

# “Discharge Program on Post-Operative Care of Infants Undergoing Cardiac Surgery; Evaluation of Its Effect on Parents and Infants”

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## Abstract

**Background:** Children with critical congenital heart diseases (CHD) need surgery or catheter interventions within one year of life to survive. Open heart surgeries are high-risk procedures that require long term follow-up. The parents of infants must be knowledgeable and confident to provide care for their child even after discharge. The present study aimed to administer a Multi-Component Intervention Program (MCIP) regarding the care of infants after cardiac surgery and to assess the effectiveness of MCIP on knowledge, confidence, level of satisfaction of parents and patient care outcomes among infants undergoing cardiac surgery.

**Materials and Methods:** A quasi-experimental study was conducted among 48 parents and their infants who underwent cardiac surgery. The knowledge and confidence of parents were assessed with structured questionnaire and rating scale before and after MCIP administration. Before discharge, the level of satisfaction of parents was evaluated. A month after discharge, patient care outcomes (Weight for age Z (WAZ) score were assessed.

**Results:** The study showed a significant improvement in the knowledge score ( $p < 0.001$ ) and confidence score ( $p < 0.001$ ) of parents after the administration of MCIP. The majority of parents (79%) were satisfied with the program administered. The mean WAZ score of infants significantly improved ( $p < 0.05$ ) after one month of discharge.

**Conclusion:** The results signify the importance of having a structured discharge program to improve the quality of care of infants after cardiac surgery and to ensure continuity of care after discharge.

**Keywords:** Cardiac Surgery, Infants, Multi-Component Intervention Program

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## I. Introduction

Congenital heart disease (CHD) is defined as “a gross structural abnormality of the heart or intra thoracic great vessels that is actually or potentially of functional significance”<sup>1</sup>. CHD is the most common birth defect<sup>2</sup>, causing significant mortality within one year of life<sup>3,4</sup>. In India, CHD has a birth prevalence of 8.07/1000 live birth, similar to the worldwide birth prevalence reported. Children with critical CHD need surgery or catheter interventions within one year of life to survive<sup>2</sup>. Recent advancements in pediatric cardiology and cardiac surgery enable to repair or palliate the most of the CHD including the critical ones<sup>5</sup>. The diagnosis of CHD in infants gives rise to emotional distress and anxiety among the parents<sup>6</sup>. These infants are more subjected to recurrent hospitalization for respiratory tract infection, cardiac failure, cyanotic spells before surgery which resulted in psychological distress among families and consume health care resources. CHD repair is also associated with morbidities which are re-intervention, heart failure, rhythm abnormality, neuro-developmental delay, enduring medication requirement, and poor quality of life<sup>7</sup>. Even after a successful cardiac surgery many factors like the complexity of congenital heart defect, the age of the child, nutritional status of the child before surgery, the operating room events, and the quality of care during the post-operative period can affect the recovery<sup>8</sup>. Even though clinicians provide information regarding the morbidities of children after cardiac surgery to their parents, high levels of anxiety, stress and quality of clinician-parent communication can detrimentally affect parental ability to understand the information<sup>9</sup>. Consistent and effective communication

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with parents and involvement in decision making will reduce stress and anxiety<sup>10</sup>. The nurses play an important role in the care of infants undergoing cardiac surgery. Nursing care of infants and education of parents can help to enhance the quality of care.

A systematic review revealed parents of children with critical CHD are at high risk for mental health problems, especially in the immediate weeks and months following cardiac surgery<sup>11</sup>. This may lead to a defective parenting style that interferes with their children’s growth and development<sup>12</sup>. So parents need reliable information that is easy-to-understand regarding disease condition, its prognosis, medications, growth and development, feeding and nutrition, wound care, activity and follow-up which is required to provide care for infants at the hospital and home setting<sup>13</sup>. **Staveski et al 2015**<sup>14</sup> implemented Parent Education Discharge Instructions (PEDI) to educate the bedside nurses to understand the significance of discharge education and equip them with a structured approach of conducting education for the parents regarding the home care of postoperative cardiac surgery children. PEDI programs were conducted with educational materials for literate and low-literate parents and a computer-based program for nurses. The Nurse-led structured discharge teaching program was effective and found to be feasible, accessible and utilizable in the pediatric cardiac surgery unit in India<sup>15</sup>.

