

STUDY OF QUALITY OF LIFE OF CHILDREN AGED 2 YEARS TO 12 YEARS WITH HEART DISEASE.

1. **VINAY K SINGH**- Post graduate resident, Department of Pediatrics, Gandhi Medical College, Bhopal.
2. **RAJESH PATIL** – Assistant Professor, Department of Pediatrics, Gandhi Medical College, Bhopal.
3. **BHARATI CHOUBEY** – Assistant Professor, Department of Pediatrics, Gandhi Medical College, Bhopal.
4. **SHARMILA RAMTEKE** - Associate Professor, Department of Pediatrics, Gandhi Medical College, Bhopal.
5. **MANJUSHA GOEL** - Professor, Department of Pediatrics, Gandhi Medical College, Bhopal.

Corresponding Author:

Dr BHARATI CHOUBEY – Assistant Professor, Department of Pediatrics, Gandhi Medical College, Bhopal.

Phone: +91-9425648378

Email: drbharatichoubey@gmail.com

ABSTRACT

Introduction: Heart diseases are one of the important causes of childhood morbidity and mortality. With advance in medical and surgical techniques life expectancy of children with heart diseases increased so concern shifted toward how quality of life is affected with various type of heart disease and what are important factors which affect QOL.

Objective: Assessment of quality of life in children with heart disease and various factors affecting it.

Method: This is a cross sectional observational study, all children with heart disease were enrolled and their demographic and clinical information was collected using pre designed and pre tested proforma. Quality of life of children was assessed by peds QOL 4 scale. The results were analyzed by SPSS software version 25.

Results: There were 60 children out of which 28, 17 and 15 are in age group 2-4, 5-7 and 8-12 years respectively, 52 % were male and 48% were female. According to their residence 52% were urban and 48 % belong to rural area. It is found that children belonging to higher socioeconomic status groups experiencing better QOL (quality of life) in all domains (p value 0.015), children with cyanotic heart disease shows poor QOL as compared to acyanotic and rheumatic heart disease (p value 0.04). Children with surgical management showed better QOL as compared to children on medical management. No significant association was found between QOL age, sex, residence and maternal educational status

Conclusion: In children with heart disease, quality of life is affected by type of heart disease, medical or surgical management, socioeconomic status. It was found that surgical management improves quality of life.

Keywords: Quality of life, Heart disease, Children.

INTRODUCTION

Heart diseases are one of the important causes of childhood morbidity and mortality. With advance in medical and surgical techniques life expectancy of children with heart diseases increased so concern shifted toward how quality of life is affected with various type of heart

disease¹ and what are important factors which affect QOL. Most heart diseases in children are attributed to congenital malformation of heart but children can also acquire some form of heart disease, most common being rheumatic heart disease². Congenital heart disease (CHD) refers to structural heart defect that are present at birth. Congenital heart disease covers a variety of anatomical and functional cardiac malformations. Prevalence of congenital heart disease is around 6-8 per thousand live births and incidence of rheumatic heart disease is 5.3 per thousand in Indian population³. With advances in medical field life expectancy has increased but QOL of children has affected. Quality of life of any individuals is described as their ability regarding the certain distinct domains like physical health status and functioning, psychological health status and functioning and social health status and functioning⁴. Chronic conditions such as heart disease put increased stress on the child, their parents and also on their own siblings. They have two times more risk of developing any psychological health problems than any of healthy children without any chronic disease, and thrice the risk of having mental problems, if they have any accompanying disability⁵. According to previous research, heart disease affects different parameters of child health related to quality of life, including physical health, emotional health, social health, and school functioning. In recent years, as the focus has shifted along with survival to the quality of life, health related quality of life has come out as an important measure of outcome in paediatrics.

METHODS:

This observational study was conducted from 1st April 2020 to 31st March 2021, at an academic tertiary care center, All Children between 2 yrs. to 12 yrs. of age who are diagnosed case of heart disease via 2D echocardiography were included in the study after taking informed written consent from a guardian of the child. Children with other chronic disease like chronic kidney disease, chronic liver disease were excluded from study. In our study pediatric quality of life inventory scale was used to assess quality of life of children with heart disease. Peds QL 4.0 version was designed to measure the core health dimensions as delineated by WHO⁶, including role (school) functioning.⁷ This version has been proposed as a valid and reliable tool for the measurement of paediatric HRQOL (health related quality of life)⁷.

The PedsQL 4.0 Generic Core Scale is composed of 4 sub scales-

Physical functioning- 8 items

Emotional functioning- 5 items

Social functioning- 5 items

School functioning- 3 items (for age group 25 to 48 months), 5 items (for age group 49 to 72 months).

