



Effectiveness of Nurse _Led Family Focused Program on The Physical Health Domain in Children with Congenital Heart Defects

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Abstract

Background: Assessing the effectiveness of a nurse-led family-focused program on the physical health domain of children with congenital heart defects (CHDs) is a critical area of research. CHDs are among the most common congenital anomalies, affecting nearly 1 in 100 live births. These conditions often require complex medical interventions and ongoing care, which can significantly impact the physical health and overall well-being of affected children. physical activity plays an important role in overall health and recovery congenital heart disease . Quality of life educational include specific directions to increase level of physical activity, such as walking daily or exercising regularly. Increasing physical activity can improve cardiovascular strength and reduce the risk of future heart disease. However, necessary precautions should be taken during implementing instructions, such as assessing the patient's health condition and providing appropriate medical care. **Objectives:** This study aims to assess the effectiveness of a nurse-led family-focused program in improving the physical health outcomes of children with CHDs. **Methods and Results:** a quasi-experimental design to investigate the impact of an educational program on the physical health domain for children with congenital heart defects. Purposive sampling technique which is type of non-probability sampling methods sample of (60) participants was randomly divided into two groups of 30. The study group have been exposed to the educational program for the children with congenital heart defects by the researcher. Moreover, the control group follow the traditional program provided by the Heart Center. Then educational benefits of both groups were measured on different intervals during and after the program period. **Results:** The results show statistically significant differences between two groups. Enhancement of the physical health among the study group during the period of measurement. Applng of the educational program for children with congenital heart defects program effect positively on children with CHDs. Preliminary findings indicate that the intervention group experienced significant improvements in the QoL scores compared to the control group. Key enhancements were observed in health and activities, feelings, get along with others, school, and overall QoL. P-values which are all highly significant ($P < 0.05$).It has been concluded that the patient outcomes in the study group improved during the period of the program, compared to the control



group patients whose parameters significantly deteriorated. The Overall Quality of Life domain indicates a great deal of improvement with a mean increase from 39.75 at the pre-test to 74.25 at Post-Test II high where it corresponds to an extremely high F-value 729.96. These results bring out the effectiveness of the interventions in positively impacting children's quality of life. **Conclusion:** The nurse-led family focused program to improve the physical domain of children with congenital heart defects program has improved physical health in those children who parents attended the program.

Keywords: Congenital Heart Defects, Nurse-Led Family, Physical Health.

فاعلية البرنامج الذي يركز على الاسرة بقيادة الممرض في مجال الصحة البدنية لدى الاطفال الذين يعانون من عيوب خلقية في القلب

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المخلص

الخلفية: تقييم فعالية البرنامج الذي يركز على الأسرة بقيادته الممرضين في مجال الصحة البدنية للأطفال الذين يعانون من عيوب خلقية في القلب هو مجال بحثي حيوي. تُعد عيوب القلب الخلقية من بين أكثر العيوب الخلقية شيوعاً، حيث تؤثر على ما يقرب من 1 من كل 100 ولادة حية. غالباً ما تتطلب هذه الحالات تدخلات طبية معقدة ورعاية مستمرة، مما يمكن أن يؤثر بشكل كبير على الصحة البدنية والرفاهية العامة للأطفال المتأثرين. تلعب النشاطات البدنية دوراً مهماً في الصحة العامة والتعافي من أمراض القلب الخلقية. تشمل التوجيهات التعليمية لتحسين جودة الحياة توجيهات محددة لزيادة مستوى النشاط البدني، مثل المشي يومياً أو ممارسة التمارين بانتظام. زيادة النشاط البدني يمكن أن تحسن قوة القلب والأوعية الدموية وتقلل من خطر الإصابة بأمراض القلب في المستقبل. ومع ذلك، يجب اتخاذ الاحتياطات اللازمة أثناء تنفيذ التعليمات، مثل تقييم الحالة الصحية للمريض وتقديم الرعاية الطبية المناسبة. **الأهداف:** تهدف هذه الدراسة إلى تقييم فعالية برنامج يركز على الأسرة بقيادة الممرضين في تحسين النتائج الصحية البدنية للأطفال الذين يعانون من عيوب خلقية في القلب. **الطرق والنتائج:** تصميم شبه تجريبي للتحقيق في تأثير برنامج تعليمي على مجال الصحة البدنية للأطفال الذين يعانون من عيوب خلقية في القلب. تقنية أخذ العينات الهادفة، وهي نوع من طرق أخذ العينات غير الاحتمالية، تم تقسيم عينة من (60) مشاركاً عشوائياً إلى مجموعتين من 30. تم تعريض المجموعة الدراسية للبرنامج التعليمي للأطفال الذين يعانون من عيوب خلقية في القلب من قبل الباحث. علاوة على ذلك، يتبع مجموعة التحكم البرنامج التقليدي المقدم من مركز القلب. ثم تم قياس الفوائد التعليمية لكلتا المجموعتين في فترات مختلفة خلال وبعد فترة البرنامج. النتائج: تظهر النتائج وجود اختلافات ذات دلالة إحصائية بين المجموعتين. تحسين الصحة البدنية بين مجموعة الدراسة خلال فترة القياس. تطبيق البرنامج التعليمي للأطفال الذين يعانون من عيوب خلقية في القلب يؤثر بشكل إيجابي على الأطفال الذين يعانون من عيوب خلقية في القلب. **الاستنتاج:** لقد حسن البرنامج الذي يقوده الممرضين ويركز على الأسرة لتحسين الجانب البدني للأطفال الذين يعانون من عيوب خلقية في القلب الصحة البدنية لهؤلاء الأطفال الذين حضر أبائهم البرنامج. تشير النتائج الأولية إلى أن مجموعة التدخل شهدت تحسينات كبيرة في درجات جودة الحياة مقارنة بمجموعة التحكم. لوحظت تحسينات رئيسية في الصحة والأنشطة



