Health Related Quality of Life of Children with Congenital Heart Disease Attending at Tertiary Level Hospital

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ABSTRACT

Background: Congenital heart disease is one of the common congenital anomaly among the children affecting growth and development of the child and increasing susceptibility of the child to failure to thrive. The objective of the study is to find out the overall health related quality of life of children with congenital heart disease.

Methods: A descriptive cross sectional study was carried out among 150 children with congenital heart disease attending in the pediatric out-patient department of Shahid Gangalal National Heart Centre, Bansbari, Kathmandu. The data was collected within the period of 2017/07/16 to 2017/08/16 using purposive sampling technique. Data was collected through interview technique using semi structured questionnaire. Collected data were entered in Statistical Package for Social Science 16 version and analyzed by using descriptive and inferential statistics.

Results: The study findings revealed that more than half (52.7%) of the children had satisfactory overall health related quality of life. Health related quality of life is significantly associated with age group of the child (p=0.018), and education of mother (p=0.017)).

Conclusions: It can be concluded that more than half of the children tends to have satisfactory overall health related quality of life. Ventricular septal defect is the commonest congenital heart disease. The health related quality of life of children with congenital heart disease tends to be better among those with educated mother and increasing age of the children. Therefore, awareness raising of mothers related to disease condition and care of children with congenital heart disease through mass media or proper intervention program might help to promote the quality of life of children with congenital heart disease.

Keywords: Congenital heart disease; health related quality of life.

INTRODUCTION

Congenital heart disease (CHD) is one of the most common forms of congenital anomalies. Identified risk factors in India are advanced parental age, febrile illness during pregnancy and deficiency of folic acid in diet.[1]

In Bangladesh the prevalence of CHD was found 7.8/1000 live birth[2] and the prevalence of CHD in Nepal was found to be 5.8/1000, among them Ventricular Septal Defect is the most common CHD.[3]

Physical, psychological and cognitive problems still present in those children with CHD.[4] Children with cardiac disease perceived lower quality of life than healthy children. One in 5 children with cardiac disease perceive impaired psychosocial functioning.[5] Children with severe form of CHD and children with other diseases have higher levels of social or communication impairment.[6]

This study was conducted to assess the health related quality of life of children with CHD so that the study findings will be helpful to health worker to assess the quality of life of these children, identify the risk groups and intervene early.

METHODS

A descriptive cross sectional study design was used to assess the health related quality of life (HRQOL) of children with CHD. The study was carried out in paediatric out patient department (OPD) of Shahid Gangalal National Heart Centre (SGNHC) Bansbari, Kathmandu.

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The study population for this study was children aged 2 years to 18 years diagnosed with CHD. Sample size was 150. Researchers purposively selected SGNHC, Bansbari, Kathmandu as the setting for data collection as it is the only referral center for children with heart disease. Children aged 2 to 18 years and diagnosed with CHD at least since a month ago attending Pediatric OPD at SGNHC, Bansbari, Kathmandu accompanied with their mother were taken as sample for the study.

After getting approval from University Grant Commission (UGC), NHRC and institutional review committee of SGNHC Bansbari, Kathmandu, researchers obtained the formal permission from the concerned authority for data collection by submitting written request letter. Data was collected using semi structured interview schedule developed by the researchers as per the objectives of the study. An informed written consent was obtained from mother prior to data collection. Confidentiality of the information was ensured by maintaining privacy while collecting the data and using the obtained information for the purpose of the study only. The data were collected by the researchers themselves and research assistants who were trained to administer the questionnaire at the convenient time of respondents.

Data was entered in Microsoft Excel Program. The data was edited in MS Excel and transformed into Statistical Package for Social Science (SPSS) 16 version for analysis. The data was analyzed by using descriptive statistics such as frequency, percentage, mean, standard deviation and inferential statistics Chi-square tests with level of significance as 0.05.HRQoL was divided as satisfactory and unsatisfactory HRQoL meant score equal to and more than mean score. Unsatisfactory HRQoL meant score less than mean score.

