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Pattern and determinants of health-related quality of life of adolescents with congenital heart disease in Cameroon: A single-center cross-sectional study

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Abstract

Background: Health-related quality of life (HRQoL) assessment is necessary for the management of patients with congenital heart diseases (CHD). No study has yet been reported on Cameroonian adolescents. The aim of this study was to evaluate the profile of and look for determinants of HRQoL in adolescents with CHD in Cameroon.

Methods: This was a cross-sectional study with prospective recruitment carried out on 71 adolescents diagnosed with CHD aged 12 to 18 years and recruited at the Douala General Hospital. Sociodemographic and clinical data were collected using a structured questionnaire. HRQoL was assessed using the pediatric quality of life inventory (PedsQL4.0) for child and parent reports. Multivariate linear regression was used to assess the determinants of HRQoL. Differences were considered significant for $p < 0.05$.

Results: Mean age of participants was 15 ± 2 years with 54.9% women. Mean physical and psychosocial functioning scores were 50.7 ± 13.9 and 60.5 ± 9.6 for parent report and 49.5 ± 13.4 and 59.1 ± 9.1 for child report respectively; with no significant difference according to gender. Distribution of functioning scores according to anatomical complexity showed no significant difference while it was lower in patients with a greater physiological severity and to those with no surgical intervention compared to the others. After multivariate adjustments, physiological stage 3 or 4 was negatively associated while cardiac intervention was positively associated with HRQoL.

Conclusion: CHD adolescents exhibit a low level of quality of life. Cardiac intervention positively affects HRQoL and should be targeted in the reduction of HRQoL burden from CHD in Cameroon.

Keywords

Congenital heart disease, quality of life, PedsQL, adolescents, pediatric cardiology

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Introduction

Congenital heart diseases (CHD) consist of defects in the cardiac architecture that interfere with venous drainage, septation of cardiac segments and their sequences, and regular function of valve apparatuses.[1] They are the most common cause of congenital defects and the second most common cause of life-threatening during the first year of life.[2] CHD represent an important public health concern worldwide with a prevalence of 9.87/1000 found in the Cameroonian population.[3] Improvements in diagnostic methods and cardiac surgery over the years have led to an

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increase in the life expectancy of patients with CHD and therefore an increase in the number of adolescents and adults with CHD.[4] The challenges in the management of CHD are therefore shifting from survival to physical, social, and educational well-being which is nowadays considered in the frame of quality of life (QoL).

The World Health Organization (WHO) defines QoL as the individual's perception concerning their position standards and concerns.[5] Health-related quality of life (HRQoL) in children and adolescents often includes the dimensions generally connected to daily activities, cognitive acquisitions, emotions, self-perception, and interpersonal relationships, and the environment around them.[6] With the increase in life expectancy of patients with CHD, HRQoL assessment appears necessary to evaluate the impact of disease severity, health status, treatment, and healthcare policies in the daily life of patients.[7] In clinical and pediatric contexts, HRQoL evaluation implies an ecological approach including self-perceptions and family perceptions. Although the involvement of children/adolescents in decisions about their treatment and care was recognized, the use of parent reports as complementary sources of information is also highly recommended in the pediatric context, due to the parent's responsible role in clinical decision-making processes.[8]