والمشاعر والتوافق مع الآخرين والمدرسة وجودة الحياة بشكل عام. قيم P التي هي كلها ذات دلالة إحصائية عالية ($P < 0.05$). وقد استنتج أن نتائج المرضى في مجموعة الدراسة تحسنت خلال فترة البرنامج، مقارنة بمرضى مجموعة التحكم الذين تدهورت معاييرهم بشكل كبير. وقد استنتج أن نتائج المرضى في مجموعة الدراسة تحسنت خلال فترة البرنامج، مقارنة بمرضى مجموعة التحكم الذين تدهورت معاييرهم بشكل كبير. يشير مجال جودة الحياة بشكل عام إلى قدر كبير من التحسن مع زيادة متوسطة من 39.75 في الاختبار المسبق إلى 74.25 في الاختبار اللاحق الثاني حيث يتوافق مع قيمة F عالية للغاية 729.96. تبرز هذه النتائج فعالية التدخلات في التأثير بشكل إيجابي على جودة حياة الأطفال.

الكلمات المفتاحية: عيوب القلب الخلقية، الأسرة التي تقودها الممرضة، الصحة البدنية.

INTRODUCTION

Congenital heart defects (CHD) is one of the most common congenital disorders in neonates. They have a significant impact on morbidity, mortality, and costs of healthcare for children as well as adults. Actually, more than 30% of neonatal death are caused by CHD.¹ Currently, eight among every 1000 live children have CHD. Globally, there are over 150 million live births annually, with 1.35 million of those with congenital cardiac disease. As a result, CHD is among the most prevalent birth defects, affecting over 400,000 newborns annually. Approximately 25% of these have complicated CHDs with significant death rates, while today, 85% of children with CHD live to adulthood.² The primary cause of death for children with congenital malformations of any kind is congenital cardiac abnormalities. Ventricular septal defect (VSD), atrial septal defect (ASD), and patent ductus arteriosus (PDA) are the three most prevalent forms of congenital heart defects.³ Congenital heart disease affects children born to diabetics, pregnant women with severe virus infections, smokers, drinkers, users of drugs, and some mothers with X-ray exposure. The disease has substantial effect on physical ability, quality of life, public health and the cost of healthcare.⁴ Women who give birth after the age of 35 and children with Down syndrome—a genetic abnormality—are risk factors. Early in the pregnancy, other causes include genetic disorders, ionizing radiation-induced biological consequences, and poisoning of the mother's body. Heart disease can occur at any time during pregnancy, although the risk is highest between weeks six and eight.⁵ Many factors can impact the quality of life for children with congenital heart disease. All family members influence and are influenced by the QoL of such children. Another essential aspect of caring for children with congenital heart abnormalities is educating children and their families.^{6,7} Additionally, the nurse should provide care to the family of children with a chronic or life-threatening disease, giving special attention to any possible health issues that might affect the child's quality of life.⁸ The nurse's role in caring for children with CHD requires specialized abilities in teaching their parents the necessity of meeting their requirements.⁹ The care of the nurse continues to the patient as long as the surgical procedure is planned and advised in the immediate preoperative phase.¹⁰ Physical activity improves cardiopulmonary function and decreases weight, high blood pressure, and total cholesterol levels, all of which