In this study parental confidence means parental trust in one’s own abilities to provide care for his/her infant<sup>16</sup>. If a mother lacks confidence in her abilities to care for the infant, it may negatively affect the child’s health<sup>17</sup>. According to a previous study, the more confidence a mother had, the better her knowledge and skills regarding the care of her newborns, which led to positive effects on the weight of the babies<sup>18</sup>. There is evidence that nursing education helped to increase maternal confidence when caring for infants who had congenital heart defects<sup>19</sup>.

Corrective surgeries for CHDs are high-risk procedures that need appropriate postoperative care. Surgery and postoperative ICU stay, separate the infant from parents leading to insufficient confidence in their ability to provide care for their infants<sup>18</sup>. As parents of young children undergoing heart surgery, they often experience significant distress, making it difficult for them to remember and comprehend the medical and nursing information being provided<sup>20</sup>. Consequently, one-time teaching of parents may not suffice to improve their knowledge and confidence in caring for their children. At a tertiary hospital, the workload of health care members makes it difficult to teach the parents repeatedly. The caregivers of the infants at the hospital are exhausted and this limits their receptivity to information. Thus, a multi-component intervention program (MCIP) on home care management administered during the hospital stay can help the parents feel more confident in caring for their babies. MCIP covers information regarding congenital heart surgery, Incision care, feeding and nutrition, activities, immunization, medication administration, prevention of infection, detection of complication, monitoring milestones and importance of follow up.

For our knowledge there were a limited number of studies regarding home care management of infants following cardiac surgery in India. Therefore, the aims of this study were to determine the effectiveness of MCIP on knowledge, confidence and level of satisfaction of parents and patient care outcomes.

## **II. Materials And Methods**

A quasi experimental one group pre-test post-test design was employed for the study. The ethical approval was received from the institutional ethical committee (Ref No. IECPG-263/24.3.2021). Informed written consent was taken from the parents after full explanation about the study. The protocol was registered at the clinical trials registry of India (CTRI/2021/05/033486). Data was collected from 48 parents of infants underwent cardiac surgery at a tertiary hospital at Delhi using a purposive sampling method. The sample size was calculated by *Statulator online tool*<sup>21</sup> specifying discordant proportions as knowledge. Pairs to achieve a power of 80% and a two-sided significance of 5% for detecting a difference of 0.35 between the discordant proportions and by assuming an attrition rate of 10%, the total sample size required for the study was 48.

The infants aged below 12 months who underwent cardiac surgery at AIIMS, New Delhi and their parents were included in the study. Infants with chronic diseases other than congenital heart diseases and syndromic diseases and who underwent palliative surgery for congenital heart diseases were excluded from the study. Parents who cannot follow instructions and the parents having another child who had undergone cardiac surgery also had excluded from the study.

On the first day of transfer of children from cardiothoracic ICU to ward, the baseline data of parents and infants were collected. Multi-component intervention program was administered for three days from day 2. The total duration of the MCIP was 2 hours. MCIP includes various components like an overview of congenital heart diseases and surgery, incision care, feeding and nutrition, activities, immunization, medication administration, prevention of infection, detection of complication, monitoring milestones, importance of follow up. To facilitate efficient and uniform teaching a video was developed in local language including incisional care, medication administration, hand washing, assessment of temperature and respiration. PowerPoint presentations were used to teach other components. The MCIP was validated by one pediatric cardiologist, 1

cardiologist and 3 nursing experts. MICP video was sent to parents' WhatsApp number for further reference after discharge from hospital. Parents were asked to contact the researcher if they have any queries.

