

**ASSESSMENT OF HEALTH-RELATED QUALITY OF LIFE AMONG SCHOOL-AGED
CHILDREN WITH CHRONIC HEART DISEASE**



**A THESIS PAPER TO BE SUBMITTED TO DEPARTMENT OF PEDIATRICS AND CHILD
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ACRONYMS

AHA.....	American Heart Association
CHD.....	Congenital Heart Disease
CI.....	Confidence Interval
CMP.....	Cardiomyopathy
CRVHD.....	Chronic Rheumatic Valvular Heart Disease
CVD.....	Cardiovascular Disease
DCMP.....	Dilated Cardiomyopathy
EOPD.....	Emergency Out-patient Department
HF.....	Heart Failure
HRQoL.....	Health-Related Quality of Life
NYHA.....	New York Heart Association
PedsQL.....	Pediatrics Quality of Life Inventory Scale
QOL.....	Quality of Life
RHD.....	Rheumatic Heart Disease
SPHMMC.....	Saint Paul's Hospital Millennium Medical College
SPSS.....	Statistical Package for Social Sciences
WHO.....	World Health Organization

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ABSTRACT

Background: Health-related quality of life (HRQoL) has become an important measure for evaluating patients with non-curable chronic diseases. The aim of this study was to assess HRQoL and its associated factors among school-aged children with chronic heart disease.

Methods: A hospital-based, cross-sectional prospective study was conducted from February 3 to July 3, 2019. A total of 106 school-aged children with heart disease who visited SPHMMC, Pediatrics department during the study period were included in the study. Data were collected by using the standardized PedsQL 3.0 Cardiac Module questionnaire to assess quality of life. Multi-variable linear regression was used to identify associated factors with HRQoL among patients with heart disease.

Results: Mean PedsQL scores for children with cardiac disease were significantly lower than healthy norms for overall HRQoL and physical functioning. The mean Total Score was **72.83±9.28 (p=0.040)**. The mean scores for physical health, psychosocial, emotional and cognitive domains were **66.05±13.12 (p=0.007)**, **79.58±8.52 (p=0.065)**, **76.21±9.65 (p=0.047)** and **78.38±9.75 (p=0.045)**, respectively. The highest mean score was observed in the social health domain (**82.51±11.04, p=0.750**). Disease type, duration of illness and socioeconomic status (SES) including paternal educational status & current occupation as well as average monthly income were identified to affect HRQOL domains (**p<0.001**).

Conclusion: The findings from this study indicated that all dimensions of HRQoL of children with heart disease were compromised in the study setting. It also identified important predictors such as socioeconomic status, disease category and duration of illness. These findings entail the need for intervention to improve the HRQoL in children with heart disease beyond the provision of standard treatments

Introduction

Many infants are born each year with congenital cardiovascular defects. Although most cardiovascular disease (CVD) in children is attributed to congenital malformations, children also develop other forms of acquired CVD including cardiomyopathies (CMP), rheumatic heart disease, arrhythmias and complications of systemic conditions like vasculitis, adding to the prevalence of pediatric CVD (1).

Cardiac disease, as one of the CVD, accounts for significant cases of patient visits, although the burden for specific etiology & epidemiological pattern of heart disease differs greatly between developed nations and sub-Saharan countries. In the later, rheumatic heart disease remains a major public health issue while congenital heart disease (CHD) bears poor prognosis(1).

Africa has one of the highest prevalence of heart disease in children and young adults including CHD and RHD, though the true burden of the disease may be underestimated mainly due to the paucity of data and the poor outcome of African children with CHD (2).

Overall, CHD has an estimated prevalence of 8-12 per 1000 live births each year but reported figures vary worldwide. Paucity of data, lack of prioritization of cardiac care services, access to care in general, poor health infrastructure, lack of trained personnel, limited access and early mortality are responsible for underestimation of the figure in low & middle-income countries (3).

Several recent publications have profiled the epidemiology of CHD in children & young adults in Africa, emphasizing the burden of CHD among patients referred with suspected heart disease (2). Among this group of people, the prevalence appears to be dramatically much higher according to the data from different countries. For example, in Cameroon, 13.1% of patients with suspected cardiac pathologies aged between 2months & 41yrs (mean 10+-9yrs) during a 4yr study were diagnosed with CHD. Data from northern Nigeria reported that among 1321 patients (aged 9days to 35years) with abnormal echocardiogram, 122 (9.3%) had CHD. Though the majority of CHDs are simple & easily correctable, limited access to surgery leads to early a compromised quality of life and early death as a teen in these children (4, 5).

