The Impact of Congenital Heart Disease on the families of affected children in African setting: Reliability and the Validity of The PedsQL Family Impact Module- The Swahili Version

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Abstract

Background

The Pediatric Quality of Life Inventory™ (PedsQL™) Family Impact Module, a valuable assessment tool for health-related quality of Life (HRQoL), is not accessible in Swahili. This study evaluated the construct validity of the PedsQL™ Family Impact Module in assessing HRQoL for Swahili speakers in Eastern Africa, Tanzania, particularly focusing on families of chronic congenital heart disease (CHD) with both operated and unoperated children.

Methods

The cross-sectional study involved primary caregivers at a national referral cardiac centre. Descriptive statistics for continuous and categorical variables were employed. Translation and cross-cultural adaptation of the Family Impact Module (FIM) were conducted. The "known-groups method" was used to establish construct validity, while internal consistency reliability was assessed using Cronbach's alpha coefficient at a value of $\geq$ 0.70. HRQoL was measured using a Likert linear analogue scale. Mean scores, standard error of the mean (SEM) and Cohen's d-effect size were used to summarize the results. Group comparisons were made using a t-test, and predictors of HRQoL were analysed using generalized linear models. The significance level was set at a $p < 0.05$.

Results

The Swahili version of the FIM for internal consistency showed high reliability ($\alpha = 0.99$). The module was applied to 204 primary caregivers and was mostly answered by mothers, 74.0% of whom had an average of 9.5 + 3.6 years of schooling. The socioeconomic status (SES) of families was moderate at 0.68 ± 0.17 but statistically significantly higher in the operated group (0.71 ± 0.14; p-value < 0.001): This **group also had a significantly higher HRQoL (**91.5 vs. 84.7, d = 0.60, p-value < 0.001 **and a much better emotional well-being** (d = 0.71). Notably, the overall family functioning, particularly the family relations and communication, did not differ between groups. SES and operative status were the only significant predictors of the caregiver's HRQoL, with p < 0.001. Principally, QoL **was** not predicted by **the** child's age, CHD severity, number of cardiac lesions, medication use, or the parent's level of education.

Conclusion

The study validated the Swahili PedsQL™ Family impact module for chronic illnesses in the Swahili-speaking population. It highlighted improved quality of life due to cardiac treatment and ongoing issues in communication, family dynamics and functioning post-surgery. Recommendations included health care providers addressing these gaps proactively, advocating community support for affected families and caregivers prioritizing positive family relationships to enhance overall well-being.

What is new and important?

1. The Swahili version of the PedsQL Family Impact Module is ready for Swahili speakers to use. It helps assess the impact of chronic childhood illness on parents.
2. Cardiac surgery positively influences caregivers' QoL, but family dynamics and communication are not affected by surgery and must be addressed.

INTRODUCTION

The survival rates of children born with congenital heart disease (CHD) have significantly improved over the past few decades (1). This has led to more children living into adulthood, but it has also resulted in a rise in the number of children living with chronic heart conditions, which has a profound impact on families (1, 2).

Families react differently to the burden of chronic childhood disease and, in particular, to CHD. Research has shown that some families cope remarkably well with this challenge, while others find it difficult. This variation in response is partly due to factors such as the family's financial status, the complexity of CHD, and sociodemographic factors such as education, occupation, and country of origin (3, 4, 5, 6, 7, 8). Given that children largely rely on families, it is essential for healthcare professionals to gain a better understanding of how families manage the stressors related to CHD. This understanding will help healthcare professionals provide the necessary support and intervention to improve the quality of life (QoL) of pediatric cardiac patients (9, 12).

