

Research Article

Health Quality of life of children and adolescents with congenital heart disease in Moi Teaching and Referral Hospital Eldoret, Kenya

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Abstract

Introduction: Congenital heart diseases (CHD) in low- and middle-income countries, remains a leading cause of mortality and morbidity amongst children and adolescents due to the patients and family's inability to access diagnostic and surgical care. In the last century, however, survival has improved, but there remains scarce evidence in Africa of the health-related quality of life (HRQoL) among these affected children.

Objective: This study set out to assess the HRQoL and its determinants in this group of children with CHD presenting at a tertiary referral hospital in Kenya.

Patients and Methods: This was a hospital based cross-sectional study at the Moi Teaching and Referral hospital, Kenya conducted between November 2023 and June 2024. The participants were children and adolescents aged 0-18 years, who had a confirmed echocardiographic diagnosis of congenital heart disease, as well as being on follow up for at least 6 months in the cardiology clinics. The recruitment was done consecutively. HRQoL was assessed using age-appropriate EuroQol instruments (EQ-5D-Y and EQ-5D-5L). The primary outcome was overall HRQoL, categorised using visual analogue scale thresholds. Sociodemographic and clinical data were collected using structured tools. Associations were evaluated using χ^2 tests and multivariable logistic regression, with significance set at $p < 0.05$.

Results: A total of 107 participants was included (median age 4.0 years [IQR 1.4–10.0]; 54.2% male). The commonest lesion was acyanotic CHD (81.1%), with ventricular septal defect (32.7%), atrial septal defect (22.4%), and patent ductus arteriosus (16.8%) being the most prevalent defects. Only 24.3% of the participants had had Surgical correction performed on them.

Amongst all the participants, 72.9% had optimal HRQoL, 10.3% suboptimal, and 16.8% poor HRQoL. Many of the children and adolescents reported no limitations in mobility (86.9%) or self-care (87.9%), however, substantial impairments were observed in usual activities (44.8%), pain or discomfort (49.6%), and anxiety or depression (42.1%).

CHD-related hospital admissions ($p=0.045$) and comorbidities ($p=0.005$) were significantly associated with poorer HRQoL. Functional impairments, including reduced mobility ($p<0.001$), self-care limitations ($p=0.010$), impaired usual activities ($p=0.034$), pain or discomfort ($p=0.001$), and anxiety or depression ($p=0.014$)—were strongly associated with reduced HRQoL. In contrast, age at diagnosis, sex, surgical intervention, and disease severity (Ross heart failure classification) were not significantly associated with HRQoL.

Conclusion: The overall quality of life in this cohort was reported as satisfactory, however many of the participants

experienced significant functional and psychosocial impairments. These findings highlight the need for integrated, patient-centred care models in resource-limited settings that extend beyond survival and anatomical correction to address psychosocial wellbeing and functional outcomes. Strengthening access to early diagnosis, reducing hospitalizations, and integrating mental health support into paediatric cardiology services are critical to optimize quality of life of pediatric patients with CHD.

Keywords: Congenital Heart Disease; Children and Adolescents; Health- Related Quality of Life; Resource Limited Settings.

Introduction

The most common congenital anomaly is congenital heart disease, and worldwide it remains a leading contributor to pediatric morbidity and premature mortality in children and adolescents. In the past 50 years, CHD global prevalence has been on the rise, driven mainly by improved detection and earlier diagnosis especially in high income countries [1]. However, this change in the epidemiological pattern has not been geographically homogeneous. Great differences have been observed between low and high income settings, whereby, in the low -income countries there is still limited access to diagnostic and therapeutic services [2]. In addition, up to 75% of cardiovascular disease related deaths occur in low and middle income countries (LMICs), indicating the lopsided burden borne by resource-constrained health systems [3].

In sub-Sub-Saharan Africa, CHD remains an important impediment to achieving good public health. Population-based studies suggest relatively high prevalence rates; for instance, a study in Nigeria reported 18.1 cases per 1,000 children, with the vast majority presenting with acyanotic lesions [4]. Although the burden is high, late diagnosis persists; In Kenya, for example nearly 50% of affected children are diagnosed after the first year of life, and this makes it difficult to institute timely intervention, leading to unnecessary otherwise preventable complications and overall negative outcomes [5,6].