Caring for children with CHD is highly emotionally and financially demanding. In sub-Saharan African countries like Cameroon, The lack of financial means faced by many families hurts the management of children with CHD[9]; particularly in medical costs, surgical procedures and traveling for medical care. Moreover, most children are isolated because of their condition and treated differently; which can contribute to physical deconditioning[10] and increase the risk of mental problems.[11] In addition to the deficiency of data on HRQoL in children/adolescents with chronic conditions, data on those with CHD are really scarce, particularly in low-middle-income countries (LMICs). Few studies conducted have shown significantly poor self-reported and parent-reported HRQoL of children with CHD compared to healthy controls.[12–14] For instance, using the Pediatric Quality of Life Inventory (PedsQL), a recent study in South India shown a significantly poor median HRQoL total score in healthy compared to CHD patients in children (91.3 vs 80.4), preadolescents (91.3 vs 67.1), and adolescents (89.1 vs 69.6).[13] HRQoL of patients with CHD varies widely across studies and may be dependent on economical, sociodemographic, and medical conditions of patients[15,16] and can be used as a good indicator of patient wellbeing and care. Understanding their HRQoL will also help in improving symptom relief and rehabilitation. It is also helpful for decision making during medical care and can help predict treatment success and is therefore of prognostic importance.[17] However, studies have not yet been reported in Cameroonian CHD patients. The primary aim of this study was to evaluate the level of HRQoL of adolescents with CHD in Cameroon and secondary, to look for sociodemographic and clinical determinants of HRQoL.

Material and methods

Design and participants

This was a cross-sectional prospective hospital-based study carried out in the Department of Internal Medicine and the service of Cardiology of the Douala General Hospital which is a reference center for pediatric cardiology in Douala. Participants were adolescents (12 to 18 years) outpatients from both genders diagnosed with CHD. Patients followed up in the service are coming from all parts of Douala and also from many other cities around. Participants selected based on their medical records were contacted using their telephone number and invited to participate in the study. Patients with additional chronic conditions different from CHD like trisomy and mental development retardation were excluded from the study. Also, adolescents with recent hospitalization or any cardiac intervention less than one year were excluded. Participants were recruited using a consecutive and exhaustive sample strategy. Over 131 patients registered in the service and called, 71 responded and accepted to participate in the study. Of the other 60 patients, 16 were deceased, 30 were unavailable via their phone number or refused to participate, 12 had travelled to other cities and two had a physical disability. The study was approved by the institutional review board of the University of Douala and signed informed consent was obtained from parents or tutors prior to their enrollment.

Patients and their parents were interviewed in the service cardiology by a well-trained research assistant (post-graduate medical student) using a structured questionnaire on sociodemographic, clinical and HRQoL data. Sociodemographic parameters were age, gender, residence, and level of education. Clinical data were symptoms of CHD and the presence of cyanosis.

Disease classification

CHD was classified according to anatomical and physiological classifications. Anatomical malformation severity was classified as simple, moderate, and complex according to the 32nd Bethesda classification.[4] The Ross classification was used to define the physiological classification of the disease. Participants were classified into four groups (Stage 1 to Stage 4) according to the severity of the congestive heart failure.[18]

HRQoL evaluation

HRQoL was assessed using the French version of the Pediatric Quality of Life inventory 4.0 (PedsQL 4.0) which is a generic core and age-specific scale dedicated

to assessing HRQoL of children and adolescents.[19] The PedsQL4.0 is a 23-item questionnaire evaluating physical (8 items), emotional (5 items), social (5 items), and school functioning (5 items). Psychosocial health is measured as a combination of the emotional, social, and school functioning dimensions. Participants' responses are reported on a 5-point Likert scale ranging from Never (0 points) to Almost always (4 points). The responses were reverse scored and transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). These were then summed up for each scale and divided by the corresponding number of items to obtain total scores and psychosocial subtotal scores. Higher scores indicate a better health-related quality of life. PedsQL4.0 is one of the most reliable and validated tools to assess HRQoL in children and adolescents with various conditions.[20] The French version of the questionnaire that we used has also been validated by a previous study.[21]

Statistical analysis

Data were collected and analyzed using SPSS 20 software (IBM Corp). PedsQL4.0 scores are presented in mean ± standard deviation (SD) while categorical variables are presented in counts and percentages. For statistical comparisons, the physiological classification variable was transformed into a 2-group variable (i.e. stage 1 and 2 vs stage 3 and 4) while anatomical classification was considered a 3-group variable (simple, moderate, and complex). PedsQL4.0 scores were compared according to gender, physiological classification, and treatment modalities using the non-parametric Mann–Whitney test. Comparison of PedsQL scores according to anatomical classification groups was made using a multi-group comparison Kruskal–Wallis test. Bonferroni post-hoc test was used for 2 × 2 comparisons. Multivariate generalized linear models were used to assess determinants of the physical and psychosocial functioning of HRQoL. Concerning covariates, age was used as a continuous variable, and categorical variables were dichotomized before the analysis. Variables with at least a p-value less than 0.1 in univariate analysis were entered into the multivariate model. Differences were considered significant for $p < 0.05$.