The outcome variables were the knowledge, confidence and level of satisfaction of parents and patient care outcomes including weight for age Z score (WAZ), mortality within 30 days of discharge, frequency of utilization of clinical services.

The tools used for the study were

#### **Tool I: Knowledge questionnaire**

Structured Knowledge questionnaire was used to assess the knowledge of parents regarding the care of infants after cardiac surgery. Each correct answer was given a score of one. The maximum score of the questionnaire was 20 and the minimum score was 0. The criterion measured as follows-

- Excellent: Knowledge score between 15-20 ( $\geq 75\%$ )
- Good: Knowledge score between 10-14 (50-75%)
- Inadequate: Knowledge score below 10 ( $< 50\%$ )

The questionnaire was found to be reliable with Cronbach's Alpha value of 0.768.

#### **Tool II: Parental confidence rating scale.**

The Karitane Parenting Confidence Scale (KPCS) is a standardized tool designed to assess the confidence of parents in their abilities to provide care for infants. The KPCS administered during transfer of infants to the ward after cardiac surgery and repeated at the time of discharge. This method helped to understand the confidence of parents achieved during the time of hospital stay. This also identified an area where parents will need more support to care for their babies<sup>16</sup>.

The possible score range is 0–45, with high scores being favorable. The KPCS had an internal consistency with Cronbach's alpha (0.81), test-retest reliability (0.88), and discriminant and convergent validity. The rating scale was pilot tested on 5 parents, with a Cronbach's Alpha value of 0.815.

#### **Tool III: Likert scale for assessing the level of satisfaction of parents**

A self-developed structured Likert scale was used for assessing the level of satisfaction of parents on multi-component intervention program regarding the care of infants after cardiac surgery. The satisfaction scores were graded as satisfied ( $\geq 80\%$ ), not satisfied ( $< 80\%$ ). Reliability of the Likert scale was established by the split-half method (Guttman split-half coefficient=0.954).

#### **Tool IV: Proforma for patient care outcomes.**

It included self-developed proforma to assess the patient care outcomes. Proforma consisted of the weight of the infant one month after discharge, mortality within 30 days of discharge and the frequency of utilization of clinical services.

##### **a. Weight-for-age Z (WAZ) score**

The weight of the infant was checked by a calibrated weighing machine. Weight-for-age Z scores (WAZ) was calculated with WHO Anthro software version 3.2.2, January 2011, (World Health Organization, Geneva, Switzerland) available from <http://www.who.int/childgrowth/en>.

##### **b. Frequency of utilization of clinical services**

Information was collected from parents regarding the required number of OPD visits, emergency visits, admission, consultation with a nearby hospital, telephonic nursing assistance required within 1 month after discharge from the hospital.

##### **c. Mortality within 30 days of discharge**

The number of infant deaths that occurred during one month follow-up period was identified.

#### **Data collection Procedure:**

- ❖ The infant and their parent were screened on the day of transfer to the cardiac ward after surgery.
- ❖ A good rapport was established with parents and infants.
- ❖ Written informed consent was taken from the parents after explaining the purpose of the study and assuring confidentiality.
- ❖ Socio-demographic proforma and clinical profile filled by direct questioning and

from the medical records.

- ❖ The knowledge assessment questionnaire and confidence rating scale were administered on day 1 with the help of tool II and tool III. Both tools took 10 minutes to be completed.
- ❖ Multi-component intervention program was administered for three days from day 2. The total duration of the program was 2hour.
- ❖ Knowledge, confidence and satisfaction of parents were assessed with the help of tool II, tool III, and tool IV respectively. Parents took 10 minutes to complete each tool.
- ❖ The entire filled questionnaire was coded and named properly.
- ❖ MICP video was sent to parents' WhatsApp number for further reference after discharge from hospital. Parents were asked to contact the researcher if they have any queries.
- ❖ After one month during the follow-up visit to OPD, the weight of the infants were monitored and other outcomes were assessed by direct questioning to the parents.