On the other hand, rheumatic heart disease (RHD) remains the leading cause of acquired heart disease among the young worldwide. It has been projected that more than 15million people suffer from RHD globally with estimated incidence of 13-14 cases per 100,000 each year. Recent surveys from Mozambique, Uganda, & Senegal demonstrated that echocardiography detects a significant additional number of children with clinically silent disease, estimated to 7.5-51.6 per 1000 children (6).

It has been calculated that if 1.5% of people with RHD die each year, the approximate number of deaths would range from 233,000 to 294,000 per year worldwide (7). A large multinational African study demonstrated that RHD prevails as the most frequent cause of heart failure among children & adolescents and importantly the 6month mortality is as high as 17.8%. In addition to high mortality, RHD should bear high morbidity due to scarcity of preventive programs across most sub-Saharan countries, which may strongly impact on social, educational & economic issues (7, 8).

QOL is a general and subjective concept, which has been defined as the “overall life satisfaction”. The World Health Organization (WHO), however, emphasizes this growing concept by defining it as individual’s perception of their position in life in the context of the cultural & value systems in which they live, in relation to their goals, expectations, standards and concerns (9). This recognizes the multidimensional nature of QOL, including psychological, social and economic functioning.

The aim of this study was to describe and compare self-reported physical and psychosocial quality of life of children who have heart disease with that of healthy pediatric population and to assess modifiers of health-related quality of life

Statement of the Problem

Pediatric heart disease, one of the most common chronic illnesses in children, encompasses both congenital heart disease and various acquired conditions like rheumatic heart disease, cardiomyopathies, arrhythmias and others. An estimated 15million children die or are crippled annually by treatable or preventable heart disease in children in low & middle-income countries (3).

Global efforts to reduce childhood mortality have focused on reducing deaths from communicable disease with little to no attention focusing on pediatric CHD & acquired heart disease. Lack of awareness access to care, poor health infrastructure, competing health priorities, and critical shortage of specialists are main reasons why pediatric heart disease have not been addressed in low resource settings (2).

Significant advances in medical & surgical care have dramatically improved the life expectancy of children with heart disease. As a result, attention must be focused on the outcomes of treatment beyond survival in these growing patient population with quality of life (QOL) emerging as an important health concern. More recently, however, assessment of quality of life in these patients has been given more attention, although patient reported outcomes are not systematically quantified by care-givers & pediatric cardiologist, who rely primarily on symptoms and disease complications (1).

The magnitude of this problem is difficult to estimate in Ethiopia since there is limited data available but a cross-sectional echocardiographic screening of RHD in schoolchildren aged 6-18yrs from 28 randomly selected schools was done in 2016 by Yadeta D and etal. The study found that of the total 3238 children, 44 patients (1.4%) met the world heart federation criteria while 15 patients (0.5%) met the criteria for borderline disease (10). Another study conducted in 2004 G.C by Estegenet G and et al at pediatric cardiac clinic at Tikur Anbessa Hospital showed that among the total of 324 patients seen, 54.6% of them had CHD, 39.2% had RHD and 6.2% patients had non-rheumatic acquired heart disease. Thus, both congenital and RHD are still a significant cause of morbidity in Ethiopian children (11).

Significance of the study

It is obvious that chronic heart disease has a significant negative impact on affected children. Understanding the physical and psychosocial aspect of quality of life can enlarge doctor-patient interaction & help on decision making in routine clinical practice. Beyond medical treatment, integration into school is important to increase Health-related Quality of life (HRQoL) in children and adolescents surviving chronic heart disease. The aim of this study is to assess functional status and determine medical & socio-demographic variables affecting health related quality of life in school aged children and adolescents with chronic heart disease at SPHMMC, pediatrics department.

Significant gap exists in understanding the perception & impact of the disease from patients' point of view, resulting in large discrepancies to clinical response and long term outcome. Because current medical care provided for such patients is primarily concerned with pharmacologic intervention, this study will try to assess the physical, functional and psychosocial dysfunctions in these patients and identify factors affecting these variables. This will help to isolate the affected health domains in each follow-up visits and intervening early to improve long-term outcomes. In addition as there is limited data on the subject in developing countries like Ethiopia, the findings of this study can serve as base line data.

