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Educational Benefits of Nurse-Led Family-Focused Care for Children with Congenital Heart Defects: A Comprehensive Evaluation

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ABSTRACT

Background: Congenital heart defects (CHDs) are structural abnormalities of the heart present at birth that can affect a child's overall health, growth, and development. Are the most common type of birth defect, affecting approximately 1 in 100 live births. These conditions often require complex medical interventions and long-term management, significantly impacting the health and well-being of affected children and their families. This approach recognizes that parents play a crucial role in their child's care and education. By involving families in the care process, nurses can help create a supportive environment that addresses the unique needs of children with CHDs. The management of CHDs involves a multidisciplinary approach, where the role of nurses, particularly in family-focused care, has become increasingly vital. A comprehensive evaluation of these practices is essential to identify best practices and optimize the care provided to these vulnerable populations. Benefits of Nurse-Led Family-Focused Care: Enhanced Communication, Emotional Support, Education and Empowerment and Holistic Care.

Objectives: this study aim to investigate the effect of educational benefits of nurse-led family-focused care among children with congenital heart defects.

Methods and Results: a quasi-experimental design to investigate the impact of an educational program on the quality of life 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. and 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 quality of life among the study group during the period of measurement. Appling of the educational program for children with congenital heart defects program effect positively on children with CHDs.

Conclusion: The Family-centered educational program to improve the quality of life of children with congenital heart defects program has improved quality of life in those children who parents attended the program.

Keywords: *Congenital Heart Defects, Nurse-Led Family, Quality of Life.*

1. 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]

Quality of life (QoL) is defined as the individual's perception related to their state in life in terms of the cultural structure and system of values in which they live, The concept of QoL includes an individual's distinct physical and mental well-being, degree of self-sufficiency, interpersonal connections, surrounding circumstances, and personal beliefs.[6] The management of CHDs in children should take into account not only the medical element of the condition but also how cardiac illnesses impact the child's daily activities and, in turn, their QoL[7]. Approximately 60% of children with CHD experience poor weight gain and growth failure [8].

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 [9,10]

Quality of life are very important since some factors lead to the worsening of the patient's condition, such as socioeconomic status and number of blocked arteries., which negatively affects the physical status of the clients [11,12].

The nurse's role in caring for children with CHD requires specialized abilities in teaching their parents the necessity of meeting their requirements [13]. The care of the nurse continues to the patient as long as the surgical procedure is planned and advised in the immediate preoperative phase [14].

Clinical nurse specialists are essential in helping patients with congenital heart disease by offering their specialized knowledge, skills, support, and guidance. Individuals with congenital heart disease require specialized lifelong monitoring [15]. The role of nurses in caring for children with congenital heart defects (CHD) is multifaceted, encompassing clinical, educational, and psychosocial responsibilities. Nurses are essential in providing comprehensive care that addresses the unique needs of these patients and their families throughout the continuum of care, from prenatal diagnosis to postoperative management [16].

Pediatric nurses are essential in helping parents while also treating the symptoms of their child's heart disease and decreasing the care burden[17]. The nurses work closely with children to evaluate their requirements, recognize risk factors for surgery, and learn about their vulnerabilities. On the other hand, nurses manage or carry out comprehensive nursing interventions[18].. Although it is generally accepted that multidisciplinary management and follow-up of heart failure patients are effective to improve patient adherence, reduce hospital readmissions and improve survival [19,20].

2. METHODS AND MATERIALS

A quasi-experimental design was use to investigate the educational benefits of nurse-led family-focused care for children with congenital heart defect in improving the quality of life. 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 quality of life 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

