Research Square

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Effectiveness of a Nurse-Led Transition Care Guidance on Caregiver Outcomes and Post-Discharge Care of Children with Congenital Heart Disease: A Mixed-Method Study

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Research Article

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Abstract

Background

Children with congenital heart disease (CHD) require continuous and complex care after hospital discharge. Hospital to home transition is the most vulnerable phase for both children and caregivers. After hospital transition caregivers independently have to perform all the care procedures for their children without any supervision, they experience challenges regarding difficulty managing symptoms, medications, and follow-up care during the transition from hospital to home. Structured transition care interventions led by nurses may improve caregiver preparedness and child health outcomes.

Aim

To evaluate the effectiveness of a nurse-led transition care guidance (NL-TCG) program in improving caregiver knowledge, self-efficacy, satisfaction, and post-discharge outcomes among children with congenital heart disease.

Methods

A mixed-method exploratory sequential design was used in a tertiary care hospital in eastern India. Phase I involved qualitative exploration using focus group discussions with nurses, paediatric consultants, and caregivers to identify challenges in transition care. Findings informed the development of a nurse-led transition care guidance intervention. In Phase II, a quantitative study was conducted among caregivers of children aged 0–3 years diagnosed with congenital heart disease. Consecutive sampling was used to recruit participants. The intervention included caregiver assessment, structured education and skill training, resource support, and telephone follow-up up to 60 days after discharge. Caregiver knowledge, self-efficacy, satisfaction, and child post-discharge outcomes were assessed using validated tools.

Results

The intervention group demonstrated a significant improvement in caregiver knowledge and self-efficacy scores after the implementation of NL-TCG compared to baseline and control groups ($p < 0.05$). Caregiver satisfaction with transition care services was also significantly higher among the intervention group. Additionally, improved post-discharge outcomes and reduced hospital readmissions were observed.

Conclusion

The nurse-led transition care guidance program effectively enhanced caregiver preparedness and improved transition care outcomes among children with congenital heart disease. Integrating structured nurse-led transitional care interventions in pediatric cardiac care may support safer hospital-to-home transitions.

Introduction

Congenital heart disease (CHD) refers to structural or functional abnormalities of the heart or great vessels that are present at birth and arise due to abnormal cardiac development during foetal life [1]. These abnormalities may involve defects in the heart walls, valves, or blood vessels and can affect normal blood circulation. Common forms of CHD include ventricular septal defect, atrial septal defect, patent ductus arteriosus, and Tetralogy of Fallot [2,3]. The severity of congenital heart disease varies from mild defects that require minimal intervention to complex conditions requiring lifelong medical management and surgical correction [4].

Globally, the prevalence of CHD is estimated to be approximately 8–10 per 1000 live births, accounting for nearly 1.35 million infants born with congenital heart defects each year [5]. In India, over 200,000 children are born with CHD annually, with a prevalence of approximately 8–9 per 1000 live births [5]. In Odisha study reported a prevalence of approximately 7.4 cases per 1000 live births among children evaluated for congenital heart disease. In this study, acyanotic congenital heart diseases constituted about 80% of cases, while cyanotic heart diseases accounted for approximately 18% [6].

Children diagnosed with congenital heart disease often require long-term medical follow-up and continuous care throughout childhood. Even after surgical correction or medical treatment, many children continue to require ongoing monitoring for complications, medication management, nutritional support, and regular clinical evaluations. As a result, the responsibility for day-to-day care largely shifts to parents or primary caregivers once the child is discharged from the hospital [7].