Literature review

Chronic pediatric heart disease is often associated with residual symptoms, persisting functional restriction and late sequel for psychosocial development. It is therefore, increasingly important to evaluate the health-related quality of life of children and adolescents with chronic heart disease. The aim of most of the studies conducted was to determine medical and socio-demographic variables affecting health-related quality of life in school-aged children and adolescents with chronic heart disease. Most of the studies used the standard pediatric quality of life inventory (PedsQL) 4.0 core scales & disease specific cardiac module to assess affected patients' QoL while others focused on parent-proxy perspectives or comparative methods with pediatric norms using the same scale.

In one study conducted at Cambridge University in 2017, Pediatric Quality of Life Inventory was administered to 375 children and adolescents and 386 parental caregivers. Medical information was obtained from the charts while the socio-demographic information was provided by the patients and caregivers. Greater disease severity, low school attendance, current cardiac medications, current parental employment, uncertain or limited prognosis, number of night spent in a hospital, and need for treatment in a pediatric aftercare clinic independently contributed to lower health-related quality of life (self-report: $R^2=0.41$; proxy-report: $R^2=0.46$). High correlations between self-reports and parent-proxy reports indicated concordance regarding the evaluation of a child's health-related quality of life (12).

In another study done by Karen Uzark, Karen Jones, Joyce S and et al... at pediatric cardiology clinic at Cincinnati Children's Hospital Medical Center over a three month period in 2008, a total of 475 individuals, children aged 5 to 18 years and parents of children 2 to 18 years were included and the PedsQL generic scales and Cardiac Module were administered during a pediatric cardiology outpatient visit. By self-report, mean PedsQL scores for children with CVD were significantly lower than healthy child norms for physical and psychosocial functioning. Psychosocial quality of life scores were classified as significantly impaired as reported by 21% of children >8 years of age. Even among children with less severe CVD, 19.2%

reported significantly impaired psychosocial quality of life. By parental report, overall PedsQL scores were not significantly different from healthy children, and both the 8-12 year-old and teenage groups had lower mean psychosocial scores than healthy peers. Parent-reported mean PedsQL scores for both physical and psychosocial quality of life were significantly lower with more CVD. Children with more severe cardiovascular disease reported lower mean scores for physical functioning, but smaller differences in psychosocial quality of life were observed related to disease severity (1)

A multicenter controlled cross-sectional study to assess the QOL of school children with congenital heart disease was carried out between April 2009 and October 2011 in two pediatric cardiology units, Montpellier University Hospital, France and Brussels Saint-Luc University Hospital, Belgium in 10 school classes from 3rd to 12th grade. 282 children with CHD aged from 8 to 18 years in the two centers. Children's QOL was self-reported with KIDSCREEN-52 questionnaires and reported by parents as well. QOL scores of each dimension were compared between CHD and controls and between the classes of disease severity. Age and gender adjusted self-reported QOL scores were lower in CHD children than in controls for physical well-being, financial resources, peers/social support, and autonomy in the multivariate analysis. Parent-reported scores were lower in CHD children for physical, psychological well-being, peer/social support, and school environment dimensions. Similarly, the disease severity had an impact on physical well-being, financial resources, and peers/social support for self-reported dimensions, and on physical well-being ($p < 0.001$), psychological well-being, peers/social support and school environment for parent-reported dimensions (13).

In a study done in Africa, convenient sample of 100 school-age children with rheumatic fever and their mothers were selected from outpatient clinic and inpatient pediatric cardiac departments of EL-Shatby Children University Hospital, Alexandria, Egypt. Data was collected from children aged 8 to 12 years & free from any associated disease. The PedsQL questionnaire was used as a tool and the study revealed that the majority (78.3%) of school-age children with RF had a neutral HRQOL and less than a quarter of them had high HRQOL. Only small percent (8.7%) of studied subjects had poor HRQOL. Children's parents' reports

confirmed such results, where there were significant positive correlations between children reports and their parent reports in the majority of studied items of HRQOL (14).

