



QUALITY OF LIFE AMONG PARENTS OF CHILDREN WITH CONGENITAL HEART DISEASE IN SELECTED HOSPITAL, ERNAKULAM

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ABSTRACT

Background of the study: Congenital heart diseases are abnormalities of cardiac structure that are present from birth. The abnormalities in the development of heart typically arise in the third to eighth week of gestation. Congenital heart disease (CHD) is now estimated to be the second most prevalent chronic illness. Congenital heart defects can be detected at ultrasound but are sometimes not diagnosed until birth, which can cause stress and heightened emotion within the family. A child's chronic illness has effects that have pervasive consequences for family life. As the disease course progresses, the impact on parent's health tends to decrease but the risk of developing long term psychological issues among the parents remains high, that causes significant reduction in quality of life. **Methodology:** To determine the quality of life, descriptive design was selected with quantitative research approach. Convenience sampling technique was used. Sample size of 200 were taken. Parents of children with congenital heart disease at selected hospital, Ernakulam were included in the study. Data collection instruments were included by using demographic proforma and WHO Quality of life Questionnaire to assess the quality of life among parents of children with congenital heart disease. **Results:** The findings show majority of the subjects had average level of quality of life due to the congenital heart diseases among their children. **Conclusion:** Present study suggests that the need for education /training program to improve quality of life and stress reduction for parents of children with congenital heart diseases.

KEY WORDS: Assess, quality of life, congenital heart disease, parents, children.

INTRODUCTION

Congenital heart diseases are abnormalities of cardiac structure that are present from birth. The abnormalities in the development of heart typically arise in the third to eighth week of gestation.^[1] Congenital heart disease (CHD) is now estimated to be the second most prevalent chronic illness. Worldwide, the prevalence of CHD is estimated at about 8 per 1,000 live births.^[2] Soon after birth, babies with a critical state of health due to CHD must undergo surgery or interventional treatment in many cases as early as the first year of life.^[3] Today, however, 95% of these children reach adulthood as a result of the success of modern treatment options. With improvement in basic neonatal medical care in most parts of our country, the traditional contributors to neonatal mortality such as birth asphyxia and infections have reduced in numbers. This has hence thrust greater focus on CHD. Facilities with capability to diagnose and

intervene on neonates with critical CHD are available in most states.^[4] Although there has been remarkable progress in disease management, the performance and physical abilities vary enormously due to a variety of CHD types.

Congenital heart defects (CHD) can be detected at ultrasound but are sometimes not diagnosed until birth, which can cause stress and heightened emotion within the family. Parents face challenges including dealing with surgical procedures for their child and integration. A child's chronic illness may have effects that have pervasive consequences for family life. Recently, attention has focused on resiliency variables, especially social support and coping strategy, regulating the impact of stress.^[5] As the disease course progresses, the impact on parent's health tends to decrease, but the risk of developing long-term psychological issues among the

parents remains high. As there are many variations of CHD which sometimes occur in combination and with differing severities, prognosis and treatment may vary between individuals. NICE guidance (National Institute for Health and Care Excellence 2016) advises that “children, young people may need support, and sometimes expert psychological intervention, to help with distress, coping, and building Resilience” and emotional and psychological wellbeing should be discussed regularly particularly at times of transition.^[6] Presence of CHD has been shown to increase the vulnerability of the whole family to psychological and social distress. However, using the perspective of coping, many studies also show that parents and families manage to adjust to the presence and demands of childhood conditions.^[7] Parental with the pediatric care of CHD and well-being among the parents, with the specific aim of: (a) assessing the extent of psychosocial problems and grade of satisfaction with care and (b) modeling factors associated with satisfaction and well-being among the parents. A holistic care of CHD, need for psychosocial resources and social vulnerability in the adaptation process is recommended to improve parental satisfaction with the care of CHD.^[8] Parents of children born with CHD experience profound stress, from the time of diagnosis, through the infant’s hospitalization for cardiac surgery, and in the months and years that follow. While survival for neonatal cardiac surgery had dramatically improved, children remain at risk for neuro developmental delay, including fine and gross motor, speech, cognitive, behavioral, and academic difficulties. Many children must return for additional surgeries or interventions throughout childhood. Quality of life of parents of chronically ill children has become increasingly important as the mortality rates associated with such illnesses have decreased and survival rates have increased.^[9,10]