It was developed through focus groups, cognitive interviews, pretesting, and field-testing measurement development protocols⁸. PedsQL 4.0 is available as 21 items for children aged 25 to 48 months whereas, for children aged 49 months to 72 months, a 23-item version is used. Two items namely "Forgetting things" and "Paying attention in class" are excluded from the "school functioning" subscale of the 23-item version for children aged 25 to 48 months.

Peds QL questionnaire was applied to all patients admitted during the study period of 12 months (from 1st April 2020 to 31st March 2021) those following inclusion criteria. A total of 60 heart disease patients were enrolled in the study (age group 2 -12 yrs.). Sample size was

calculated taking the institutional prevalence of heart disease. Demographic profile, mother & father education status, socioeconomic status via modified kuppusswamy scale and anthropometric measurements (weight, height, head circumference, mid upper arm circumference, weight/height) were taken and Peds QOL applied and score were taken and entered into a pretested case record form. Peds QL questionnaire is available for different age groups that is for 2-4 years, 5-7years, and 8-12years. For Children belonging to age groups 2-4year proxy report were collected from mothers and rest all groups are self-reported.

Statistical analysis:

All data collected were entered into the master chart. Mean and SD were calculated for quantitative data. Quality of life of children in different groups were compared using ANOVA test in different groups. Statistical analysis was carried out using SPSS software. P value < 0.05 was taken as significant.

RESULTS:

A total of 60 children were enrolled in the study, out of which 27 (45%) were diagnosed case of acyanotic CHD and 21 (35%) cyanotic CHD and 12 (20%) RHD. According to age 28 (47%), 15 (28%) and 17 (25 %) in age group 2-4, 5-7 and 8-12years respectively. Male to female ratio was comparable male were 31 (52%) and female were 29(48%). According to residence 31 (52 %) were urban and 29 (48%) were from rural area. As per socioeconomic status 11 (18%) from upper middle class, 31 (52 %) from lower middle, 16 (28%) from lower upper and 2 (4 %) from lower class. According to nutritional status 21 (35%) were severe acute malnourished, 10 (17 %) were moderate acute Malnourished and rest were normal in children less than 5year age. In children more than 5 years 11 (18%) were moderately undernourished and 10 (17%) were severely undernourished (Table 1).

Variable	Distributions	Frequency (percentage %)
Age	2-4 yrs	28 (46.6%)
	5-7 yrs	15 (25%)
	8-12 yrs	17 (28.3%)
Sex	Male	31 (51.6%)
	Female	29 (48.4%)
Residence	Urban	31 (51.6%)
	Rural	29 (48.4)
Father's education	Nil to <Primary Education	2 (0.03%)
	Primary Education	5 (0.08%)
	High school	17 (28.3%)
	Higher secondary	19 (31.6)
	Graduate	15 (25%)
	Post Graduate	2 (0.03%)
Mother's education	Nil to <Primary Education	8 (13.3%)
	Primary Education	13 (21.6%)
	High school	20 (33.3%)

	Higher secondary	15 (25%)
	Graduate	4 (0.06%)
Socio economic status	Upper	0
	Upper middle	11 (18.3%)
	Lower middle	31 (51.6%)
	Upper lower	16 (26.7%)
	Lower	2 (0.03%)
Nutrition status	Normal	8 (13 %)
Children < 5yrs.	Severe acute malnutrition	21 (35%)
	Moderate acute malnutrition	10 (17%)
Children > 5yrs.	Moderate under nutrition	11 (18 %)
	Chronic under nutrition	10 (17%)

Table no (1): Demographic profile

No significant association of QOL found with age, sex, residence and maternal educational status. relation of QOL with age (figure no 1).

In our study it was found that children belonging to higher socioeconomic status experiencing better QOL in all domains (physical, school, emotional and social) with mean QOL score 67.21 ± 17.99 for upper middle, 63.78 ± 18.48 for lower middle, 61.50 ± 17.46 for lower upper and 4.03 ± 9.06 for lower SES class (p value :0.015) figure (2).