Quality of life encompasses an individual's well-being and satisfaction, including both objective and subjective factors. These factors comprise physical, material, social, and emotional well-being and are evaluated based on personal values (23). Among all the aspects of QoL, health-related quality of life (HRQoL) is considered the most susceptible to the impact of illness (11). QoL has become a crucial tool for evaluating healthcare, assessing the impact of interventions, and enabling patient-centred care (23). Its importance lies in empowering patients to actively participate in their care, facilitating the allocation of resources, formulating health policies, and contributing to the scientific understanding of diseases, conditions, and treatment outcomes (24).

Since the observed trend in QoL and its effect on families vary across countries (2–4, 12–14), early studies recommended that its measurement be culturally appropriate and sensitive by ensuring local participation when adopting the existing QoL tools (15, 18, 20, 29). The utilization of various study instruments may have led to disparate outcomes regarding QoL in the existing literature (30). Studies on QoL and the impact of CHD on families are lacking in lower-middle-income countries (LIMCs). It is essential to understand the impact of CHD on these settings since the burden of CHD is high and access to care is limited (10). However, the PedsQL Family Impact Module, a reliable tool for measuring the impact of chronic childhood disease on families, is not accessible in all languages and has yet to be translated into Swahili.

Our study, therefore, has two-fold objectives. First, we aimed to evaluate the Swahili version of the PedsQL Family Impact Module instrument for its content validity, internal consistency, reliability, and responsiveness. Second, we aimed to use the Swahili version to measure the effect of chronic pediatric conditions on families. Specifically, we will compare the operated and unoperated children. We aim to explore the impact CHD has on families and to assess the effect of surgery on family QoL, determining if surgery makes a difference and identifying any residual effects that can be addressed in Tanzania's context. We hypothesize that family

functioning and family QoL are lower in families of patients who are still waiting for surgical correction of their heart condition.

METHODS

Study Design

This cross-sectional descriptive study was approved by Research Ethics Committee at the Jakaya Kikwete Cardiac Institute (#AB.123/307/01H/40). The study followed the ethical guidelines of the 1975 Declaration of Helsinki. The translation process followed the guidelines provided by the MAPI (41).

Study Setting

The study and instrument validation were conducted in Dar es Salaam, Tanzania. The consent of the original authors was obtained through the MAPI research trust to utilize and translate the module into Swahili. Primary caregivers were recruited during their visits to the outpatient department (OPD) at the Jakaya Kikwete Cardiac Institute (JKCI). Established in 2015, JKCI is the sole public national referral facility serving over 60 million Tanzanians and individuals from neighbouring countries. The pediatric OPD operates from Monday to Friday, excluding weekends and public holidays, seeing approximately 30 patients daily. Since its establishment, the institute has successfully treated over 2000 children with heart diseases, with approximately 75% of whom have CHD (unpublished hospital data).

Recruitment of Study Participants

Primary caregivers were eligible for inclusion if they had a child (1) between 2 and 18 years old and (2) had confirmed CHD for which they had curative or palliative surgery (> six months ago) or if they still needed intervention. Caregivers were excluded if their children had been (1) diagnosed with a syndrome, if (2) had severe comorbidities influencing QoL, or if (3) cognitive impairment of either the patient or caregiver affected the understanding of the questionnaire. To determine the care burden of chronic CHD more clearly, parents of children less than two years old were excluded.

Sample Size and Data Collection

The study included a total of 204 families of children with different CHDs, half of whom had previously undergone surgery (n = 100, 49.0%), and the other half still awaited surgical correction (n = 104, 51.0%). A sample of 92 caregivers per group was warranted for reliable statistical analyses based on an expected difference of 5 points between mean HRQOL scores between groups, a power of 0.8, and a probability of 0.05. The data were collected for three months between September and December 2022. After a careful explanation of the study and after providing informed consent, the parents or caregivers were recruited. A face-to-face interview was deployed to eliminate illiteracy. Interviews were conducted individually by trained research assistants (RL, NG), who were native speakers of Swahili language and were supervised by the first authors. The interviews were conducted while families waited for medical care and took place in a separate room to guarantee privacy. Each interview lasted for 15–20 min to complete the data collection tools with each parent.