MATERIALS AND METHODS

Research approach and design

Quantitative research approach with descriptive study design

RESULTS AND DISCUSSION

SECTION I

Sample characteristics based on socio-demographic variables: Table: 1

Frequency and percentage distribution of demographic variables according to baseline characteristics

n=200

SINO	VARIABLES	FREQUENCY(F)	PERCENTAGE(%)
1	AGE IN YEARS		
	Below 20 Years	0	0
	20-29 Years	101	50.5
	30-39 Years	72	36
	40 and above	27	13.5
2	GENDER		
	Male	162	81
	Female	38	19
	Others	0	0

Research setting

This study was conducted in selected hospital, Ernakulum.

Population

Parents of children with congenital heart diseases with age group of 2-12 years at selected hospital

Sample and sampling technique

200 Parents of children with congenital heart diseases at selected hospital, Ernakulum. Sampling technique used for the study was convenience sampling.

Data collection instruments

Tool consists of two section.

Section I: The first section included the demographic information. The tool first contains age in years, gender, marital status, educational status, occupation, income, duration of the illness, type of congenital heart disease, possibility to detect the congenital heart disease during the pregnancy period.

Section II: Questionnaire on quality of life among parents of children with congenital heart disease. It consists of 26 items with regards to quality of life among parents of children with congenital heart disease. Each questions have only one correct response. Total score is 100, >65 relatively high QOL, 45-65 moderate QOL, < 45 low QOL.

Procedure for data collection

The ethical clearance was obtained from IRB of the institution for conducting the study. Purpose of the study was explained and an informed consent was obtained from each sample. The data were analyzed by using descriptive and inferential statistics. Demographic data was analyzed using frequency and percentage. Quality of life among parents of children with congenital heart disease was analyzed by computing range of mean, median and standard deviation. Association between quality of life with selected demographic variables of parents of children with congenital heart disease will analyzed chi-square test.

3	EDUCATIONAL STATUS		
	Primary	10	5.0
	Secondary	32	16
	Higher Secondary	60	30
	Graduate/post graduate	98	49
4	MARITAL STATUS		
	Married	167	83
	Single/unmarried	0	0
	Widow/widower	12	6
	Divorced/separated	21	10.5
5	OCCUPATION		
	Not working	52	26.1
	Agriculture	20	10.1
	Employee at private organization	92	46
	Self-employed	24	12
	Government graduate	12	6
6	INCOME		
	<5000/month	35	17.5
	5000-10000/month	44	22.0
	10000-15000/month	85	42.5
	>15000/month	36	18

Belongs to the age group below 20 years, 101 (50.5%) in the age group of 20- 29 years, 72(36%) in the age group of 30-39 years and 27(13.5%) in the age group of 40 years and above. In case of gender 162(81%) were males and 38(19) % of them were females. On the basis of educational status majority of them 98 (49%) were graduate/postgraduate, 60(30%) were higher secondary. 32(16%) were secondary and 10(5%) were primary. In aspect of marital status results shows that most of them 167(83%) were married, 12(10.5%) of them widowed,

21(10.5%) was divorced/separated and 0(0%) was single/unmarried. Regarding occupation majority of them 92(46%) were employee at private organization, 52(26.1%) were not working, 24(12%) were self-employed, 20(10.1%) was agriculture and 12(6%) were government graduate. On the basis of monthly income, majority of them 85 (42.5%) were earning 10000 - 15000, 44(22%) of them were earning 5,000-10,000, 36(18%) were earning >15000 and 35(17.5%) of them were earning <5000 per month.

SECTION B: CLINICAL DATA OF THE CHILD

Table:2
Frequency and percentage distribution of sample characteristics based on clinical variables.