Results

The distribution of CHD abnormalities is presented in Table 1. The most represented CHD was ventricular septal defect which represented more than one-fourth of the sample followed by pulmonary atresia, tetralogy of Fallot, and patent ductus arteriosus which represented 15.5%, 14.1%, and 11.3% respectively.

The mean age of recruited participants was 15 ± 2 years, mostly composed of women (54.9%). The sociodemographic and clinical characteristics of participants are presented in Table 2. Almost all the participants (97.2%) were coming from the urban area and all the participants were schooling. Dyspnea was the most common symptom encountered (69%), followed by asthenia and cyanosis. CHD with great complexity represented 25.4% of the sample and less than 40% of patients had a cardiac intervention.

Table 1. Distribution of CHD according to their severity.

Abnormalities	*N*	%
Ventricular septal defect	18	25.4
Pulmonary atresia	11	15.5
Tetralogy of Fallot	10	14.1
Patent ductus arteriosus	8	11.3
Pulmonic valve stenosis	7	9.9
Atrial septal defect	5	7
Transposition of the great arteries	5	7
Coarctation of the aorta	2	2.8
Atrioventricular canal defects	2	2.8
Tricuspid atresia	2	2.8
Subaortic stenosis	1	1.4

Table 2. Characteristics of participants.

		N	%
Age (years)	12	7	9.9
	13–18	64	90.1
Gender	Female	39	54.9
	Male	32	45.1
Residence	Rural	2	2.8
	Urban	69	97.2
School level	Primary	10	14.1
	Secondary	59	83.1
	University	2	2.8
Symptoms	Asthenia	38	53.5
	Dyspnea	49	69
CHD severity	Simple	23	32.4
	Moderate	30	42.3
	Severe	18	25.4
Cyanosis	Non-cyanotic	46	64.8
	Cyanotic	25	35.2
Ross classification	Stage 1	14	19.7
	Stage 2	33	46.5
	Stage 3	16	22.5
	Stage 4	8	11.3
Treatment	Cardiac intervention	28	39.4
	Medical treatment	43	60.6

Parent and child reports of HRQoL (mean and 95% confidence interval) scores are presented in Table 3. Data are compared between male and female gender. The mean of total scores for parent and child reports were 58.0 ± 10.2 and 56.3 ± 9.9 respectively. According to the parent report, mean scores for physical and psychosocial domains were 50.7 ± 13.9 and 60.5 ± 9.6 respectively while it was 49.5 ± 13.4 and 59.1 ± 9.1 for the child report respectively. Almost all the parent and child

domains were not significantly different between male and female groups except for the social domain of child report which was significantly higher in females than in males ($p = 0.030$).

Table 4 presents the distribution of HRQoL scores according to anatomical and physiological classifications of the CHD. Using the classification based on the level of structural abnormalities, almost all the variables were not significantly different between simple, moderate, and complex levels. Using the Bonferroni post-test, physical functioning was significantly lower in participants with great complexity compared to participants with simple complexity (45.3 ± 15.9 vs 50.4 ± 12.0 respectively, $p < 0.05$). Using the physiological classification, HRQoL was significantly lower in participants on stage 3 and 4 compared to those on stage 1 and 2 for parent report physical functioning (53.5 ± 11.1 vs 45.1 ± 17.3; $p = 0.043$), psychosocial functioning (56.3 ± 11.2 vs 62.7 ± 8.1; $p = 0.019$), total score (53.5 ± 12.4 vs 60.4 ± 8.3, $p = 0.014$) and child report physical functioning (43.7 ± 14.7 vs 52.4 ± 11.6, $p = 0.017$), and total score (52.8 ± 11.4 vs 58.6 ± 8.0; $p = 0.033$) respectively.

