ORIGINAL RESEARCH

Psychometric properties and validation of the Malawian Cerebral Palsy Quality of Life-child (CP QoL-Child) questionnaire for primary caregivers

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Abstract

Background

Cerebral palsy (CP) is the leading cause of childhood disability worldwide, with a significantly higher burden in low- and middle-income countries (LMIC). In Malawi, children with CP often face limited access to rehabilitation services, social exclusion, and poor health outcomes, all of which negatively affect their quality of life (QoL). Although the CP QoL-Child is a validated instrument for assessing QoL in children with CP, no culturally adapted or translated version existed for Malawi.

Aim

This study aimed to translate, culturally adapt, and validate the CP QoL-Child primary caregiver version into Chichewa for use in Malawi.

Methods

This cross-sectional study involved 62 caregivers of children with CP in Malawi. The CP QoL-Child for Primary Caregivers was translated into Chichewa following standard guidelines. Internal consistency was assessed with Cronbach's alpha and test–retest reliability with intraclass correlation (ICC). ANOVA was used to explore associations with GMFCS levels.

Results

The Chichewa CP QoL-Child showed excellent internal consistency ($\alpha = 0.96$ overall; domain $\alpha = 0.65$–0.96). Test–retest reliability was strong, with ICCs ranging from 0.84 to 0.96. The Access to Services domain had the lowest internal consistency ($\alpha = 0.65$), while the highest temporal stability was found in Feelings about Functioning and Emotional Well-being (ICC = 0.96).

Conclusion

The Chichewa version of the CP QoL-Child for Primary Caregivers shows strong reliability and offers a valuable tool for understanding and improving the quality of life of children with CP in Malawi, with potential to inform interventions and policy.

Keywords (1-7): cerebral palsy, CP QoL-Child, quality of life, Health-Related Quality Of Life, disability, Malawi

Introduction

Cerebral Palsy (CP) is the major cause of childhood disability worldwide[1]. The incidence in high -income countries (HIC) is 2-3 per 1000 live births[2]. The current prevalence of CP in LMICs is not well understood but is estimated to be (3.1–3.7 per 1000 children), approximately double the rate reported in High Income Countries (HICs) (1.6–2.9 per 1000 children[3]. Despite the fact that approximately 85% of children with a disability live in LMICs, fewer than 5% have access to basic rehabilitation and supportive services[4]. CP is a lifelong condition caused by brain damage that occurs during pregnancy or infancy[5]. It is primarily characterized by abnormalities in movement and posture and is frequently accompanied by comorbidities such as intellectual impairment, feeding difficulties, epilepsy, and chronic pain[6,7]. Individuals with CP, particularly in resource-limited settings, are disproportionately affected by stigma, neglect, and discrimination, which often lead to social marginalization[8]. Collectively, these factors often lead to significant limitations in activity and participation of children with CP[6,9]. These challenges contribute to a reduced quality of life (QOL), compared to their developing peers (without CP)[10,11]. Previous studies have demonstrated that this reduction in QoL extends to caregivers of children with CP, highlighting broader psychosocial impact of the condition on these families[8,12,13].

Given these challenges, the assessment of Health-Related Quality of Life (HR QOL) is an important outcome measure that provides valuable insight into the impact of the condition on the child's well-being and functioning. The Quality of Life Questionnaire for Children with Cerebral Palsy (CP QOL-Child), developed and validated by international experts[14], is based on the International Classification of Functioning, Disability and Health (ICF model). The ICF model emphasizes health and health-related domains such as capacity, performance, and participation of children with CP[14]. The CP QOL-Child has demonstrated strong psychometric properties and clinical utility and has been translated in a variety of cultural and linguistic settings across both high- and low-income countries[15]. The CP QOL comprises four versions tailored to the child's age and cognitive ability to self-report. In instances where self-assessment is not feasible, the primary caregiver serves as the respondent. The present study focuses specifically on the CP QOL-Child version for primary caregivers of children aged 4 to 12 years in Malawi, where CP is the most common physical disability[16].