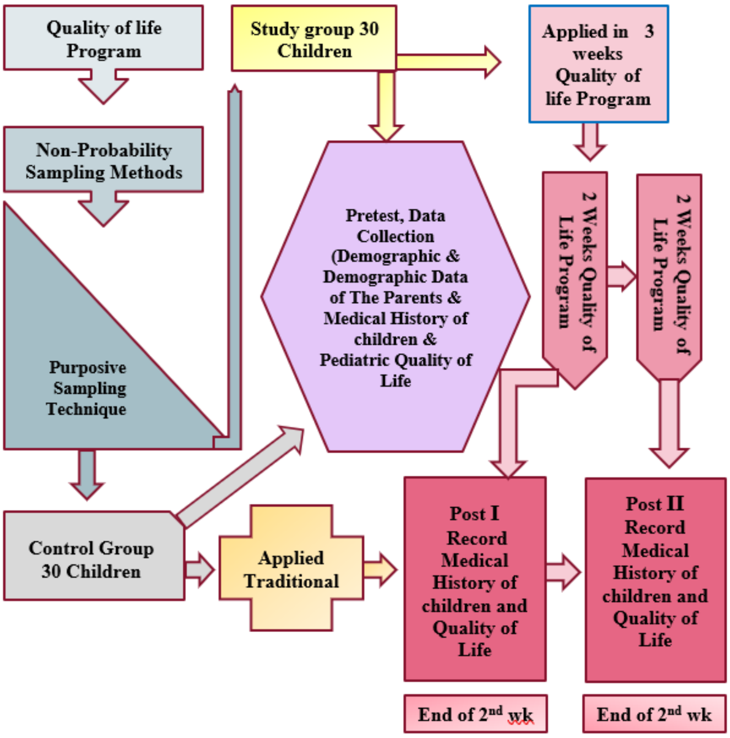

Figure (1) Show the Steps of Quality of Life Program

Results

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 0.28 NS
	10-11	11	36.7	10	33.3	
	≥ 12	5	16.7	4	13.3	
Gender	Male	20	66.7	17	56.7	0.64 0.42 NS
	Female	10	33.3	13	43.3	
Educational Status	Do not read and write	4	13.3	5	16.7	3.12 0.37 NS
	read and write	9	30.0	21	70.0	
	Primary School	17	56.7	4	13.3	
Sequence between family members	1	5	16.7	4	13.3	1.47 0.47
	2	4	13.3	7	23.3	

	3	8	26.7	3	10.0	NS
	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 0.22 NS
	Rural	12	40.0	16	53.3	

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 0.18 NS
	32-41	10	33.3	17	56.7	
	42-51	11	36.7	6	20.0	
Mother's Age	22-31	10	33.3	10	33.3	0.48 0.58 NS
	32-41	14	46.7	18	60.0	
	42-51	6	20.0	2	6.7	
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 Status	< 300000	5	16.7	4	13.3	2.47 0.27 NS
	300000-600000	7	23.3	9	30.0	
	601000-90000	6	20.0	8	26.7	
	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 heavy	20.75	20.75	Poor	15.75	18	Poor
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 kids my age can do	60.75	19.25	Moderate	25	21.75	Poor
18	It is hard to keep up when I play with other kids	60	15.5	Moderate	23.25	19.5	Poor
19	It is hard to pay attention in class	50	20.75	Moderate	24.25	19	Poor
20	I forget things	39.25	15.75	Moderate	27.5	20	Poor
21	I have trouble keeping up with my schoolwork	55.75	18.25	Moderate	25	20.75	Poor
22	I miss school because of not feeling well	72.5	24	Good	32.5	23.75	Poor
23	I miss school to go to the doctor or hospital	77.5	21	Good	43.25	22.75	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	89.25	15.75	Good	40	27.5	Moderate
2	It is hard for me to run	63.25	18.25	Good	14.25	18.25	Moderate
3	It is hard for me to do sports activity or exercise	62.5	17	Good	11.75	15.75	Moderate
4	It is hard for me to lift something heavy	50.75	15.25	Moderate	14.25	18.25	Moderate
5	It is hard for me to take a bath or shower by myself	89.25	15.75	Moderate	50.75	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 nigh 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 (see also figure 1).

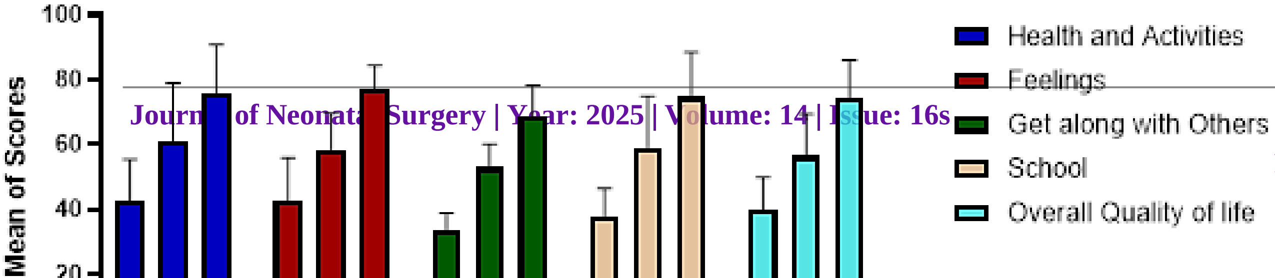

Figure (2) Repeated measures comparisons for the differences in the mean of scores of children's quality of life (study group). (1): Pre-Test. (2) Post-Test I (3) Post-Test II

Discussion

Table (4.1) 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.

Conclusions

The results of the study provided strong support family-centered educational program to improve the quality of life of children with congenital heart defects program has improved the quality of life 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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