Preparing caregivers to effectively manage their child's condition at home is therefore a critical component of paediatric cardiac care. Caregivers must be able to administer medications correctly, manage feeding difficulties, maintain infection prevention practices, and recognize early warning signs of clinical deterioration. However, studies have shown that many parents feel insufficiently prepared to take these responsibilities after hospital discharge, which can lead to anxiety, uncertainty, and reduced confidence in caregiving abilities [8]. The period immediately following hospital discharge represents a particularly vulnerable transition phase for children with congenital heart disease and their families. During this transition from hospital to home, caregivers must adapt to new caregiving roles while managing complex health needs without continuous professional supervision. Inadequate discharge preparation, lack of caregiver education, and limited follow-up support during this period may increase the risk of complications, emergency visits, and hospital readmissions [9].

Structured transitional care interventions have been identified as effective strategies to address these challenges. Nurse-led transitional care programs typically include comprehensive caregiver education, practical skill training, written educational resources, and follow-up support through telephone calls or home visits. Such structured programs aim to enhance caregiver knowledge, improve self-efficacy in caregiving tasks, and ensure continuity of care after hospital discharge. Evidence suggests that these interventions can significantly improve caregiver preparedness and reduce preventable complications and hospital readmissions among children with chronic health conditions [10].

Therefore, current study aim to develop and implement a nurse-led transitional care guidance program (NLTCG) to bridge the gap between hospital care and home management for children with congenital heart disease. By strengthening caregiver knowledge, skills, and confidence, NLTCG can support safer transitions from hospital to home and improve overall health outcomes for children with congenital heart disease.

Methodology

Study Design

This study adopted a to develop and evaluate a Nurse-Led Transitional Care Guidance (NLTCG) program for caregivers of children with congenital heart disease. The study was conducted in two phases. The first phase involved qualitative phase to identify challenges faced by caregivers during the transition from hospital to home The second phase involved a quantitative study to evaluate the effectiveness of the developed intervention on caregiver outcomes.

Study Setting

The study was conducted in the pediatric medicine units of a tertiary care teaching hospital in eastern India. The hospital serves as a referral centre for paediatric cardiac conditions and caters to patients from various districts of the state.

Phase I: Qualitative Phase

Participants

Participants in the qualitative phase included paediatric consultants, staff nurses working in pediatric wards, and caregivers of children diagnosed with congenital heart disease.

Sampling Technique

A purposive sampling technique was used to select participants who had experience in caring for children with congenital heart disease or were involved in their clinical management.

Data Collection

Data were collected through focus group discussions (FGDs) using a semi-structured interview guide. The discussion guide included open-ended questions related to caregiving challenges, discharge preparation, information needs, and barriers experienced during the transition from hospital to home. Each focus group discussion lasted approximately 45–60 minutes and was audio-recorded with the consent of participants.

Data Analysis

The qualitative data were transcribed verbatim and analyzed using Braun and Clarke's thematic analysis method. The analysis involved familiarization with the data, coding of meaningful segments, identification of themes, reviewing and refining themes, and final interpretation. The findings from this phase guided the development of the Nurse-Led Transitional Care Guidance intervention.

Phase II: Quantitative Phase

Study Population

The study population consisted of caregivers of children diagnosed with congenital heart disease admitted to pediatric wards of the study hospital.

Sample Size

The sample size was calculated using the formula:

$n = 2SD^2 (Z\alpha/2 + Z\beta)^2 / d^2$

Based on the estimated effect size and standard deviation obtained from previous studies, the required sample size was 32 participants in each group.

Sampling Technique

A consecutive sampling technique was used to recruit eligible participants who met the inclusion criteria during the study period.

Inclusion Criteria

- • Caregivers of children aged 0–3 years diagnosed with congenital heart disease confirmed by echocardiography
- • Caregivers willing to participate in the study
- • Caregivers available for follow-up after discharge

Exclusion Criteria

- • Children with severe comorbid conditions other than respiratory illnesses
- • Children who had undergone previous cardiac surgery
- • Caregivers who were unable to participate in follow-up communication

Data Collection Tools

The data collection tools used in this study included a caregiver knowledge questionnaire, self-efficacy checklist, caregiver satisfaction tool, and a post-transition telephone follow-up assessment form. All tools were developed by the researchers based on an extensive review of literature and findings from the qualitative phase of the study. Content validity of the instruments was established by a panel of five subject experts in pediatric nursing and cardiology. The Content Validity Index (CVI) for all tools ranged between 0.90 and 1.00, indicating excellent validity. The final English versions of all tools are provided as Supplementary File 1.