SI NO	VARIABLES	FREQUENCY(F)	PERCENTAGE(%)
7	DURATION OF ILLNESS		
	Recently identified	35	17.5
	Less than 6 months	56	28
	6 months to 1 year	57	28.5
	1 year to 5 years	43	21.5
	5 year and above	9	4.5
8	TYPES OF CONGENITAL HEART DISEASE		
	Atrial Septal Defect	55	27.5
	Ventricular Septal Defect	59	29.5
	Tetralogy of Fallot	51	25.5
	Pulmonary valve stenosis	35	17.5
9	FAMILY HISTORY OF CONGENITAL HEART DISEASE		
	YES	119	59.5
	No	81	40.5
10	IS IT POSSIBLE TO DETECT THE CONGENITAL HEART DISEASE DURING THE PREGNANCY PERIOD		
	Yes	120	60
	No	80	40
11	HISTORY OF ANY OTHER ILLNESS		
	Yes	119	59.5
	No	81	40.5

With respect of duration of the illness, most of them 57(28.5%) had less than 6 months to 1year of duration of illness, 56(28%) had less than 6 months of duration of illness, 43(21.5%) had 1 year to 5years of duration of illness and 9(4.5%) had recently identified. Regarding types of congenital heart disease 59(29.5%) of them had ventricular septal defect, 55(27.5%) of them were atrial septal defect, 51(25.5%) were tetralogy of fallot and 35(17.5%) were belongs to pulmonary valve stenosis. Based on family history of congenital heart disease

119(59.5%) of them had family history & 81(40.5%) did not had any family history of congenital heart disease. Regarding possibility to detect the congenital heart disease during the pregnancy period 119(59.5%) of them given response as it can be detected & 80 (40%) of them responded as it can't be detected. With respect of history of any other illness 119(59.5%) of them had other illness & 81(40.5%) of them did not have any other illness.

SECTION II:

Table 3: Distribution of parents according to quality-of-life assessment
n=200

QUALITY OF LIFE	SCORE	LEVEL OF RESPONDENTS	
		NUMBER	PERCENTAGE
LOW	<45	34	17
AVERAGE	45-65	146	73
HIGH	>65	20	10

Table 2: Depicts the quality of life among Parents of children with congenital heart diseases. It was evident

that majority 87(87%) had average, 8(8%) of them had poor and 5(5%) of them had high state of quality of life.

Table 4: Distribution of mean and standard deviation of quality-of-life.

	Minimum score	Maximum score	High	Average	low	Meanvalue	Standard deviation
Quality of life (QOL)	32	86	10	73	17	69.22	9.368

Table: 4 shows that among 200 samples majority of them (73%) had average quality of life with a mean score of 69.22 and standard deviation 9.368.

SECTION 3

Chi square value showing association between quality of life with demographic variables

The data shows that there is significant association between quality of life with selected demographic variables like duration of illness and type of congenital heart disease. Since the calculated chi square value is more than the table value at 0.01 level of significance. Hence the research hypothesis H3 is accepted. The data shows that there is no significant association between age, gender, educational status, marital status, occupation, income, family history of congenital heart disease & history of any other illness.

DISCUSSION

In order to achieve the objectives of the study, descriptive research design was adopted. The subject was selected by convenience sampling technique. The findings of the study have been discussed in relation to the objectives.

Quality of life among parents of children with congenital heart disease

Present study was supported by a similar quantitative study conducted by Forod salehi et al to assess the

Quality of life and happiness among mothers of children with congenital heart disease and mothers of healthy children. The findings of the reference study showed significant differences between quality of life and happiness among mothers of children with congenital heart disease and mothers of healthy children (P=0.001). The present study and supporting studies shows that quality of life of parents can be affected by congenital heart diseases.

Association between quality of life among parents of children with congenital heart disease with demographic variables

The findings of the present study are supported by a descriptive study conducted by Manu raj et al. The result of reference study revealed that there is an association between quality of life with selected demographic variables like duration of illness & type of illness. The present study results along with the supportive study result shows that there is an association between quality of life among parents of children with congenital heart disease with demographic variables.

CONCLUSION

congenital heart diseases are the most common defect in children. Parents of children born with CHD experience profound stress, from the time of diagnosis, through the infant's hospitalization for cardiac surgery, and in the months and years that follow. The study findings

revealed that the quality of life is average among parents of children with congenital heart diseases. The chi-square value shows that there is significant association between quality of life among parents of children with congenital heart disease with demographic variables like duration of illness and type of congenital heart disease.

Conflict of interest: Nil

Source of funding: self

Ethical clearance: Permission had taken from the Institutional Review Board of Amrita Institute of Medical Science, Amrita Institute of Medical Science, Kochi. Consent was obtained from each subject prior to the study.

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