While the instrument has been validated in various settings,

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it has not yet been validated in Malawi, where data are scarce and the needs of children with CP are considerable. Given that quality of life perceptions are influenced by cultural and environmental factors, a culturally adapted version is essential[17]. Therefore, this study aimed to validate the Chichewa-translated and culturally adapted version of the CP QoL-Child for use by primary caregivers of children with Cerebral Palsy in Malawi. Through a process of translation, cultural adaptation and psychometric validation.

Methods

Study Design and Ethics

This was a cross-sectional validation study conducted between February and July 2023. Ethical approval was obtained from the Malawian Medical Ethical Board (COMREC, P.08/22/3714), and permission to adapt, translate and validate the CP QOL-Child was secured from its developers at Deakin University, Australia. For the validation process internationally accepted methodology was used, as described by Davis E et al[18].

Participants

A convenience sample of 62 primary caregivers of children with CP (aged 4–12 years) was recruited from multiple sites within Mangochi District, Malawi. Mangochi District Hospital is the main district referral hospital and hosts a dedicated CP outpatient clinic, with outreach clinics in both Bolera and Njereza, Since 2022, these clinics provide multidisciplinary care; involving physiotherapy, medical- and nutritional care to children with CP. Up to date the clinic serves more than 300 children. To capture both more urban and rural perspectives on quality of life, recruitment was deliberately spread across these sites. Additionally, home visits were conducted for families who faced significant difficulties travelling to any of the clinic sites. This multi-site approach ensured broader geographical representation within the district and a more complete picture of the lived experiences of children with CP and their primary caregivers. The sample size is similar to other LMIC validation studies of the CP QoL-Child[19-21]. A convenience sampling method was chosen, as participant recruitment depended on the availability of patients at the specified locations within the time frame. According to Mattar[22], a convenience sample is appropriate when random selection is not feasible due to time, financial, or resource constraints. Inclusion required all types of cerebral palsy in children aged 4 to 12 years, with the parent/caregiver being the primary caregiver and possessing a comprehensive understanding of the Chichewa language. Participants were excluded if the diagnosis was unclear or if the child's primary caregiver was unavailable. After consenting the primary caregiver, and upon agreeing to participate, the primary caregiver signed the Informed Consent Form, or if unable to write, a thumbprint was used with a witness present to verify the process.

Translation and Cultural Adaptation

The translation process followed international guidelines as described earlier[18,23]. Firstly, two independent forward translations into Chichewa were made, by experienced translators, one was an anthropologist with experience in cross-cultural research translation, and the other one a professional certified translator, who were knowledgeable in both English language and the target language Chichewa as well as familiar with the Malawian culture and context. Next, a group of experts in CP met for a reconciliation meeting to compare and assess the two resulting translations in terms of understandability, comprehensibility, and conceptual equivalence. The group consisted of a Malawian physiotherapist, nutritionist and rehabilitation technician, each with a minimum of five years experience working with children with CP, and a medical doctor of Dutch origin who served as the principal investigator of the study, who was already working in Malawi three years prior to the study. The experts were also asked to focus on any cultural and linguistic differences between English and Chichewa that could cause difficulties in the translated version. A reconciled (Chichewa) version was derived from this meeting. A different independent translator conducted the back-translation to English. This translator was a native Chichewa speaker with excellent English proficiency, working professionally as a cultural translator. Subsequently, a meeting was held with members of the research group (BvdM, AN, AC), along with the forward translator and backward translators, to review conceptual discrepancies and finalize the Chichewa version. The finalized version was pretested with six caregivers, consistent with recommended sample sizes for pretesting[23]. One item about access to school was revised for clarity.

Data Collection and Instrument Administration

Two trained research assistants administered the CP QOL-Child (primary caregiver version) through structured interviews, given the low literacy levels among participants. During the training, the interviewers were instructed to read each question aloud to the caregiver and record their response on the questionnaire, without intervening or commenting on the question or response. The questionnaire, comprises 66 items grouped into seven domains 1) social well-being & acceptance (12 items), 2) feelings about functioning (12 items), 3) participation & physical health (11 items), 4) emotional well-being & self-esteem (6 items), 5) access to services (8 items), 6) pain & the impact of disability (12 items), and 7) family health (4 items). Sociodemographic data were recorded, and the severity of CP was assessed using the Gross Motor Function Classification System (GMFCS), a standardized tool used to classify the severity of motor function limitations[24]. Due to lack of another validated QoL questionnaire in Malawi it was not possible to check for construct validity against an external measure; this was consistent with the guidelines set by the original developers[23]. All caregivers of children with cerebral palsy who were included in the study were asked to return after 2 to 4 weeks to repeat the questionnaire, enabling assessment of test-retest reliability. Of the 62 participants, 21 (33.9%) returned for the retest assessment. Non-return was primarily attributed to difficulties with travel and availability rather than withdrawal from the study.

