

Effectiveness of Discharge Educational Program on Quality of Life and Post-operative Complications for Children after Cardiac Surgery

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Abstract: Postoperative discharges teaching and follow-up are important services which can prevent unnecessary delays in discharge and assure the accessibility of adequate support afterward. Aim of the study was to evaluate the effectiveness of discharge educational program on quality of life and post-operative complications for children after cardiac surgery. Setting: The study was conducted at the cardiac surgery ward at Bahtem hospital affiliated to Ministry of Health in Bahtem city. Design: A quasi-experimental design was used to achieve the goal of this study. Subjects: 80 children accompanying their mothers were selected purposively and divided equally into study and control groups. Tools of data collection: Five tools were utilized; personal and medical data assessment sheets, knowledge assessment questionnaire, pediatric cardiac specific quality of life formats, pediatric quality of life scale and post-operative complications assessment sheet. Results: There was a highly statistical significant difference between study and control groups regarding total level of mother's knowledge ($p < 0.001$). The total quality of life and total cardiac specific quality of life for children was not significant between the two groups before discharge education ($p = 0.306$ & 0.423) respectively, but after discharge education, a significant difference was observed between the two groups at one month and three months of program implementation ($p < 0.000$). Besides, post-operative complications were significantly lower for children in the study group at one month and three months of program implementation than in the control group ($p < 0.000$). Conclusion: Based on the results of the current study, it can be concluded that, the discharge program plays an important role in increasing mother's knowledge, improving children's quality of life and decreasing post-operative complications. Recommendation: All children scheduled for cardiac surgery and their families are in need to an adequate knowledge and self-care skills to improve short and long-term outcomes after discharge.

Keywords: Cardiac surgery, children, discharge educational program, post-operative complications, quality of life.

1. INTRODUCTION

The first 30 days instantly following discharge from hospital after cardiac surgery is a critical period for the continuous health of children. It is a period with high levels of stress, readmission and mortality¹. Fulfilling suggested activity targets, actively engaging with health providers, and taking medications as prescribed are all important components of preserving cardiac health and coming back to optimum function². To have the option to do this effectively, children must be set up with sufficient knowledge about their condition and be offered guidance concerning what should and shouldn't do when returning to home. In addition, children should learn about the importance of medication adherence, the significance of managing related complication and cardiologist follow up³.

Congenital heart disease is defined as a gross structural abnormality of the heart or intrathoracic great vessels that is actually or potentially of functional significance⁴. Worldwide, CHD are the main heart diseases found in children and have been recognized as a major contributor to childhood morbidity and mortality, especially in developing countries⁵.

Globally, the prevalence of CHD is eight cases per 1000 live births across the globe, representing 1.35 million newborns each year with CHD in which more than half of them need surgery during the first year of their lives⁶. The disease differs from one country to another, in America 6.61 per thousand live births, in the UK, 3.17, in Finland 1.95, in Denmark 6.18, in Sweden 3.57, in Australia 4.31 and in Canada 12.5 per 1000 live birth⁷. In Egypt, The prevalence was 1.0 per 1000 in Egyptian children⁸.

Most of the CHD are thought to be multifactorial and result from a combination of genetic and environmental factors. According to recent update report of the American Heart Association, atrial septal defect (ASD), ventricular septal defect (VSD), tetralogy of fallot (TOF), patent ductus arteriosus (PDA), pulmonary stenosis, aortic stenosis, coarctation of aorta, and atrioventricular septal defect account for 85% of all CHDs⁹.

Heart disease in children is a rising global health problem. Recent advances in diagnosis and therapy of these diseases have increased the survival of children¹⁰. So, the focus has shifted from just survival to better management of the morbidity including poor quality of life, neurodevelopmental problems and issues related to educational training¹¹. Furthermore, The advancements has been so effective over the last forty years that almost 1.5 million births are born with CHD around the world annually, 85% of them are reaching the adulthood¹².

Quality of life (QOL) reflects the patient's perception of the impact of the illness and its treatment on their life. QOL assessment in congenital heart disease (CHD) is often complicated by multiple disease categories, heterogeneity of disease severity, choice of therapeutic procedures and wide range of possible outcomes¹³. The child postoperatively may face problems in term of physical, emotional and social wellbeing leading to functional impairments. Such impairments are known to directly impact the overall clinical outcomes in CHD¹⁴. A previous study have documented that children with uncorrected CHD have significantly reduced QOL compared with controls particularly in the physical and psychosocial domains¹⁵.

Postoperative discharge teaching and follow-up are the important services which can prevent unnecessary delays in discharge and assure the accessibility of adequate support afterward. The discharge period is a chance to have a positive effect on children's outcomes and ought to be a priority for the healthcare team^{16,17}. Children experiencing cardiac surgery need to make considerable modifications based on knowledge to adapt to the new life situation¹⁸. Nurses are the key element to the success of the educational process and can be the essential practitioners who teach surgical children how to cope with their post-surgical care after discharge, guiding toward autonomous self-care as well as move toward accomplishing their goals and dreams for the future¹⁹.

Significance of the study:

Congenital heart diseases are the second leading cause of death in infancy and childhood¹¹. The incidence of CHD has been reported to range from 4 to 50 cases per 1000 live births. Despite advances in detection and treatment, congenital heart diseases account for 3% of all infant deaths²⁰. Besides, these abnormalities can be life-threatening in early childhood and children born with severe forms are at 12 times higher risk of mortality in the first year of life. Thus, hundreds of thousands of children die each year from CHD, while millions of them stay in an urgent need of treatment in the developing world²¹.

Cardiovascular surgery witnessed enormous advances during the past century with good outcomes²². Unfortunately, the majority of children with CHD in developing countries are deprived of necessary care hence leading to high morbidity and mortality. Early detection of CHD is necessary to improve the quality of life and to reduce morbidity and mortality of children²³.

For successful long- term outcomes after discharge, children with cardiac surgery need teaching program about home care management concerning feeding regimens, medication administration, appropriate self-care activities, incision care, infection prevention strategies and knowing when to seek medical attention. Previous studied showed that there was an evidence that education of children and their families at discharge is essential and lead to better outcomes such as alleviate postoperative problems, reduce readmissions rate and improve quality of life^{24,25,26}. Despite best efforts at education, most children are at risk for poor outcomes due to improper management at home after discharge²⁷.

Subsequently, the researchers felt the necessity to conduct this study hoping that the results obtained can enable children to self-manage their care at home, improve their quality of life and thus reduce postoperative complications.

Aim of the study:

The aim of this study was to evaluate the effectiveness of discharge educational program on quality of life and post-discharge complications for children after cardiac surgery.

Research hypotheses:

- Children who will receive the discharge educational program will have higher quality of life scores than those in the control group.
- Children who will expose to discharge educational program will have lower postoperative discharge complications than those in the control group.
- Mothers of children in the study group will gain a satisfactory knowledge regarding discharge instruction than mothers of children in the control group.

2. SUBJECTS AND METHOD

Research design:

A quasi- experimental design was utilized to achieve the aim of this study.

Research Setting:

The study was conducted at the cardiac surgery ward at Bahteem Hospital affiliated to Ministry of Health in Bahteem City. The ward is equipped with monitors, and defibrillators. It consisted of 14 rooms. Each room contains 2 beds.

Subjects:

Type: purposive sample

Size: 80 children accompanying their mothers were recruited for this study and selected after fulfilled the following criteria.

Inclusion criteria:

- Children with cardiac surgery aged ≤ 12 years
- Willing to take part in the study

Exclusion criteria:

- Children with associated extra cardiac malformations or genetic Disorders

Technique: The study subjects were divided into two matched groups. **Group I** (study group) consisted of 40 children accompanying their mothers who received discharge educational program and routine care and **Group II** (control group) included the other 40 children accompanying their mothers who received only the routine care administered by nurses at cardiac surgery ward.

Tools of Data Collection:

Five tools were used to collect data pertained to this study.