In high income countries advances in pediatric cardiac surgery has ensured that survival in children with CHD is over 90%, unlike LMICs where access to this life saving care remains severely unavailable. This inaccessibility is due to inadequate funding, limited infrastructure and equipment, and shortages of skilled personnel [7,8]. Less than 5% of children with CHD in Kenya undergo corrective surgery [9]. As a result, most of them live with uncorrected defects, predisposing patients to chronic complications, impaired functional status, and reduced survival.

Apart from surgically addressing the anatomical anomaly, it has been noted that the Health- related quality of life (HRQoL), plays a crucial part in young children

and adolescents with CHD. Health related quality of life encompasses physical, psychological, and social dimensions and is influenced by factors such as, disease severity, age at diagnosis, treatment interventions, and psychosocial adaptation [10]. Evidence from high-income settings suggests that children with complex CHD—particularly those with single-ventricle physiology—experience significantly reduced HRQoL compared with their healthy peers [11]. However, there seems to be a complex interaction between clinical and contextual factors, because other studies have found results that show that the QoL can be preserved irrespective of disease severity.

Some children with CHD who have undergone corrective surgery have also been observed to experience impaired HRQoL even after the procedure, suggesting that long-term outcomes extend beyond anatomical repair [11]. Despite this, data from LMICs—particularly in sub-Saharan Africa—remain scarce. In Kenya, there is a notable paucity of evidence examining HRQoL among children and adolescents living with CHD, limiting the ability to provide context-specific, patient-centered care.

In view of the high burden of disease in relation to CHD and within the context of resource setting, it is necessary therefore to generate local data to inform clinical practice and health policy. This study set out to assess the quality of life of children and adolescents with CHD, characterize the clinical profile of the participants and identify factors associated with HRQoL outcomes, with the aim of providing holistic care strategies and improve long-term outcomes in this population.

Methods and patients

Study design and setting

We conducted a hospital-based cross-sectional study among children and adolescents with congenital heart disease (CHD) attending the pediatric cardiology clinic at Moi Teaching and Referral Hospital (MTRH) in Eldoret, western Kenya. MTRH is a level 6 national referral and teaching hospital and the second-largest public tertiary

hospital in Kenya, serving a large catchment population across the North Rift region. The pediatric cardiology clinic is held weekly at the Chandaria Cancer and Chronic Diseases Centre. It is run by a combination of pediatric residents, medical officers and pediatric cardiologists. The echocardiography studies are done by certified echocardiographers and the pediatric cardiologists. All images are overread by the pediatric cardiologists. The American society of echocardiography guidelines are utilized [5,6]. Data collection was undertaken between November 2023 and June 2024.

Participants

Eligible participants were children and adolescents aged 0–18 years with echocardiographically confirmed CHD who had been on follow-up at the MTRH pediatric cardiology clinic for at least 6 months. We excluded patients who were acutely ill at presentation and unable to participate, and those whose caregivers could not communicate in English or Kiswahili. Written informed consent was obtained from caregivers, and assent from children aged 7 years and above.

Sample size and sampling

The sample size was calculated using Fisher's formula based on a pre-study estimate of 10.5% prevalence of anxiety disorders among children with CHD [1]. Using a 95% confidence level ($Z=1.96$) and adjusting for a 15% non-response rate, the minimum sample size was 170 participants. Participants were recruited consecutively during routine clinic visits over the study period until the required sample size was attained.

Data collection procedures

Data were collected by the principal investigator and trained research assistants using a structured data collection tool. Sociodemographic and clinical variables included age at the time of study, age at diagnosis, CHD subtype, surgical history, treatment regimen, anthropometric measurements, comorbidities, and medication adherence which was defined as the extent to which participants took prescribed medications as directed by healthcare providers. Adherence was assessed through self-report or proxy-report and categorized as perfect (90–100%), good (75–89%), average (50–74%), or poor (<50%), based on the proportion of missed medication days per week. To reduce recall bias, reported adherence was cross-checked against clinic records where available.