Ivan Wilmot, Amy Cassidy and et al. conducted a prospective cross-sectional study at Texas Children's Hospital which took over from 1st of October 2009 to 31st of July 2010 and compared health-related quality of life in children with heart failure with healthy children, children with chronic conditions and children with CVD. Families (n=63) and children (n=73) aged 2-20 years with heart failure (HF) were enrolled and compared with data previously published for healthy individuals (n=5480), those with chronic conditions (n=247), and those with cardiovascular disease (n=347). Patients and parents completed the PedsQL 4.0 questionnaire and PedsQL scores including total, psychosocial health summary, and physical were compared between groups. In general, patients with HF had lower scores than the healthy population ($p=0.001$), and comparable scores with those with chronic conditions. Furthermore, children with heart failure had decreased health related quality of life (HRQoL) scores as the American Heart Association (AHA) stage of heart failure increased, such that patients stage CHF had higher scores. In addition, children with heart failure reported significantly impaired HRQoL compared with healthy children and similar scores compared with children with chronic conditions. Children with heart failure appear to have progressive impairment of health-related quality of life with advancing stage of heart failure (15).

Methods and Materials

Study setting

The study was conducted at SPHMMC in the department of pediatrics and Child Health. The department of pediatrics and Child Health provides in-patient and out-patient services. The out-patient services include providing treatment and follow up care for children with different kinds of chronic diseases. Cardiac follow up clinic is one of those clinics which provide follow up care and treatment for children with chronic cardiac disease. Nurses, pediatric resident doctors and pediatric cardiologists run the clinic. The clinic is functioning on Wednesdays and on average 7-10 children with cardiac disease are being seen on the clinic days. Rheumatic heart disease and congenital cardiac disease are the cases commonly seen in the clinic.

Study design and Period

A hospital based cross sectional prospective study was conducted over six month period from Feb 3 to July 31. The study was conducted at SPHMMC, pediatric department in the cardiac clinic, EOPD and ward.

Sampling

One hundred and six consecutive cases of known cardiac disease who had follow up visit during the study period and who met the inclusion criteria were included in the study

Inclusion and exclusion criteria

Inclusion criteria:

All children who were diagnosed with cardiac disease and who appeared in the hospital for follow up visit or for medical care during the study period

Exclusion criteria:

Patients who had a major developmental disability or associated non cardiac conditions such as chronic renal or respiratory diseases that might be expected to affect **QOL** were excluded.

Measures

To assess health-related quality of life of patients, we computed the standardized **PedsQL 3.0 cardiac module** after getting the permission from the authors. The Pedsql 3.0 cardiac module is a reliable and valid, disease specific module that includes items specific to heart disease (20-22, 24). It includes the following five scales: symptoms (seven items), perceived physical appearance (three items) treatment anxiety (four items), cognitive problems (five items) & communication (three items). Patients report the degree of their function using a **5-point likert scale** ranging from 0 to 4. These responses are reverse scored and linearly transformed to 0 to 100 scales with a higher score indicating a higher **QoL**. For ease of interpretation **PedsQL** is further categorized into major domains. Physical functioning scale is the same as the physical score. The psychosocial scale is computed from the emotional, social and cognitive scores. In addition, the computed mean of physical and psychosocial scales are used to generate the Total summary score.

Data Collection

Data was collected by trained general practitioner doctors using the standardized questionnaire PedsQL 3.0 cardiac module. Data were collected by interviewing the patients and their attendants. The subjects were contacted for the interview when they appear in the cardiac clinic for follow up care of the children. Data collectors strictly followed for redundancy of interview and interviewed medical record numbers were separately coded in order to avoid repeated interview. Demographic characteristics and health function status were collected by interviewing the attendants. Patients' diagnosis as well as echocardiographic characteristics of cardiac lesions was taken from medical charts.

Data Analysis Procedures

Data were coded, recoded, cleaned and explored to identify outliers, missing values and inconsistencies. For the purpose of this analysis, dummy variables were created for categorical variables such as demographic characteristics (age, ethnicity, occupation of parents) , duration of illness and diagnosis of patients. The coded data were checked for completeness and analyzed by using **SPSS v.25**.

