test mean scores that reached 10.4 ± 2.1 and 11.1 ± 2.0, along with a p-value of 0.09, showing no significant change. The results demonstrate that care providers learned effectively about managing congenital heart disease from the educational intervention. (Table 3).

Table 3: Caregiver Knowledge Scores on CHD Management

Group	Pre-test Mean ± SD	Post-test Mean ± SD	p-value (within group)
Intervention	10.2 ± 2.3	17.6 ± 1.8	**< 0.001**
Control	10.4 ± 2.1	11.1 ± 2.0	0.09

Comparison of Post-Intervention Outcomes Between Groups

Results from the post-test demonstrated substantial variations between participants in the intervention and control groups. The participants in the intervention group exhibited a

meaningful increase in their NVS health literacy scores (5.4 ± 0.6) than participants in the control group (3.1 ± 1.3) at a p-value of < 0.001. The CHD knowledge score revealed that the intervention group registered a mean score of 17.6 ± 1.8 points, whereas the control group achieved 11.1 ± 2.0 points with a p-value < 0.001. The intervention group showed higher mean confidence scores regarding home care at 4.6 ± 0.5 points than the control group at 3.2 ± 0.7 points, with $p < 0.001$ significance. Research data demonstrates that the implemented intervention improved health literacy, knowledge, and confidence significantly. (Table 4).

Table 4: Comparison of Post-Intervention Outcomes Between Groups

Outcome Measure	Intervention Mean ± SD	Control Mean ± SD	p-value (between groups)
NVS Health Literacy Score (Post-test)	5.4 ± 0.6	3.1 ± 1.3	< **0.001**
CHD Knowledge Score (Post-test)	17.6 ± 1.8	11.1 ± 2.0	< **0.001**
Confidence in Home Care (Self-rated 1–5)	4.6 ± 0.5	3.2 ± 0.7	< **0.001**

Discussion

Health literacy and knowledge about congenital heart disease management improved substantially for intervention group caregivers after they received educational materials. The intervention group experienced substantial health literacy score improvements according to $p < 0.001$, and their scores increased from 2.8 to 5.4. The caregivers demonstrated significant improvements in their knowledge of CHD management since the intervention started from an initial mean of 10.2 to 17.6 at $p < 0.001$. According to previous research, Al-Makhamreh et al., (2024) presented evidence confirming that health education customized for caregivers produces higher health literacy and enhanced pediatric health knowledge.

The control participants exhibited minimal adjustments in health literacy alongside CHD knowledge scores between pre and post-measurements, yet the findings were statistically insignificant according to p-values of 0.31 and 0.09. The research data demonstrates how the implemented intervention directly influenced participant outcomes when compared to the education levels of the control group, which remained minimal. The literature shows that delivering specialized educational resources brings superior outcomes than conventional instruction practices (Lautz et al., 2024). Results from this study indicate that targeted educational programs play an essential role in developing better caregiver knowledge and self-assurance.

The research discovered that caregivers self-assessed their home care abilities twice as confidently after group intervention. Their initial point evaluation was 3.2, yet it rose to 4.6 on a 5-point scale. The research data aligns with Joseph et al., (2023), who documented that caregivers who received chronic disease education displayed stronger capabilities in home child care. Health education that matches individual needs produces enhanced caregiver self-confidence for handling CHD, which remains vital for child health success when dealing with chronic conditions.

The research discovered that no substantial variations existed between the two groups based on demographic variables of age, gender make-up and educational backgrounds and familial ties to the children (Gonella et al., 2025). Since the groups share similar backgrounds, the initial group comparisons guarantee that researchers can link research outcomes to the intervention procedure. The outcome validity of the study results proves stronger because of this design feature El Refae et al., (2021). demonstrated through their work that demographic variables do not impact intervention results on caregiver knowledge and confidence levels, like the present study.

The research findings demonstrate that educational approaches substantially improve caregiver health literacy and disease-specific knowledge, enhancing their abilities to care for children

with chronic conditions. The study's reliability is affected by its usage of self-reported caregiver confidence measures, which might produce biased results. Reported data from clients is influenced by two bias factors: the desire to portray a good image and the difficulty in retaining details. Both factors may lead to the overestimation of their confident acting capacity. The intervention proved effective by significantly improving tested knowledge and health literacy attributes. Research from Walters et al., (2020) confirmed that health education helps caregivers acquire practical knowledge, even though their self-reported confidence data showed certain limitations.

Researchers compared this study's findings against other pediatric chronic health management interventions involving caregivers and presented similar outcomes. Through their research, Yang et al., (2022) demonstrated that health literacy interventions positively impacted caregivers' knowledge and management results by using structured and interactive methods, which this study adopted. These program-based educational efforts, which enhance caregiver health literacy alongside CHD knowledge, demonstrate their ability to empower caregivers, thus producing better quality care for children with CHD.

Conclusion

Researchers proved that specially designed educational sessions successfully enhanced caregiver capabilities to learn about CHD while providing effective home management skills for their affected children. Participants who received the educational intervention demonstrated significant advancements in their knowledge about CHD and home-based condition management skills, which resulted in statistical productivity. The control participants showed minimal growth because the focused educational method proved beneficial. The study shows caregivers need access to appropriate skills and information to treat children with CHD because it results in better patient outcomes.

Health education initiatives demonstrate their worth by improving caregiver abilities and self-assurance, thus enabling better home patient care and potentially leading to better child health results. Strong evidence from the research supports healthcare professionals in implementing this type of intervention across care settings because these programs enhance caregiver capabilities and result in better pediatric care delivery with chronic health conditions like CHD.

Recommendations

Multiple practice and research recommendations follow from the study findings:

1. Healthcare providers need to implement specific educational programs that mirror this study's approach for improving caregiver understanding of pediatric chronic conditions and their health literacy abilities.
2. Future research needs long-term follow-up assessments to determine how durable educational program effects are on caregivers' knowledge levels, confidence levels, and health literacy.
3. A wider investigation must study the full reach of caregiver education systems on child health status by measuring hospital stays, treatment adherence levels and life quality standards.
4. Future interventions need to adapt their approach for diverse caregiver populations, including cultural factors, literacy abilities, and resource accessibility levels.
5. The research implies that educational programs about chronic conditions should become part of regular pediatric healthcare services.
6. Research should analyze similar intervention methods for child caregivers who maintain children with different chronic illnesses to verify if these study results would extend across diverse medical conditions.
7. Standard assessment tools must be developed and established to measure caregiver comprehension and comfort when caring for pediatric illnesses.

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