Health-related quality of life (HRQoL) was assessed using the EuroQol instruments (EQ-5D-Y and EQ-5D-5L), which

have been validated for pediatric populations and used in African settings [12–15]. Age-appropriate versions were administered as follows: proxy versions for children aged 0–7 years, interviewer-administered questionnaires for those aged 8–15 years, and self-administered EQ-5D-5L for adolescents aged 16 years and older. Authorization to use these questionnaires was obtained from EuroQol group (ID 58833). The instruments assess five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, each graded on three levels of severity. A visual analogue scale (VAS) was used to capture self-rated overall health status. Both English and Kiswahili versions were used depending on participant preference.

CHD diagnoses were confirmed using echocardiography in accordance with American Society of Echocardiography pediatric guidelines [5,6].

Outcome measures

The primary outcome was HRQoL. Responses across the five EQ-5D domains were scored on a three-level scale (1=no problems, 2=some problems, 3=severe problems). Impaired HRQoL was defined as the presence of any domain scored as level 2 or 3. Secondary outcomes included clinical characteristics and factors associated with impaired HRQoL.

Statistical analysis

Data were analyzed using R software version 4.1.2. Continuous variables were summarized using medians and interquartile ranges or means and standard deviations as appropriate, while categorical variables were presented as frequencies and proportions.

Bivariate analyses were performed using χ^2 tests or Fisher's exact tests for categorical variables, and appropriate parametric or non-parametric tests for continuous variables. Multivariable logistic regression was used to identify independent predictors of impaired HRQoL, with results reported as adjusted odds ratios (aORs) and 95% confidence intervals (CIs). A p-value of less than 0.05 was considered statistically significant.

Ethical considerations

Ethical approval was obtained from the Moi University/MTRH Institutional Research and Ethics Committee (IREC), and administrative approval from the CEO of MTRH. (IREC/673/2023. Approval number; 0044616). Participation was voluntary, with the right to withdraw at any time. Confidentiality was maintained through de-identification of data and secure storage of study materials.

The study posed minimal risk to participants and adhered to principles of beneficence, autonomy, and justice.

Results

Participant Characteristics

A total of 107 children and adolescents with congenital heart disease (CHD) were included in the analysis. The median age at diagnosis was 3.0 months (IQR 1.0–7.5; range 0.03–96), indicating that most cases were identified in early infancy. At the time of study, the median age was 4.0 years (IQR 1.4–10.0; range 0.28–18), reflecting a predominantly young cohort under long-term follow-up.

There was a slight male predominance (58 [54.2%]) compared with females (49 [45.8%]). Nearly half of the participants (52 [48.6%]) had no formal education, consistent with the young age distribution, while 38 (35.5%) had primary education, 16 (15.0%) secondary education, and only one participant (0.9%) had attained tertiary education (Table 1).

Table 1: Social demographic characteristics.

Variables	Values
Age at diagnosis in months	
Median (IQR)	3.0 (1-7.5)
Range	0.03 – 96
Current age in years	
Median (IQR)	4.0 (1.4-10.0)
Range	0.28 – 18
Gender	
Male	58 (54.2%)
Female	49 (45.8%)
Education level	
None	52 (48.6%)
Primary	38 (35.5%)
Secondary	16 (15.0%)
Tertiary	1 (0.9%)

Clinical Characteristics

Half of the participants (54 [50.5%]) had no CHD-related hospital admissions in the six months preceding enrolment in the study, while 26 (24.3%), 21 (19.6%), and 6 (5.6%) had one, two, and three admissions, respectively, indicating a substantial burden of recurrent hospitalization among a subset of patients.

Regarding functional impact, 61 (57.0%) reported no missed school days, whereas 32 (29.9%) missed 1–5 days, and 14 (13.1%) missed more than 5 days, suggesting that CHD affected school attendance in a minority of cases.

Most participants had no comorbid conditions (84 [78.5%]), while 23 (21.5%) had at least one comorbidity. Surgical correction was uncommon, with only 26 (24.3%) having undergone surgery compared with 81 (75.7%) who had not.

Treatment regimens varied, with 32 (29.9%) receiving monotherapy, 36 (33.6%) dual therapy, and 28 (26.2%) triple therapy. Adjunctive therapies included anticoagulants in 15 (14.0%) and penicillin prophylaxis in 11 (10.3%) in those with concurrent Rheumatic heart disease. Notably, adherence to treatment was high, with 73 (70.2%) reporting perfect adherence and 30 (28.8%) good adherences (Table 2).

