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IMPROVING THE QUALITY OF LIFE IN CHILDREN WITH CONGENITAL HEART DISEASES ATTENDING OUTPATIENT CLINIC IN ZAGAZIG UNIVERSITY HOSPITAL , EGYPT

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ABSTRACT

Introduction: Congenital heart diseases are among the most common birth defects and are the leading cause of birth defect-related deaths. In Egypt, it was found that the prevalence of congenital heart diseases was 1.01/1,000 live births. The most common cardiac defects are ventricular septal defects. Children with congenital heart diseases experience decreased health related quality of life. ***Aim:*** This study aimed at improving health-related quality of life of the children through applying an educational program about the most important aspects of the disease and how to deal with it. ***Subjects and methods:*** An intervention study (pre-post self-control study) was carried out on 54 patients aged (10 – 18 years) with congenital heart diseases by providing health education session to the patient and their parents.The patients were assessed using PedsQL Pediatric Quality of Life Inventory Version 4.0 and PedsQL Cardiac Module Version 3.0 to assess health related quality of life before and after intervention. ***Results:*** This study showed that patient education intervention caused significant improvements in all quality of life domains among the patients. ***Conclusion:*** Patient education is considered a very effective method that could be applied by health care providers in order to improve the quality of life of children suffering from congenital heart diseases.

Keywords : Quality of life , congenital heart disease .

INTRODUCTION

Quality of life, as defined by WHO 1998, is individuals' perception of life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns. It was found that congenital heart disease patients experience decreased quality of life . In Egypt, it was found that the prevalence of congenital heart diseases was 1.01/1,000 live births. (1)

Patients with CHD have important gaps in their knowledge about particular aspects of the disease, treatment, or preventive measures. Patients' poor knowledge may have major consequences. To enhance overall health status and to improve the quality of life, patients are expected to adopt certain health behaviors which could be conducted to them by suitable patient education. (2)

Patients and method: An intervention study (pre- post self-control study) was carried out on 54 patients with congenital heart diseases aged between 10 and 18 years and who attended pediatric outpatient clinic were included. Children less than 10 years old ,adults (more than 18 years old) ,patients with any co-morbid chronic diseases and those coming accidentally or not intended to regularly follow up at this clinic were excluded from the study. The sample size was calculated taking into account that the mean of pain control domain of quality of life score

before intervention (estimated from previous studies) was 55.0± 28.3 while at 2 months after, the pain control was 66.0±22.2 assuming 95% confidence interval and 80% power of the test. [3]
The study was carried by the following steps:

1) Pre- intervention stage: after taking a verbal consent from the patients and their parents, the questionnaire sheet was filled for each patient to assess socio-demographic and disease specific characteristics and the pretest (PedsQL Pediatric Quality of Life Inventory Version 4.0 and PedsQL Cardiac Module Version 3.0) was filled to assess the quality of life. [4]

2) Intervention stage: an educational session was given for each patient and his/her parents in about 10 minutes as a group session. The education message quoted from: Moons et al., 2005 ,Wiener et al., 2008 and Baumgartner et al., 2010, [2,5,6] contained information about symptoms and complications of congenital heart diseases, the importance of proper diet, adequate sleep and compliance to medical treatment, allowed activities and exercises to avoid, taking care of psychological and social aspects in the patient's life and what to do at school. A booklet and a short summary of the message were given to each patient to help him/her to remember all the information given.

3) Post intervention stage: after two months of follow up, evaluation of the intervention was conducted through refilling of the same questionnaires measuring the quality of life (post-test).

Data analysis: Collected data were presented and analyzed statistically by using SPSS version 16.

The study results

This study showed that the mean age of the studied group was 14±3.2 years old. The percentage of females was (59.3%). The majority of cases (83.3%) were residents of rural areas and most of patients (40.7%) were of very low socioeconomic level. About (34.4%) of parents of the patients had a positive history of consanguinity and about (22.2%) of them had a positive family history of the disease in 1st and 2nd degree relatives. Most of the cases (81.5%) were diagnosed before the first year of age. The duration of treatment of the cases was in parallel increase with age, with a mean duration of treatment 13.3±0.7 years.