Data were entered into Microsoft Excel and analysed using IBM SPSS Statistics version 27. Data files were encrypted and password-protected, with access restricted to study personnel only.

Reliability Testing and Analysis

Descriptive statistics were used to characterize the study population. Test-retest reliability was assessed in 21 participants who completed the questionnaire a second time after 2–4 weeks, this is with enough time between to exclude memory effect, but not long enough to avoid changes in QOL25. Intra-observer reliability was evaluated using Intraclass Correlation Coefficients (ICC), with ≥0.75 considered excellent; satisfactory when $0.4 \leq ICC < 0.75$ and weak when $ICC < 0.4$; p-values <0.05 were considered statistically significant. Internal consistency for all domains was assessed using Cronbach's alpha. An alpha value of ≥0.70 was considered acceptable, ≥0.80 good, and ≥0.90 excellent.

Scoring and Psychometric Evaluation

Items were rated on a 9-point scale, then transformed to a 0–100 scale (with higher scores indicating better QoL), except for one question in domain 6, regarding pain & the impact of disability, rated on a 5-point scale (range 1–5). Domain scores were averaged and analysed. A priori, items with missing data exceeding 30% of responses were excluded from analysis, as high non-response rates suggest reduced suitability of an item for use across the full spectrum of CP impairments. One-way ANOVA was used to assess associations between GMFCS levels and QoL domains, with significance set at $p < 0.05$. Normality of domain scores was assessed using the Shapiro-Wilk test prior to analysis

Results

A total of 62 primary caregivers of children with cerebral palsy (CP) completed the Quality of Life (QoL) questionnaire. Demographic data for both children and their caregivers is presented in table 1. The median age of the children was 7.56 years (IQR: 5-10), and 50% were male. The majority of the children (72.6%) were diagnosed with the spastic subtype of CP. In terms of functional severity, GMFCS level was available for 61 children;11 (18.0%) were classified as GMFCS Level I, 8 (13.1%) as Level II, 15 as Level III(24.6%), 10 (16.4%) as Level IV and 17 (27.9%) as level V. Table 1 summarizes demographic details, including CP subtype, comorbidities such as epilepsy, CP subtype, caregiver demographics, and socio-economic indicators. Most primary caregivers were mothers (66.1%) and the majority were female (88.7%). Only 19.4% of caregivers had completed secondary education. 45,1% of the caregivers were unemployed, and only 27.4% reported being able to consistently afford three meals per day.

Most items had less than 5% missing data. However, when an item was missing in more than 30% of responses from primary caregivers, we excluded it from further analysis. Given that the CP QOL-Child is intended for use with all children with cerebral palsy across the full spectrum of impairments, a high rate of non-response suggests that the item may be less suitable for inclusion in a health-related quality of life (HRQoL) questionnaire. Therefore, 11 questionnaire-items were excluded from the final analysis. These items concerned the availability of specialized equipment, the availability of respite care (which in the Malawian context was already adapted to extra help in care, but still had very low response) and the accessibility of school as those services and equipment is almost not available in Malawi. Specifically, the following items were excluded: questions 4 and 12 from the Social Well-being & Acceptance domain; question 17 from Participation & Physical Health; questions 41–43, 57–59, and 61 from Access to Services; and question 45 from Pain and Impact. See Appendix B for full details about missing questions and how questions were adapted to Malawian context.