Table 2: Clinical characteristics.

Variables	Values
CHD-related Admissions	
0	54 (50.5%)
1	26 (24.3%)
2	21 (19.6%)
3	6 (5.6%)
Missed school days	
Never	61 (57.0%)
1-5 days	32 (29.9%)
6-10 days	9 (8.4%)
>10 days	5 (4.7%)
Comorbidity	
No	84 (78.5%)
Yes	23 (21.5%)
Surgery	
No	81 (75.7%)
Yes	26 (24.3%)
Treatment modality	
Monotherapy	32 (29.9%)
Dual therapy	36 (33.6%)
Triple therapy	28 (26.2%)
Adjunctive treatment	
Anticoagulant	15 (14.0%)
Penicillin	11 (10.3%)
Self-reported adherence to treatment	
Average	1 (1.0%)
Good	30 (28.8%)
Perfect	73 (70.2%)

CHD Phenotype and Lesion Characteristics

The majority of participants had acyanotic CHD (86 [81.1%]), while 24 (22.4%) had cyanotic lesions. Among acyanotic defects, ventricular septal defect (VSD) was the most common (35 [32.7%]), followed by atrial septal defect

(ASD) (24 [22.4%]) and patent ductus arteriosus (PDA) (18 [16.8%]). Less frequent lesions included atrioventricular septal defects (4 [3.7%]) and atrial myxoma (4 [3.7%]).

Among cyanotic CHD, truncus arteriosus (8 [7.5%]) and PDA-associated cyanotic physiology (7 [6.5%]) were the most frequently reported, followed by tetralogy of Fallot (3 [2.8%]) and ventricular septal defects with cyanosis (3 [2.8%]). Other complex lesions, including transposition of the great arteries and tricuspid atresia, were rare (Table 3).

Table 3: CHD severity and valve lesion characteristics.

Variables	Values
Nature of defect	
Acyanotic	86 (81.1%)
Cyanotic	24 (22.4%)
Type of acyanotic	
ASD	24 (22.4%)
VSD	35 (32.7%)
PDA	18 (16.8%)
AVSD	4 (3.7%)
Atrium myoma	4 (3.7%)
Subaortic ridge	1 (0.9%)
Type of cyanotic	
ASD	1 (0.9%)
VSD	3 (2.8%)
PDA	7 (6.5%)
Truncus arteriosus	8 (7.5%)
Pulmonary atresia	1 (0.9%)
Tetralogy of Fallot	3 (2.8%)
Tricuspid atresia	1 (0.9%)
Transposition of great artery	1 (0.9%)
Tricuspid valve abnormalities	1 (0.9%)

Health-Related Quality of Life

Across the five EuroQoL domains, most participants reported no problems with mobility (93 [86.9%]) and self-care (94 [87.9%]). However, impairments were more evident in functional and psychosocial domains.

Difficulties in usual activities were reported by 48 (44.8%) participants, including 4 (3.7%) with severe limitations. Pain or discomfort was reported by 53 (49.6%), while 45 (42.1%) reported some degree of anxiety or depression.

Overall, 78 (72.9%) participants had optimal quality of life ($\geq 80\%$), 11 (10.3%) had suboptimal quality of life (71–79%), and 18 (16.8%) had poor quality of life ($\leq 70\%$).

According to Ross heart failure classification, most participants had some degree of functional limitation (70 [65.4%]), while 29 (27.1%) had severe limitations and only 8 (7.5%) had no symptoms (Table 4).

Table 4: Health related Quality of life.

Variables	Values
Mobility	
None	93 (86.9%)
Some	13 (12.1%)
A lot	1 (0.9%)
Self-care	
None	94 (87.9%)
Some	12 (11.2%)
A lot	1 (0.9%)
Usual Activities	
None	59 (55.1%)
Some	44 (41.1%)
A lot	4 (3.7%)
Pain/Discomfort	
None	54 (50.5%)
Some	48 (44.9%)
A lot	5 (4.7%)
Anxiety or Depression	
Not	62 (57.9%)
A bit	43 (40.2%)
Very	2 (1.9%)
EuroQoL (overall quality of life)	
Poor ($\leq 70\%$)	18 (16.8%)
Suboptimal (71-79%)	11 (10.3%)
Optimal ($\geq 80\%$)	78 (72.9%)
Ross classification	
No problems	8 (7.5%)
Some problems	70 (65.4%)
Many problems	29 (27.1%)

Factors Associated with Health-Related Quality of Life

Results from bivariate analysis revealed that CHD-related hospital admissions were significantly associated with poorer quality of life ($p=0.045$), with participants who had prior admissions more likely to report poor or suboptimal EuroQoL scores compared with those without admissions.