Intervention: Nurse-Led Transitional Care Guidance (NLTCG)

The intervention consisted of four major components (Fig. 1).

1. Assessment

On the first day of admission, baseline assessment of the child’s clinical condition and caregiver’s knowledge and caregiving practices was conducted using structured assessment tools.

2. Education and Skill Training

Structured education sessions were provided to caregivers from the third day of admission until discharge. The sessions covered topics such as:

- • Basic understanding of congenital heart disease
- • Medication administration
- • Feeding management
- • Infection prevention
- • Recognition of warning signs and complications

Teaching methods included demonstration, re-demonstration, and the teach-back method to ensure caregiver understanding and skill acquisition.

3. Resource Support

Caregivers were provided with a home-care booklet containing detailed instructions on child care, medication schedules, warning signs requiring medical attention, and contact information for emergency support.

4. Telephone Follow-up

Post-discharge telephone follow-up was conducted at 15, 30, 45, and 60 days after discharge. The purpose of the follow-up calls was to reinforce caregiver education, address concerns, and monitor the child's health status.

Result

Development of the Nurse-Led Transition Care Guidance (NLTCG): Qualitative Findings

A total of 25 stakeholders, including caregivers of children with congenital heart disease, pediatric nurses, and pediatric consultants, participated in the qualitative phase of the study. Data were collected through focus group discussions and analyzed using inductive thematic analysis following Braun and Clarke's approach (Table 1).

The analysis generated codes, subthemes, and major themes representing the challenges faced by caregivers during the hospital-to-home transition phase.

Table 1
Themes and Sub-themes Identified from Qualitative Analysis

Themes	Sub-themes
Challenges in Medication Administration	Adherence to medicine schedule in Home Care Settings
Access to Healthcare Facilities	Access to Healthcare Facilities
Language Barriers and Communication Challenges	Language Barriers and Communication Challenges
Family Dynamics & Unavailability of support in child care	Family Dynamics & Unavailability of support in child care
Need for Follow-up & Post-discharge Support	Need for Follow-up & Post-discharge Support
Readiness for discharge	Readiness for discharge
Post discharge care continuity	Need for Culture congruent Discharge Instructions

Phase 2 : Quantitative Phase Findings

Table 2
Comparison of Mean Pre-Post Test Knowledge Scores between Control and Intervention Groups Using Independent t-test **(n = 32 + 32=64)**

Measurement Points	Group	Mean ± SD	df	t	p-value
Pre-test	Control	8.06 ± 3.29	62	5.336	0 .07
	Intervention	12.19 ± 2.88			
Post-test	Control	8.63 ± 3.61	62	15.831	
	Intervention	21.44 ± 3.04			0 .001

Table 2 shows Independent t-test result shows at baseline, the mean pre-test score of the intervention group was (12.19 ± 2.88) and of the control group was (8.06 ± 3.29). This difference was not statistically significant, *t(62) = 5.336, p = 0.07*. At post-test, the intervention group had a higher mean knowledge score (21.44 ± 3.04) compared to the control group (8.63 ± 3.61). The difference was highly significant, *t(62) = 15.831, p < 0.001*, indicating that the nurse-led transition care guidance was effective in improving caregivers' knowledge. Thus, H_o2 was rejected, indicating a significant improvement in caregiver knowledge following the intervention.