Tool I: Personal and medical data assessment sheets:

It was designed by the researchers after reviewing the related and recent literature to assess the personal and medical data for the studied subjects and cover three fundamental sections: **The first section** is related to personal data of children which include age, gender, birth order and level of education. **The second section** is related to personal data of mothers' such as age, level of education, occupation, residence, consanguineous marriage and social class. **Third section** covers medical data such as, duration of heart disease, weight and height percentile, previous hospitalization and chief complain, family history of cardiac or chronic disease, length of hospital stay, and type of congenital heart disease.

Tool II: Knowledge assessment questionnaire:

It was designed by the researchers based on the related literature as **Hockenberry and Wilson, (2015)²⁸**; **Hinkle and Cheever, (2014)²⁹**; **Davidson and Bonow, (2011)³⁰** to assess mothers' knowledge about various aspects of discharge

instructions. It consisted of 11 closed ended questions in the form of multiple choice questions related to care of incision, measures to prevent wound infection, feeding regimens after surgery, pain relief, correctly administering medication, kind of activities that can be performed after surgery, which person should avoid close contact with the child, clothing, periods of rest needed after surgery, follow up appointments, and danger signs for calling doctor.

Scoring system for mothers' knowledge: Each correct answer was given one degree and zero for incorrect or don't know answers. The total scores were ranged from (0 – 11). Those who obtained a score less than 60 % were considered an unsatisfactory level of knowledge while those who obtained a score more than or equal to 60% were considered a satisfactory level of knowledge.

Tool (III): Pediatric Cardiac Specific Quality of Life Formats (version 3.0): It was adopted from Uzark et al., (2003)³¹ to report cardiac disease-specific aspects of quality of life for children aged (2-12 years) which comprised of child self-report and parent-proxy report formats. Both formats contained the same items. One format (child self-report) is answered by the child himself and the other format (parent self-report) is answered by the mothers. The researchers assist the children younger than six years in filling the formats. It was composed of 27 items comprising six dimensions related to heart problems and treatment (7 items). The treatment barriers (5 items), perceived physical appearance (3 items), treatment anxiety (4 items), cognitive problems (5 items), and communication (3 items).

Scoring system: A five-point Likert response is used for child self-report and parent proxy report from 0= never a problem, 1= almost never a problem, 2= sometimes a problem, 3= often a problem to 4= almost always a problem). These response scales were converted to 0-100, being (0=100, 1=75, 2=50, 3=25, 4=0). The score is calculated by counting the points given to the items for each dimension. The total score was obtained by calculating the sum of the scores and dividing by 27. In this respect, the higher score indicated a higher QOL, whereas the lower score demonstrated a lower QOL.

Tool (IV): Pediatric Quality of Life Scale, (version 4.0): It was adopted from Varni et al., (2007)³² to assess Quality Of Life (QOL) in children that completed by their parents from children perspective. This scale was composed from 23 items grouped under four subscales namely; physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items).

Scoring system: A 5-point Likert response scale from 0= never a problem, 1= almost never a problem, 2= sometimes a problem, 3= often a problem to 4= almost always a problem was employed for scoring responses from subjects. These response scales were converted to 0-100, being (0=100, 1=75, 2=50, 3=25, 4=0). The score is calculated by counting the points given to the items for each dimension. The total score was obtained by calculating the sum of the scores and dividing by 23. A higher score represents higher quality of life.

Tool (V): Post-operative Complications Assessment Sheet:

It was designed by the researchers based on Agarwal et al., (2014)³³ to assess post-operative complications in children after discharge. It included ten complications subscale related to cardiovascular complications (decreased cardiac output & arrhythmia), respiratory complications (shortness of breath, atelectasis, pneumothorax, the need of tracheostomy & prolonged mechanical ventilation), renal complications (hematuria & urinary tract infection), gastrointestinal complications (loss of appetite, nausea, vomiting, diarrhea, constipation & GI bleeding), neurological complications (dizziness & fatigue), sleep problems (insomnia & nightmares), psychological problems (pessimism & fear) problems in social life (refusal to see visitors & unwillingness to social contact), wound complications (redness, swelling, infection) and hospital readmission.

Tools validity:

Tools of data collection were translated into Arabic and reviewed for their content validity by three juries (two in pediatric nursing from the Faculty of Nursing Benha University, and one in pediatric cardiologist from the Faculty of Medicine Benha University) who are experts in the related field and selected to test the content validity of the instruments and to judge its clarity, comprehensiveness, relevance, simplicity, and accuracy. All of their comments were taken into consideration; some items were re-phrased to reach the final version of the tools. The tools were considered valid from the experts' perspective.

Reliability assessment:

The developed and validated tools for the personal and medical data sheet, knowledge assessment questionnaire, the pediatric cardiac quality of life formats (version 3.0), the pediatric quality of life scale (version 4.0) and post-operative complication sheets were tested for reliability on a sample of 10 subjects. Test retest results using Cronbach's alpha coefficient revealed that all items were significantly differ and has a correlation above the threshold of significance ($r=0.76, 0.73, 0.85, 0.91 \text{ \& } 0.78$) respectively.

Administrative and Ethical consideration:

All the relevant principles of ethics in the research were followed. Before starting the practical work, an official letter explaining the purpose of the study was obtained from the faculty dean of nursing to the hospital director to carry out the study and collect the necessary data. Participants' (children and their mothers) consent to participate was obtained after informing them about their rights to participate, refuse, or withdraw at any time. Total confidentiality of any obtained information was ensured. The study maneuver could not entail any harmful effects on participants.

Pilot Study:

A pilot study was carried out on 10% (8) of the total study sample to test the applicability, clarity, relevance, feasibility of study tool, sequence of questions to maintain consistency and time needed. Subjects under pilot study were excluded from the present study to avoid sample bias and contamination. This phase took one month (beginning of June 2018 till end of June 2018).

Field work:

The following phases were adopted to fulfill the aim of the current study; assessment, planning, implementation, and evaluation phases. These phases were carried out from the beginning of July 2018 to the end of April 2019 covering ten months.

A) Assessment phase:

This phase encompassed interviewing with children accompanied their mothers to collect baseline data. At the beginning, the researchers greet the study subjects; explaining the purpose of the study in a simple way and taking written approval to participate in the study. Then, the researchers start to classify children who met the inclusion criteria into study and control group through serial numbers of cases by using simple random sample. Whereas, the children who had single numbers were chosen in the study group, while the children who had double numbers were chosen in the control group. The control group was recruited first to prevent sample bias/contamination. The first pre-test tools were distributed to collect baseline data (Tool I, II, III & IV). Average of 5-6 children accompanied their mothers were interviewed per /week. The time required for complete the study tools ranged between 25-35 minutes.

B) Planning:

Based on baseline data obtained from pre-test assessment and relevant review of literature, the discharge program was developed by the researchers according to children' level of understanding in simple Arabic language. The booklet was distributed to each child accompany his mother in the study group to be considered as a reference value.

C) Program implementation:

The implementation phase was achieved through sessions. Each session started by a summary of the previously session and the objectives of the new one. Motivation and reinforcement during session were used in order to enhance sharing in this study.

The program was carried out at the study settings through (4) sessions which conducted by the researchers within one week before discharge from hospital, the content of sessions covered the following: **Session I:** Measures to prevent wound infection, care of incision. **Session II:** Correctly administering medication, pain control. **Session III:** Feeding regimens, activity or exercise to be avoided after surgery, which person should avoid close contact with the child, clothes, periods of rest needed after surgery. **Session IV:** Follow up appointments and danger signs for calling doctor. Children were divided according to their lesions into 2 main groups a cyanotic and cyanotic. Then both groups were subdivided into 8 subgroups, 5 children accompanying their mothers in each subgroup. The duration of time in each session was about 45 minutes. Sessions started at 11 Am according to children readiness.