Comorbidity was also strongly associated with impaired quality of life ($p=0.005$); participants with comorbid conditions had a higher proportion of poor outcomes (39.1%) compared with those without comorbidities (10.7%).

Functional and symptom-related domains demonstrated the strongest associations with overall quality of life. Impaired mobility was highly associated with poor EuroQoL scores ($p<0.001$), with more than half (57.1%) of those reporting mobility limitations classified as having poor quality of life.

Similarly, impairments in self-care ($p=0.010$), usual activities ($p=0.034$), pain or discomfort ($p=0.001$), and anxiety or depression ($p=0.014$) were all significantly associated with reduced quality of life.

In contrast, age at diagnosis ($p=0.458$), gender ($p=0.73$), missed school days ($p=0.35$), surgical intervention ($p=0.84$), adjunctive treatment ($p=0.53$), and Ross

classification ($p=0.54$) were not significantly associated with overall quality of life (Table 5 and Figure 1).

Discussion

In this study, the overall health-related quality of life of the participants was reported as optimal, however there was still a large percentage of these young children and adolescents with CHD who reported significant impairments

Table 5: Association between EuroQoL and patients' characteristics.

Variables	EuroQoL			p-value
	Poor	Suboptimal	Optimal	
Age at diagnosis	2.5 (1.5 – 7)	2 (0.5 – 5)	3 (1 – 9)	0.458
Gender				0.73
Male	9 (15.5%)	5 (8.6%)	44 (75.9%)	
Female	9 (18.4%)	6 (12.2%)	34 (69.4%)	
CHD-related Admissions				0.045
None	5 (9.3%)	4 (7.4%)	45 (83.3%)	
Yes	13 (24.5%)	7 (13.2%)	33 (62.3%)	
Missed school days				0.35
<=5days	14 (15.1%)	9 (9.7%)	70 (75.3%)	
>5days	4 (28.6%)	2 (14.3%)	8 (57.1%)	
Comorbidity				0.005
No	9 (10.7%)	9 (10.7%)	66 (78.6%)	
Yes	9 (39.1%)	2 (8.7%)	12 (52.2%)	
Surgery				0.84
No	13 (16.0%)	9 (11.1%)	59 (72.8%)	
Yes	5 (19.2%)	2 (7.7%)	19 (73.1%)	
Adjunct treatment				0.53
Penicillin	1 (20.0%)	1 (20.0%)	3 (60.0%)	
Penicillin & Anticoagulant	0 (0.0%)	1 (16.7%)	5 (83.3%)	
Anticoagulant	2 (22.2%)	0 (0.0%)	7 (77.8%)	
Ross classification				0.54
No problems	2 (25.0%)	0 (0.0%)	6 (75.0%)	
Have problems	16 (16.2%)	11 (11.1%)	72 (72.7%)	
Mobility				<0.001
None	10 (10.8%)	10 (10.8%)	73 (78.5%)	
Some/A lot	8 (57.1%)	1 (7.1%)	5 (35.7%)	
Self-care				0.010
None	12 (12.8%)	10 (10.6%)	72 (76.6%)	
Some/A lot	6 (46.2%)	1 (7.7%)	6 (46.2%)	
Usual Activities				0.034
None	5 (8.5%)	6 (10.2%)	48 (81.4%)	
Some/A lot	13 (27.1%)	5 (10.4%)	30 (62.5%)	
Pain/Discomfort				0.001
None	2 (3.7%)	6 (11.1%)	46 (85.2%)	
Some/A lot	16 (30.2%)	5 (9.4%)	32 (60.4%)	
Anxiety or Depression				0.014
Not	5 (8.1%)	8 (12.9%)	49 (79.0%)	
Abit/very	13 (28.9%)	3 (6.7%)	29 (64.4%)	