PedsQL Family Impact Module

The PedsQL™ Family Impact Module is a 36-variable questionnaire encompassing six scales on parents' self-reported functioning: 1) physical functioning (6 items), 2) emotional functioning (5 items), 3) social functioning (4 items), 4) cognitive functioning (2 items), 5) communication (3 items), and 6) worry (2 items). Additionally, two scales measure overall Family functioning: 7) Daily activities (3 items) and 8) Family relationships (5 items) see Appendix1 (supplementary material). The answers were scored on a Likert scale, with responses ranging from never a problem (0) to almost always a problem (4). The responses were reverse scored and linearly transformed to 0-100, where a higher score indicated better functioning of the family or less impact of the chronically ill child on the family. A total score was calculated only if > 50% of the items were answered, as proposed by Varni et al. (22) A total scale score was calculated by summing all 36 items and dividing them by the number of items answered. Two summary scores were calculated: the caregiver HRQOL score (20 items) and the family functioning summary score (8 items). The first was computed by summing the six scales and dividing by the number of items answered. The second was calculated by adding daily activity and family relationships and dividing by the number of items answered.

Translation and cross-cultural adaptation

Permission was sought and retrieved from the original author of the questionnaire through the Mapi Research Trust to use and translate the questionnaire. Translation was performed according to the translation protocol provided by the Mapi Research Trust (41).

Swahili transformation from the English version was carried out in five steps. First, two bilingual translators who were native Swahili speakers independently performed two translations from the original English-language instrument into Swahili. In the second step, a third person analyzed the two translated versions (T1 and T2) and paid special attention to the meaning of the words in the different languages to ensure similar effects from respondents of other cultures. The aim was to identify possible difficulties in understanding the questionnaire, and a synthesis version (T3) was developed due to this process. The third step involved back-translation of the synthesis version (T3) by a 4th person fluent in English who had no access to the original instrument. A fifth translator, fluent in English and whose native language was Swahili, compared the original and back-translated versions in the fourth step. The analysis of semantic equivalence between the original and back-translated questionnaires was assessed from the perspective of the referential meaning of the constituent terms/words and the general meaning of each item. A preliminary qualitative evaluation of the proposed synthesis was conducted in the fifth step. The PedsQL™ Family Impact Module was applied to ten individuals, and the interviewer conducted cognitive debriefing interviews. During these interviews, the interviewees could suggest changes in words, phrases, and expressions. They could also present examples to clarify the question and express opinions on the questionnaire's acceptability, relevance, and ease of comprehension. No major changes were made, as parents/primary caregivers reported no problems understanding the interviewer or the questions. The team unanimously agreed that the original family impact model was appropriate for the African setting and the Swahili context.

Clinical and sociodemographic variables

Sociodemographic and clinical data, including the age of the child, gender, and place of residence were collected. Cardiac diagnoses of children were categorized based on ICD-10 classification and day–to–day level of functioning and heart failure symptoms severity using the Ross classification (supplementary file 3). [46]. The Bethesda disease complexity classification classified Cardiac diagnoses based on anatomic complexity as

simple, moderate, or complex. [47]. Socioeconomic status (SES) was assessed using an adaption of the WAMI index, originally published by Psaki and colleagues [48]. This index uses four domains (wealth indicators, mean maternal education, hygiene, and family income) to calculate a score between 0–1, where a higher score indicates a higher SES. Adaptions were made to fit Tanzania's social and cultural context (e.g., owning a chair was changed to owning a mobile phone). The adapted WAMI index can be found in supplementary file 4.