On assessing the quality of life among congenital heart disease patients, including physical, emotional, social, school functioning, cardiac and total quality of life scores before and after intervention, it was found that there were highly statistically significant improvements in all quality of life scores after the intervention. This study also showed that, there was a significant decrease in percentage of patients with poor Qol scores and a significant increase in the percentage of patient with very good scores in all domains after application of the educational program. Regarding socioeconomic characteristics, there were no statistically significant differences in total QoL score among patients before intervention regarding age, gender, residence or socioeconomic level, while after the intervention, Improvements in all QOL scores were lower among patients of middle socioeconomic level.

Table (1): Sociodemographic Characteristics of studied congenital heart disease patients.

Characteristics	*No.(54)*	*%*
Age per years		
10-12	13	24.1
13-15	20	37.0
16-18	21	38.9
Mean ± SD	14±3.2	
Gender:		
Males	22	40.7
Females	32	59.3
Residence:		
Rural	45	83.3
Urban	9	16.7

Characteristics	*No.(54)*	*%*
Socioeconomic level:		
Very low	22	40.7
Low	17	31.5
Middle	15	27.8

Table (2): Distribution of cases according to the sociodemographic characteristics of their parents.

Characteristics	*No.(54)*	*%*
Education of fathers:		
Illiterate	18	33.3
read and write	12	22.2
Primary and preparatory Secondary Higher level	16	29.7
	8	14.8
Education of mothers:		
Illiterate	16	29.6
Read and write	11	20.4
Primary and preparatory Secondary	18	33.3
Higher level	9	16.7
Occupation of fathers:		
Not working	3	5.5
Farmers	16	29.6
Laborers	30	55.6
Business men	4	7.4
Employee	1	1.9
Occupation of mothers:		
Housewives	51	94.4
Workers	3	5.6

Table (3) Distribution of patients according to disease specific characteristics.

Characteristics	*No.(54)*	*%*
Consanguinity of parents:		
Yes	51	94.4
No	3	5.6
Similar condition in family(1st and 2nd degree relatives):		
Yes	12	22.2
No	42	77.8
Age of diagnosis		
Before the 1st year of age	44	81.5
After the 1st year of age	10	18.5
Duration of treatment for each age group	***Mean±SD(years)***	
5- <8		
8- < 13	4.81±1.03	
13-18	8.94±1.31	
	12.34±0.74	

Table (4) Quality of life scores among patients before and after intervention.

Measure	*Before the intervention*	*After the intervention*	*Paired Wilcoxon test*	*P value*
Physical functioning score				
Median	43.75	56.25	5.40	0.000**
Range	83.38(1.00-84.38)	87.50(6.25-93.75)		
Emotional functioning score				
Median	25.00	50.00	5.60	0.000**
Range	74.00(1.00-75.00)	89.00(1.00-90.00)		
Social functioning score				
Median	50.00	75.00	5.03	0.000**
Range	99.00(1.00-100.00)	99.00(1.00-100.00)		
School functioning score				
Median	40.00	57.50	4.75	0.000**
Range	99.00(1.00-100.00)	99.00(1.00-100.00)		
Generic QOL score				
Median	37.50	63.04	6.21	0.000**
Range	80.52(1.00-81.52)	68.48(20.65-89.13)		
Cardiac functioning score				
Median	48.00	65.74	5.75	0.000**
Range	83.00(5.00-88.00)	89.52(5.00-94.52)		
Total QOL score				
Median	43.36	61.50	6.065	0.000**
Range	74.29(8.00-82.29)	76.04(13.02-89.06)		

**P ≤ 0.01 is highly significant

Table (5) Distribution of patients according to total quality of life score before and after intervention.

Characteristic	*Before intervention*		*After intervention*		*P value*
	No.	%	No.	%	
Poor	14	25.9	3	5.6	0.001**
Fair	17	31.5	13	24.1	0.125
Good	20	37.0	28	51.9	0.008**
Very good	3	5.6	10	18.5	0.016*

N.B: McNemar test of significance
**P ≤ 0.01 is highly significant
*P ≤ 0.05 is significant

Table (6) Total functioning score of quality of life before intervention in relation to some sociodemographic characteristics.