In the descriptive analysis the mean with SD frequency and percentages were calculated. To compare self-reported scores with those in the healthy children data base, two sample t- test (independent t-test was used. To assess for modifiers of health related quality of life, simple and multivariable linear regressions were fitted for all the five domains of HRQOL(dependent variables) after linearity assumptions was checked by scatter plots and absence of *hetrosceandasticity*.

Multicollinearity was checked and the maximum variable inflation factor (VIF) reported was 1.468 which indicates that there was no multicollinearity threat. Variables with a p-value less than 0.05 were considered statistically significant.

Ethical Consideration

Ethical clearance was sought from the ethical committee of SPHMMC. Respondents were given a written consent prior to their participation in the study. A written consent form was developed that stipulates clearly that their participation will be voluntary, they have the freedom to refuse to respond to any of the questions, and also they have a full freedom to withdraw from the evaluation at any time. It was made clear from the beginning that no payment will be made to individuals in return for participating in the study and confidentiality & storage of data was explained to the participants. In addition, it was made clear that the answers provided during the course of the interview would be treated with utmost confidentiality and used for study purpose only. The written consent was translated to Amharic language.

Results

Characteristics of the Study Participants

A total of 106 children with chronic heart disease were included in the study. A little over half of the participants (**59.4%**) were females and the majority of them were in the age category of **8-12years** (n=62) with mean age of **9.7±2.9yrs**. Most of the study participants were from Oromia region (**54.7%**), followed by Addis Ababa (24.5%) and the rest from other areas. About half (n=53) of the participants are from a family with an average monthly income of 1000-3000birr and nearly 25% of them get less than 1000birr making the majority of participants socioeconomic status in the lower class. The rest of the characteristics are summarized in **Table1**

Table 1 Characteristics of study Participants (N=106)

Variables	Category	Frequency (n)	Percent (%)
Age of the child	5-7yrs	18	17
	8-12yrs	62	58.5
	13-18yrs	26	24.5
Sex of the child	Male	43	40.6
	Female	63	59.4
Childs' school level	None	9	8.5
	Grade 1-4	56	52.8
	Grade 5-8	40	37.7
	Grade 9-12	1	0.9
Duration of Illness	<6 months	27	25.5
	6-23 months	41	38.7
	24-59 months	20	18.9
	>60 months	18	17
Diagnosis of the child	Sever CRVHD	44	41.5
	Mild-moderate CRVHD	39	36.8
	DCMP	5	4.7
	CHD and others	16	17

HRQoL among Children with Chronic Heart Disease

Around 47.2% of the respondents scored below the mean in overall total HRQoL. Among the 6 domains, patients scored highest in the social domain (**82.51±11.04**). The minimum and maximum mean scores of the study participants in total scores were **32.7** and **89.7**, respectively (**table 2**).

Table 2 Profile of health-related quality of life among children with heart disease attending SPHMMC (N=106), 2019

Domains	Minimum	Maximum	Mean	SD	%of participants who scored below the mean
Physical function	21.4	96.4	66.05	13.12	44.3
Psychosocial function	44.4	98.0	79.58	8.52	38.7
Emotional function	44.38	100.0	76.21	9.65	46.2
Social function	32.9	100.0	82.51	11.04	34.9
Cognitive function	50.0	100.0	78.38	9.75	53.8
Total Scores	32.7	89.7	72.83	9.28	46.2

Comparison of HRQoL Scores between Children with Heart Disease and Healthy Children

PedsqL scores for children with heart disease were significantly lower compared with healthy children for Total and Physical functioning scores. 1SD below the population mean represents a meaningful cutoff point for significantly impaired QoL (21). Although the mean psychosocial scores are lower than healthy subjects, as it reflects the lower emotional & cognitive scores, Mean Social scores were found to be comparable with healthy children (**Table 3**).

Table 3 Mean PedsQL Scores for Healthy Children and Children with Heart Disease

Domain	HC(n=5480) Mean(SD)	HD(n=106) Mean(SD)	p value (independent t-test)
Total Score	83.84(12.65)	72.83(9.28)	0.040
Physical health	87.53(13.50)	66.05(13.12)	0.007
Psychosocial health	81.87(14.09)	79.58(8.52)	0.065
Emotional health	79.33(18.15)	76.21(9.65)	0.047
Social health	85.15(16.76)	82.51(11.04)	0.750
Cognitive health	81.12(16.45)	78.38(9.75)	0.045

HC= healthy children, HD= heart diseased children SD= standard deviation

Two-sample t-tests were done to compare for means

Modifiers of Health-related quality of life

Effects of age, gender, ethnicity, socioeconomic status (SES), duration of illness and disease category were evaluated. There was no significant difference in PedsQLI 3.0 cardiac module score with regard to age, gender, ethnicity and parental marital status.