The sessions were repeated for different groups and the basic content was the same for all groups. So, the program took (8) weeks. Methods of teaching were modified lectures, group discussion, questions and answers, demonstration and re-demonstration in addition to proper visual aids such as data show, handout, and real objects.

D) The evaluation Phase:

For both groups; evaluations of mothers' knowledge was done two times pre and immediately post implementation of discharge program, while pediatric quality of life scale and pediatric cardiac specific quality of life formats were evaluated three times (pre, after one month, & three months). Moreover, post- discharge complications were evaluated two times at one month and three months post discharge program implementation.

Statistical design:

The collected data were organized, categorized, tabulated and analyzed using SPSS advanced statistics version 20. Numerical Data were expressed as mean and standard deviation as appropriate. Qualitative data were expressed as frequency and percentage. The comparison was done using Chi-square test. For quantitative data, comparison between two groups was done using independent t-test. Reliability of the interviewing questionnaire was done using Cronbach's Alpha. The observed differences and associations were considered as follows: Non- significant at $P > 0.05$, significant at $P < 0.05$ and highly significant at $P < 0.001$.

3. RESULT

Table (1): Distribution of the studied children according to their personal data (n=80)

Personal data	Study Group (n=40)		Control Group (n=40)	
	No	%	No	%
Age:				
-3- < 6years	8	20.0	7	17.5
-6- < 9years	19	47.5	21	52.5
-9-12 years	13	32.5	12	30.0
Range	3.0-12.0		3.0-11.5	
Mean±SD	6.9±1.8		6.37±0.51	
Gender:				
-Male	25	62.5	26	65.0
-Female	15	37.5	14	35.0
Residence				
Urban	17	42.5	18	45.0
Rural	23	57.5	22	55.0
Child's birth order:				
-First	11	27.5	12	30.0
-Second	22	55.0	23	57.5
-Third	5	12.5	4	10.0
-Fourth	2	5.0	1	2.5
Level of education				
Nursery	8	20.0	7	17.5
Primary	32	80.0	33	82.5

Table (1) presents the personal data of the studied children. It is evident that the mean age in both study and control groups were 6.9±1.8 and 6.37±0.51years respectively. Regarding children's gender, the table shows that more than half (62.5%) of children in the study group was males compared to 65% of the controls. Concerning to residency, it is noticed that more than half (57.5 % & 55%) of children in both study and control groups respectively were from rural area. As regard the child birth order, the table indicates that more than half (55% & 57.5%) in both study and control groups

respectively were second birth order and the majority of cases (80% & 82.5%) were enrolled at primary level of education.

Table (2): Distribution of the studied children according to their medical data (n=80)

Medical data	Study Group (n=40)		Control Group (n=40)	
	No	%	No	%
Age of diagnosed of illness (years):				
-< 3	6	15.0	8	20.0
-3+	34	85.0	32	80.0
Previous hospitalization				
-Yes	30	75.0	31	77.5
-No	10	25.0	9	22.5
Chief complain				
-Chest infection	30	75.0	31	77.5
- Family history of cardiac disease	21	52.5	13	32.5
- Family history of chronic disease	20	50.0	17	42.0
Height ≤ 10th percentile	25	62.5	26	65.0
Weight ≤ 10th percentile	25	62.5	26	65.0
Length of hospital stay (day):				
7-<14	27	67.5	10	25.0
-14+	13	32.5	30	75.0

It is evident from table (2) that the majority of cases (85% & 80%) in both study and control groups respectively discovered at age of three years or more. Concerning to previous hospitalization, 75% and 77.5% of both study and control groups respectively were admitted previously to the hospital complaining from chest infection. However, 52.5%, 50% and 32.5%, 42.5% in both study and control groups respectively have family history of cardiac diseases and chronic disease. Regarding the child's weight and height percentile, it is clear that more than half (62.5%) of children in the study group, their weight and height were less than 10th percentile compared to 65.0% of the controls. As regard period of stay in hospital, it is found that more than two thirds of children (67.5%) in the study group spent seven to less than 14 days in hospital compared to 25% of the controls.

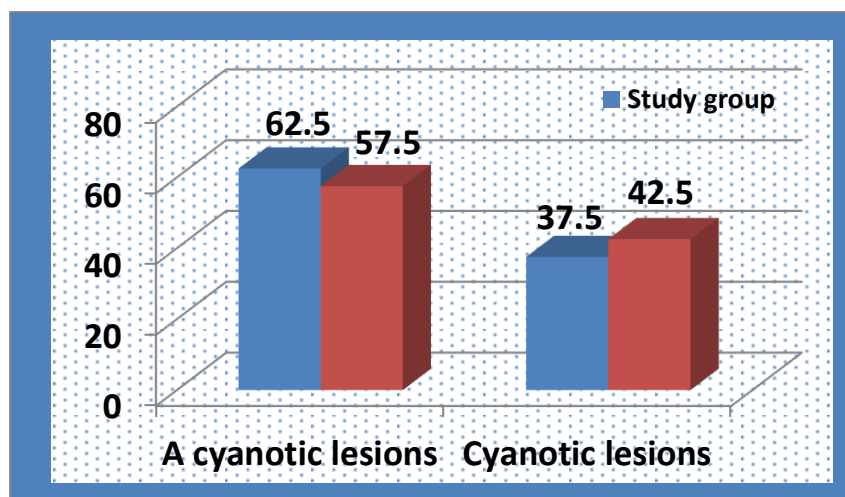


Figure (1): Distribution of the studied children according to their type of congenital heart diseases

Figure (1) illustrates that a cyanotic lesions were represent respectively more than half (62.5% & 57.5%) in both study and control groups. While, cyanotic lesions were represent more than one third (37.5%) in the study group compared to 42.5% of the controls.

Table (3): Distribution of the studied mothers according to their personal data (n=80)

Personal data	Study Group (n=40)		Control Group (n=40)	
	No	%	No	%
Age:				
< 35years	18	45.0	19	47.5
35+	22	55.0	21	52.5
Range	21.0-45.0		22.0-46.0	
Mean±SD	33.3±6.7		34.2±7.8	
Mother's education:				
Illiterate	18	45.0	17	42.5
Read and write	6	15.0	11	27.5
Primary	9	22.5	5	12.5
Secondary	4	10.0	5	12.5
University or higher	3	7.5	2	5.0
Occupation:				
Working	10	25.0	12	30.0
Not working(housewife)	30	75.0	28	70.0
Consanguinity	24	60.0	26	65.0
Social class				
Low	19	47.5	20	50.0
Middle	10	25.0	11	27.5
High	11	27.5	9	22.5

Table (3) reveals the personal data of the studied mothers; it is observed that the mean age of both study and control groups were 33.3±6.7 and 34.2±7.8years respectively. In relation to mother's' education, more than two fifth (45% & 42.5%) in both study and control groups respectively were illiterate. Additionally, three quarters (75%) of mothers in the study group were housewife compared to more than two thirds (70%) in the controls. Regarding to consanguinity, it is found that more than half (60%) & less than two thirds (65%) in both study and control groups respectively had positive consanguinity. Concerning to the social class, the table shows that 47.5% of mothers in the study group belonged to low social class compared to 50% of the controls.

Table (4): Comparison between study and control groups regarding total level scores of mother's knowledge throughout the study periods (n=80)

Mother's level of knowledge	Pre discharge program					post discharge program				
	Study group (n=40)		Control group (n=40)		X ² (P -value)	Study group (n=40)		Control group (n=40)		X ² (P -value)
	No	%	No	%		No	%	No	%	
Satisfactory	10	25.0	6	15.0	4.455 0.553 NS	31	77.5	8	20.0	7.654 <0.001*
Unsatisfactory	30	75.0	34	85.0		9	22.5	32	80.0	

***High statistical significant differences P-value <0.001**

Not Significant (NS) P>0.05

It is clear from **table (4)** that 75% and 85% of the studied mothers in both study and control groups have unsatisfactory level of knowledge pre-discharge program implementation with no significant differences. In contrast, post implementation of discharge program, there was a highly statistical significant difference between study and control groups regarding total level scores of mother's knowledge, where about slightly more than three quarters (77.5%) of them in the study group had satisfactory level of knowledge compared to 20% of the controls (p<0.001).