Statistical analysis

Data were entered into Redcap version 16 directly during the interviews and uploaded to the Statistical Package for Social Sciences version 28 after the collection period ended. Simple descriptive statistics were performed to describe sociodemographic characteristics. The mean (SD) and median (IQR) were calculated for continuous variables. Frequencies and percentages were calculated for categorical variables. The internal consistency reliability was determined using Cronbach's alpha coefficient. Values ≥ 0.70 were considered acceptable for comparisons between groups, and a correlation of > 0.30 as the minimum standard for supporting corrected item-internal consistency (31, 32, 33). Construct validity was established using the "known-groups method". The known-groups method compares scale scores across groups known or expected to differ in the construct being investigated (31). Effect size, as utilized in these analyses, was calculated by taking the difference between the operated and unoperated sample mean, divided by the pooled standard deviation. Cohen's d effect sizes of HRQoL scores were measured (total, parental functioning, overall family functions and for each dimension); Effect sizes for differences in means designated as small (0.20), medium (0.50) or large (0.80); $p < 0.05$ was set as statistically significant (32, 33). Caregiver-reported HRQoL were compared between operated and unoperated groups using an independent sample two sided t-test. A difference of 5 points in mean scores was set as clinically relevant. Generalized linear models (GLM) were used to determine the associations between family HRQoL and social demographic variables. The identified predictors searched through the literature were age, gender, SES, child's age of operation and operative status (2–6). Backward elimination based on significance level (with stepwise elimination of the least significant variables was performed. Variables with a significance level of 0.1 were included in the model. The assumptions for GLM were checked in the final model.

RESULTS

Sociodemographic characteristics of study participants

The Family Impact Module (FIM) was applied to 204 primary caregivers of children with a CHD. Table 1 displays the characteristics of the participants. Most caregivers were from Dar es Salaam (53.9%). FIM was mostly answered by mothers 74.0% who had an average of 9.5 + 3.6 years of schooling. Overall socioeconomic status (SES) of the family was moderate at 0.68 ± 0.17, and all baseline characteristics were equal between operated and unoperated except for higher SES in post-operative group (0.71 ± 0.14; p value < 0.001). The mean age of their children was 6.3 ± 3.7 years. Whereas operated children were much older (7.6 + 4.1 vs 5.1 + 2.7; p value < 0.001) and diagnosed earlier at age less than one year (67.8% vs 47.1% respectively), the complexity of cardiac lesions were the same between the two groups, dominated mostly by simpler and moderate lesions. Expectedly, unoperated children were more symptomatic, with only 41.0% being asymptomatic versus 87.0% in operated group.

Table 1
Baseline Characteristics of Participants

Demographic characteristics	Unoperated (n = 104)	Operated (n = 100)	Total	P value
Region n(%)	57 (54.8)	53 (53.0)	110 (53.9)	0.796***
Dar es Salaam	47 (45.2)	47 (47.0)	94 (46.1)	
Other				
Role n (%)				0.476***
Mother	80(76.9)	71(71.0)	151 (74.0)	
Father	18(17.3)	19(19.0)	37 (18.1)	
Other	6(0.06)	10 (10.0)	16 (0.08)	
Socioeconomic status mean + SD	N = 103	N = 100	N = 203	
Mean score	0.66 ± 0.20	0.71 ± 0.14	0.68 ± 0.17	**0.015***
Maternal education level (0−16 years)	9.602 ± 3.60	9.430 ± 3.62	9.517 ± 3.60	0.735 **
Income (Tsh/household/month)	28	15	43	**< 0. 001***
< 100,000	29	15	44	
100,000-250,000	20	44	64	
250,000-450,000	27	26	53	
> 450,000				
Child characteristics				
Age in years (mean ± SD)	5.1 ± 2.7	7.6 ± 4.1	6.3 ± 3.7	**< 0.001***
Age at diagnosis	n = 104	n = 96	114 (57.0)	**0.002***
< 1	49 (47.1)	65 (67.8)	86 (43.0)	
> 1	55 (52.9)	31 (32.2))		
Time since diagnosis (years)	2.86 ± 2.51	6.31 ± 3.86	4.53 ± 3.66	**< 0.001***
Classification (%)	41 (39.4)	35 (35.0)	77 (37.7)	0.125
Simple	47 (45.2)	38 (38.0)	82 (40.2)+	
Moderate	16 (15.4)	27 (27.0)	45 (22.1)	
Complex				
ROSS classification	51 (49.0)	87 (87.0)	138 (67.6)	**< 0.001***
I	34 (32.7)	10 (10.0)	44 (21.6)	
II	13 (12.5)	1 (1.0)	14 (6.9)	

