ASSESSMENT OF QUALITY OF LIFE IN CHILDREN WITH HEART DISEASE AND VARIOUS FACTORS AFFECTING IT.

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Abstract

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 group2-4,5-7 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.

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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 [1] 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 disease.[2] congenital heart disease (CHD) refers to structural heart defect that are present at birth. CHD 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 population.[3]

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 functioning.[4] 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 disability.[5]

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.

AIM AND OBJECTIVE

This observational study was conducted one year period from April 2020 to march 2021, at an academic tertiary care center, in central India. Aim of this study was-
Assessment of quality of life in children with heart disease and various factors affecting it.
Quality of life of children was assessed by peds QOL 4 scale.

METHODS:

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 asses quality of life of children with heart disease.

Peds QL 4.0 version was designed to measure the core health dimensions as delineated by WHO,[6] 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 Peds QL 4.0 Generic Core Scale is composed of 4 sub scales-
1] Physical functioning- 8 items
2] Emotional functioning- 5 items
3] Social functioning- 5 items
4] 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 protocols.[8] Peds QL 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 (April 2020 to 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 kuppuswamy scale.
- Anthropometric measurements (weight, height, head circumference, mid upper arm circumference, weight/height) were taken and Peds QL 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.

OBSERVATIONS AND 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 5-year age. In children more than 5 years 11 (18%) were moderately undernourished and 10 (17%) were severely undernourished

Table no- 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%)

QOL	Medical	Surgical	P – VALUE
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

-We found that no significant association of QOL found with age, sex, residence and maternal educational status. relation of QOL with age.
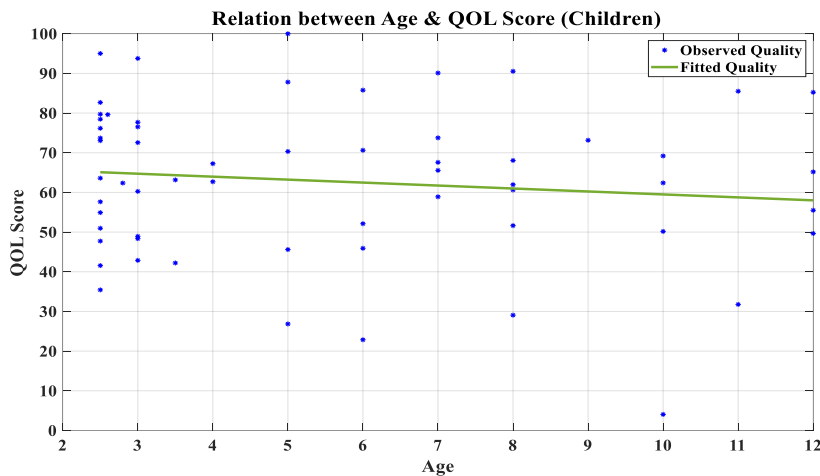

-In our study it was found that children belonging to higher socioeconomic status experience better QOL in all domains (physical, school, emotional and social) with mean QOL score 67.21±17.99 for upper middle, 63.78±18.48 for lower middle, 61.50±17.46 for lower upper and 4.03±9.06 for lower SES class (p value :0.015) (figure 2).
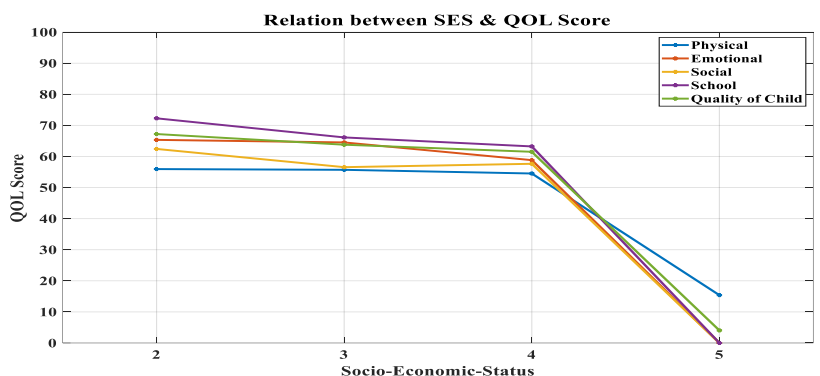
-According to socioeconomic status, QOL is most affected in physical functioning and least affected in school functioning. There was a drastic decline in mean for all domains seen between class 4 and 5. Children with cyanotic heart disease showed poor QOL (mean score :42.30±14.15) as compared to acyanotic (mean score :73.22±11.49) and rheumatic heart disease (72.48±14.32) with significant p value 0.04.
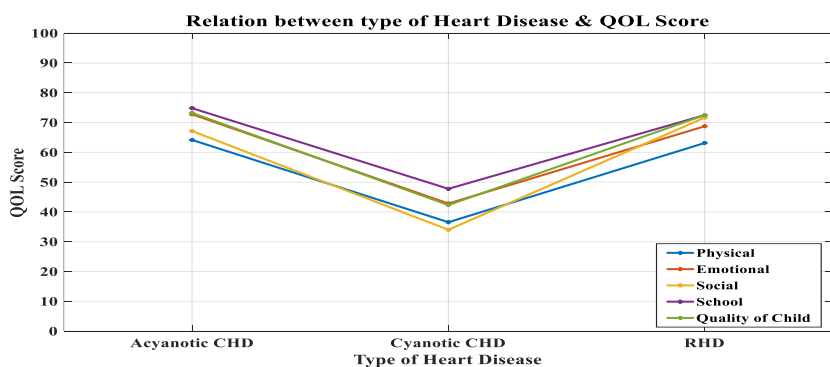
Relationship of quality of life with types of heart disease