Table (5): Mean quality of life scores in the study and control groups throughout the study periods (n=80)

Domains of QOL	Pre discharge program			One month after program			3months after program		
	Study group (n=40)	Control group (n=40)	t-test / P- value	Study group (n=40)	Control group (n=40)	t-test / P- value	Study group (n=40)	Control group (n=40)	t-test / P- value
	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
Physical health	61.9±11.2	60.5±12.2	1.387 (0.215)	77.1±20.4	64.4±12.7	13.790 *(0.000)	89.2±12.9	65.9±13.5	14.449 *(0.000)
Emotional functioning	60.4±14.3	59.6±16.9	1.125 (0.157)	78.8±14.8	62.2±20.2	12.876 *(0.000)	84.5±17.3	64.3±12.6	13.281 *(0.000)
Social functioning	61.7±12.1	61.0±11.6	0.632 (0.987)	79.8±17.3	63.5±13.2	13.521 *(0.000)	88.8±13.7	64.1±13.5	13.687 *(0.000)
School functioning	59.3±14.4	58.3±13.6	1.372 (0.198)	71.3±14.1	60.1±12.7	10.720 *(0.000)	77.3±16.0	62.7±12.8	9.853 *(0.000)
Total QOL	60.8±10.7	59.9±10.5	1.183 (0.306)	76.8±14.1	62.6±11.2	11.214 *(0.000)	84.9±16.2	64.3±12.1	10.910 *(0.000)

*High statistical significant differences P-value <0.001

Not Significant (NS) P>0.05

Apparently, **table (5)** clarifies that the total mean scores for all quality of life domains were higher in the study group at one month and three months after discharge program implementation than in the control group with a significant differences (76.8±14.1 & 84.9±16.2 verses 62.6±11.2 & 64.3±12.1, P<0.001) respectively, including higher physical health (77.1±20.4 & 89.2±12.9) in the study group compared to (64.4±12.7 & 65.9±13.5) of the controls, emotional functioning (78.8±14.8 & 84.5±17.3) in the study group compared to (62.2±20.2 & 64.3±12.6) of the controls. Social functioning, (79.8±17.3 & 88.8±13.7) in the study group compared to (63.5±13.2 & 64.1±13.5) of the controls and school functioning (71.3±14.1 & 77.3±16.0) in the study group compared to (60.1±12.7 & 62.7±12.8) of the controls.

Table (6): Mean cardiac specific quality of life scores as reported by children and their mothers in both study and control groups throughout the study periods (n=80)

Cardiac-specific quality of life	Groups	Pre discharge program		1months after program		3 months after program	
		Children reported	Mothers reported	Children reported	Mothers reported	Children reported	Mothers reported
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
-Heart problems and treatment	Study group(n=40)	62.4 ± 5.32	59.7±6.32	75.1±13.8	71.5±12.7	82.8±9.38	77.4±7.88
	Control group(n=40)	61.6±7.11	58.6±9.07	64.3±5.30	63.8±6.58	67.9±5.30	64.8±6.58
	t-test / P- value	2.178 (0.072)	0.357 (0.733)	6.299 *(0.001)	5.321 *(0.001)	9.654 *(0.000)	7.654 *(0.000)
-Treatment barriers	Study group(n=40)	62.7 ± 7.27	58.7±9.51	82.7±14.7	78.8±6.26	92.5±10.24	82.6±8.79
	Control group(n=40)	60.6±8.32	57.7±9.77	63.9±5.14	61.3±7.48	66.9±7.41	64.3±7.66
	t-test / P- value	0.636 (0.548)	1.231 (0.371)	11.205 *(0.000)	10.751 *(0.000)	19.158 *(0.000)	12.248 *(0.000)
-Physical appearance	Study group(n=40)	59.4 ± 13.2	56.5±6.86	83.4±14.7	79.3±8.96	84.9±9.25	80.7±9.22
	Control group(n=40)	58.8±5.11	54.2±7.21	64.8±8.77	63.7±7.99	66.2±8.91	64.2±8.65
	t-test / P- value	2.163 (0.062)	0.984 (0.274)	15.125 *(0.000)	8.147 *(0.000)	13.521 *(0.000)	12.928 *(0.000)

-Treatment anxiety	Study group(n=40) Control group(n=40)	59.3 ±13.6 58.9±6.21	55.0±6.23 47.6±6.56	81.5±14.3 64.4±7.08	78.8±6.14 63.1±6.93	87.6±9.45 64.7±8.17	81.8±11.05 66.4±5.14
	t-test / P- value	0.542 (0.642)	2.513 (0.067)	10.211 *(0.000)	8.120 *(0.000)	17.128 *(0.000)	13.215 *(0.000)
-Cognitive problems	Study group(n=40) Control group(n=40)	59.0±6.04 58.7±6.41	56.8 ± 5.56 56.9±4.33	84.7±7.56 63.3±8.13	79.9±11.4 62.9±7.17	92.5±11.11 65.3±7.99	83.0±10.28 64.6±8.83
	t-test / P- value	2.127 (0.079)	0.452 (0.629)	14.170 *(0.000)	9.157 *(0.000)	20.143 *(0.000)	10.643 *(0.000)
- Communication	Study group(n=40) Control group(n=40)	58.2±6.30 57.8±7.42	56.5 ± 11.3 54.8±5.11	82.3±14.78 63.6±7.80	77.8±16.8 62.5±6.97	88.4±9.73 65.7±8.18	82.8±9.87 64.6±8.19
	t-test / P- value	0.441 (0.675)	1.627 (0.589)	13.498 *(0.000)	7.350 *(0.000)	12.094 *(0.000)	13.279 *(0.000)
-Total	Study group(n=40) Control group(n=40)	60.17±3.25 59.4±1.23	57.2±3.47 54.9±4.12	81.62±5.18 62.2±4.73	77.7±5.29 61.8±5.27	88.1±4.63 65.4±3.28	81.4±5.21 63.2±4.63
	t-test / P- value	0.686 (0.423)	2.367 (0.068)	16.042 *(0.000)	11.827 *(0.000)	15.689 *(0.000)	17.543 *(0.000)

***highly statistical significant differences at P < 0.001**

Clearly, **table (6)** reveals that children and their mothers in both study and control groups reported lower QOL in all domains of cardiac specific quality of life particularly physical appearance, treatment anxiety, cognitive problems and communication pre-discharge program implementation. Meanwhile, after discharge program implementation both children and their mothers in the study groups demonstrated higher significant difference concerning all domains of cardiac specific quality of life at one month and three months than in the control group (P<0.000).

Table (7): Children's postoperative complications after program implementation in both study and control groups throughout the study periods (n=80)

Complications	one months after program				X ² (P value)	Three months after program				X ² (P value)
	Study group (n=40)		Control group (n=40)			Study group (n=40)		Control group (n=40)		
	No	%	No	%		No	%	No	%	
Gastrointestinal system										
No problem	23	57.5	7	17.5		36	90.0	21	52.5	
-Loss of appetite	8	20.0	18	45.0	13.913	2	5.0	9	22.5	16.414
-Nausea	1	2.5	2	5.0	*0.008	0	0.0	2	5.0	*0.001
-Vomiting	2	5.0	3	7.5		0	0.0	0	0.0	
-Constipation	6	15.0	10	25.0		2	5.0	8	20.0	
Sleep problems										
-no problem	35	87.5	22	55.0	11.667	39	97.5	28	70.0	10.141
-Insomnia	5	12.5	18	45.0	*0.001	1	2.5	12	30.0	*0.001
Wound complication										
-No complication	34	85.0	24	60.0	9.448	38	95.0	31	77.5	6.646
-Infection	6	15.0	16	40.0	*0.002	2	5.0	9	22.5	*0.010
Hospital readmission										
Yes	4	10.0	12	30.0	5.000	2	5.0	9	22.5	3.962
No	36	90.0	28	70.0	*0.025	38	95.0	31	77.5	*0.047

***Highly statistical significant differences P-value <0.001**

Table (7) indicates that the post-operative complications were lower for children in the study group than in the control group at one month and three months after discharge program implementation with a statistical differences as p<0.000.