Table 3
Independent t Test for Pre-Post-Test Self-Efficacy Scores between Groups (n = 32 + 32=64)

Test	Group	Mean ± SD	df	t	p-value
Pre-test	Control	9.00 ± 5.80	62	0.63	0.06
	Intervention	10.0 ± 12.92			
Post-test	Control	9.47 ± 4.61	62	19.3	0 .001
	Intervention	39.28 ± 7.37			

# p < 0.05 considered statistically significant. df-degree of freedom

Table 3 shows In the pre-test, the mean self-efficacy score of caregivers in the intervention group (M = 10.0, SD = 12.92) was slightly higher than that of the control group (M = 9.00, SD = 5.80). However, the difference between the groups was not statistically significant (t(62) = 0.63, p = 0.06), indicating comparable baseline self-efficacy levels.

In the post-test, caregivers in the intervention group demonstrated a markedly higher mean self-efficacy score (M = 39.28, SD = 7.37) compared to the control group (M = 9.47, SD = 4.61). This difference was statistically significant (t(62) = 19.3, p < 0.001), indicating a significant improvement in self-efficacy among caregivers who received the intervention.

Figure 2 shows in the control group 90.6% reported only moderate satisfaction, and only 9.4% reported high satisfaction. In the intervention group 40.6% reported moderate satisfaction, while the 59.4% reported high satisfaction

Table 4
Adherence to Follow-Up Visits Between Groups (n = 32 + 32=64)

Follow-up Type	Control Group (n = 32)	Intervention Group (n = 32)
Scheduled visits	32 (100%)	32 (100%)
Unscheduled visits	10 (31.3%)	3 (9.4%)

Table 4 shows all participants in both groups attended the scheduled follow-up visits (100% adherence). However, the number of unscheduled visits was higher in the control group (10/32, 31.3%) compared to the intervention group (3/32, 9.4%). This indicates that the intervention was effective in reducing unplanned visits, reflecting better caregiver preparedness and confidence in managing the child at home

Figure 3:**-post-discharge health service utilization between the control group** and

intervention group

Figure 4 presents the distribution of readmissions within 30 and 60 days post-discharge among the control and intervention groups. In the control group, 21.9% of children were readmitted within 30 days and 9.4% within 60 days. The intervention group had fewer early readmissions, with only 2.4% within 30 days, while 9.6% occurred within 60 days,

Discussion

The present study developed and evaluated a Nurse-Led Transition Care Guidance (NL-TCG) model to improve hospital-to-home transition among caregivers of children with congenital heart disease. The model incorporated structured education, skill training, teach-back evaluation, and post-discharge telephone follow-up to enhance caregiver preparedness. These components are consistent with established transitional care approaches such as Naylor's Transitional Care Model, the Care Transitions Intervention, and Project RED, which emphasize early assessment, caregiver education, and continuity of care. However, unlike these predominantly adult-focused models, the NL-TCG model was tailored to paediatric care by emphasizing caregiver skill-building, repeated demonstrations, and structured telephonic follow-up rather than home visits.

The findings demonstrated a significant improvement in caregivers' knowledge following the intervention, with 67.5% achieving satisfactory levels, whereas no improvement was observed in the control group. This is consistent with previous studies where structured discharge education significantly improved caregiver knowledge. For instance, studies among mothers of NICU-discharged infants and neonatal care programmes reported significant increases in post-test knowledge scores ($p <$

0.001) (11, 12) Similarly, studies involving caregivers of children with congenital heart disease showed significant improvement in mastery scores following structured discharge education (13, 14). The BRIDGE programme also demonstrated higher maternal knowledge levels compared to controls (15), while a study in Iran reported highly significant improvements in caregiver knowledge post-intervention (16). These findings collectively reinforce that structured, individualized education, as implemented in the NL-TCG model, is effective in enhancing caregiver understanding.