-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, who underwent 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 2 and figure 4).
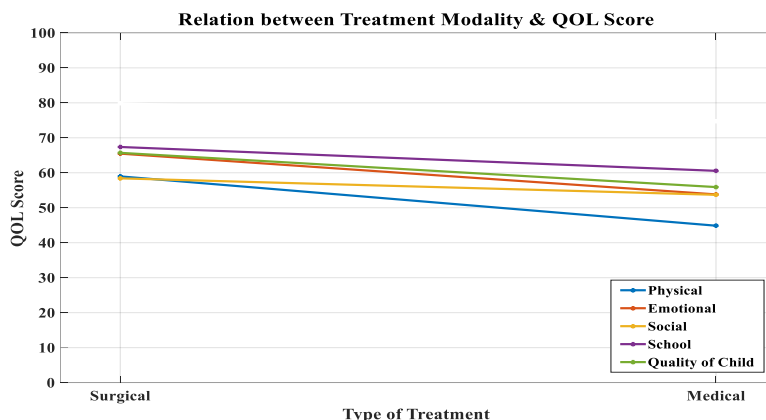
Relationship of quality of life with treatment modality

-According to nutritional status, children having 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).
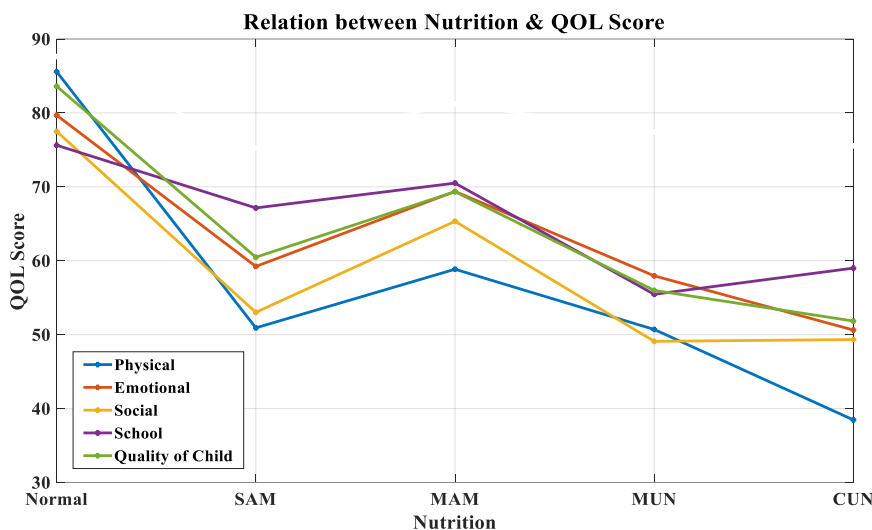
Relationship of quality of life with nutritional status of child(SAM- severe acute malnutrition, MAM- moderate acute malnutrition, MUN- moderate undernutrition, CUN- chronic under nutrition)

DISCUSSION:
-We found that no significant association of QOL found with age, sex, residence and maternal educational status. relation of QOL with age.
Several studies are done previously to assess health related QOL in children with heart disease, out of them mostly found that QOL was affected in 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]

- 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 class 4 and 5.

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 motor and cognitive functioning.[1]

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 communication.[10]

- In our study, domain wise analysis in different type of heart disease, QOL is most affected in physical functioning and least affected in school functioning. Children, who underwent 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.

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 adjustment.[11]

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 autonomy.[12] Abassi et al have found that the HRQOL in children with CHD is good enough and quite similar that of control group.[14]

- 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.

Ophelie Loup et al, analysed 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]

CONCLUSION:

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, mode of management, socioeconomic status, and nutritional status. Nutritional status of children is one of major determinant of quality of life in children with heart disease.

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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