Table (8): Relation between total mean scores of children's quality of Life and their type of CHD in the study and control groups through the study periods (n=80)

	Total QOL								
	Pre discharge program			One month after program			3months after program		
	Study group (n=40)	Control group (n=40)	t-test / P- value	Study group (n=40)	Control group (n=40)	t-test / P- value	Study group (n=40)	Control group (n=40)	t-test / P- value
	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
A cyanotic lesions	61.3±14.4	60.9±10.4	1.291 (0.233)	80.5±19.4	63.8±11.2	14.195 *(0.000)	89.4±11.9	64.8±13.5	15.218 *(0.000)
Cyanotic lesions	60.9±13.2	59.8±12.7	1.173 (0.164)	69.6±12.7	61.8±14.8	11.894 *(0.000)	70.8±13.7	62.2±11.8	12.487 *(0.000)

***High statistical significant differences P-value <0.001**

Not Significant (NS) P>0.05

It is evident from **table (8)** that there was a significant relationship between total mean scores of QOL and type of CHD as $p < 0.000$. It was observed that the total mean scores of QoL was lower in children with cyanotic CHD in the study group than children with a cyanotic CHD at one month and three months after program implementation.

4. DISCUSSION

Pediatric cardiac surgery in developing countries is a major challenge. The outcome of children after cardiac surgery (CS) relies upon the child's condition, the type of defect, the kind of surgery performed and how to care the child at home after discharge. Discharge Planning is an extension of the nursing service that can help to deliver the best care possible and promote children's self-management following discharge³⁴. There is an evidence that efficient discharge teaching leads to improve quality of life, and lessen post-CS complication^{35, 36}. Hence, this study was done with the aim to evaluate the effectiveness of discharge educational program on quality of life and post- discharge complications for children after cardiac surgery.

Two matched groups recruited in this study, As regards gender, the present study result clarified that male children constitute more than half in the study group and less than two thirds of the control group. This could be attributed to the tradition of families from rural areas who give more consideration regarding male sex and are anxious in looking for medical help than female. This result is corresponding with **Pilankar et al., (2019)**³⁷ who assessed parental perception of quality of life in children following cardiac surgery and found that 57.8% of children were males. Similarly, this finding is in the same context with **Sen et al., (2017)**³⁸ who carried out a study to find out the disease pattern of CHD among children in present situation at pediatric cardiology unit in a center outside Dhaka and found that 63.21% of children were male. Contrarily, this study is contradicting with **Al-Mesned et al. , (2012)**³⁹ who studied incidence of severe congenital heart disease at the province of Al-Qassim Saudi Arabia and reported that the frequency was the same for males and females.

Concerning child weight and height, the result indicated that more than half in the study group and more than two thirds of the control group were respectively below 10th percentile for weight and height. These finding could be interpreted as the etiology of poor growth in these children is multifactorial as hypoxia and defective perfusion to the growing tissues, hyper metabolic state because of increased metabolic rate and malnutrition due to decreased appetite. No gender difference in the affection of growth was detected in our study. These findings are consistent with **Atwa and Safar, (2014)**⁴⁰ who evaluated the effect of sex on the outcome of congenital heart diseases in children and revealed that 35.6% and 34.6% of children in our study were below 10th percentile for weight for age and height for age respectively. Besides, there was no gender difference in the affection of growth among male and female children with CHDs. Furthermore, this finding is in agreement with **Meshram and Gajimwar, (2018)**⁴¹ who found that 44.19% of children with CHDs were severely malnourished.

As regards children previous hospitalization due to chest infection, the current study revealed that three quarters and nearly more than three quarters of children in both study and control groups were admitted previously to the hospital due to chest infection. This could be due to the fact that more than two fifth of mothers in both study and control groups were illiterate which leads to misunderstand the physician's instruction about case management and this may contribute to deterioration of their children's medical condition and so more need for hospitalization. This finding is in concurrence with **Daymont et al., (2013)**⁴² who studied Growth in children with congenital heart disease and emphasized that Prolonged hospitalization due to respiratory tract infections is more common in children with CHD.

On the same scope, the study results declared that, about more than half and nearly one thirds of the children in study and control groups had family history of cardiac diseases. This finding may be due to a genetic family predisposition for cardiovascular disease which is one of the risk factors for cardiovascular related illnesses. This opinion goes in accordance with **Hinkle and Cheever (2014)**²⁹ who concluded that traditional risk factors for cardiovascular-related illnesses include the non-modifiable factors of sex, race, age, genetic, and family history for cardiovascular disease.

Regarding residence, the results of the present study demonstrated that more than half of children in both study and control groups were from rural area. This finding may be interpreted as unavailability of specialized hospitals affording open heart surgery in rural areas. This finding is in harmony with the study done by **Rashid et al., (2016)**⁴³ who determined pattern of congenital heart disease in a developing country tertiary care center : Factors associated with delayed diagnosis and revealed that nearly 60% children came from rural areas.

One of the notable findings of the current study was that more than half and less than two thirds in both study and control groups respectively had positive consanguinity marriage. This could be due to that the marriage from the first degree relatives is very popular tradition in rural community which in turn may acts as predisposing factor that expands the susceptibility of developing congenital heart disease. Additionally, lack of knowledge and education about the risk factors of CHD are obstacles that increase the risk of CHD occurrence. The finding is coincided with **Fazeriandy et al., (2018)**⁴⁴ who studied Consanguinity and congenital heart disease in offspring and found that there was a significant relationship between consanguinity and the risk of CHD occurrence in the offspring ($P=0.033$). Likewise, this finding was consistent with **Fung et al., (2013)**⁴⁵ who assessed impact of prenatal risk factors on congenital heart disease in the current era and concluded that Consanguineous marriage is a risk factor for CHD in offspring. In this regard, **Shieh et al., (2012)**⁴⁶ suggested that the risk for congenital heart disease is increased in consanguineous unions in the studied populations, principally at first cousin level and closer.

In an attempt to assess knowledge of mothers about discharge instructions; the results of the current study clarified that three quarters and majority of the studied mothers in both study and control groups have unsatisfactory level of knowledge at the pre-discharge program implementation. This could be due to various reasons as; more than two fifth of mother's were illiterate, low levels of mother's social standard, lack of enthusiasm from hospital administration to apply discharge program for pediatric patients and their families before discharge. This result is in agreement with **Elsobky et al., (2018)**⁴⁷ who evaluated the effect of pre-hospital discharge care program on mothers' knowledge and reported practice regarding discharge care of children after congenital heart surgery and show that all items of mother's knowledge were unsatisfactory pre-program implementation. Similarly, This finding is supported by **Remya, (2010)**⁴⁸ who conducted a study to assess the effect of group teaching on mother's knowledge about home care of children after congenital heart surgery and found that mothers of both study and control groups have low knowledge mean scores pre-program (5.25 ± 1.58 and 4.1 ± 1.29) respectively. In contrast, This result is contradicting with **Pramila and Chandni (2017)**⁴⁹ who carried out a study to assess knowledge of mothers regarding home care of children undergone cardiac surgery with a view to develop an information booklet and found that more than half (55%) of the mothers had moderate knowledge at baseline assessment.