RESULTS

Out of 150 children about half (52.7%) of the children were between 2-5 years of age. Median age of the children was 5 years. More than half (58.7%) of the children were male. More than one third (38%) of the children had one sibling. Almost half (49.3%) of the children were the first child. More than half (58.7%) of the respondents belong to 25-34 years age group with mean age of 31.09 ± 6.5. More than one third (45.5%) of the respondents had janajati ethnicity. Most (82.7%) of the respondent were Hindu. Most (81.3%) of the respondent had income sufficient for 6 to 12 month.

Less than one third (31.3%) of the respondent belonged to secondary level of education. Two third (66%) of the respondent were housewife. More than half (56%) of the respondents belong to nuclear family.

Table 1. Disease related Information of Children with CHD (n=150).

Variables	Frequency	Percent
Diagnosis/Type		
Ventricular septal defect(VSD)	52	34.7
Atrial septal defect(ASD)	43	28.7
Tetralogy of fallot	29	19.3
Patent ductus arteriosus(PDA)	19	12.7
Aortic stenosis	4	2.7
Pulmonary stenosis	3	2.0
Age at diagnosis		
0-1 years	71	47.3
2-4 years	46	30.7
5-7 years	11	7.3
8-12 years	18	12.0
12-18 years	4	2.7
Duration of Illness		
<6 months	11	7.3
6-12 months	20	13.3
13-18 months	6	4.0
19-24 months	19	12.7
> 24 months	94	62.7
Surgical Management		
Done	51	34.0
Not done	99	66.0

Table 2. Status of HRQoL of Children with CHD on different Subscales of HRQoL (n=150)

HRQoL	Satisfactory	Unsatisfactory
Physical (Mean ± SD =2.58± 0.89)	78(52.0%)	72(48.0%)
Psychological (Mean ± SD =2.76± 0.71)	81(54.0%)	69(46.0%)
Social (Mean ± SD =3.44± 0.59)	95(63.3%)	55(36.7%)
Disease related (Mean ±SD=2.56± 0.90)	79(52.7%)	71(47.3%)
Overall (Mean ±SD=2.78± 0.71)	79(52.7%)	71(47.3%)

Table 3. Association of Child Characteristics with Status of HRQOL of Children with CHD (n=150).

| Variable | HRQOL Status | | Chi square Value | P value |
	Unsatisfactory	Satisfactory		
Sex				
Male	42(47.7%)	46(52.3%)	0.013	0.908
Female	29(40.8%))	33(41.8%)		
Age group of the child				
2-5 years	46(58.2%)	33(41.8%)		
6-11 years	19(35.8%)	34(64.2%)	7.981	0.018
12-18 years	6(33.3%)	12(66.7%)		
Presence of Sibling				
Yes	17(54.8%)	14(45.2%)	0.883	0.374
No	54(45.4%)	65(54.6%)		

Table 4. Association of Mother's characteristics with Status of HRQOL of Children with CHD (n=150).

| Variable | HRQOL Status | | Chi Square Value | P value |
	Unsatisfactory	Satisfactory		
Age of mother				
Less than 35 years	54(49.1%)	56(50.9%)	0.511	0.475
35 years and more	17(42.5%)	23(57.5%)		
Ethnicity				
Brahmin Chhetri	34(50%)	34(50%)	0.373	0.830
Janjati	26(45.6%)	31(55.4%)		
Others	11(44%)	14(56%)		
Religion				
Hindu	62(50%)	62(50%)	2.04	0.153
Others	9(34.6%)	17(65.4%)		
Economic status				
Income enough for 6 month	6(31.6%)	13(68.4%)	2.30	0.316
Income enough for 6 to 12 month	60(49.2%)	62(50.8%)		
Income enough for 12 month and surplus	5(55.6%)	4(44.4%)		

Education of Mother				
Can't read and write	37(60.7%)	24(39.3%)	8.13	0.017
Primary	26(41.3%)	37(58.7%)		
Secondary and above	8(30.8%)	18(69.2%)		
Occupation of Mother				
Non Job Holder	52(51.0%)	50(49.0%)	1.70	0.192
Job Holder	19(39.6%)	29(60.4%)		
Family type				
Nuclear	40(47.6%)	44(52.4%)	0.006	0.937
Joint	31(47.0%)	35(53.0%)		