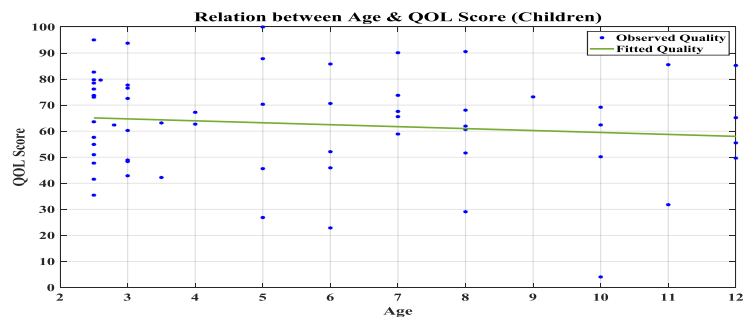


Figure (1): Relationship of quality of life with age of child

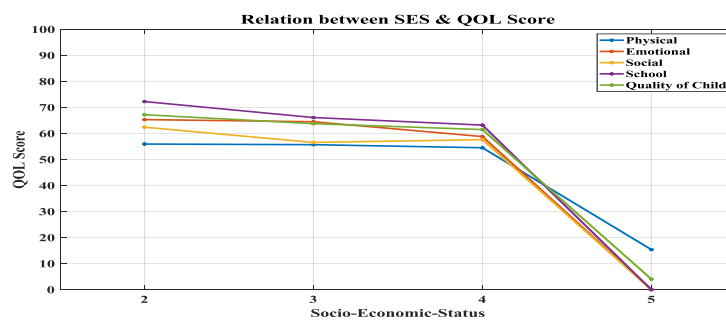


Figure (2): Relationship of quality of life with socioeconomic status of parents

According to socioeconomic status QOL is most affected in physical functioning and least affected in school functioning. There was a drastic decline in mean for all domains seen between

QOL	Medical	Surgical	P – VALUE
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n class 4 and 5.

Children with cyanotic heart disease showed poor QOL (mean score :42.30±14.15) as compared to acyanotic (mean score :73.22±11.49) and rheumatic heart disease (72.48±14.32) with significant p value 0.04 (figure 3). According to domain wise analysis in different type of heart disease QOL is most affected in physical functioning and least affected in school functioning. Children with surgical management showed better QOL (mean score: 65.70±21.03) as compared to children on medical management (mean score: 55.91±18.13) with significant p value 0.042, (table no 2 and figure 4).

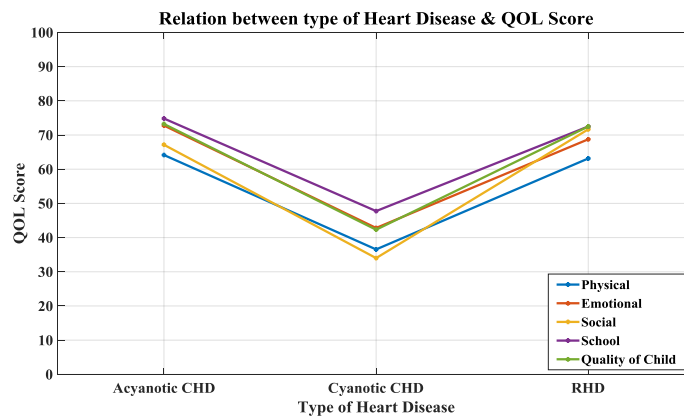


Figure (3): Relationship of quality of life with types of heart disease

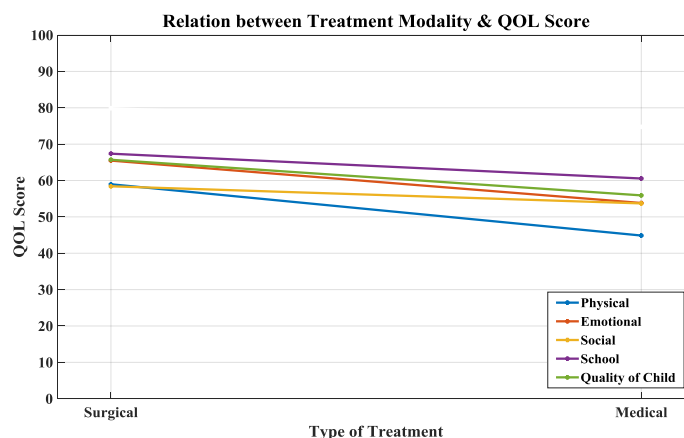


Figure (4): Relationship of quality of life with treatment modality

PHYSICAL QOL M ± SEM	44.87±22.46	58.97±21.12	0.023
EMOTIONAL QOL M ± SEM	53.81±19.78	65.47±19.18	0.036
SOCIAL QOL M ± SEM	53.70±22.69	58.41±22.94	0.467
SCHOOL QOL M ± SEM	60.55±22.02	67.38±19.76	0.240
CHILD QOL M ± SEM	55.91±21.03	65.70±18.13	0.042

Table no (2): Relationship of QOL with treatment modality

According to nutritional status, children belonged to severe acute malnutrition the QOL was (60.47±18.41) and with chronic malnutrition mean score for QOL was (51.83±20.50) as compared to normal nutritional status (83.62±13.17) or moderate malnutrition (69.33±17.09) with significant p value 0.002 (figure 5).