The finding of the current study approved that mothers who received the discharge educational program showed significant improvement in their knowledge. It showed that three quarters of them in the study group had satisfactory level of knowledge post-discharge program implementation compared to less than one quarters in the controls. This could be due to the provision and explanation of the discharge program instruction in clear and simple language according the mothers level of comprehension. This finding is similar with **Wanisa and A-Kaji, (2019)**⁵⁰ who determined the effectiveness of a supportive educative nursing system program on knowledge and caregiver role for caring children with

congenital heart disease and found that caregiver's knowledge in the experimental group were significantly higher than that in the control group ($p < 0.01$). Likewise, This finding goes in accordance with **Staveski et al., (2015)**²⁷ who assessed parent's knowledge regarding discharge instruction for care of children with cardiac surgery after education program and found that parent knowledge mean scores increased significantly from $(1.76 \pm 1.4$ to 3.68 ± 0.852 , $p < 0.005$) after the discharge program implementation. Besides, this finding is compatible with **Wu et al., (2015)**¹ who evaluated the effectiveness of discharge planning on maternal caring knowledge, maternal caring behavior, maternal discharge readiness and the re-hospitalization of children with ventricular septal defect and pulmonary arterial hypertension and revealed that maternal caring knowledge in the intervention group was significantly higher compared to the control group ($p < 0.001$).

The current result indicated that children in both study and control groups showed lower total mean scores for all quality of life domains pre-discharge program implementation. This result is in harmony with **Rai et al., (2019)**⁵¹ who compared generic Health related quality of life in children/adolescents with CHD to that of controls and revealed that children with CHD reported a global reduction of HRQOL in compared with controls. However, this result is consistent with **Sertçelik et al., (2018)**⁵² who evaluated the effects of the severity and symptoms of congenital heart disease on children's quality of life and concluded that the total quality of life subscales was significantly lower ($p < 0.001$). Furthermore, **Mellion et al., (2014)**⁵³ who conducted a study to assess Health-related quality of life outcomes in children and adolescents with congenital heart disease and demonstrated reductions for all scales of generic HRQOL. Correspondingly, **Areias et al., (2013)**⁵⁴ who conducted a study in Portugal to evaluate Long term psychosocial outcomes of congenital heart disease (CHD) in adolescents reported that quality of life perception was poorer in adolescents who underwent cardiac surgery.

After implementation of discharge program, children in the study group demonstrated higher total mean scores for all quality of life domains at one month and three months compared to the controls. This could be due to the clarity, simplicity of the program content that help in improving children's quality of life. This finding is compatible with **Sadeghi et al., (2013)**³⁵ who conducted a study to assess the effect of a discharge program on quality of life among school-age children suffering from congenital heart disease and undergoing surgery which revealed a significant improvement in the mean scores of all domains of quality of life at the study group post-program implementation ($p < 0.001$).

Concerning disease-specific Cardiac quality of life (QOL) assessment, the current finding showed that children in both study and control groups reported lower mean scores in all domains particularly physical appearance, treatment anxiety, cognitive problems and communication pre-discharge program implementation. This could be explained by the physical appearance tended to be a problem because most children felt embarrassed about their post-operative scars and considered this a "stigma" that gives rise to comments and questions especially at the school. Moreover, these children are at risk for anxiety issues because of overprotective motherhood behavior and ignorance of what will happen as a result of the surgery. Besides, it is relevant that the cognitive problem experienced by children is associated with the severity of the disease as well as some children found difficult to tell other people about their heart disease. This result matches with **Atmadja et al., (2017)**⁵⁵ who conducted a study to assess quality of life in children with congenital heart disease after cardiac surgery and revealed that 35% of post-operative children were at risk for physical appearance problems, 80% were at risk for anxiety problems, 40% were at risk for cognitive problems, and 80% were at risk for communication problems at the baseline assessment.

Apparently, the present study finding pointed out interesting differences between children and their mothers reported in both study and control groups regarding cardiac specific quality of life pre-program implementation, whereas both of them showed deficit in all domains, but the mothers rate their cardiac specific quality of life to be worse than their children. From the researchers' point of view, mothers might be affected by their expectations for the children and having various definitions and understanding of a disease and its consequences for the future. This result highlights the importance of obtaining information about children's health situation from both mothers and children. The current finding is in agreement with **Rai et al., (2019)**⁵¹ who revealed that both children and parents reported lower cardiac specific quality of life at the baseline assessment.

Following the implementation of discharge program, both children and their mothers demonstrated significantly higher mean scores in all domains of cardiac specific quality of life at one month and three months after discharge program

implementation compared to the controls. This finding is similar with **Pilankar et al., (2019)**³⁷ who revealed that all cardiac quality of life domains concerning problems with treatment, perceived physical appearance, treatment anxiety, cognition and communication showed higher significant difference at the initial follow-up of 3-6 months after discharge as $p < 0.05$.

As a result of this discharge educational program, all complications of children after discharge were lower in the study group at one month and three months post program implementation compared to the controls. This could be due to the education given before the discharge had an effect on increasing both children and their mother's awareness, improving their quality of life and thus reduce post-operative complication. This finding is in agreement with **Liu et al., (2019)**⁵⁶ who conducted a study to evaluate the impact of a family caregiver training program in Kolkata, India on post-operative health perceptions and outcomes after cardiothoracic surgery and found that Post-discharge 30-day complication rates were significantly lower for the care companion program group compared to the standard of care group (14.5% versus 34.4%, respectively, $P < 0.003$).

The current findings illustrated that children in the study group demonstrated lower gastrointestinal, sleep and wound problems as loss of appetite, nausea, constipation, insomnia and wound infection at one month and three months after discharge program implementation compared to the controls. This finding is on the same wavelength with **Akbari, and Celik, (2015)**⁵⁷ who investigated the effect of discharge training and counseling on post-discharge problems and reported that post-operative problems were lower in the intervention group than in the control group at the first follow up after discharge training and counseling. Whereas, more than 10% of the reported problems in the intervention group were loss of appetite, constipation, insomnia, weakness and wound edema. Additionally, all these problems were resolved at the second and third follow-up phases compared to 88% of these problems in the control group were unsolved.

The current study result reported that only ten percent of children in the study group readmitted to hospital after one month of discharge program implementation compared to two fifth in the controls. In this respect **Veronovici et al., (2014)**³⁴ mention that discharge education seems essential and useful for children to recognize the process of the disease, because increasing children's information can result in development of self-care and decrease in re-hospitalization rates. This finding is compatible with **Azhar, (2019)**⁵⁸ who studied unplanned hospital readmissions following congenital heart diseases surgery and found that the rate of readmission among pediatric patients was 10.5% within 30 days and 15.9% after one year of discharge following the congenital heart surgeries. Likewise, **Kogon et al., (2012)**⁵⁹ who studied risk factors associated with readmission after pediatric cardiothoracic surgery and reported that 10.8% of children with CHD in Atlanta were readmitted after their corrective surgeries within 30 days. Conversely, this finding is contradicting with **Berry et al., (2013)**⁶⁰ who conducted study to Pediatric readmission prevalence and variability across hospitals and showed that the readmission rate in children was 7% within 30 days of discharge.

Our study stated that there was a significant relationship between total children's quality of life and type of CHD. It was observed that children in the study group with cyanotic CHD showed lower total mean scores quality of life than children with a cyanotic CHD at one and three months after program implementation. This could be due to the children with cyanotic CHD complain from severe symptoms, a higher number of operations, a higher rate of medication use, and limitations in daily life. This finding is in compliance with **Freitas et al., (2013)**⁶¹ who conducted a cohort study on psychosocial adjustment and psychopathology in adolescents with congenital heart disease and reported that QoL was lower in children who had cyanotic CHD and a history of surgery. Equivalently, this finding is in agreement with **Tahirovic et al., (2010)**⁶² who studied does the severity of congenital heart defects affect disease-specific health-related quality of life in children in Bosnia, Herzegovina and found that QoL perception was lower in children with cyanotic heart disease compared with children who had left-to-right shunt anomalies and obstructive anomalies. Conversely, This finding is contradicting with **Neuner et al., (2011)**⁶³ who evaluated Sense of coherence as a predictor of quality of life in adolescents with congenital heart defects: a register-based 1-year follow-up study and found that QoL in children with CHD was not influenced by disease severity.