In addition to knowledge, caregiver self-efficacy improved markedly in the intervention group, with most caregivers progressing from poor to satisfactory or excellent levels. This finding is supported by previous studies demonstrating improved caregiver competence following transitional care interventions. A quasi-experimental study in Southern India reported significant improvements in caregiving practices ($p < 0.001$) (17), while the BRIDGE programme showed significant enhancement in caregiver skills (180. Similarly, the STEPSTONE randomized controlled trial reported improvements in parental involvement and disease-related knowledge (19). Other studies have also demonstrated substantial gains in caregiving competence and behaviour following structured education and follow-up support (20, 21, 22). Evidence from caregiver training programmes, including those conducted in Kolkata, further supports sustained improvements in caregiver activation and confidence post-discharge (23). Additionally, post-discharge telephone follow-up has been shown to significantly improve self-efficacy scores (24), highlighting the importance of continued support, a key component of the NL-TCG model.

Caregiver satisfaction was significantly higher in the intervention group, reflecting improved discharge readiness, communication, and adequacy of information. These findings align with previous studies demonstrating that structured discharge planning enhances caregiver satisfaction. A randomized controlled trial reported significantly higher maternal discharge readiness following structured interventions (25), while hospital-to-home transition programmes also showed improved readiness scores (26). Family-Centred Care interventions have similarly demonstrated significant increases in satisfaction levels (27), and Train-to-Home programmes have highlighted improved caregiver understanding and preparedness (28). Furthermore, studies have shown that post-discharge follow-up communication significantly enhances satisfaction, and structured discharge instruction programmes have reported high satisfaction scores among caregivers (29, 30). These findings support the role of individualized education, clear communication, and follow-up in improving caregiver satisfaction, as observed in the present study.

Importantly, the NL-TCG model resulted in significant improvements in post-discharge outcomes, including reduced new symptoms, fewer home-care difficulties, and decreased healthcare utilization. The intervention group demonstrated lower rates of unscheduled visits and readmissions, including early readmissions, indicating improved caregiver preparedness and effective home management. These findings are consistent with studies reporting improved caregiver confidence and reduced readmissions following structured discharge interventions (31, 32). A Swedish study demonstrated significantly lower readmission rates post-intervention, while studies in South West England and other settings reported reductions in emergency visits and readmissions following discharge programmes (32). However, some

studies have reported non-significant reductions in readmissions (33), which may be attributed to the absence of structured education or limited follow-up. Overall, the findings suggest that the NL-TCG model is an effective and feasible intervention for improving caregiver knowledge, self-efficacy, satisfaction, and post-discharge outcomes. By integrating structured education, skill-based training, teach-back validation, and follow-up support, the model addresses critical gaps in transition care and provides a comprehensive strategy to reduce preventable complications and healthcare utilization among children with congenital heart disease.

Abbreviations

CHD
Congenital Heart Disease
NL-TCG
Nurse-Led Transition Care Guidance

Declarations

Ethical Statement

Ethical approval for this study was obtained from the Institutional Ethics Committee of AIIMS,Bhubaneswar.All methods were carried out in accordance with relevant guidelines and regulations. Written informed consent was obtained from all participants prior to participation in the study.

Consent for publication

Not applicable.

Data Availability Statement

The datasets generated and/or analyzed during the current study are not publicly available due to institutional restrictions but are available from the corresponding author on reasonable request and with permission from the Institutional Ethics Committee.

Competing interests

The authors declare that they have no competing interests.

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Author Contributions

SRP: Conceptualization, writing original draft & editing.

APS: Conceptualization, Supervision,Review

BD: Conceptualization, Supervision,Review

Trial Information

(CTRI Reg.No-CTRI/2023/07/054787),Reg.Date-07.05.2023

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Figures



Figure 1

Nurse-Led Transition Care Guidance Model (NL-TCG)