Table 5. Association of Disease related Characteristics with Status of HRQOL of Children with CHD (n=150).

| Variable | HRQOL Status | | Chi Square Value | P value |
	Unsatisfactory	Satisfactory		
CHD Diagnosis				
Acynotic	56(46.3%)	65(53.7%)	0.278	0.598
Cynotic	15(51.7%)	14(48.3%)		
Duration of illness				
Less than one year	19(61.3%)	12(38.7%)	3.754	0.053
More than one year	51(42.9%)	68(57.1%)		
Surgical Management				
Done	25(49.0%)	26(51.0%)	0.088	0.767
Not done	46(46.5%)	53(53.5%)		

DISCUSSION

This descriptive cross sectional study on HRQoL of children with CHD attending at tertiary level hospital was conducted among 150 children attending in the OPD of SGNHC, Kathmandu. This study revealed that slightly higher proportion of male (47.7% of male children had and 40.8% female children) had CHD whereas a study conducted in apparently healthy 9420 school children in Kathmandu Vally[7] revaled a higher prevalence of CHD among female. This difference may be probably due to difference in the type of population in the two studies and due to cultural value of male children in Nepalese society in seeking treatment in this study.

This study revealed that about one third (34.7%) of the children with CHDhad VSD which is similar to the finding of the study carried out in Bangladesh[2] which revealed

that among 51 children who were suffering from CHD, VSD was found in29.4%. A study conducted among hospitalized children aged day one of life to 14 years of age in Eastern Nepal[8] revealed somewhat similar finding that 28.8% children had VSD however, ASD was found to be most common CHD (that is 52%) showing a higher prevalence of ASD in Eastern Nepal. Less than half of the children (47.3%) in this study were diagnosed ar the age of less than 1 year. Similar finding was reported in a study conducted in a teaching hospital in Dhulikhel[3] which found that CHD was identified during infancy among 46 % children. This study, revealed that about two third (62.7%) of the children had illness for more than two years and 66% had not undergone surgical management that contrasts with the findings in the study [9] on a total of 282 CHD patients which revealed that two-thirds had at least one cardiac surgery procedure.

Regarding HRQoL, more than half (52%) of the children were found to have satisfactory physical HRQoL, 54% had satisfactory psychological HRQoL and 63.3% had satisfactory social HRQoL indicating that social HRQoL is the least affected domain of HRQoL. This finding is in contradiction to the finding of the study [6] which reported that psychosocial quality of life of children ≥8years of age was found to be significantly impaired in 21% of children. This study also revealed that more than half (52.7%) of the children had satisfactory overall HRQoL. This finding is in contradiction to the finding of the study, which showed that quality of life was impaired in some children in particular those with more severe cardiac disease.[10]

This study showed significant association of HRQoL with age group of the children(p=0.018) indicating that with increasing age, the quality of life also increases. This might be because with increasing age, the concept of quality of life also broadens and with the support of parents, friends and people around them they learn to accept the limitations imposed by the disease condition and attempts to excel in the area they are capable of.

This study also found a significant association of HRQoL of children with education level of mothers (p=0.017) indicating that HRQOL is likely to be more satisfactory when the mothers of the children with CHD higher level of education. Similar finding was reported in the study[9] which showed that educational level of the parents was significantly associated with their children's quality of life. The rationale behind this could be due to the development of favorable environment for the growth of children by an educated mother as per the need of the child which will help to reduce the feeling of physical limitations and psychological stress as well as help to reduce the impairment in children.

This study, revealed no statistical significant association of HRQOL with sex of children, presence of sibling, age of mother, ethnicity, religion, economic status and occupation of mother and family life.

CONCLUSIONS

It can be concluded that more than half of the children tends to have satisfactory overall HRQoL. VSD is the commonest CHD. The HRQoL of children with CHD tends to be better among those with educated mother and increasing age of the children. Therefore, awareness raising of mothers related to disease condition and care of children with CHD through mass media or proper intervention program might help to promote the quality of life of children with CHD.

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