Demographic characteristics	Unoperated (n = 104)	Operated (n = 100)	Total	P value
III	6 (5.8)	2 (2.0)	8 (3.9)	
IV				

n = number of individuals; ROSS denotes severity of heart failure; Classification based on Bethesda disease complexity classification; *Levene's test < 0.05, equal variance assumed, **Levene's test < 0.05, equal variances not assumed *** chi square asymptotic significance (2-sided).

Construct validity of Family Impact Module

Table 2 presents the Internal consistency reliability: Cronbach's alpha coefficient of the Swahili version of the PedsQL™ FIM, the means, standard deviations, analysis of effect sizes, and t test results of the responses on each subdomain of the PedsQL™ Family Impact Module in the pre- and post-operation groups. The total impact, parent HRQOL and family summary scores (a = 0.99, 0.91 and 0.81 respectively) were reliable for comparing groups and individual scale scores in both the operated and unoperated groups. When assessed separately, some subscales had values near or below 0.70. For instance, the communication subscale had the lowest value of 0.36. The emotional and social functioning subscales had Cronbach's alpha coefficients of 0.52 to 0.67. All item-scale correlations met the minimum standards for supporting corrected internal consistency (Table 2)

Health Related Quality of life

The analysis results indicate that families with operated children had a better family quality of life. This group had significantly higher PedsQL™ FIM scores than the unoperated group (91.5 vs 84.7, d = 0.60, p-value < 0.001), which was clinically meaningful. All areas except communication (d = 0.08) showed higher postoperative HRQoL effect sizes. The operated group's emotional well-being was significantly higher with a largest effect size (d = 0.71). There were only small differences in family functioning (daily acitivites, family relations, respectively d = 0.26 and 0.28, both non-significant between the two groups (Table 2).

Table 2
Scale descriptors for the PedsQL™ Family Impact Module: comparisons between primary caregivers of operated and unoperated children with CHD

Subscale	Alpha	Unoperated n = 104		Operated n = 100		Difference	Effect Size	P value
		Mean	SD	Mean	SD			
Total Impact Score	0.994*	84.76	11.87	91.50	10.39	-6.74	-0.604	< 0.001**
Parent HRQOL Functioning Summary Score	0.908*	80.78	14.27	89.84	11.75	-9.06	-0.691	< 0.001**
Physical Functioning	0.637	82.85	17.42	90.33	13.13	-7.48	-0.484	< 0.001*
EmotionalFunctioning	0.676	73.75	20.30	86.65	15.70	-12.90	-0.709	< 0.001**
Social Functioning	0.711*	86.00	19.66	92.63	13.31	-6.63	-0.393	0.005
Cognitive Functioning	0.603	81.15	19.35	90.20	16.08	-9.05	-0.508	< 0.001***
Communication	0.364	88.70	14.12	89.83	13.84	-1.13	-0.081	0.564
Worry	0.523	90.72	12.64	95.80	9.07	-5.08	-0.460	0.001**
Family Functioning Summary Score	0.808*	89.48	17.82	93.59	13.73	-4.11	-0.258	0.066*
Daily Activities	0.644	86.86	24.71	90.74	17.12	-3.88	-0.182	0.193
Family Relations	0.775*	91.06	16.53	95.30	13.21	-4.24	-0.283	0.044

n = number of individuals; SD = standard deviation; a = Cronbach's internal consistency reliability coefficient alpha; Effect sizes are designated as small (0.20), medium (0.50), or large (0.80). *p < 0.05. **p < 0.01. ***p < 0.001 based on independent sample t tests