5. CONCLUSION

Based on the results of the current study, it can be concluded that, the discharge program plays an important role in increasing mother's knowledge, improving children's quality of life and decreasing post-operative complication. Henceforth, these results support the proposed hypotheses.

6. RECOMMENDATION

In view of the findings of the present study, the following recommendations can be suggested:

- 1- All children scheduled for cardiac surgery and their families are in need to an adequate knowledge and self-care skills to improve short and long-term outcomes after discharge.
- 2- Provision of seminars to raise nurse's awareness about the benefits of children's discharge education for their provision of care.
- 3-highlight the importance of increase awareness about various health hazards associated consanguineous marriages especially in rural areas.
- 4- Recommended replication of the study on a larger probability sample chosen from different geographical areas in Egypt to obtain more generalizable data.

REFERENCES

- [1] **Wu X, Li Q, and Chen J.** Discharge planning for children with ventricular septal defect and pulmonary arterial hypertension in China. *International journal of nursing sciences.* June 2015; 2(2): 167-172.
- [2] **Dalal HM, Doherty P, and Taylor RS.** Cardiac rehabilitation. *British Medical Journal.* 2015 ; 351: 5000.
- [3] **National Heart Foundation of Australia.** 6 steps to cardiac recovery [Internet]. 2016 [cited 2018Apr 10]. Available from: https://www.heartfoundation.org.au/images/uploads/publications/HF_PhaseOne_six_steps_to_cardiac_recovery3.pdf.
- [4] **Tantchou Tchoumi JC, Butera G, and Giamberti A.** Occurrence and pattern of congenital heart diseases in a rural area of sub-Saharan Africa. *Cardiovascular Journal of African.* 2011; 22: 63–6.
- [5] **Chelo D, Nguetack F, and Menanga AP.** Spectrum of heart diseases in children: an echocardiographic study of 1,666 subjects in a pediatric hospital, Yaounde, Cameroon. *Cardiovascular Diagnosis Therapy.* 2016; 6:10–19.
- [6] **Kouame BD, N'guetta-Brou IA, and Kouame GSY.** Epidemiology of congenital abnormalities in West Africa: results of a descriptive study in teaching hospitals in Abidjan: Cote d'Ivoire. *African Journal of Pediatric Surgery* 2015; 12:51–5.
- [7] **Van der Linde D, Konings EE, Slager MA, Witsenburg M, Helbing WA, Takkenberg JJ, et al.** Birth prevalence of congenital heart disease worldwide: A systematic review and meta-analysis. *Journal of American College Cardiology.* 2011; 58: 2241–7.
- [8] **Massoure PL, Roche NC, and Lamblin G.** Cardiovascular disease in children in Djibouti: a single-center study. *Pan African Medical Journal.* 2013 ; 14:141.
- [9] **Roger VL, GO AS, Lloyd-Jones DM, Benjamin EJ, Berry JD, and Borden WB.** Heart disease and stroke statistics - 2012 update a report from the American Heart Association. *Circulation* 2012; 125: e2-e220. Available from: <http://circ.ahajournals.org>
- [10] **Saenz RB, Beebe DK, and Triplett, LC.** Caring for infants with congenital heart disease and their families. *American Family Physician.* 2010; 59(7):1857-68.
- [11] **Nousi D, and Christou A.** Factors affecting the quality of life in children with congenital heart disease. *Health SciSence Journal.* 2010; 4:94–100.
- [12] **Sabzevari, S.** The burden of care: mother's experiences of children with congenital heart disease.2016; 4(4):374-385.
- [13] **Marino BS, Uzark K, Ittenbach R, et al.** Evaluation of quality of life in children with heart disease. *Progression of Pediatric Cardiology* 2010; 29:131–8.

- [14] **Drakouli M, Petsios K, Giannakopoulou M, et al.** Determinants of quality of life in children and adolescents with CHD: a systematic review. *Cardiology Young* 2015; 25:1027–36.
- [15] **Raj M, Sudhakar A, and Roy R.** Health-related quality of life in infants and toddlers with congenital heart disease: a cross-sectional survey from South India. *Arch Disease Child* 2018; 103:170–5.
- [16] **Bonow RO, Douglas LM, Zipes DP, and Libby P.** Braunwald's Heart Disease: A textbook of cardiovascular medicine. 9th ed. USA: Elsevier; 2012. p. 1793-811.
- [17] **Allen HD, Driscoll DJ, Shaddy RE, and Feltes TF.** Moss & Adams' Heart Disease in Infants, Children, and Adolescents, 8th ed., Lippincott Williams & Wilkins Philadelphia, 2013. p.1894.
- [18] **Cebeci F, and Celik SS.** Effects of discharge teaching and counseling on anxiety and depression level of CABG patients. *Turkish Journal of Thoracic Cardiovascular Surgery* 2011; 19:170-6.
- [19] **Landolt MA, Buechel EV, and Latal B.** Predictors of Parental Quality Of Life after Child Open Heart Surgery: a 6-Month Prospective Study. *The Journal of Pediatrics*. 2011; 158:37–43.
- [20] **Chinawa JM, Eze JC, and Obi I.** Synopsis of congenital cardiac disease among children attending University of Nigeria Teaching Hospital Ituku Ozalla, Enugu. *BMC Research Notes*. 2013; 6:475.
- [21] **Otaigbe BE, and Tabansi PN.** Congenital heart disease in the Niger Delta region of Nigeria: a four-year prospective echocardiographic analysis. *Cardiovascular Journal of Africa*. 2014; 25:265–8.
- [22] **van der Linde D, Konings EE, and Slager MA.** Birth prevalence of congenital heart disease worldwide: a systematic review and meta analysis. *Journal of American College Cardiology*. 2011; 58:2241–7.
- [23] **Bagher N, Maliheh S, Arezo M, Mostafa Q, and Mohammad JG.** Prevalence and pattern of congenital heart disease among neonates in Gorgan, Northern Iran (2007-2008). *Iran Journal of Pediatric*. 2011 Sep; 21 (3):307-12.
- [24] **Albert NM, Paul S, and Murray M.** Complexities of care for patients and families living with advanced cardiovascular diseases: Overview. *Journal of Cardiovascular Nursing*. 2012; 27:103-13.
- [25] **Berkes A, Varni JW, Pataki I, Kardos L, Kemeny C, and Mogyorosy G.** Measuring health-related quality of life in Hungarian children attending a cardiology clinic with the Pediatric Quality of Life Inventory. *European Journal of Pediatric*. 2010; 169:333-47.
- [26] **Fredericks S, and Yau T.** Educational intervention reduces complications and re-hospitalizations after heart surgery. *West Journal of Nursing Research* 2013; 35:1251-65.
- [27] **Staveski SL, Parveen VP, Madathil SB, Kools S, Franck LS.** Parent education discharge instruction program for care of children at home after cardiac surgery in Southern India. *Cardiology in the Young*. 2015; 1 – 8. doi:10.1017/S1047951115002462.
- [28] **Hockenberry MJ, and Wilson D. (2015).** Wong's nursing care of infants and children. 9th ed. St. Louis: Mosby Elsevier, p. 33.
- [29] **Hinkle, J. and Cheever, K. (2014):** Textbook of Medical Surgical Nursing, 13 ed., Lippincott Williams & Wilkins, 43 – 55 & 1126 -1129.
- [30] **Davidson, C.J. and Bonow, R.O. (2011):** Braunwald's Heart Disease: A Textbook of Cardiovascular Medicine. Philadelphia, Pa: Saunders Elsevier .9thed. Chap 20.
- [31] **Uzark K , Jones K , and Burwinkle TM .** The Pediatric Quality of Life Inventory™ in children with heart *disease*. *Progression of Pediatric Cardiology* 2003; 18:141–9.doi:10.1016/S1058-9813(03)00087-0
- [32] **Varni JW, Limbers CA, and Burwinkle TM.** Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL 4.0 generic core scales. *Health Quality of Life Outcomes*. 2007; 5:2.