are effective ways to improve quality of life.¹¹ physical activity is associated with advantages for health, Pediatric QoL was improved by exercise training, which may also be linked to decreased morbidity and mortality.¹² Children with congenital heart disease (CHD) often manage to reach adulthood without significant physical issues, yet many face challenges such as muscular deconditioning, reduced exercise capacity, and diminished quality of life. Factors like parental overprotection and limits set by physicians can hinder their physical activity. Additionally, young children with CHD encounter specific physical health challenges along with the development of new abilities, making transitions into school particularly difficult for both them and their families. These challenges can impact their social interactions, academic performance, and overall well-being, highlighting the need for supportive environments that encourage active participation in physical activities.¹³ Children with congenital heart defects (CHD) should avoid sedentary lifestyles and should generally follow physical activity (PA) recommendations. Encourage physical activity (PA) among children CHD patients. Not to mention that physical, emotional, and psychosocial development in children are all dependent on PA. Children with CHD should be encouraged to live a physically active lifestyle, and as a result, current sports recommendations for the majority of patients with simple and moderate CHD include participation in competitive sports, leisure sports, and unrestricted PA in accordance with World Health Organization (WHO) recommendations for healthy children, i.e., daily participation of 60 minutes in moderate-to-vigorous PA that is developmentally appropriate and enjoyable.¹⁴

Methods:

A quasi-experimental design was use to assessing the effectiveness of nurse-led family-focused program for children with congenital heart defect in improving the physical health domain. The researcher in the present study used informed consent to protect participant rights. Before beginning the study, the researcher obtains a formal agreement from Medical Research Ethics Committee (MREC) for ethical study approval in compliance with the requirements for conducting human. Specialized Center for Cardiac Surgery and Catheterization in Diwaniyah, Women and Children Teaching Hospital was the designated site to obtain the necessary sample. purposive sampling technique which is type of non-probability sampling methods was chosen in order to collect accurate and representative data, and 60 children participated in a study. All of the children have been diagnosed with congenital heart disease (CHD), and they went to the Diwaniyah Maternity and Children Teaching Hospital, Specialized Center for Cardiac Surgery and Catheterization, either for follow-up and consultation or for cardiac catheterization. Subsequently, the study and control groups of the research sample were assigned to two groups of thirty children each. The study group has been exposed to the researcher's efforts to improve the physical health



for children participating in educational programs; the control group is the group that has not been exposed to the researcher's educational program. Thirty children in each group selected according to certain criteria; (Children with congenital heart disease who were between the ages of 8 and 12 years at the time of the study, Who had been diagnosed by echocardiography. ,Children of both genders, Cooperative children who are capable of learning and understanding., children are of Arabic nationality., Children without psychiatric issues who were able to speak and communicate and who were approved to participate in the study). The data collected through **Part I: Social-Demographic Information** of children with congenital heart defects involve (5) objects and their parents involve (4) objects. **Part II: Medical History** of children with CHDs which composed of (6) objectives. **Part III: Pediatric Quality of Life Inventory Version 4.0** includes 23 items with a 5-point Likert scale (0 = not a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a problem, and 4 = almost often a problem). The inventory available in a variety of variations adapted to different children's ages (8-12). It consists of self-report questions for children (aged 8 to 12).The PedsQL can distinguish between healthy children and those with acute or chronic health issues.