Table 1. Participant Characteristics (N=62)

	N	%
Age in years (median, IQR, range)	7.56 (5-10; 4-17)	
Boys	31	50.0
Disability subtype		
Spastic	45	72.6
Athetoid (dyskinetic)	11	17.8
Hypotonic	4	6.5
Mixed	1	1.6
Epilepsy – yes	18	29.0
GMFCS		
Level 1	11	18.0
evel 2	8	13.1
Level 3	15	24.6
Level 4	10	16.4
Level 5	17	27.9
Attending school – yes	22	35.5
Recruitment location		
Inpatient clinic	8	12.9
Outpatient clinic	43	69.4
Home visits	10	16.1
Caregiver age (years) (median, IQR, range)	29 (24-38; 14-67)	
Caregiver female	55	88.7
Caregiver relation to child		
Mother	41	66.1
Father	6	9.7
Grandmother	9	14.5
Other	5	8.1
Family size*		
<3	1	1.6
3-5	26	42
>5	32	51.6
Caregiver Marital status		
Married	42	67.7
Divorced	15	24.2
Widowed	4	6.5
Caregiver Work status		
Unemployed / piece work	28	45.1
Farmer	7	11.3
Business	22	35.5
Employed	3	4.8
Caregiver education level		
None	9	14.5
Primary	40	64.5
Secondary	12	19.4
Caregivers report affording 3 meals per day - yes	17	27.4

* Family size refers to the total number of people living in the same household, including parents and children

Table 2. Descriptive Statistics and Psychometric Properties of the CP QOL-Child Questionnaire for primary caregivers. (Values transformed to 0–100 scale in accordance with the CP QoL-Child Manual[23])

Domain*,**	Transformed score*	Cronbach Alpha	ICC (95%CI) (n=21)
Social well-being & acceptance (10 items)	74.2 [13,86]	0.82	0.88 (-0.06-0.96)
Feeling about functioning (12 items)	52.81 [23,98]	0.91	0.96 (0.86-0.99)
Participation & Physical health (10 items)	53.18 [26,13]	0.96	0.84 (0.32-0.96)
Emotional well-being & self-esteem (5 items)	53.97 [27,85]	0.94	0.96 (0.64-0.99)
Access to services (5 items)	58.73 [25,14]	0.65	0.86 (-0.49-0.99)
Pain & the impact of disability (7 items)	47.94 [24,49]	0.70	0.87 (0.28-0.98)
Family Health (4 items)	45.41 [21,73]	0.82	0.93 (-0.74-1.00)
Overall	55.05 [13,75]	0.96	N/A

Values are expressed as mean ± SD (range).

CP QOL-Child: cerebral palsy quality of life for children.

*All items were transformed to a scale with a possible range of 0–100 in accordance with the CP QOL-Child Manual and averaged per each domain.

**A full list of questions used for analysis can be found in Appendix A

#Values between 0.70 and 0.90 indicate high reliability.

† For all domains, higher scores indicate better quality of life. In the Pain & Impact of Disability domain, higher scores indicate less pain and lesser impact of disability

Table 3. QoL Domain Scores by GMFCS Level

	GMFCS Level										
	I		II		III		IV		V		
Domain	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Anova
Social well-being & acceptance	78,9	10,8	85,0	7,6	79,1	6,9	74,4	9,5	61,8	16,5	<0,001
Feelings about functioning	71,3	15,4	75,1	17,0	59,3	17,3	46,8	19,6	28,2	14,7	<0,001
Participation & Physical health	76,6	8,7	75,8	5,2	55,4	16,7	48,0	27,4	28,5	23,2	<0,001
Emotional well-being & self-esteem	76,1	9,7	82,8	9,5	57,7	21,6	48,3	26,8	26,1	19,7	<0,001
Access to services	53,2	24,3	71,9	12,1	61,5	16,2	61,1	18,5	49,2	21,2	0,071
Pain & the impact of disability	31,5	28,9	47,5	26,3	39,4	22,4	50,4	18,8	64,9	14,9	0,002
Family Health	48,3	23,4	56,0	10,6	56,7	12,4	38,8	18,5	32,5	25,8	0,007
Overall	62,3	8,0	70,6	7,4	58,4	10,3	52,5	12,7	41,6	10,0	<0,001

† For all domains, higher scores indicate better quality of life. In the Pain & Impact of Disability domain, higher scores indicate less pain and lesser impact of disability

The highest mean score was observed in the Social Well-being & Acceptance domain (M = 74.2, SD = 13.86), while the lowest was in Family Health (M = 45.41, SD = 21.73). The overall QoL score was 55.05 (SD = 13.75). Descriptive statistics and psychometric properties for each domain are presented in Table 2.