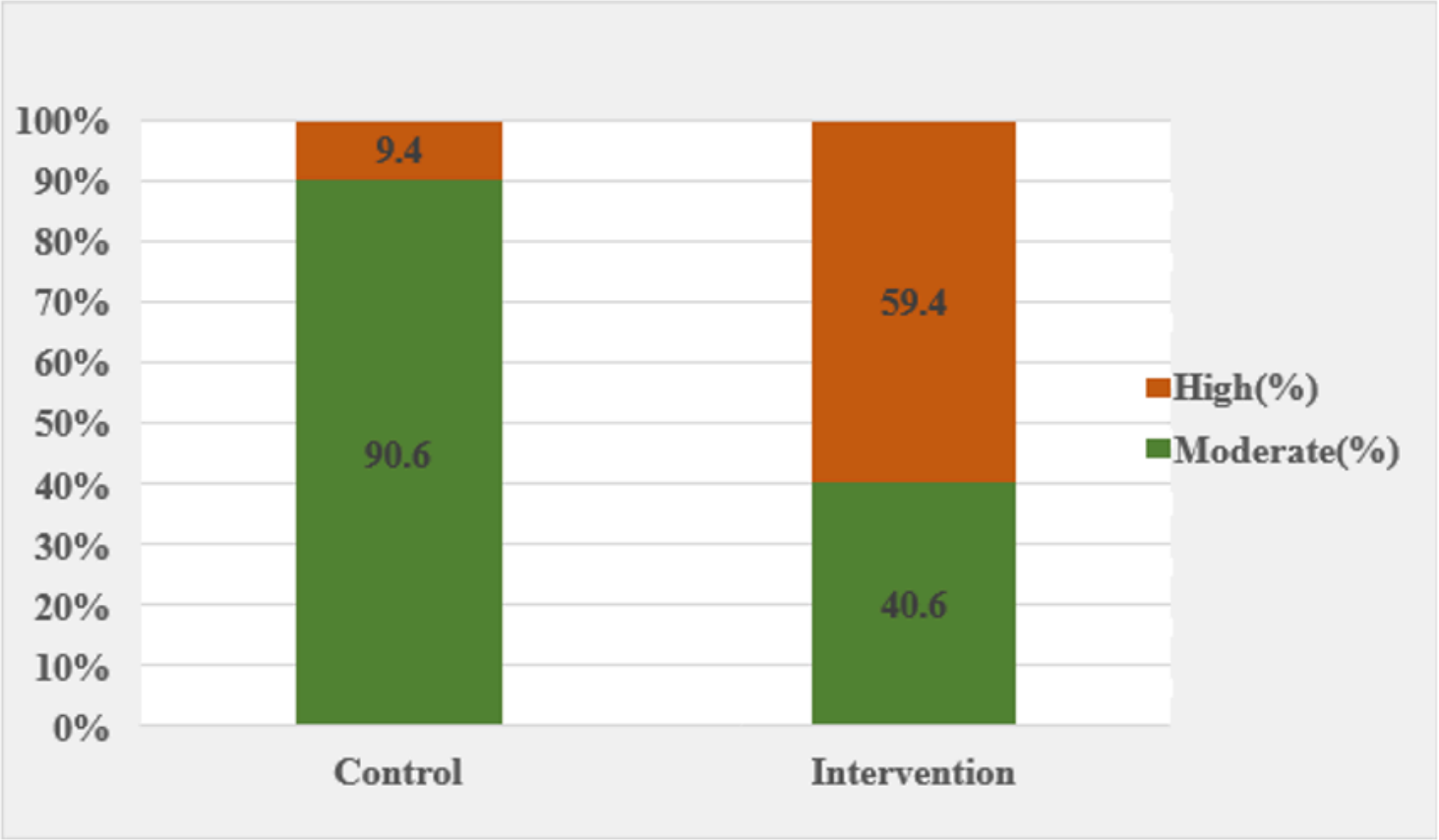


Figure 2

Comparison of Overall Satisfaction Levels Between Control and Intervention Groups

shows in the control group 90.6% reported only moderate satisfaction, and only 9.4% reported high satisfaction. In the intervention group 40.6% reported moderate satisfaction, while the 59.4% reported high satisfaction