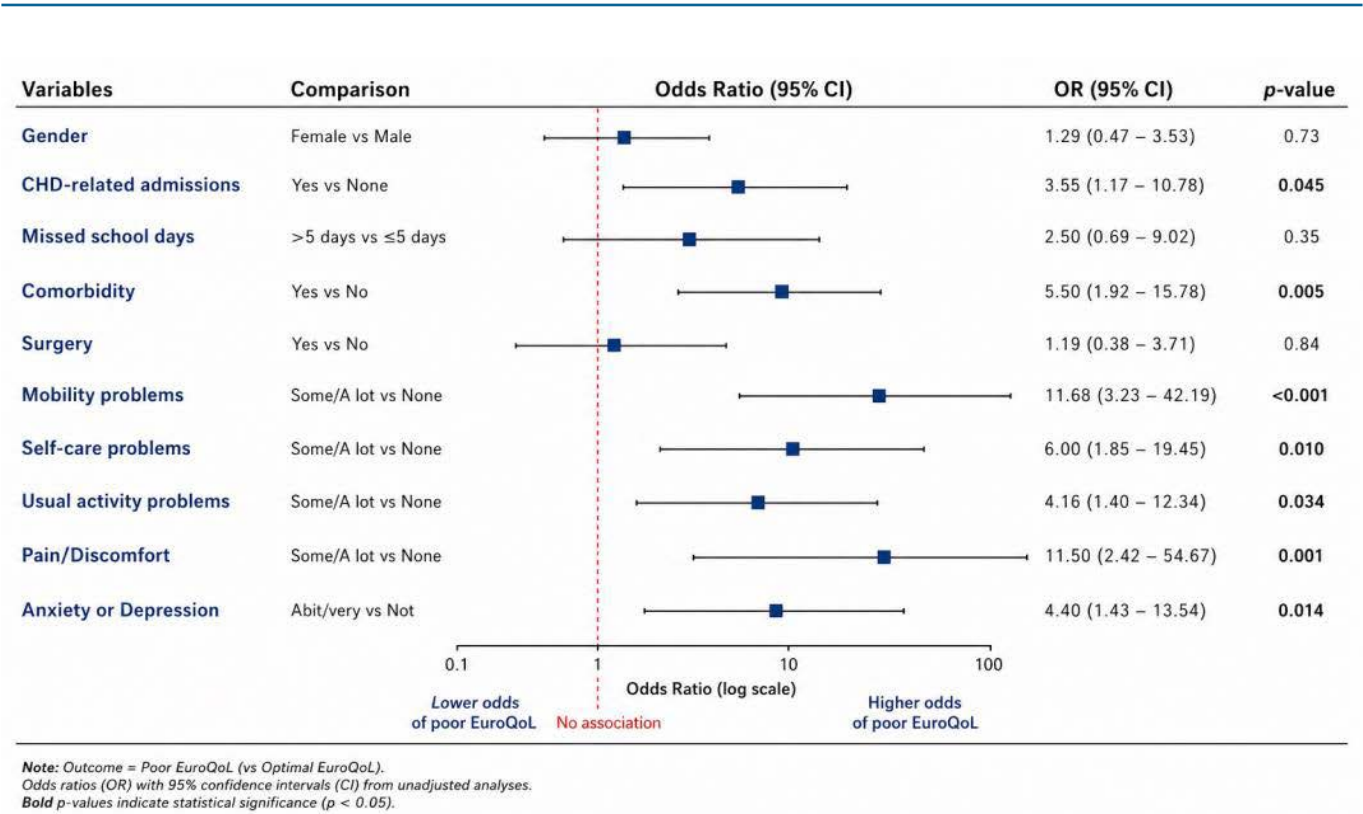


Figure 1: Association between EuroQoL and patients’ characteristics.

in the domains of functional and psychological well-being. Our results therefore underscore the fact that, although survival seems to be improving in Low- and middle-income countries, in this group of children, the gains might not be present in the broader sense of wellbeing.

Acyanotic CHD was the predominant lesion in this study and there was an early median age at diagnosis. When compared to earlier Kenyan and regional studies, where there were considerable delays in diagnosis beyond the infancy period, might imply that there is now an improvement in disease detection in this region [1,2].