**Data analysis:**

The data collected were first coded and summarized in the master data sheet. Analysis was done based on the objectives of the study. STATA version 14 was used to analyze the data using descriptive statistics (mean, median, frequency, percentage and standard deviation) and inferential statistics (paired t-test, chi-square test, fisher’s exact test).

**III. Results**

The mean age of the parents was  $27.98 \pm 5.05$  years. Mothers make up the majority of parents (85.42%), and 87.50% of parents were Hindus. 47.92% of parents were educated up to intermediate level. The majority of parents were unemployed (66.7%), and some of them (39.58%) had a monthly family income between ₹ 20,001-30,000. The majority of parents (89.59%) didn’t receive any information regarding infant care. Only 22.02% of the parent had consanguineous marriages. 95.83% of the family had no history of congenital heart disease (Table-1).

**Table-1: Frequency and percentage distribution of demographic characteristics of Parents.**  
n =48

Socio-demographic variable	Frequency (%)
<b>Age in years (Mean ± SD)</b>	27.98 ± 5.05
<b>Relationship with infant</b>	
Mother	41(85.42)
Father	7(14.58)
<b>Religion</b>	
Hindu	42(87.50)
Muslim	6(12.50)
<b>Educational status</b>	
Graduate or postgraduate	17(35.41)
High school/intermediate/diploma	23(47.92)
Illiterate/primary school	8(16.67)
<b>Occupation</b>	
Government Job	4(8.34)
Private job	8(16.67)
Business/self-employed	4(8.33)
Unemployed	32(66.67)
<b>Monthly family income in rupees</b>	
≤10,000	4(8.33)
10,001-20,000	17(35.42)
20,001-30,000	19(39.58)
30,001-40,000	1(2.08)
40,001-50,000	4(8.33)
≥50,001	3(6.25)

<b>Source of information regarding infant care*</b> Doctors Nursing officers No information	4(8.33) 6(6.25) 43(89.58)
<b>Consanguineous marriage</b> Yes No	11(22.92) 37(77.08)
<b>Family history of CHD</b> Yes No	2(4.17) 46(95.83)

*\*More than one source were reported by mothers*

The total mean knowledge score before and after administration of MCIP was 12.33±2.94 and 17.42±2.10 respectively. Paired t-test showed this difference in mean knowledge score was statistically significant (p-value <0.001) with a t value of -11.90. Thus, it can be interpreted that, with the administration of MCIP, parental knowledge regarding the care of infants after cardiac surgery has significantly improved. (Table-2).

**Table-2: Comparison of Knowledge scores of parents regarding the care of infant after cardiac surgery before and after administration of MCIP.**

Variable	Pre-test		Post-test		p-value
	Mean±SD	Range	Mean±SD	Range	
<b>Knowledge</b> Min Score=0 Max Score=20	12.33±2.94	4,18	17.42±2.10	11,20	<0.001* (t = -11.9)

**n=48**

*\*significant at p value<0.001*

*paired t test*

The mean total confidence score of parents regarding the care of infants before administration of MCIP were 30.15±6.79 which were increased significantly (p<0.001) to 36.96±5.29 with a t value of -6.14 (Table-3).