However, disease category, duration of illness and socioeconomic status including parental educational status& current occupation and average monthly income affected the Total Summary Score ($p<0.001$). Mean physical score was also affected by SES ($p=0.02$) and more by disease category and duration of illness ($p<0.01$). With regard to Psychosocial domain, SES and duration of illness were observed to affect the mean score ($p<0.01$). **(Table 4)**

Table 4 Multivariable linear regression model showing independently associated factors with domains of HRQoL in children with heart disease attending SPHMMC, 2019

HRQoL and its Domain	Unstandardized Coefficient(B)	95% CI for B	p value
Total score domain(n=106)			
Constant	74.28	(61.44-87.12)	<0.001
Parent educational status	6.42	(4.68-8.17)	<0.001
Current occupation	3.84	(2.01-5.68)	<0.001
Average monthly income	9.88	(7.02-12.75)	<0.001
Duration of illness	4.44	(2.09-6.78)	<0.001
disease category	3.02	(1.26-4.79)	0.001
Physical health domain(n=106)			
Constant	72.57	(54.40-90.76)	<0.001
Parent educational status	5.54	(3.47-7.62)	0.009
Current occupation	3.66	(1.48-5.81)	0.002
Average monthly income	8.74	(5.34-12.14)	<0.001
Duration of illness	3.70	(0.92-6.49)	<0.001
disease category	3.02	(1.22-5.42)	<0.001
Psychosocial health domain(n=106)			
Constant	75.54	(63.74-87.39)	<0.001
Parent educational status	7.28	(5.57-8.98)	<0.001
Current occupation	4.00	(2.21-5.80)	<0.001
Average monthly income	11.04	(8.24-13.89)	<0.001
Duration of illness	5.18	(2.90-7.47)	<0.001
Disease category	2.74	(1.02-4.47)	0.002

Emotional health domain(n=106)			
Constant	79.47	(65.90-93.04)	<0.001
Parent educational status	7. 35	(5.49-9.21)	<0.001
Current occupation	3.40	(1.43-5. 34)	0.001
Average monthly income	10.68	(7.63-13.73)	<0.001
Duration of illness	5.20	(2.81-7.80)	<0.001
disease category	2.29	(0.41-4.17)	0.017
Social health domain(n=106)			
Constant	78.01	(62.76-93.27)	<0.001
Parent educational status	7.09	(5.15-9.04)	<0.001
Current occupation	4.49	(2.45-6.54)	<0.001
Average monthly income	11. 39	(8.21-14.58)	<0.001
Duration of illness	5.19	(2.58-7.80)	<0.001
disease category	3.17	(1.21-5.14)	0.002
Cognitive health domain(n=106)			
Constant	78.00	(62.63-89.37)	<0.001
Parent educational status	7.66	(5.86-9.46)	<0.001
Current occupation	3.52	(1.62-5.41)	<0.001
Average monthly income	12. 31	(9.36-15.27)	<0.001
Duration of illness	4.22	(1.80-6.64)	0.001
disease category	3.07	(1.25-4.89)	0.001

Discussion

When children with heart disease are compared with healthy children, it is evident that they have significant impairment in health-related quality of life. This study tried to assess the overall HRQOL profile with its domains and associated factors among children with chronic heart disease. According to these findings, the overall mean HRQOL among study subjects was moderate (72.83 ± 9.28) when compared with other findings (1, 13, 15-19). A study conducted by Ivan Wilmot et al has also reported comparable level of HRQOL among patients with chronic heart disease (74.918 ± 6) (15).

Children with chronic heart disease showed impaired all domains of HRQOL of the study subjects but physical health was the most affected domain (66.05 ± 13.12). This finding is consistent with studies done in Egypt, United States and Europe (1, 13-15). This consistency could be explained by heart diseases manifesting more physically than in the psychosocial domains. It could also be justified by patients with heart disease having a higher rate of complications like pulmonary vascular disease & recurrent chest infections which tend to affect their day to day physical activity of these children.