Table 3. Distribution of PedsQL scores according to gender.

	All participants		Female		Male		
Total	mean ± SD	95%CI	mean ± SD	95%CI	mean ± SD	95%CI	*p*
Parent report							
Physical	50.7 ± 13.9	47.4–54.0	51.8 ± 12.4	47.8–55.9	49.2 ± 15.3	43.6–54.8	0.626
Emotional	59.3 ± 10.9	56.7–61.9	59.6 ± 9.6	56.5–62.8	58.9 ± 12.3	54.4–63.4	0.977
Social	61.6 ± 10.4	59.1–64.1	63.2 ± 9.6	60.0–66.4	59.7 ± 11.0	55.7–63.7	0.220
School	60.6 ± 11.5	57.8–63.3	61.5 ± 10.3	58.1–64.9	59.4 ± 12.6	54.8–64.0	0.501
Psychosocial	60.5 ± 9.6	58.2–62.8	61.5 ± 8.3	58.7 –64.2	59.3 ± 10.9	55.4 –63.3	0.441
Total parent	58.0 ± 10.2	55.6–60.5	59.1 ± 8.9	56.1–62.0	56.8 ± 11.5	52.6–61.0	0.536
Child report							
Physical	49.5 ± 13.4	46.3–52.7	51.8 ± 10.3	48.4–55.2	46.7 ± 15.9	40.7–52.6	0.193
Emotional	57.7 ± 10.6	55.2–60.2	57.9 ± 10.4	54.5–61.4	57.3 ± 10.8	53.4–61.3	0.813
Social	59.7 ± 9.9	57.4–62.1	61.9 ± 9.6	58.8–65.1	57.0 ± 9.5	53.5–60.5	0.030
School	59.8 ± 11.2	57.1–62.5	62.1 ± 11.1	58.4–65.7	57.0 ± 10.7	53.1–60.9	0.081
Psychosocial	59.1 ± 9.1	56.9–61.2	60.6 ± 8.9	57.7 –63.5	57.1 ± 9.1	53.9 –60.4	0.096
Total child	56.3 ± 9.9	54.0–58.7	58.1 ± 9.3	55.0–61.2	54.2 ± 10.2	50.4–57.9	0.081

SD: standard deviation; CI: confident interval.

Table 4. Distribution of PedsQL scores according to disease severity.

	Anatomical classification				Physiological classification		
	Simple mean ± SD	Moderate mean ± SD	Complex mean ± SD	*p*	Stage 1–2 mean ± SD	Stage 3–4 mean ± SD	*p*
Parent report							
Physical	50.4 ± 12.0	54.1 ± 13.5	45.3 ± 15.9	0.087*	53.5 ± 11.1	45.1 ± 17.3	0.043
Emotional	59.3 ± 8.7	61.5 ± 10.4	55.6 ± 13.7	0.244	61.5 ± 9.6	55.0 ± 12.4	0.036
Social	62.8 ± 6.4	61.8 ± 11.5	59.7 ± 13.0	0.819	63.7 ± 9.5	57.5 ± 11.3	0.020
School	63.5 ± 8.2	60.5 ± 11.5	56.9 ± 14.5	0.348	62.8 ± 10.1	56.3 ± 13.1	0.062
Psychosocial	61.9 ± 6.2	61.3 ± 9.9	57.4 ± 12.5	0.577	62.7 ± 8.1	56.3 ± 11.2	0.019
Total parent	61.9 ± 6.2	61.3 ± 9.9	57.4 ± 12.5	0.419	60.4 ± 8.3	53.5 ± 12.4	0.014
Child report							
Physical	52.6 ± 11.5	50.1 ± 13.7	44.6 ± 14.0	0.261	52.4 ± 11.6	43.7 ± 14.7	0.017
Emotional	59.6 ± 8.2	58.8 ± 10.2	53.3 ± 13.2	0.263	60.0 ± 9.2	53.1 ± 12.0	0.024
Social	59.6 ± 8.5	61.5 ± 9.5	56.9 ± 12.0	0.503	60.0 ± 9.3	59.2 ± 11.3	0.99
School	58.5 ± 10.0	62.5 ± 10.6	56.9 ± 13.4	0.224	62.1 ± 10.0	55.2 ± 12.5	0.03
Psychosocial	59.2 ± 6.5	60.9 ± 8.9	55.7 ± 11.7	0.291	60.7 ± 7.7	55.8 ± 10.8	0.056
total child	57.5 ± 6.8	58.2 ± 9.7	53.0 ± 11.9	0.337	58.6 ± 8.0	52.8 ± 11.4	0.033