**Table-3: Comparison of confidence score of parents before and after implementation of MCIP**

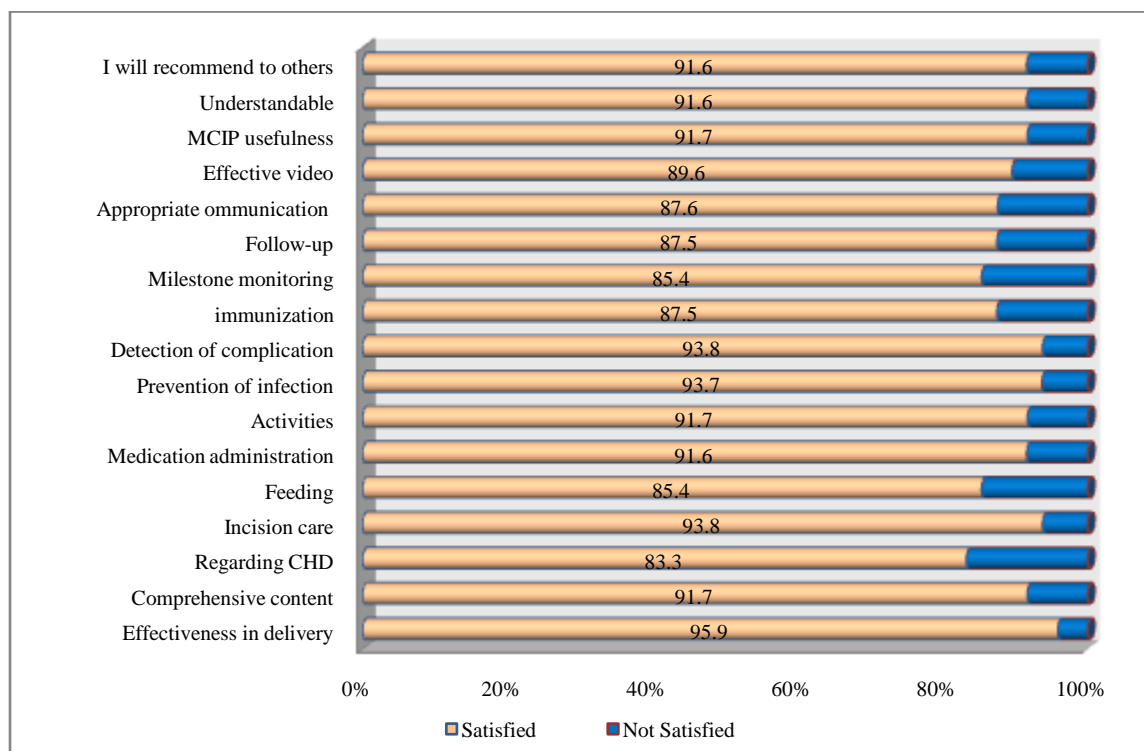
Variable	Pre-test		Post-test		p-value
	Mean ±SD	Range	Mean ±SD	Range	
<b>Confidence</b> Min score=0 Max score=45	30.15±6.79	17,44	36.96±5.29	22,45	<0.001* (t= -6.14)

**n=48**

*\*significant at p<0.001*

*paired t test*

The study finding observed a significant (p<0.001) increase in the post-test confidence score of parents regarding the care of infants at home after the implementation of MCIP. The majority of parents (95.9%) were satisfied with the effectiveness of the delivery of the MCIP. Satisfaction towards the aspects of CHD, milestone monitoring and feeding was lesser when compared to other domains(Figure-1).



**Fig-1: Percentage distribution of satisfaction of parents related to components of MCIP**

The mean WAZ score of infants before discharge from the hospital were  $-3.39 \pm 1.49$ , which increased to  $-3.11 \pm 1.35$  one month after discharge. A paired t-test demonstrated this improvement was significant with  $p < 0.05$ . (Table-4).