Flowchart of Steps of the Study

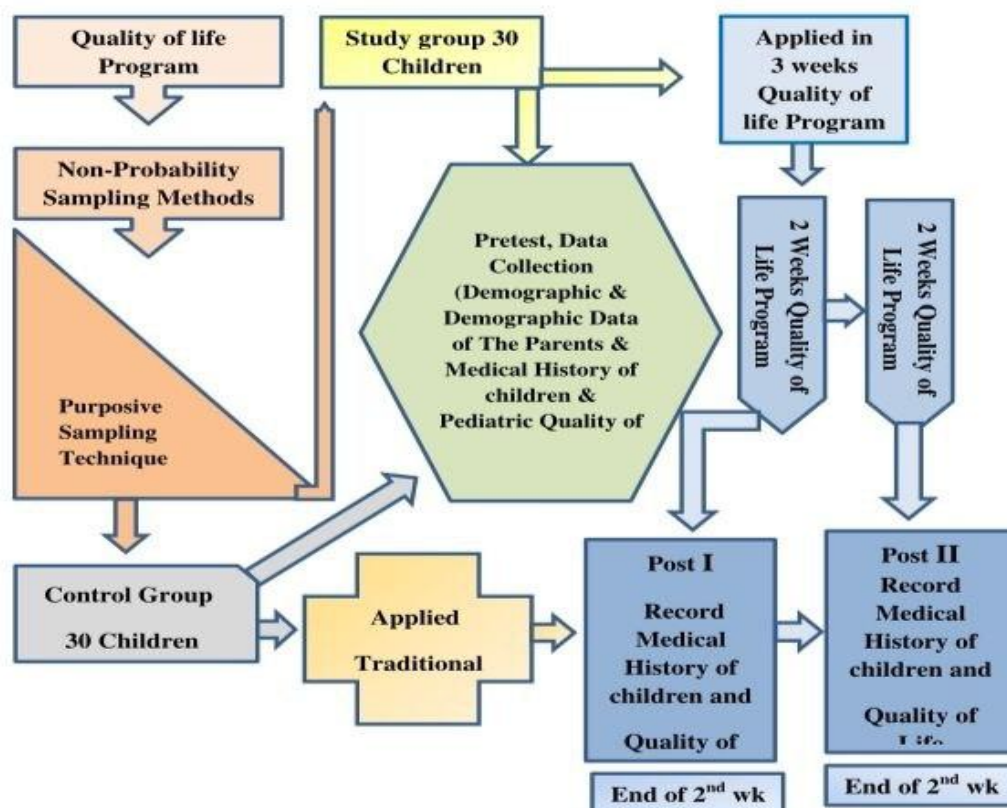




Table (4.1) Descriptive statistics (frequency and percentage) for the children's demographic data of both study and control groups

Demographic data		Control Group		Study Group		χ^2 P value
		Freq. (N=30)	Percent.	Freq. (N=30)	Percent.	
Age / Years	8-9	14	46.7	16	53.3	2.48
	10-11	11	36.7	10	33.3	0.28
	≥ 12	5	16.7	4	13.3	NS
Gender	Male	20	66.7	17	56.7	0.64
	Female	10	33.3	13	43.3	0.42 NS
Educational Status	Do not read and write	4	13.3	5	16.7	3.12
	read and write	9	30.0	21	70.0	0.37
	Primary School	17	56.7	4	13.3	NS
Sequence between family members	1	5	16.7	4	13.3	1.47 0.47 NS
	2	4	13.3	7	23.3	
	3	8	26.7	3	10.0	
	4	5	16.7	6	20.0	
	5	4	13.3	4	13.3	
	6	2	6.7	2	6.7	
	7	2	6.7	4	13.3	
Residence	Urban	18	60.0	14	46.7	3.0
	Rural	12	40.0	16	53.3	0.22 NS

NS: Non-Significant at $P > 0.05$

Table (4.1) gives descriptive statistics of the demographic data on children of the study and control groups: age, sex, educational status, family member sequence, and residence. The outcome of the chi-square test shows that there are no statistically significant differences between the two groups for all the demographic variables ($P > 0.05$). Age distribution indicates that most of the children are between 8 to 9 years old; 46.7% belongs to the control group while 53.3% belongs to the study group. The chi-square value was 2.48, which is meaningful too. For gender distribution also, a higher proportion of males exists in both the groups, i.e., 66.7% in the control group and 56.7% in the study group. The difference is not significant ($P = 0.42$). In terms of educational status, 13.3% of the children in the control group are illiterates as compared to 16.7% of the children in the study group; 30.0% of the children in the control group are literate as opposed to 70.0% of the children in the study group; and 56.7% of the children in the control group are attending primary school, compared to 13.3% of the children in the study group. For birth order, the



distributions are relatively similar for both groups. For residence, 60.0% of children in the control group live in urban areas and 46.7% of children in the study group. These findings have demonstrated that these two groups are comparable across these demographic variables, which means that differences, if any, in outcomes can lesser be attributed to these factors. These results provide further evidence of comparability between the study and control groups at baseline in terms of demographic characteristics, hence making it unlikely that these differences in outcomes were influenced by baseline demographic characteristics.

Table (4.2) Descriptive statistics (frequency and percentage) for the Parents' demographic data of both study and control groups

Demographic data		Control Group		Study Group		χ^2 P value
		Freq. (N=30)	Percent.	Freq. (N=30)	Percent.	
Father's Age	22-31	9	30.0	7	23.3	1.48
	32-41	10	33.3	17	56.7	0.18
	42-51	11	36.7	6	20.0	NS
Mother's Age	22-31	10	33.3	10	33.3	0.48
	32-41	14	46.7	18	60.0	0.58
	42-51	6	20.0	2	6.7	NS
Father's Educational Level	Illiterate	2	6.7	2	6.7	0.67 0.48 NS
	Read and write	2	6.7	7	23.3	
	Primary school	4	13.3	5	16.7	
	Intermediate	3	10.0	5	16.7	
	Preparatory School	7	23.3	3	10.0	
	Institute	8	26.7	5	16.7	
	College	2	6.7	2	6.7	
	Postgraduate	2	6.7	1	3.3	
Mother's Educational Level	Illiterate	0	0.0	6	20.0	1.33 0.67 NS
	Read and write	3	10.0	6	20.0	
	Primary school	8	26.7	6	20.0	
	Intermediate	8	26.7	3	10.0	
	Preparatory School	2	6.7	2	6.7	
	Institute	6	20.0	3	10.0	
	College	3	10.0	4	13.3	
	Postgraduate	0	0.0	0	0.0	
Father's Socio-economic	< 300000	5	16.7	4	13.3	2.47
	300000-600000	7	23.3	9	30.0	0.27
	601000-90000	6	20.0	8	26.7	NS