Internal consistency of the questionnaire was evaluated using Cronbach's alpha. The total scale demonstrated excellent reliability (α = 0.96). Domain-level reliability ranged from acceptable to excellent (α = 0.65–0.96). The Access to Services domain demonstrated the lowest internal consistency (α = 0.65), indicating questionable reliability; all other domains exceeded 0.70, indicating good to excellent reliability.

Test–retest reliability of the questionnaire was assessed using intraclass correlation coefficients (ICCs). The total scale demonstrated good to excellent temporal stability, with domain-level ICCs ranging from 0.84 to 0.96. The Participation & Physical Health domain showed the lowest reliability (ICC = 0.84), while the highest reliability was observed in Feelings about Functioning and Emotional Well-being & Self-esteem (both ICC = 0.96). Confidence intervals varied in width across domains, with several, including Access to Services, Family Health, and Social Well-being & Acceptance, showing wide intervals and negative lower bounds, indicating variability in measurement stability across domains.

Floor and ceiling effects were assessed of all domains using a threshold of ≤5 and ≥95 on the transformed 0–100 scale, with ≥15% considered clinically meaningful. No domain exceeded this threshold. The highest floor effect was observed in the Pain & Impact of Disability domain (9.7%, n=6), followed by Participation & Physical Health and Emotional Well-being & Self-esteem (both 6.5%, n=4), and Family Health (4.8%, n=3). Ceiling effects were minimal across all domains, not exceeding 1.6% in any domain

An analysis of variance (ANOVA) was conducted to assess the relationship between the GMFCS levels and QoL domain scores (Table 3). QoL is higher in children with CP with a lower GMFCS. Specifically, children with higher levels of motor impairment (GMFCS IV and V) were associated with lower QoL scores. The only domain not showing significant differences across GMFCS levels was Access to Services (p = 0.071).

Discussion

This study aimed to validate a Chichewa-translated and culturally adapted version of the CP QoL-Child questionnaire for use by primary caregivers of children with cerebral palsy (CP) in Mangochi district, Malawi, following internationally accepted methodology, as described by Davis E et al[18,23]. To our knowledge, this is the first study to validate the CP QoL-Child tool in Malawi, and the first in sub-Saharan Africa. The instrument was translated into Chichewa, Malawi's most widely spoken language, providing a culturally appropriate and linguistically accessible tool to assess quality of life in children with CP and their caregivers in this setting. The tool will be made publicly available through the official CP QoL website (https://www.oceaniaacademy.org/research/cpqol/) following publication, facilitating its use by clinicians and researchers across Malawi

Psychometric Properties

The Chichewa version of the CP QoL-Child showed strong psychometric properties. Internal consistency was excellent for the full scale (Cronbach's α = 0.96), with subscale alphas ranging from 0.65 (Access to Services) to 0.96 (Participation and Physical Health). All domains exceeded the acceptable threshold of 0.60, in line with validation studies from Australia[14] (α = 0.74–0.93), Brazil[26] (α = 0.76–0.90), Japan[27] (α = 0.72–0.89), Turkey[28] (α = 0.63–0.93), Iran[29] (α = 0.61–0.87), and Pakistan[30] (α = 0.80–0.82), confirming the tool's cross-cultural reliability.

Eleven items were excluded from the final analysis based on a missing data threshold of more than 30%, as high non-response rates suggest reduced suitability of an item across the full spectrum of CP impairments. The excluded items concerned the availability of specialised equipment, respite care, and access to schooling — services largely unavailable in Mangochi District (see Appendix B). Notably, difficulties with the Access to Services domain are not unique to this study and have been reported across multiple other CP-QoL Child validation studies, including the original Australian validation[14,26], suggesting these items may require broader contextual adaptation for use in low-resource settings. This domain warrants specific caution in interpretation: internal consistency was below the accepted threshold (α = 0.65), no significant association was found with GMFCS level (p = 0.071), test-retest reliability showed wide confidence intervals, and domain scores showed a non-linear pattern across GMFCS levels. We propose that in settings where specialised services are largely unavailable, this domain may reflect awareness of service gaps rather than actual access to services — a fundamentally different construct. Scores in this domain, should therefore be interpreted with considerable caution in similar low-resource settings, and revision of this domain in collaboration with the original developers would be a valuable priority for future research.