- [33] **Agarwal HS, Wolfram KB, Saville BR, Donahue BS, and Bichell DP. (2014):** Postoperative complications and association with outcomes in pediatric cardiac surgery. *Journal of thoracic and cardiovascular surgery*. 148; (2):609-616.
- [34] **Veronovici NR, Lasiuk GC, Rempel GR, and Norris CM.** Discharge education to promote self-management following cardiovascular surgery: An integrative review. *European Journal of Cardiovascular Nursing*. 2014; 13(1):22–31.
- [35] **Sadeghi F, Kermanshahi S, Memarian R.** The effect of the designed discharge planning on the quality of life in school-age children with congenital heart disease undergoing heart surgery. *Sci J Hamadan Nurs Midwifery Facul*. 2013;21(1):15-24. (Persian).
- [36] **Lushaj EB, Nelson K, Amond K, Kenny E, Badami A, and Anagnostopoulos PV.** Timely Post-discharge Telephone Follow-Up is a Useful Tool in Identifying Post-discharge Complications Patients after Congenital Heart Surgery. *Pediatric Cardiology*. 2016 Aug; 37(6):1106-10.
- [37] **Pilankar NN, Jiandani1 MP, Mehta1 AA, and. Kulkarni DV.** Parental perception of quality of life in children following cardiac surgery. *International Journal of Contemporary Pediatrics*. 2019 Jul; 6(4):1673-1679.
- [38] **Sen SS, Barua T, Dey D, Chowdhury MA, and Nessa L.** Pattern of Congenital Heart Disease in Children Presenting at Paediatric Cardiology Unit in Chattagram Maa Shishu-O-General Hospital, Chittagong. *Chattagram Maa-O-Shishu Hospital Medical College journal*. July 2017; 16(2): 40-43.
- [39] **Al-Mesned A, Al-Akhfash AA, and Sayed M.** Incidence of severe congenital heart disease at the province of Al-Qassim, Saudi Arabia. *Congenital Heart Disease*. 2012; 7(3):277-82. doi: 10.1111/j.1747-0803.2011.00614.x.
- [40] **Atwa, ZT and Safar, HH. (2014):** Outcome of congenital heart diseases in Egyptian children: Is there gender disparity. *Egyptians Pediatric Association Gazette*. 62, 35–40.
- [41] **Meshram RM, and Gajimwar VS.** Prevalence, profile, and pattern of congenital heart disease in Central India: A prospective, observational study. *Nigerian Journal of Cardiology*. 2018; 15:45-49.
- [42] **Daymont C, Neal A, Prosnitz A, and Cohen MS.** Growth in children with congenital heart disease. *Pediatrics* 2013; 131:e236–42.
- [43] **Rashid U, Qureshi AU, Hyder SN, and Sadiq, M.** Pattern of congenital heart disease in a developing country tertiary care center: Factors associated with delayed diagnosis. *Annual Pediatric Cardiology journal*. 2016 Sep-Dec; 9(3): 210–215. Doi: 10.4103/0974-2069.189125.
- [44] **Fazeriandy A, Ali M, Saing J, Tobing T, and Adriansyah R.** Consanguinity and congenital heart disease in offspring. *Paediatrica Indonesiana journal*. April 2018; 58(2):75-79.
- [45] **Fung A, Manlhiot C, Naik S, Rosenberg H, Smythe J, and Loughheed J.** Impact of prenatal risk factors on congenital heart disease in the current era. *Journal of American Heart Association*. 2013;2:e000064.
- [46] **Shieh JT, Bittles AH, and Hudgins L.** Consanguinity and the Risk of Congenital Heart Disease. *Am J Med Genet A*. 2012 May; 158A (5): 1236–1241. doi: 10.1002/ajmg.a.35272
- [47] **Elsobky FA, Amer SA, and Sarhan AE.** The effect of pre-hospital discharge care program on mothers' knowledge and reported practice for children after congenital heart surgery. *Journal of Nursing Education and Practice* 2018, 8 (9): 122-130.
- [48] **Remya RS.** The effect of group teaching on mother's knowledge about home care of children after congenital heart surgery. *Published Diploma in Cardiovascular and Thoracic Nursing*. University of Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum. 2010; p. 43.
- [49] **Pramila P, and Chandni M.** Knowledge of Mothers Regarding Home Care of Children undergone Cardiac Surgery with a View to Develop an Information Booklet. *An Official Journal of NMC, Birgunj, Nepal*. 2017; 2(1): 38-43.

- [50] **Wanisa TW, and A-Kaji HS.** The Effect of Education Program on Knowledge and Role in the Caregiver for Children with Congenital Heart Disease Aged 0 - 3 Years. *Princess of Naradhiwas University Journal.* 2019; 11(3):233-243
- [51] **Raj M, Sudhakar A, Roy R, Champaneri B, Sudevan R, Kaboli C, and Kumar RK.** Health-related quality of life (HRQOL) in children and adolescents with congenital heart disease: a cross-sectional survey from South India. *BMJ Pediatrics Open* 2019; 3(1):1-11.
- [52] **Sertçelik T, Alkan F, Yalın Sapmaz Ş, Coşkun Ş, and Eser E.** Life quality of children with congenital heart diseases. *Turkish Pediatric Arsivi.* 2018; 53: 78-86.
- [53] **Mellion K, Uzark K, and Cassedy A .** Health-related quality of life outcomes in children and adolescents with congenital heart disease. *Journal of Pediatric.* 2014; 164:781–8.
- [54] **Areias ME, Pinto CI, and Vieira PF.** Long term psychosocial outcomes of congenital heart disease (CHD) in adolescents and young adults. *Transl Pediatric.* 2013; 2: 90-8.
- [55] **Atmadja S, Tobing TC, Evalina R, Sofyani S, and Ali M.** Quality of life in children with congenital heart disease after cardiac surgery. *Paediatrica Indonesiana.* 2017; 57 (6): 285-290.
- [56] **Liu J, Alam SS, Guhabiswas R, Waajid MS, Chakrabarty S, Purkayastha RD, Popat R, and Gupta R.** Impact of a family caregiver training program in Kolkata, India on post-operative health perceptions and outcomes of cardiothoracic surgical patients. *Journal of Global Health Reports.* November 2019; 17.
- [57] **Akbari M, and Celik SS.** The effect of discharge training and counseling on post-discharge problems in patients undergoing coronary artery bypass graft surgery. *Iranian Journal of Nursing Midwifery Research* 2015; 20:442-9.
- [58] **Azhar AS.** Unplanned hospital readmissions following congenital heart diseases surgery. *Saudi Medical Journal.* 2019 Aug; 40(8): 802–809.
- [59] **Kogon B, Jain A, Oster M, Woodall K, Kanter K, and Kirshbom P.** Risk factors associated with readmission after pediatric cardiothoracic surgery. *Annual Thoracic Surgery.* 2012; 94:865–873.
- [60] **Berry JG, Toomey SL, Zaslavsky AM, Jha AK, Nakamura MM, and Klein DJ.** Pediatric readmission prevalence and variability across hospitals. *Jama.* 2013; 309:372–380.
- [61] **Freitas IR, Castro M, and Sarmiento SL.** A cohort study on psychosocial adjustment and psychopathology in adolescents and young adults with congenital heart disease. *BMJ Open* 2013; 3: e001138.
- [62] **Tahirović E, Begić H, Nurkić M, Tahirović H, and Varni JW.** Does the severity of congenital heart defects affect disease-specific health-related quality of life in children in Bosnia and Herzegovina? *European Journal of Pediatric* 2010; 169: 349-53.
- [63] **Neuner B, Busch MA, Singer S, Moons P, Wellmann J, Bauer U, Nowak-Gottl U, and Hense HW.** Sense of coherence as a predictor of quality of life in adolescents with congenital heart defects: a register-based 1-year follow-up study. *JDBP.* 2011; 32(4):316–327.