Status	901000-120000	5	16.7	7	23.3	
	> 1200000	7	23.3	2	6.7	
Mother's Socio-economic Status	< 300000	17	56.7	21	70.0	1.28 0.31 NS
	300000-600000	9	30.0	5	16.7	
	601000-90000	4	13.3	4	13.3	
Father's Occupation	Employee	21	70.0	19	63.3	0.67 0.56 NS
	Unemployed	9	30.0	11	36.7	
Mother's Occupation	Employee	13	43.3	10	33.3	0.89 0.46 NS
	Unemployed	17	56.7	20	66.7	

NS: Non-Significant at $P > 0.05$

Table (4.2) gives the descriptive statistics for the parents' demographic data, comparing the study and control groups. It presents an analysis of parents' age, occupation, educational level, and socio-economic status. As shown by the chi-square test results, there are no statistically significant differences between the groups for all these variables ($P > 0.05$), implying that the parents in both groups are comparable. For example, most fathers in both sets are working, with 70.0% in the control set and 63.3% in the study set ($P = 0.56$). Also, most mothers in both sets do not have jobs, with 56.7% in the control set and 66.7% in the study set ($P = 0.46$). About school level, fathers in both sets are spread across different education levels, with no large differences ($P = 0.48$). Mothers in the study set have a bit more illiteracy (20.0%) than the control set (0.0%), but this difference is not important ($P = 0.67$). Socio-economic status also shows comparable distributions. Most of the parents fall within various income ranges. For example, 30.0% of mothers in the control group and 16.7% in the study group fall within the 300,000–600,000 income range. These findings confirm that there are no significant demographic differences between the parents in the study and control groups which ensures baseline equivalence for further comparisons.

Table (4.3) Assessment and mean of scores of children's quality of life at the pre-test measurement for both study and control groups

No .	Items	Study Group			Control Group		
		MS	SD	Assess.	MS	SD	Assess.
1	It is hard for me to walk more than one block	60.75	35.75	Moderate	45	16.5	Moderate
2	It is hard for me to run	36.75	21.5	Moderate	18.25	18.5	Moderate
3	It is hard for me to do sports activity or exercise	30.75	22.5	Poor	14.25	15.75	Poor
4	It is hard for me to lift something	20.7	20.7	Poor	15.7	18	Poor



	heavy	5	5		5		
5	It is hard for me to take a bath or shower by myself	48.25	24.5	Moderate	46.75	15.75	Moderate
6	It is hard for me to do chores around the house	51.75	23.5	Moderate	42.5	19.75	Good
7	I hurt or ache	44.25	19.25	Moderate	32.5	16.25	Poor
8	I have low energy	48.25	24.5	Moderate	37.5	23.5	Moderate
9	I feel afraid or scared	47.5	29	Moderate	38.25	20.5	Moderate
10	I feel sad or blue	54.25	21.75	Moderate	34.25	18	Moderate
11	I feel angry	21.75	18.25	Poor	26.75	20.75	Poor
12	I have trouble sleeping	52.5	21	Moderate	36.75	19.5	Moderate
13	I worry about what will happen to me	36.75	23.5	Moderate	27.5	24.75	Poor
14	I have trouble getting along with other kids	37.5	20.5	Moderate	30	20.25	Poor
15	Other kids do not want to be my friend	32.5	22	Poor	30	16.5	Poor
16	Other kids tease me	25	24.5	Poor	19.25	17	Poor
17	I cannot do things that other kids my age can do	35.75	19.25	Moderate	30.75	21.5	Poor
18	It is hard to keep up when I play with other kids	37.5	21.5	Moderate	31.75	22.75	Poor
19	It is hard to pay attention in class	38.25	21.5	Moderate	28.25	18.25	Poor
20	I forget things	23.25	17.25	Poor	28.25	21.5	Poor
21	I have trouble keeping up with my schoolwork	40	22.25	Moderate	25.75	21.25	Poor
22	I miss school because of not feeling well	46.75	23.5	Moderate	44.25	25.25	Moderate
23	I miss school to go to the doctor or hospital	40.75	25.75	Moderate	49.25	18	Moderate

MS: Mean of Scores; SD: Standard Deviation; Poor: MS = 0-33; Moderate: MS = 34-66; Good: MS ≥ 67