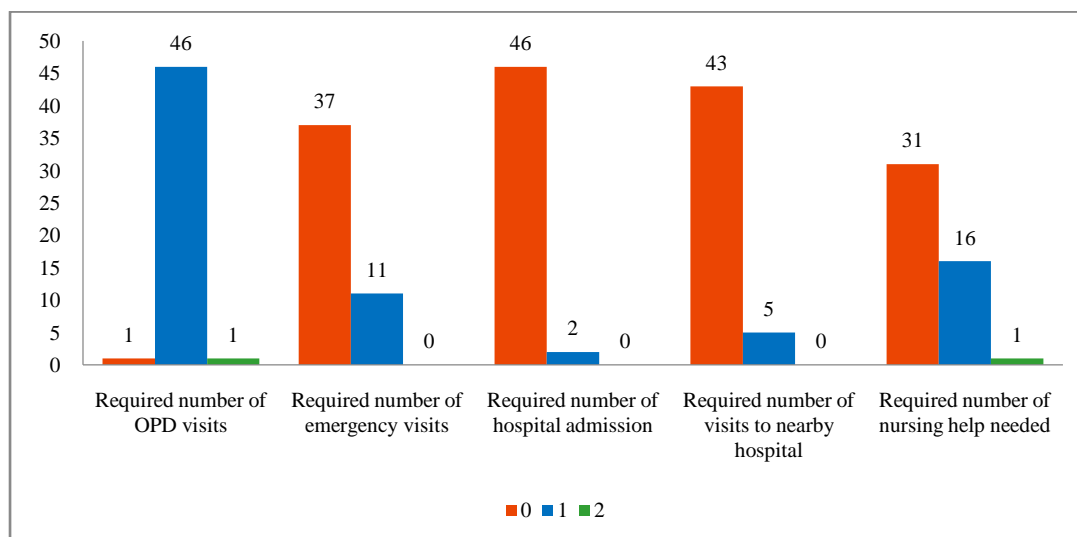
**Table-4. Comparison of Weight for Age Z(WAZ) score of the infants before and after administration of the intervention.**

n=45

Variable	Pretest	Range	Post-test	Range	p-value
Weight for Age Z score (WAZ)	$3.39 \pm 1.49$	-6.52, 0.76	$3.11 \pm 1.35$	-6.01, -0.18	$< 0.05^*$ (t= -3.04)

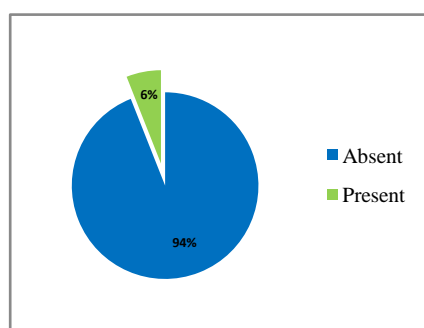
\*Significant at  $p$  value  $< 0.05$  paired t-test

The frequency of the utilization of acute clinical services by infants during a month follow up period were assessed. 46 infants presented to the outpatient department once and one infant visited twice during the follow-up period. Eleven infants required an emergency visit once, two infants required hospital admission once. Five infants visited a nearby hospital once. A total of 16 infants required telephonic nursing assistance once, and one infant sought nursing help twice (Figure-2).



**Figure-2: Frequency distribution of the utilization of clinical services during one month follow-up period.**

The percentage distribution of mortality within 30 days of discharge among infants following cardiac surgery were 6%. (Figure-3).



**Figure-3: Percentage distribution of mortality within 30 days of discharge of infants following cardiac surgery**

The educational status of parents had a significant ( $p < 0.05$ ) association with the knowledge category. Other variables like age, relation with infant, occupation, family income were not showing any association with knowledge scores (Table-5).

**Table-5. Association of knowledge category with socio-demographic variables of parents.**

n =48

Variable	Pre-test knowledge score			Chi-square	p-value
	Excellent	Good	Inadequate		
<b>Age in years</b>				2.66	0.73
16-24	2(15.38)	10(76.92)	1(7.69)		
25-34	7(23.33)	18(60)	5(16.67)		
35-44	2(40)	3(60)	0		
<b>Relation with infant</b>				0.34	1
Father	1(14.29)	5(71.43)	1(14.29)		
Mother	10(24.39)	26(63.41)	5(12.2)		

Variable	Pre-test knowledge score			Chi-square	p-value
<b>Educational status</b>					
Graduate/postgraduate	11(37.93)	15(51.72)	3(10.34)	10.47	0.02* (<0.05)
High school/intermediate	0	10(90.91)	1(9.09)		
Illiterate/primary	0	6(75)	2(25)		
<b>Occupation</b>					
Government job	0	3(100)	0	10.96	0.11
Private job	5(62.5)	2(25)	1(12.5)		
Business /self-employed	1(20)	4(80)	0		
Unemployed	5(15.63)	22(68.75)	5(15.63)		
<b>Monthly family income</b>					
≤10,000	1(25)	1(25)	2(50)	12.70	0.23
10,001-20,000	2(11.76)	13(76.48)	2(11.76)		
20,001-30,000	4(21.05)	13(68.42)	2(10.53)		
30,001-40,000	2(50)	2(50)	0		
40,001-50,000	1(33.35)	2(66.65)	0		
≥50,001	1(100)	0	0		