A quarter of the study participants had undergone surgical correction of CHD lesions. This study has similar findings to those seen in other African settings—including Nigeria and Ethiopia— where definitive surgical correction remains limited, with most children living with unrepaired lesions [5,16,17]. In our cohort, fewer than one-quarter had undergone surgery, closely mirroring reports from Ghana and Uganda where surgical access remains below 10–20% due to financial and infrastructural constraints [16,18]. These persistent disparities continue to shape long-term outcomes across the region.

Notwithstanding these challenges, up to three quarters of the participants reported Optimal HRQoL. A study in South Africa reported similar findings, whereby children

and adolescents with severe CHD still presented with relatively preserved overall HRQoL. This may be due to adoptive coping mechanisms and family support structure counteracting the perceived impairment [19]. Nonetheless, just as in our study, domain-specific challenges persisted. Studies from Nigeria and Sudan have similarly documented high rates of functional limitation, pain, and psychosocial distress among children with CHD, indicating that these burdens are consistent across diverse African contexts [17-20].

The high frequency of pain/discomfort, limitations in usual activities, and anxiety/depression in our cohort aligns with broader African evidence showing that children with CHD experience hidden morbidity beyond overt clinical symptoms. School absenteeism and significant psychological distress was reported in over 40% in a study in Ethiopia amongst children with CHD. These findings closely mirror our observations regarding missed school days and impaired daily functioning [5,6]. These data collectively suggest that the lived experience of a CHD child/adolescent in African settings is characterized by chronic functional compromise and under-recognized mental health burden.

The key determinants of Impaired HRQoL in this study were hospital admissions and comorbidities. Regionally,

similar associations have been observed, where repeated hospitalization have been linked to worse functional outcomes and increased caregiver burden [18-24]. In Uganda, for instance, children with frequent admissions for cardiac complications were significantly more likely to have poor quality of life scores, underlining the progressive impact of disease severity and healthcare disruption [6]. There is therefore a need to put into place measures in the health care systems, that ensures hospitalizations in this group of children is reduced as much as possible. These measures should include community-based interventions in order to optimize success of policy reforms.

Surgical intervention was not associated with improved HRQoL in our study. While this may appear counterintuitive, similar observations have been reported in South African and Nigerian studies, where delayed surgery, residual lesions, and limited postoperative follow-up attenuated expected gains in quality of life [7,8]. This underscores that in LMIC contexts, the benefits of surgical correction are closely tied to timing, perioperative care, and long-term follow-up factors that remain suboptimal in many African health systems.

The lack of association between clinical severity measures, such as Ross heart failure classification, and HRQoL is also in keeping with findings from African and global studies which might imply that clinician-assessed disease severity does not fully capture patient-perceived wellbeing [7,10]. It is therefore imperative to integrate patient-reported outcome measures into routine clinical care to better inform holistic management strategies.

From a health systems perspective, these findings highlight several priorities across sub-Saharan Africa. First, improving access to early diagnosis and timely surgical intervention remains fundamental. Second, there is a critical need to integrate psychosocial and mental health services into pediatric cardiology care, given the high burden of anxiety, depression, and functional limitation observed across multiple African studies. Third, strengthening chronic care models—including decentralized follow-up and community-based support—may reduce hospitalization's and improve overall quality of life.

Cumulatively, this study adds to the limited but growing body of African evidence on HRQoL in children with CHD. It demonstrates that while survival is improving, significant unmet needs persist in functional and psychosocial domains. Addressing these gaps will require a shift towards

comprehensive, patient-centered care models that extend beyond structural cardiac correction to encompass the broader determinants of wellbeing.

Conclusion

The overall quality of life in this cohort was reported as satisfactory, however many of the participants experienced significant functional and psychosocial impairments. These findings highlight the need for integrated, patient-centred care models in resource-limited settings that extend beyond survival and anatomical correction to address psychosocial wellbeing and functional outcomes. Strengthening access to early diagnosis, reducing hospitalizations, and integrating mental health support into paediatric cardiology services are critical to optimize quality of life of pediatric patients with CHD.

Author Contributions

M.K.: Conceptualization, Data curation, Methodology, Project administration, Validation, Writing—original draft. N.A.E.: Conceptualization, Data curation, Methodology, Writing—original draft, Writing—review & editing of manuscript. All authors have read and agreed to the published version of the manuscript.