CHD: congenital heart disease.
*Significant difference between complex and simple groups.

According to the parent report, participants who had a cardiac intervention exhibited a significantly higher physical, psychosocial, and total score compared to the others ($p = 0.016$, $p = 0.020$, and $p = 0.011$ respectively) (Table 5). Likewise, physical functioning and total score according to the child report were significantly higher in participants who had received cardiac intervention compared to the others ($p = 0.003$ and $p = 0.024$ respectively).

Univariate and multivariate analysis of determinants of HRQoL (physical and psychosocial functioning scores) are presented in Table 6. Results are presented for parent and child report. After univariate analysis, complex level of severity, cyanoses, and physiological stage 3 or 4 Ross classification were associated with a reduction of physical and psychosocial functioning scores while cardiac intervention was associated with increased scores ($p < 0.1$). After multivariate analysis, stage 3 and 4 classification of CHD was negatively associated with physical and psychosocial functioning HRQoL scores in parent report (β (95%CI): −7.78 (−14.4; −1.18 and −5.88 (−10.4; −1.34) respectively) and child report (β (95%CI): −7.71 (−13.7; −1.66) and −4.53 (−8.94; −0.11) respectively). Cardiac intervention was positively associated with the psychosocial functioning score in the parent report (β (95%CI): 7.49 (1.51; 13.5), $p = 0.032$).

Table 5. Distribution of PedsQL scores according to treatment modality.

	Cardiac intervention mean ± SD	Medical mean ± SD	*p*
Parent report			
Physical	55.2 ± 12.6	47.7 ± 14.2	0.016
Emotional	62.0 ± 9.7	57.6 ± 11.5	0.122
Social	64.5 ± 9.8	59.8 ± 10.6	0.078
School	64.6 ± 8.5	57.9 ± 12.5	0.022
Psychosocial	63.7 ± 8.6	58.4 ± 9.9	0.020
Total parent score	61.6 ± 9.3	55.7 ± 10.4	0.011
Child report			
Physical	55.4 ± 10.5	45.7 ± 13.9	0.003
Emotional	60.9 ± 9.5	55.6 ± 10.9	0.052
Social	61.8 ± 10.5	58.4 ± 9.4	0.169
School	62.0 ± 10.5	58.4 ± 11.7	0.216
Psychosocial	61.5 ± 8.2	57.4 ± 9.4	0.064
Total child score	59.5 ± 9.1	54.2 ± 10.1	0.024

Discussion

Participants in our study generally exhibited a low level of HRQoL scores which were quite similar in self and parent report. Overall, psychosocial functioning was 10 points higher than physical functioning score in parent and child reports. Globally, total, physical, and psychosocial functioning scores were not significantly different according to gender, and disease complexity. On the contrary, participants with fewer physiological complications and those who attended a cardiac intervention had significantly higher total, physical, and psychosocial scores than the others for self and child reports. Physical and psychosocial scores were positively associated with less physiological complications, non-cyanotic CHD, and cardiac intervention. The current study is the first to assess HRQoL in the Cameroonian adolescent CHD population. Specificity of age in our study can be helpful for targeted public health interventions and for further studies.