Characteristics	*Median and range*	*Test of significance*	*P value*
Age			
10-12	Median: 100.26	Kruskal wallis= 0.165	0.921
	Range:136.57(27.52-164.09)		
13-15	Median: 82.65		
16-18	Range:107.45(34.66-142.11)		
	Median:100.76		
	Range:147.99(15.94-163.93)		
Gender:			
Males	Median:82.08	Mann whitney= 0.968	0.333
	Range:147.99(15.94-163.93)		
Females	Median:100.51		
	Range:136.57(27.52-164.09)		
Residence:			
Rural	Median:83.78	Mann whitney= 0.638	0.523
	Range:148.14(15.94-164.09)		
Urban	Median:101.93		
	Range:125.54(38.39-163.93)		
Socioeconomic level:			
Very low	Median:61.01	Kruskal wallis= 4.916	0.086
	Range;114.59(27.52-142.11)		
Low	Median:100.26		
	Range:129.43(34.67-164.09)		
Middle	Median:116.87		
	Range:147.99(15.94-163.93)		

Table(7) Total score of quality of life after intervention in relation to some sociodemographic characteristics.

Character	*After intervention*	*Test of significance*	*P value*
Age			
10-12	Median:136.65	Kruskal wallis=1.46	0.481
	Range:151.13(26.74-177.87)		
13-15	Median:115.42		
	Range:104.63(67.35-171.98)		
16-18	Median:117.10		
	Range:132.00(34.10-166.10)		
Gender:			
Males	Median:114.56	Mann whitney=296	0.329
	Range:143.77(34.10-177.87)		
Females	Median:128.83		
	Range:150.04(26.75-176.78)		

Character	*After intervention*	*Test of significance*	*P value*
Residence:			
Rural	Median:120.00 Range:151.13(26.74-177.87)	Mann whitney=174	0.508
Urban	Median:137.27 Range:122.28(43.83-166.10)		
Socioeconomic level		Kruskal wallis=6.94	
Very low	Median:100.29 Range:137.88(34.10-171.98)		0.031*
Low	Median;140.87 Range:132.96(43.83-176.78)		
Middle	Median:137.28 Range:151.13(26.74-177.87)		

*P ≤ 0.05 is significant

DISCUSSION

In the context of the dramatically improved survival rates of patients with a CHD in recent decades, there is increased interest in how these individuals experience their quality of life. [7] . Empiric evidence supports that children with cardiac diseases experience decreased health related quality of life [8,9,10] . Identification of modifiable factors affecting health related quality of life will allow for the development of interventions which aim at increasing the health related quality of life in this large subgroup of children with cardiac disease.[11]

It was found that (34.4%) of parents of the patients had a positive history of consanguinity. This result is supported by a study conducted at Mansoura University, Egypt. The study found that the frequency of total positive parental consanguinity among the studied cases was significantly higher compared to control children.[12] Similarly, Becker et al., 2001 [13], in Saudi Arabia, have reported that first cousin consanguinity in CHD patients was significantly higher than in the general population.

It was also found in this study that about (22.2%) of CHD patients had positive family history of the disease, this is a relatively high percentage supported by the results of Settin et al., 2008 [12] who found that the percentage of positive family history in cases was higher than controls (11.6% vs 4% respectively). Also, Bassili et al., 2000, in a study in Egypt, have reported a higher percentage of positive family history and parental consanguinity in their studied sample of CHD patients than in the general population in Alexandria. [1]

After application of educational sessions, there was a highly statistically significant improvement in all quality of life scores. This result is in consistence with (Edraki et al., 2014) [14].

The study showed significant improvements in all quality of life scores in the intervention group after 2 months. Also, (West et al., 2009) [15] found a significant improvement immediately and 2 months after the intervention. The 2 months interval duration to measure the effect of the intervention on the quality of life in the two previous studies also was used in this study. This duration was found to be the minimal time required to make a change in the quality of life. [14,15]

This study also showed that, there was a significant decrease in percentage of patients with poor Qol scores and a significant increase in the percentage of patient with very good scores in all domains after application of the educational program. This result is in consistence with the results obtained from . [16,17]

Regarding factors affecting quality of life. There were significant improvements in all Qol scores after intervention in all age groups except in the school functioning score in patients aged 16-18 years old. Also, the least improvements

were in the patients of (16-18) years old. These results indicates that improvement in QoL is more difficult with increasing age towards adolescence and adulthood.