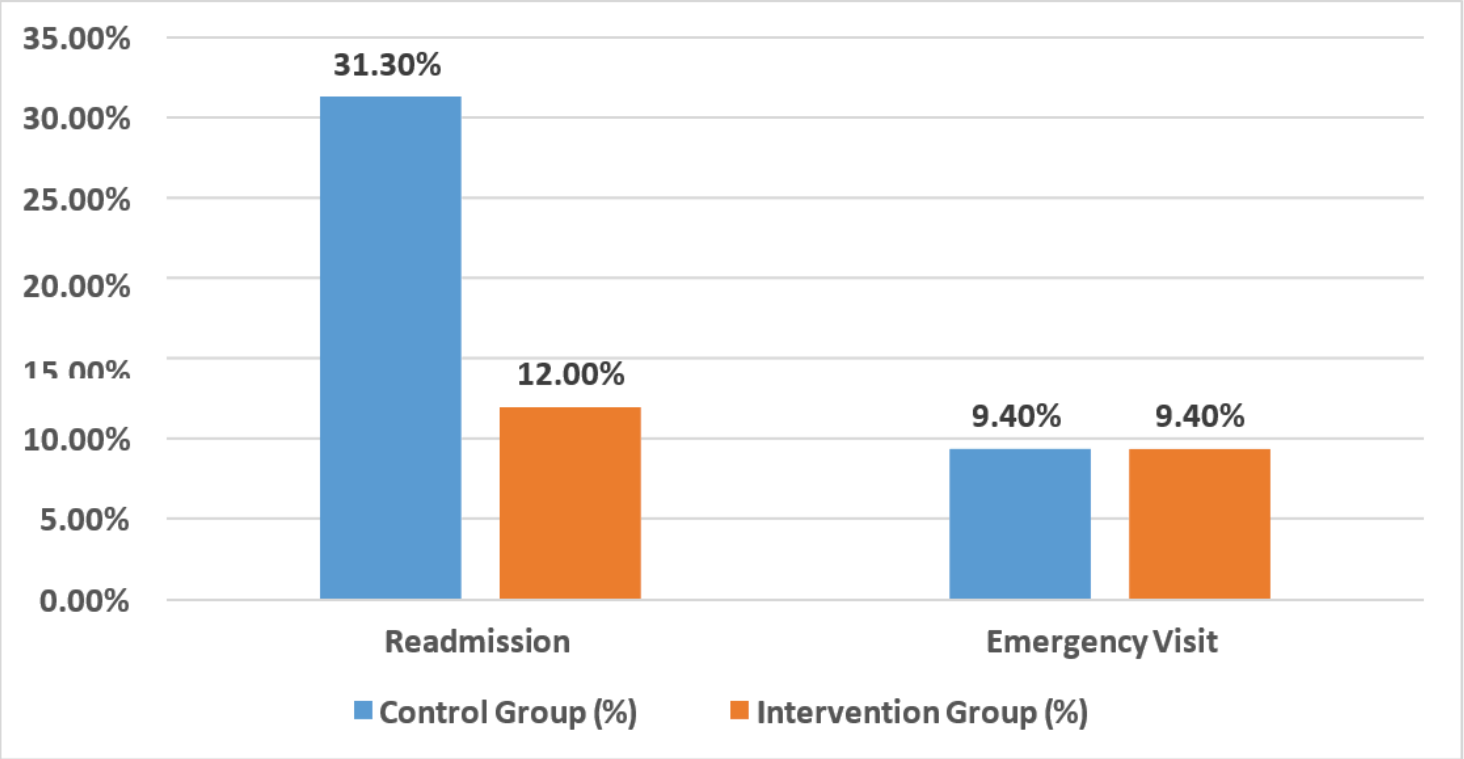


Figure 3

post-discharge health service utilization between the control group and **intervention group**

shows the percentage of caregivers in the control and intervention groups who utilized post-discharge health services, including readmissions, emergency visits, and unscheduled OPD visits. The control group had higher utilization across all categories compared to the intervention group. Specifically, readmissions were 31.3% in the control group versus 12% in the intervention group**,** emergency visits were equal at 9.4% in both groups.