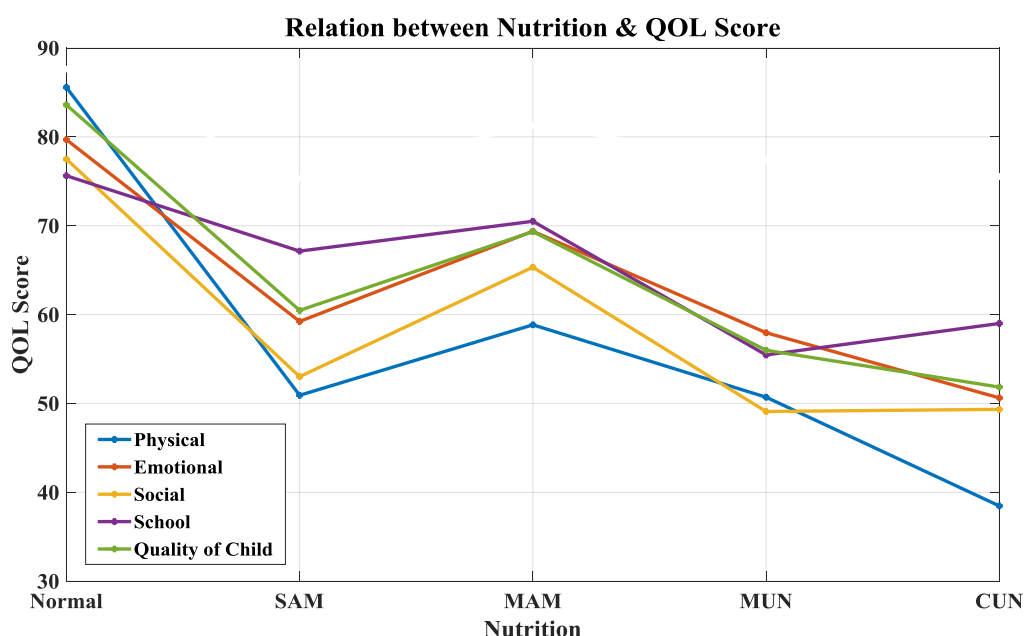


Figure (5): Relationship of quality of life with nutritional status of child

DISCUSSION: The result of our study showed significantly lower health related QOL score in all domains including physical, social, emotional and school functioning with regard to type of heart disease management type, socioeconomic status, and nutritional status.

Nutritional status of children is one of major determinant of quality of life in children with heart disease.

Several studies are done previously to assess health related QOL in children with heart disease out of them mostly found that QOL were affected by heart disease by various socioeconomic factors type of heart disease, severity of disease and their management^{1,9,10,11,12}. Few of them also found that QOL is not affected according of type of heart disease, gender and other factors^{13,14}. Yvette krol et al found that children have lower quality of life in the domains like motor functioning, Autonomy and cognitive functioning.⁹ A.W. Spierer et al found that children with congenital heart disease obtained significantly lower scores on motor functioning ($p<.001$), cognitive functioning ($p=0.001$) and positive emotional functioning ($p=0.016$), indicating poorer functioning, motor and cognitive functioning appeared to be significantly poorer in boys and girls with congenital heart disease as compared to peers of same age groups of reference population¹. Li Xiang et al assessed impact of family socioeconomic Status on Health-Related Quality of Life in Children with Critical Congenital Heart Disease, family SES significantly affected all dimensions of HRQOL except for treatment barriers, treatment anxiety, physical appearance and communication¹⁰. Rometsch et al found that patients reported worse physical HRQOL than controls but similar mental HRQOL and psychological adjustment. Female CHD patients showed worse physical and mental HRQOL and poorer psychological adjustment than males. In CHD patients, a lower educational level and lower physical exercise capacity predicted lower physical HRQOL, but complexity of CHD was not related to HRQOL or psychological adjustment¹¹. P. Amedro et al assessed QOL scores of CHD and controls and between the classes of disease severity and found that QOL scores were lower in CHD children than in controls for physical well-being, financial resources, peers/social support, and autonomy¹². Ophelie Loup et al Analysis for cyanotic verses acyanotic patients and found lower quality of life ($p = 0.69$) for cyanotic group (TGA, TOF) and no higher anxiety ($p = 0.69$) nor depression ($p = 0.14$) scores when compared with acyanotic (VSD). This study shows that grown-up with congenital heart disease patients after congenital heart disease surgery have an excellent quality of life without any significant difference between diagnostic groups (TOF, TGA, VSD) or between the possibility of surgery (cure, correction or palliation)¹³. Abassi et al was found that the HRQOL in children with CHD is good enough and quite similar that of control group¹⁴.

CONCLUSION:

Children with heart diseases have poor QOL because of disease per se, but there are factors like age, type of heart disease, treatment modality, nutritional status and socio-economic status which may affect quality of life.

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