This finding was also detected by (Dulfer et al., 2014). [18] They found that older patients (aged 16 to 25) had less improvements than younger patients (aged 10 – 15).

This could be explained by that worries increase with age regarding physical appearance and its effect on relations and marriage. Physical limitations is negatively affecting patients' employment and subsequently their income in the future. Older age group patients have more autonomy and independence from parents. This autonomy leads to lacking long-term compliance as they take their medications by their own so they can skip them with no compulsion from their parents. [19] Adolescents with CHD have an increased risk of developing behavioral problems due to the physiological nature of this period of age. A life stage characterized by irreverence (which is the lack of respect for people or things that are generally taken seriously) and the will to experience new feelings. [20]

The study also showed that improvement in social QoL score was higher among the youngest patients in the study (10-12 years old), while improvement in school QoL score was higher in patients of (13-15) years old.

These results could be explained by that younger children do not perceive a difference in their ability from that of a healthy peer. Similarly younger children may receive more assistance in their daily activities and therefore not perceive that they may have difficulty performing certain tasks. These variations in ability may become evident as the children age and are able to objectively compare their abilities to their peers. They are also more dependent on their parents with psychological and social support. These factors could explain the higher improvement in social QoL score among them. [21]

The higher improvement in school performance in patients of (13-15) years could be attributed to parents' overprotective educational styles at this age, as they start to recognize the importance of educational needs of their child.

There were highly significant improvements in all QoL scores in both males and females, with higher improvement of the school functioning QoL score in female patients. *This may be* due to better compliance of females than males to the advice regarding adaptation to a healthier life style. They slept earlier, limited the harmful food and drinks and ate more fruits and vegetables. These factors increased their attention with better school performance. This result is consistent with (Lubetkin et al., 2005) [22]

It was found that there were highly significant improvements in all QoL scores among residents of rural areas. However, residents of urban areas showed significant improvements in emotional, social, cardiac and total QoL scores, while there was no significant improvement in physical and school QoL scores. Improvements in all QoL scores were higher among residents of rural areas.

In previous studies measuring the quality of life in patients with chronic illnesses, there were diverse results and explanations regarding the effect of residence on their quality of life. ***(Gamble et al., 2011)*** [23]

Some studies suggest a better QoL scores among residents of urban areas either before or after the interventional efforts. This could be easily explained by better resources for living with better opportunities for improvement. Residents of rural areas suffer from low financial security, deprivation and less access to medical services, so it's logical that they have lower QoL scores with lower improvements. [24,25]

However, other studies surprisingly reported better QoL scores in some domains among residents of rural areas, either before or after efforts for improvement. This is possibly because they give greater weight to the relatively intangible aspects of their environment. [26] This explanation is in consistence with the WHO definition of the quality of life (individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns). So, better perception of their position in life with lower goals and expectations could explain how patients living in rural areas could have better QoL scores. Also, not all residents of rural areas suffer from poor financial conditions. In addition, in rural areas

there are less stresses regarding the requirements of modern life with more relaxing environment. (24,26)

CONCLUSION

On assessing the quality of life among congenital heart disease patients, including physical, emotional, social, school functioning, cardiac and total quality of life scores before and after intervention, it was found that the lowest QoL score before intervention was the emotional score while the highest score was the social score. After intervention, it was found that there were highly statistically significant improvements in all quality of life scores after the intervention. It was observed that the highest improvement was in the emotional functioning score, while the lowest improvement was in the school functioning score.

This study also showed that, there was a significant decrease in percentage of patients with poor Qol scores and a significant increase in the percentage of patient with very good scores in all domains after application of the educational program.

RECOMMENDATIONS

QoL should be the outcome measure of medical care not just the results of treatment or surgeries.

Assessment of the QoL should be an integral part of the patients' treatment.

Periodic educational sessions for congenital heart disease children and their parents in order to improve their quality of life.

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