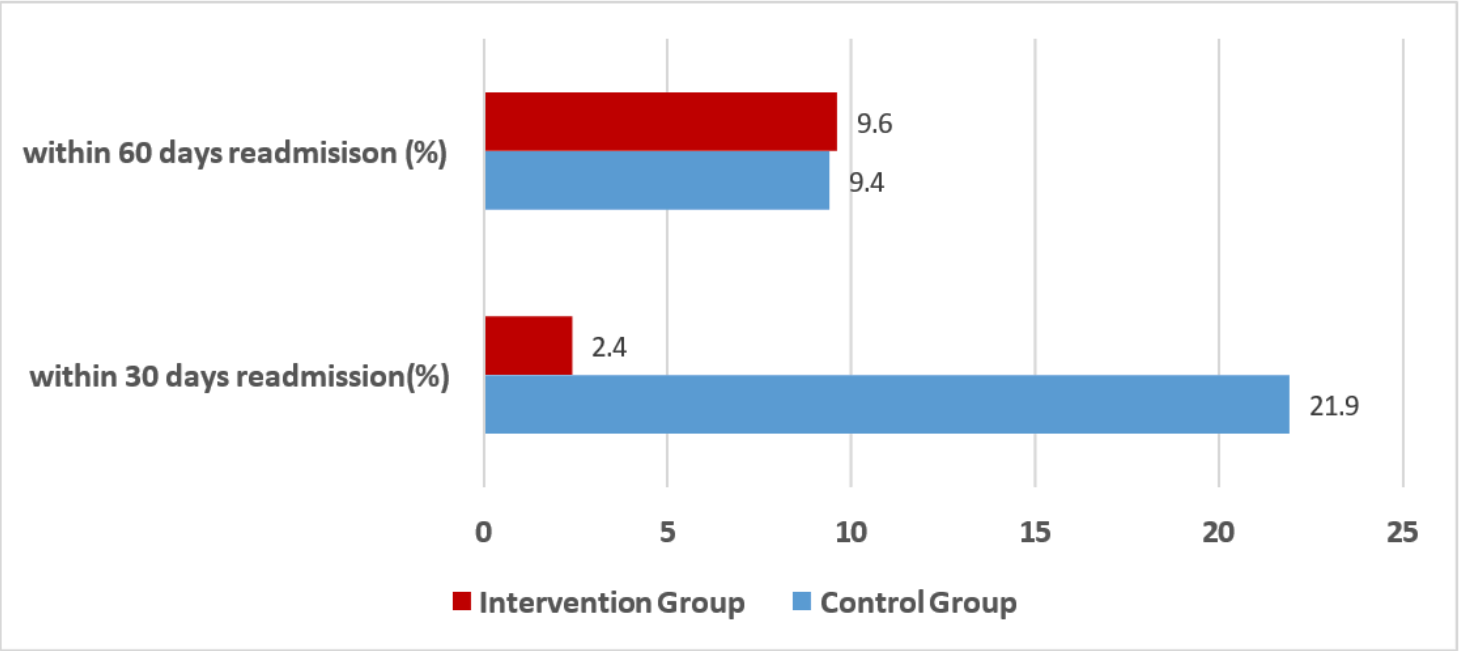


Figure 4

Distribution of Readmissions within 30 and 60 Days Post-Discharge

presents the distribution of readmissions within 30 and 60 days post-discharge among the control and intervention groups. In the control group, 21.9% of children were readmitted within 30 days and 9.4% within 60 days. The intervention group had fewer early readmissions, with only 2.4% within 30 days, while 9.6% occurred within 60 days,

Supplementary Files

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