Table 6. Factors associated with physical and psychosocial functioning of HRQoL.

	Physical functioning		Psychosocial functioning	
	Univariate β (95%CI)	Multivariate β (95%CI)	Univariate β (95%CI)	Multivariate β (95%CI)
Parent report				
Age (years)	−0.34 (−2.28; 1.59)		0.12 (−1.22; 1.46)	
Female gender	2.62 (−4.04; 9.29)		2.13 (−2.48; 6.74)	
Complex severity	−7.16 (−14.6; 0.30)[a]	−3.19 (−12.1; 5.70)	−4.13 (−9.35; 1.08)	
Cyanoses	−6.42 (−13.2; 0.38)[a]	−4.31 (−12.3; 3.67)	−3.85 (−8.60; 0.90)[a]	−3.55 (−8.03; 0.93)
Ross stage 3–4	−8.47 (−15.2; −1.73)[b]	−7.78 (−14.4; −1.18)[b]	−6.41 (−11.04; −1.78)[b]	−5.88 (−10.4; −1.34)[b]
Cardiac intervention	7.57 (1.00; 14.1)[b]	5.39 (−1.14; 11.9)	5.28 (0.73; 9.83)[b]	4.04 (−0.39; 8.46)[a]
Child report				
Age (years)	−0.20 (−2.04; 1.64)		−0.30 (−1.57; 0.96)	
Female gender	4.99 (−1.26; 11.2)		3.51 (−0.78; 7.79)	
Complex severity	−6.54 (−13.6; 0.56)[a]	−1.60 (−9.75; 6.55)	−4.45 (−9.33; 0.44)[a]	−2.31 (−8.25; 3.63)
Cyanoses	−6.56 (−13.0; −0.12)[b]	−5.06 (−12.4; 2.25)	−3.80 (−8.26; 0.66)[a]	−2.37 (−7.71; 2.96)
Ross stage 3–4	−8.72 (−15.1; −2.36)[c]	−7.71 (−13.7; −1.66)[b]	−4.88 (−9.32; −0.43)[b]	−4.53 (−8.94; −0.11)[b]
Cardiac intervention	9.45 (3.39; 15.5)[c]	7.49 (1.51; 13.5)[b]	4.11 (−0.23; 8.44)[a]	2.77 (−1.60; 7.13)

β: coefficient of regression; CI: confidence interval.
[a]$p < 0.05$; [b]$p < 0.01$; [c]$p < 0.001$.

Due to the limited time to collect data, participants were invited using their phone numbers. This methodological approach differs from other studies where the patients were recruited during their spontaneous or routine medical consultation. Although unreported in the results, one part of the patients that we could not enroll in this study was those with unavailable phone numbers, were deceased or had a physical limitation. The other part was those whose parents thought they were in good health and did not need to participate in the study. It is suspected that some patients accepted because they thought that their child was not in good care and the invitation was a good opportunity to have a medical consultation or the opportunity to have a cardiac intervention. This could explain the low level of physical and psychosocial QoL observed in our participants compared to other studies.[13,22–25] This refusal to participate can also be understood under the concept of sense of coherence which explains that patients with chronic diseases cope with their disease and find their health status satisfying.[26] The low level of HRQoL found in our study compared to others can also be explained by differences in population structures and socioeconomic status; other studies are being carried out in developed and high-income countries. Recent studies found a strong correlation between low socioeconomic status and poor QoL in adolescents with CHD.[9,27] Although we have not reported the socioeconomic status in this study, almost all the patients face critical socioeconomic conditions. Moreover, the follow-up of patients with CHD and cardiac interventions are very costly and there are no sustainable public health solutions to support patients. Moreover, most of the patients that undergone cardiac interventions have benefited from humanitarian foreign cardiac surgery missions in the country. Currently, cardiovascular services available in LMICs remain severely limited, in contrast to the rapid progress seen in the rest of the world.[28] However, the absence of a control group of healthy participants makes it difficult to appreciate the real difference in QoL that can be imputed to CHD. Our results show that socioeconomic status could be a great interplay in the management of CHD patient through their HRQoL.