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Institutional Review Board statement

We obtained ethical approval from the institutional ethics and review committee of Moi University/Moi Teaching and Referral Hospital (protocol code 0004616 and 18th December 2023 approval)

Informed Consent Statement

Informed consent was obtained from all subjects involved in the study.

Data Availability Statement

Avail on request

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Conflicts of Interest

The authors declared no conflicts of interest

References

1. Liu Y, Chen S, Zühlke L, Black GC, Choy MK, Li N, et al. Global birth prevalence of congenital heart defects 1970–2017: updated systematic review and meta-analysis. *Lancet Glob Health*. 2020;8(4):e455–63.
2. Zimmerman MS, Sable CA. Congenital heart disease in low- and middle-income countries: a global perspective. *Cardiol Young*. 2020;30(12):1805–11.
3. Kontchou LM, et al. Cardiovascular disease burden in low- and middle-income countries. *Glob Heart*. 2019;14(3):237–45.
4. Susan EO, et al. Prevalence and pattern of congenital heart disease in Nigeria. *Niger J Paediatr*. 2019;46(1):1–6.
5. Ng'eno BN, et al. Delayed diagnosis of congenital heart disease in Kenyan children. *East Afr Med J*. 2022;99(2):45–52.
6. Awuah PK, et al. Barriers to paediatric cardiac surgery in sub-Saharan Africa. *World J Pediatr Congenit Heart Surg*. 2023;14(1):45–52.
7. Su Z, et al. Global disparities in access to congenital cardiac surgery. *J Thorac Cardiovasc Surg*. 2022;163(3):1234–42.
8. Koech A, et al. Surgical management of congenital heart disease in Kenya: challenges and outcomes. *Ann Afr Surg*. 2018;15(2):67–72.
9. Drakouli M, et al. Health-related quality of life in children with congenital heart disease. *Cardiol Young*. 2015;25(6):1027–34.
10. Denniss AR, et al. Quality of life in children with complex congenital heart disease. *J Pediatr*. 2019;210:45–52.
11. Reiner B, et al. Quality of life outcomes in children with congenital heart disease. *Pediatrics*. 2019;144(2):e20182990.
12. Ladak LA, et al. Long-term quality of life after congenital heart disease surgery. *Circulation*. 2019;140(20):1618–27.
13. Azim S, et al. Prevalence of anxiety disorders among children with congenital heart disease. *J Pediatr Psychol*. 2021;46(5):567–75.
14. EuroQol Research Foundation. EQ-5D-Y user guide. Rotterdam: EuroQol; 2023.
15. Verstraete J, Scott D. Validation of EQ-5D-Y in African paediatric populations. *Health Qual Life Outcomes*. 2022;20:45.
16. Ngwira LG, et al. Use of EQ-5D in East African populations: validation study. *BMC Health Serv Res*. 2023;23:112.
17. Lopez L, Colan SD, Frommelt PC, et al. Recommendations for quantification methods during paediatric echocardiography. *J Am Soc Echocardiogr*. 2010;23(5):465–95.
18. Okoromah CN, Ekure EN, Lesi FE, et al. Prevalence and profile of congenital heart disease in Nigerian children. *Afr J Paediatr Cardiol*. 2017;9(1):12–18.
19. Sadoh WE, et al. Challenges in the management of congenital heart disease in Nigeria. *Niger J Paediatr*. 2018;45(3):123–30.
20. Abebe TB, et al. Clinical profile and outcomes of congenital heart disease in Ethiopian children. *Ethiop Med J*. 2020;58(2):101–10.
21. Namuyonga J, et al. Clinical outcomes and quality of life among children with CHD in Uganda. *BMC Pediatr*. 2021;21:345.
22. Zühlke L, et al. Quality of life in children with heart disease in South Africa. *Cardiol Young*. 2013;23(2):182–9.
23. Ali SKM. Psychosocial impact of congenital heart disease in Sudanese children. *Sudan Med J*. 2019;55(1):23–30.
24. Ogeng'o JA, et al. Pattern of paediatric cardiac admissions in East Africa. *East Afr Med J*. 2016;93(4):150–6.