#### IV. Discussion

After administration of Multi-Component Intervention Program regarding the care of infants following cardiac surgery had significantly improved the mean knowledge score of parents with a p value<0.001. This finding is in line with the study by **Elsobsky et al, 2018**<sup>22</sup> where they assessed the effect of discharge education on mother’s knowledge and reported practice for children after cardiac surgery and found that discharge care knowledge (related to activity, food, medication, and follow-up) before and after education had significantly improved (p<0.001).

The confidence level of parents had significantly improved from the mean score of 30.15±6.79 to 36.96±5.29 after the implementation of MCIP. These findings are agreement with another study by **Shiesh et al, 2010**<sup>23</sup> which showed improvement in maternal confidence from 70.59±13.70 to 86.83±14.40 after administration of a structured discharge education program.

Parental satisfaction towards the MCIP program was high in the present study. These results are in line with Pediatric Cardiac Surgery Parent Education Discharge Instruction (PEDI) me conducted by **Staveski et al, 2015**<sup>14</sup> where parents were highly satisfied with the program and educational materials provided.

In the present study the weight for age was compared before discharge and during one month follow up, the improvement in WAZ was found statistically significant (p<0.05). This result is consistent with the study findings by **Vaidyanathan et al, 2009**<sup>24</sup> where the WAZ score was significantly improved from discharge to 3 months follow up period with a significant p-value<0.001.

The mortality within 30-day after discharge was 6% in the present study. This finding is consistent with a study by **Stuever et al, 2021**<sup>25</sup>, who reported 8.6% mortality till the end of the 30<sup>th</sup> postoperative day after cardiac surgery.

The researcher found that around 95% (46) of infants reported to OPD during one month, 23% (11) of infants required emergency department (ED) visits, 4% (2) were readmitted to the hospital, 10% (5) visited nearby hospital 33% (16) required telephonic nursing assistance once and 2% (1) required nursing help twice. Most of these findings are in line with the study by **Raman et al, 2017**<sup>26</sup> where 6% required ED visits, 3% required an urgent visit to a primary care physician, 15% required assistance through phone. **Berry et al, 2021**<sup>4</sup> found 11.9% readmission of infants after cardiac surgery.



The association between socio-demographic characteristics of parents and knowledge category was done by chi-square test, in which the educational status of parents had a statistically significant association with knowledge category ( $p < 0.05$ ). These findings are in agreement with the study by **Poudel and Malla, 2017**<sup>27</sup> where the knowledge level of responders was statistically associated with knowledge ( $p = 0.002$ ).

## V. Conclusions

Multi-Component Intervention Program (MCIP) regarding the care of infants after cardiac surgery has been developed by the researcher to provide appropriate discharge education to the parents and thereby improving the recovery of their infants. Parents have improved their caregiving knowledge and confidence after the administration of MCIP. Parents were highly satisfied with the intervention. Infant outcomes including mortality within 30 days of discharge, frequency of utilization of clinical services, weight for age z score differences were assessed after implementing the program. This signifies the importance of having a discharge program to improve the quality of care of infants after cardiac surgery. A comprehensive, consistent discharge program can lead to effective and efficient discharge education.

The **limitations** of this study were the researcher used general education for all types of CHD and the one group pre-test post-test design used here does not control the effect of extraneous variable.

**Researcher recommends** a multi-centric study for generalizing the results and conducting RCTs that helps to conclude the effectiveness of the program by controlling other extraneous factors.

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## Conflict of Interest

None declared.

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