We found in this study that there was no significant difference of HRQoL in patients according to their anatomical disease severity. Conversely, patients with physiological stage 3 and 4 had a significantly poor HRQoL compared to the others. Moreover, physiological stage 3 and 4 was a significant contributor to poor physical and psychosocial functioning score in multivariate analysis. The non-significance of the distribution of HRQoL scores according to the anatomical complexity of the disease can be explained by the fact that participants with complex anatomical severity that has been diagnosed very early in life have accommodated their condition due to a lack of financial means for cardiac interventions. This argument can be sustained by the low proportion of patients with the surgical intervention compared to previous studies in developed countries.[29,30] Our results are similar to those of Martinez-Quintana et al.,[31] who found a significantly poor physical functioning score in CHD young adults in physiological stage 3 and 4 although no significant difference with psychosocial functioning. Consistent findings have been observed by Abassi et al.[29] in children aged 5–7 years. These results imply that physiological complications and symptoms experienced by patients may be a better contributor to poor QoL than anatomical modifications. Besides, our results suggest that the physiological classification could be more discriminating than the anatomical classification on the QoL of patients[29] and will be more useful in the clinical management of patients with CHD.

Participants who underwent cardiac intervention experienced a significantly poor QoL compared to those who did not. Differences were significant in physical, psychosocial, and total functioning for the parent report and for physical and total functioning for the child report. Although patients who underwent cardiac surgery have been reported to have poor QoL compared to healthy controls,[32–34] the comparison between CHD patients with and without surgical cardiac intervention seems to be inconclusive. Teixeira et al.[22] found that adolescents and young adults who had not undergone surgery had a better QoL both overall and in the physical and social dimensions compared to those who had surgical procedures while Aguilar-Alaniz et al.[16] found no significant differences in adolescents. In a longitudinal study, Boukovala et al.[35] found that adolescents and adults with CHD reported better physical HRQoL following surgery and catheter intervention compared to the other treatment options. Our results show that cardiac surgery and catheter intervention are the best option to improve the QoL of adolescents with CHD. Initiatives to promote early corrective treatment of CHD may help in reducing the HRQoL burden of CHD.[22]

Limitations

Although this is the first study carried out on HRQoL in Cameroonian adolescents with CHD, some limitations can be drawn. Firstly, the absence of a healthy control group makes it difficult to be conclusive on the level of QoL among our participants compared to their siblings. This could have also helped understand differences with other studies. Secondly, reporting the data about parents or tutors could have also brought information on the socioeconomic environment of the adolescents and given more precision on the determinants of HRQoL.

Conclusion

In this prospective study exploring HRQoL in adolescents with congenital disease, we found that child and parent reports of HRQoL both on physical, psychosocial, and

total functioning domains were low compared to CHD adolescents observed in other populations. Physiological classification showed a better congruence with HRQoL components than anatomical classification. Physiological classification should therefore be more useful in clinical evaluation of patients and medical follow-up. Cardiac intervention positively affects HRQoL and should be targeted in the reduction of HRQoL burden from CHD. Initiatives to promote early corrective treatment of CHD may help in reducing the HRQoL burden of CHD.

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Author contributions

F.K. and E.C.B.L. designed the study protocol and provided support for the materials. F.K., J.M.N S.M., L.V., and H.N. contributed to logistic and data collection; E.C.B.L. and J.M.N. led the statistical analyses and contributed to the manuscript draft. C.N.N.G and E.C.B.L. wrote the first manuscript draft. H.B., S.M., L.V., H.N., C.N., SD and M.S.N.E. critically contributed to analysis, discussion and interpretation of the data, and to the writing of the manuscript. All authors reviewed and approved the final manuscript draft.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

This study was performed in line with the principles of the Declaration of Helsinki. The study was approved by the institutional review board of the University of Douala (authorization N°3525/CEI-UDo/03/2023/T) and all parents signed informed consent.

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