In Table (4.3), we present the assessment and mean scores of children's quality of life at the pre-test measurement for both the study and control groups. From the table, it can be seen that there are mean scores for various items with quantifiable values, and the study group consistently scores higher mean values than the control group for most items. For instance, in walking more than one block, the study group reported more difficulty (MS = 60.75, SD = 35.75) compared to the control group (MS = 45, SD = 16.5), though all are ranked as moderate. Other items similar to this one include trouble sleeping, future worries, and school sickness or medical appointment absenteeism. However, no specific p-values are given in this table to determine statistical significance; thus, commenting on the level of difference between the groups is challenging. The labels of the assessment (like moderate, poor, good) indicate the subjective perception of ease or discomfort that the participants report, helping to highlight general trends in quality of life scores for both groups. Further statistical analysis would be needed to ascertain whether these differences are significant.

Table (4.4) Differences in mean of scores of children's quality of life between study and control groups at pre-test comparison

	Pre-Test Comparison	Mean	SD	Independent T-Test	df	P-value
Health and Activities	Study	42.75	12.5	1.17	14	0.11 NS
	Control	31.75	13.5			
Feelings	Study	42.5	13.5	1.52	5	0.19 NS
	Control	32.75	13.5			
Get along with Others	Study	33.75	5.25	1.69	7	0.14 NS
	Control	28.5	5			
School	Study	38	8.5	0.43	8	0.67 NS
	Control	35.25	10.5			
Overall Quality of Life	Study	39.75	10.75	2.55	44	0.014 S
	Control	32	9.5			

SD: standard deviation, df: degree of freedom, NS: Non-Significant at $P > 0.05$; S: Significant at $P < 0.05$

Table (4.4) shows the differences in mean scores of children's quality of life between the study and control groups at the pre-test comparison for four domains which are health and activities, feelings, getting along with others, and school plus the overall quality of life. The study group showed higher mean scores in all the domains. However, the differences were not statistically significant (NS) in the individual domains and fell over 0.05 values ($p = 0.11$ for health and activities; $p = 0.19$ for feelings). The overall quality of life gave a



statistically significant difference ($p = 0.014$, S), with the study group having a higher mean score (39.75, SD = 10.75) than the control group (32, SD = 9.5). These findings imply that, despite the fact that differences in specific domains were not significant, the study group exhibited better overall quality of life at the pre-test.

Table (4.5) Assessment and mean of scores of children's quality of life at the (post-test I) measurement for both study and control groups

No .	Items	Study Group			Control Group		
		MS	SD	Assess.	MS	SD	Assess.
1	It is hard for me to walk more than one block	75.75	24	Good	37.5	25.25	Moderate
2	It is hard for me to run	45	15.25	Moderate	15	16.75	Poor
3	It is hard for me to do sports activity or exercise	46.75	14.25	Moderate	6.75	11.25	Poor
4	It is hard for me to lift something heavy	30.75	12.5	Poor	15	18	Poor
5	It is hard for me to take a bath or shower by myself	70.75	18.75	Good	35	18	Moderate
6	It is hard for me to do chores around the house	72.5	16.5	Good	35	22.25	Moderate
7	I hurt or ache	68.25	16	Good	26.75	16	Poor
8	I have low energy	79.25	17.5	Good	32.5	18.75	Poor
9	I feel afraid or scared	61.75	22.5	Moderate	30.75	24.25	Poor
10	I feel sad or blue	53.25	18.25	Moderate	26.75	17.25	Poor
11	I feel angry	41.75	15.25	Moderate	17.5	19.75	Poor
12	I have trouble sleeping	68.25	20.75	Good	34.25	20.25	Moderate
13	I worry about what will happen to me	67.5	19.75	Good	27.5	25.75	Poor
14	I have trouble getting along with other kids	51.75	20.75	Moderate	23.25	19.5	Poor
15	Other kids do not want to be my friend	46.75	21.5	Moderate	19.25	17	Poor
16	Other kids tease me	45.75	14.75	Moderate	17.5	17.5	Poor
17	I cannot do things that other	60.7	19.2	Moderate	25	21.7	Poor



	kids my age can do	5	5	te		5	
18	It is hard to keep up when I play with other kids	60	15.5	Moderate	23.2	5	Poor
19	It is hard to pay attention in class	50	20.7	Moderate	24.2	5	Poor
20	I forget things	39.2	15.7	Moderate	27.5	20	Poor
21	I have trouble keeping up with my schoolwork	55.7	18.2	Moderate	25	20.7	Poor
22	I miss school because of not feeling well	72.5	24	Good	32.5	23.7	Poor
23	I miss school to go to the doctor or hospital	77.5	21	Good	43.2	22.7	Moderate

MS: Mean of Scores; SD: Standard Deviation; Poor: MS = 0-33; Moderate: MS = 34-66; Good: MS ≥ 67