Predictors for HRQoL of primary caregivers of children with CHD

Table 3 shows independent predictors with statistical relevance (p < 0.1) of HRQoL of primary caregivers of children with CHD. These predictors were higher SES and operative status. The QoL subdomains of the parents were not significantly predicted by the severity of CHD in their children, the age of the child, the number of cardiac lesions, medication use or i the level of education of parents (supplementary; Appendix 2). Significant predictors

Table 3
Predictors for Health-Related Quality of Life

| | B | Std. error | 95% Wald Confidence Interval | | Hypothesis Test |
			Lower	Upper	Significance
Intercept					
Operative status Pre-op vs. post-op	74.879	3.2081	68.591	81.66	< 0.001
SES (mean)	23.374	4.2749	14.995	31.3	< 0.001
(Scale)	108.662 [a]	10.8662	89.321		

SES Social Economic Status. a. Maximum likelihood estimate.

DISCUSSION

The objective of the current study was to explore the validity and internal reliability of the Swahili version of the Pediatric HRQoL FIM and to look at how CHD impacts families of operated and unoperated children at the JKCI, representing a typical LMIC setting.

We found that the Swahili version of the PedsQL FIM is reliable and valid, which is an important development for healthcare providers in Swahili-speaking regions. The Cronbach's α coefficients for the total impact and summary scores were above the recommended minimum of 0.70, which indicates that the scale is consistent and homogeneous. However, we found that the subclasses for 'physical functioning', 'cognitive functioning', 'communication', 'worry', and 'daily activities' did not achieve an alpha coefficient of 0.70 in the total sample. This is similar to the findings in Brazil when PedsQL FIM was used in 95 parents/guardians and again in San Diego and Los Angeles, USA when it was applied to 339 families of individuals aged 2−18 years with cancer (34, 35, 36). A ceiling effect was established in both studies, and subclasses were absent. As suggested by Authors from the USA, since subclasses are useful for descriptive analyses, further refinements are needed to enhance their reliability and validity, including increasing sample size (35). We therefore recommend the use of Swahili model in future studies to focus on increasing the sample size and improving the items in the subscales to ensure the best possible tools.

Construct validity was established in our study, and data showed significant differences between caregivers in the operated and unoperated groups, confirming our hypothesis that surgery positively affects the QoL of caregivers. Undeniably, our research and similar studies have shown that CHD treatment options can help families (38, 39). We wanted to investigate further if all components of QoL are positively affected by surgery; indeed, we found that the communication functioning domain, which refers to the ability of caregivers to communicate effectively about a child's health condition, seemed to be the least affected by surgery. This lack of improvement significantly impacted the QoL of primary caregivers in both groups. This finding therefore supports a well-appreciated fact that a mere receipt of a CHD diagnosis has profound effects on both families and society (16, 21). It can evoke fear and anxiety, mainly concerning the child's survival probability and can lead to social isolation and stigmatization (17, 21). Appreciating that these fears and anxiety persist even after

a child has had intervention is crucial. Physicians, therefore, should be aware of these communication needs and try to explain the child's condition in simple language at all points of contact with the patient and family and throughout the patient's follow-up journey. By taking a holistic approach to care, addressing not only the child's medical needs but also the emotional and communicative needs of caregivers, physicians can help alleviate the impact of worrying about a child's condition on families and positively influence their QoL (4, 6, 9)

Additionally, we found that the two groups had a similar impact on family functioning caused by chronic conditions. In both groups, caregivers are still struggling with their daily activities due to a lack of time and energy, regardless of whether their child has undergone surgery. This was surprising, but it can be explained by the fact that CHD requires ongoing care and hospital follow-up throughout the child's life (5). To improve the QoL for families, we suggest that health caregivers schedule follow-up visits appropriately to reduce the frequency of hospital visits. They should also critically examine the pill burden, especially for post-operative.