It should be noted that cognitive functioning is also affected by cardiovascular disease with mean score of (78.38 ± 9.75). Significantly lower cognitive and school functioning of children with CVD is consistent with findings of several recent reports suggesting that children with heart diseases as a group have higher rate of neurodevelopmental problems, with a greater frequency of difficulties related to oromotor control & expressive language, visual motor, integration, learning and attention (23,27). More school & cognitive problems for children with more severe disease are also in line with previous reports. On the other hand, this study revealed that from all domains of HRQOL, the social domain was the least affected (82.51 ± 11.04) which is in agreement with reports by other studies as well (1, 13, 15). This could be due to the better social support they receive from their families and care givers.

In contrast, a study conducted at El-Shatby children's university hospital, Alexandria, Egypt showed that majority of school-aged children with heart disease (78.3%) had neutral HRQOL and a small percentage (8.7%) of the studied subjects had poor HRQOL scores (14). This could be related to children's good response to disease process and its management.

Several modifiers of health-related quality of life have been reported in the literature, including disease severity, duration of illness, socioeconomic status (SES), and presence of pacemaker & other devices(18,25,26). In children with heart disease we evaluated for such modifiers of health related quality of life. We found no effect of age, gender and ethnicity with regard to HRQOL. Similarly, parental marital status and educational level of the child were not found to affect HRQOL. This finding is in agreement with other studies which showed similar results (1, 12, 13-16).

Among the socioeconomic status, parental educational level, current occupation and average monthly income were found to significantly lower both physical and psychosocial domains of HRQOL. Interestingly, this is a bit different from other studies finding where it only affected the psychosocial domain with no effect on physical health domain (1,12 13,15,). This may be due to the majority of children in our study were from significantly low SES which in turn can impact their physical and nutritional status, health intervention seeking behavior as well as regular follow up and care provision.

Mean physical and psychosocial health score was also found to be affected by disease category & echocardiographic severity of cardiac lesion as well as duration of illness ($p<0.01$). This is a consistent finding in other similar studies which showed that disease severity & advanced heart disease staging and prolonged duration of illness were associated with lower scores in all domains of HRQOL in children with chronic heart disease (1,13,15). The explanation for these findings could be due to the fact direct relation of disease severity with physical restriction, medication burden, recurrent hospital visits & admission and its negative impact on emotional, social and cognitive functioning.

In addition, in children with heart disease, longer duration of illness has a direct association with HRQOL domains due to longstanding physical symptoms, changes on physical appearance and associated long term complications including failure to thrive & malnutrition and pulmonary vascular diseases.

Conclusion and Recommendation

The findings from this study indicated that all dimensions of HRQOL of children with chronic heart disease were compromised in the study setting. It showed the negative impact of heart disease in children in terms of physical health & functioning and their psychosocial health. It also identified important factors such as socioeconomic status, disease category and duration of illness which are associated with lower HRQOL scores. Identification of the child with significantly impaired QOL may have the greatest clinical potential for improving outcomes for children with chronic heart disease. It can guide individualized counseling and interventions to improve QOL for these children. Recognition of emotional and social concerns can prompt referral for psychological counseling and support. Early identification of impaired school functioning such as attention-related problems should mandate more comprehensive and focused neuropsychological evaluation and targeted intervention programs. Therefore, it is crucial that the treating physician give emphasis to assess the health-related quality of life in children with heart disease and address them accordingly. It is also recommended to conduct further larger scale studies in different settings to evaluate the scope and burden of the condition and hopefully aid in implementing health policies that address the issue.

Strength of the study

This study used a standardized, internationally valid and consistent tool in order to assess HRQOL. Lack of similar studies in this topic in developing countries like Africa and especially Ethiopia, makes this study one of the very few in the area and can serve as a basis for further efforts. Furthermore, the findings in this study particularly, the socioeconomic status as a major predicting factor for impaired HRQOL including the physical health, are peculiar to this study and require due attention.

Limitation of the study

Although we used a standardized and valid tool, further study is required to assess the reliability and validity of the tool in our setup. Disease severity was based on ejection fraction and NYHA stage of heart disease in other studies while this study used only echocardiographic features of the structural cardiac lesion which is a subject for interpersonal bias and may underestimate the clinical severity of the patients.

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