Table (4.5) illustrates the quality of life of children at post-test I for both the study and control groups, with evidently different mean scores for items. The study group was generally perceived to have better quality of life. The highest mean score item was "I miss school to go to the doctor or hospital," with a value rising up to 77.5% ("Good") for the study group, and 43.25% ("Moderate") for the control group. On the other hand, the study group reported the lowest mean score (30.75%, "Poor") for "It is hard for me to lift something heavy." The control group answered with the least mean score (6.75%, "Poor") on what "It is hard for me to do sports activity or exercise." Across most items, the study group scored higher, classified as "Good" or "Moderate," in comparison to the control group's predominantly "Moderate" or "Poor" assessments. These results reflect the better quality of life for the study group than the control group during post-test I.

Table (4.6) Assessment and mean of scores of children's quality of life at the (post-test II) measurement for both study and control groups

No .	Items	Study Group			Control Group		
		MS	SD	Assess.	MS	SD	Assess.
1	It is hard for me to walk more than one block	89.2	15.7	Good	40	27.5	Moderate
2	It is hard for me to run	63.2	18.2	Good	14.2	18.2	Moderate
3	It is hard for me to do sports activity or exercise	62.5	17	Good	11.7	15.7	Moderate
4	It is hard for me to lift something heavy	50.7	15.2	Moderate	14.2	18.2	Moderate
5	It is hard for me to take a bath or shower by myself	89.2	15.7	Moderate	50.7	19	Moderate



6	It is hard for me to do chores around the house	84.25	18	Moderate	40	26.75	Good
7	I hurt or ache	80.75	17	Moderate	29.25	23.75	Good
8	I have low energy	87.5	14.25	Moderate	40	29.75	Moderate
9	I feel afraid or scared	80.75	21.5	Good	38.25	26	Good
10	I feel sad or blue	74.25	19	Moderate	28.25	23.5	Moderate
11	I feel angry	66.75	20	Moderate	19.25	19.25	Moderate
12	I have trouble sleeping	79.25	20.75	Moderate	31.75	22.75	Moderate
13	I worry about what will happen to me	85.75	17	Moderate	27.5	28	Moderate
14	I have trouble getting along with other kids	74.25	21.25	Poor	32.5	26.5	Moderate
15	Other kids do not want to be my friend	60.75	23.5	Poor	25.75	22.25	Poor
16	Other kids tease me	57.5	23	Moderate	18.25	20.75	Moderate
17	I cannot do things that other kids my age can do	75	23.75	Good	34.25	30.5	Good
18	It is hard to keep up when I play with other kids	77.5	19	Moderate	34.25	29	Moderate
19	It is hard to pay attention in class	63.25	19.5	Moderate	23.25	20.75	Moderate
20	I forget things	60	15.5	Poor	28.25	27.75	Poor
21	I have trouble keeping up with my schoolwork	72.5	24	Moderate	23.25	25.25	Moderate
22	I miss school because of not feeling well	88.25	14.25	Moderate	38.25	33.25	Moderate
23	I miss school to go to the doctor or hospital	89.25	14.25	Poor	44.25	26.75	Moderate

MS: Mean of Scores; SD: Standard Deviation; Poor: MS = 0-33; Moderate: MS = 34-66; Good: MS ≥ 67

Table (4.6) shows the quality of life of children at the post-test II measurement for both groups study and control, with much better results in the study group compared to the control group. The study group got the highest mean score 89.25%, which is "Good" for items "It is hard for me to walk more than one



block" and "It is hard for me to take a bath or shower by myself." The control group received the lowest mean scores for these items, with corresponding values of 40% and 50.75%, which were both "Moderate." For the rest of the variables, the study group had lower mean scores; its weakest point was lifting something heavy. That means this was the variable where they found it most difficult to perform an activity. The control group recorded its lowest mean score 11.75%, which is "Moderate" for "It is hard for me to do sports activity or exercise." Across most items, the study group scored higher, reflecting better quality of life whereas the control group predominantly remained in the "Moderate" range with some "Poor" classifications. This indicates that the intervention was effective in improving the quality of life for the study group.