Lastly, we found that caregivers' family relationships were affected, and surgery was not protective. Given the importance of family coherence in the positive upbringing of a child, this finding is noteworthy; studies show that chronic CHD continues to affect family relations, leading to increased levels of family conflicts, which are driven by a lack of protection for couples, fears of having another child with CHD, blaming between partners, and ultimately, a higher divorce rate observed in families with a child suffering from chronic CHD (8, 12). Although we did not look into the divorce rate in our cohort, it is important for societies to be aware of this burden and to offer supportive care to these children. Couples should also seek appropriate help to ensure family cohesiveness, as united families can provide more advantages to a child who needs lifelong care (8). Advisably, family support groups that allow families of children with CHD to come together and share their experiences should be encouraged.

Notably, CHD significantly impacts the QoL and functioning of families. Many studies have demonstrated this, including a systematic review by Bratt E. et al. (2015), which documented 40 years of trends in QoL in CHD, a study by Wray J et al. (2018) which described the QoL of children with CHD in Europe, and a recent research agenda by Sood E. et al (2021) which presented the impact of parental health and family functioning following a diagnosis of CHD. All these studies have focused on high-income country settings. However, our study has revealed an even more significant negative impact on families of unoperated children with CHD in East Africa, as well as a persistent burden in terms of communication, family functioning, and relations for the families of operated children. Therefore, we recommend that future research prioritize evidence-based interventions tailored to Low- and Middle-Income Countries (LMIC) settings to mitigate the potential long-term negative consequences of CHD on caregiver's HRQoL.

Limitations

This study is the first of its kind to describe how caregivers are impacted by CHD in Tanzania. However, there are a few limitations that should be considered. Firstly, it is a cross-sectional study, knowing that the QoL is not a fixed parameter and tends to change over time as a family's circumstances change. Therefore, it may not have been possible to capture how QoL was affected by the coping mechanisms exhibited over time in response to changes in the child's condition and the family's overall response to account for the time factor. Only children older than two years and six months after their operation were included to mitigate this. Secondly, as a single-center observational cohort study, there may have been certain deviations in individual cases, and

the data collected were likely to be prone to variability. Lastly, some details factors like divorce rate and the specific cause of disrupted family functions were not explored. Despite these limitations, the study provides valuable insights that can inform future research and improve patient care.

Conclusion

The Swahili PedsQL™ Family Impact Module has been established as an accurate and reliable tool for assessing the effects of pediatric CHD on the well-being of families and their QoL. Given its efficacy, it is recommended that this module be tested for other illnesses. Furthermore, while cardiac intervention has been proven to enhance the QoL of affected individuals, we found in our cohort that there are still gaps in communication, family functioning and relations. Therefore, medical professionals attending to children with cardiac conditions must take steps to address these communication challenges. The community should offer understanding and support to caregivers of children with CHD, and caregivers of children affected with CHD should strive to maintain cohesive family relations.

Declarations

Availability of data and materials: Data from this study will be made available on request to the corresponding Author.

Competing interests: None declared.

Patient consent: was collected digitally on paper and stored at the Jakaya Kikwete Cardiac Institute.

Ethics approval: Ethics Review Committee, Jakaya Kikwete Cardiac Institute, Tanzania (#AB.123/307/01H/40).

Patient and Public Involvement: Patients were involved in the cultural adaptation of the study tool.

Authors' contributions

NM is a PhD candidate who came up with the research topic, contributed to the study design and data collection, and provided the first draft of the manuscript. JK contributed to the study design and conducted the data collection and analysis. ZK and NL conducted data collection. JH provided fundamental insights into QOL research and provided critical feedback on results. DN, SM, SK, GS and VM Contributed to critical review, discussion and feedback on the manuscript draft. PK, DG, MS, PC and MJ provided critical feedback on the manuscript drafts and mentoring on the data analyses.

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