Table (4.7) Repeated measures comparisons for the differences in the mean of scores of children's quality of life (study group)

Domains	Repeated Measures Comparison	Mean	SD	F Test	P-value
Health and Activities	Pre-test	42.75	12.75	333.64	0.000 HS
	Post-Test I	61.25	17.75		
	Post-Test II	76	14.75		
Feelings	Pre-test	42.5	13.5	40.59	0.003 HS
	Post-Test I	58.5	11.25		
	Post-Test II	77.25	7.25		
Get along with Others	Pre-test	33.75	5.25	262.06	0.000 HS
	Post-Test I	53	7.25		
	Post-Test II	69	9.25		
School	Pre-test	37.75	8.75	86.29	0.001 HS
	Post-Test I	59	16		
	Post-Test II	74.75	13.75		
Overall Quality of life	Pre-test	39.75	10.25	729.96	0.000 HS
	Post-Test I	56.5	13		
	Post-Test II	74.25	11.75		

SD: standard deviation, df: degree of freedom, NS: Non-Significant at $P>0.05$

The table (4.7) shows a repeated measures comparison of children's quality of life in many domains which are Health and Activities, Feelings, Get along with Others, School, and Overall Quality of Life before and after two interventions (Post-Test I and Post-Test II). Findings show that there are statistically



significant improvements in all the domains over time as reflected by the F-tests and P-values which are all highly significant ($P < 0.05$). Mean scores uniformly increased from the pre-test to Post-Test II of all the domains, indicating marked enhancement in the quality of life. For example, the Overall Quality of Life domain indicates a great deal of improvement with a mean increase from 39.75 at the pre-test to 74.25 at Post-Test II where it corresponds to an extremely high F-value 729.96. These results bring out the effectiveness of the interventions in positively impacting children's quality of life .

Discussion:

Offers the demographic characteristic of the study sample for Children with Congenital Heart Defects, who participated in this study their included (30) patients for control group and (30) study group: (66,7%) males constituted the majority and (33,3%) female who's admitted to the hospitals. The data indicate that children in the study group, who participated in the nurse-led educational program, reported a substantial enhancement in their overall quality of life compared to the control group. the study group consistently scores higher mean values than the control group for most items. For instance, in walking more than one block, the study group reported more difficulty (MS = 60.75, SD = 35.75) compared to the control group (MS = 45, SD = 16.5), This improvement is particularly noteworthy in the domains of health activities, emotional well-being, and social interactions. The statistical significance observed in the overall quality of life scores ($p = 0.014$) suggests that the educational program effectively addressed the multifaceted needs of these children, promoting not only physical health but also emotional and social well-being. Educational interventions, as part of the nurse-led program, played a crucial role in empowering both children and their families. By providing tailored information and resources, nurses facilitated a better understanding of CHDs and the necessary management strategies. This empowerment is vital for parents, who often bear the responsibility of care and decision-making. The study's findings resonate with the notion that informed parents can contribute to improved health outcomes for their children, as they are more likely to engage in proactive health behaviors and adhere to medical recommendations. According to the current study's findings, children with congenital heart defects report significant changes in their QOL in the physical, emotional, social, and school domains. They also indicate that their mean improved soon after the educational program. The current study's findings can be explained by the idea that movement is crucial as well. As for the improvement in the physical domain, the mean was change from (42.75) in pre-test to (61.25) in post-test1 to (76) in post-test2. These results are consistent with Brudy et al.,(2021), who investigated the quality of life of children with congenital heart disease, PA had a positive correlation with QoL in these children. A higher QoL is more likely to be reported by pediatric patients who move more. Also consistent with other



study, The study's findings showed that QoL had a positive impact on PA, particularly in younger children. To promote high PA levels, health policy may be advised to concentrate on a general decrease in ST rather than PA promotion.¹⁵ Another study compatible with these results, show that patients with CHD can benefit via engaging in an organized exercise program for cardiac rehabilitation in order to increase their cardiopulmonary physical health, Compared to their peers, children with complex congenital heart disease are more likely to be restricted to lower-intensity activities. Also having demonstrated that aerobic exercise is beneficial for this patient group.¹⁶

Conclusions:

The results of the study provided strong support family-centered educational program to improve the physical health of children with congenital heart defects program has improved the physical health in those children who parents attended the program. These results have important implications for the management of congenital heart defects children, highlighting the effectiveness of integrated quality of life educational programs to improving the overall quality of life for children with congenital heart defects.

Recommendation:

The Ministry of Health should organize programs for parents of children with congenital heart disease to equip them with essential information and skills for managing their children's condition effectively. This will promote better management practices. Implementing training programs for individuals with congenital heart disease in their homes or within community settings, focusing on areas like nutrition, physical activity, and infection prevention. Creating health service programs in schools to support students with congenital heart defects. Raise awareness about the use of mass media, including television and radio, as well as lectures in various community organizations or health centers. Focus on educating the public about the risk factors, prevention of congenital heart disease, and home care for children affected by congenital heart disease. Longitudinal studies follow congenital heart disease children for a longer length of time to evaluate the long-term benefits. The results of this study can be utilized as the base in future research in the same environment to examine the efficacy of quality of life. The topics of quality of life can be included in the college nursing curriculum by which nursing student become very aware of details related to this topic and Non-therapeutic interventions can be taught to nursing students and staff to assist them avoid difficulties.

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