Test–retest reliability also indicated good to excellent temporal stability, with ICCs ranging from 0.84 to 0.96. This is consistent with the original validation study in Australia[14] (0.76 to 0.89) and better than the study in Iran[29] (0,47-0,84). The most stable domains were those related to emotional and functional well-being, suggesting consistent caregiver perceptions of their child with CP over time. However, wider confidence intervals, particularly in Access to Services, Family Health, and Social Well-being & Acceptance, point to variability, likely due to the small sample size and changing external conditions such as service access and economic pressures. Despite these limitations, the Chichewa version of the CP QoL-Child appears to be a reliable tool for use in Malawian contexts.

Quality of Life Outcomes

The overall quality of life score in this study was 55.05. Although few studies report a composite QoL score, limiting direct comparisons, this value is slightly higher than the 46.83 reported in Pakistan[30]. Nonetheless, it indicates that children with CP in Mangochi district experience a significantly impacted QoL. One possible explanation for the reduced QoL could be the limited unavailability and accessibility of (community-based) rehabilitation services or social support structures[31,32], compounded by the socio-economic impact caring for a child with CP places on the whole family[35]. Among the seven domains, Social Well-being & Acceptance yielded the highest mean score (74.2), aligning with findings from other countries such as Australia[14] (79.2), Poland[19] (77.7), and Turkey[28] (73.65). This pattern suggests that the children often perceive acceptance within the family and community, strength that may remain intact even in the face of physical and economic adversity[33]. The lowest scores were observed in the domains of Pain & Impact of Disability (47.94) and Family Health (45.41). The low scores in the Pain & Impact domain have been consistently reported across international studies (e.g. Pakistan[30] 45.0 ; Japan[27] 43.3) which is an expected finding since pain is negatively correlated with the quality of life of CP patients likely due to increased muscle tone and consequent joint problems in these children[34]. The Pain & Impact of Disability domain also showed an unexpected positive association with GMFCS severity, with caregivers of children at higher GMFCS levels reporting higher domain scores — indicating less perceived distress about pain and disability impact. This finding likely reflects the limitations of proxy report in this context. Caregivers of children with severe CP may underestimate pain and emotional distress due to limited communication from the child. The particularly low score in Family Health appears unique to Malawi. In comparison, other countries report higher Family Health scores, such as 68,85 in Turkey[28] and 81,93 in Pakistan[30]. This may reflect the cumulative burden of caregiving in Malawi's socio-economic context, characterized by high unemployment, limited social support, and restricted access to healthcare[35]. In our sample, nearly half of caregivers in the study were unemployed or engaged in unstable, low-income work. Only 27.4% of households could consistently afford three meals per day, and over 50% had more than five household members—factors that likely compound the caregiving burden and negatively impact caregiver health and well-being.

Association with Severity of CP

A significant association was found between GMFCS levels and QoL scores in six out of the seven domains, with children at more severe GMFCS levels consistently scoring lower QoL (table 3). This aligns with findings from Iran[29] and reflects the cumulative challenges faced by children with greater motor impairments, such as reduced autonomy, increased pain, and limited social participation, particularly in low-resource settings like Mangochi district. The structural lack of support leaves caregivers with limited means to compensate for their child's functional limitations, contributing to lower perceived quality of life36. The Access to Services domain showed no significant association with GMFCS level, likely due to universally limited service availability regardless of functional severity.

In contrast, studies from Brazil[26] and Japan[27] have not observed a strong association between GMFCS level and QoL, likely due to more developed disability service systems[36,37]. In these settings, early intervention programs, mobility aids, inclusive schooling, and caregiver support may reduce the functional impact of motor impairments, helping to equalize QoL across severity levels. These differences underscore the importance of interpreting QoL outcomes within the broader policy and service delivery context. In Malawi, the strong association between severity and QoL likely reflects not just individual impairment, but the absence of systemic support to buffer its effects.

Limitations & strengths

This study is limited by its relatively small sample size (n = 62), which may restrict the generalizability of the findings, and should be considered when interpreting the implication for clinical practice and policy in Malawi. However it was comparable to other studies in the different versions like Brazil (n=65) and Japan (n=50) [26,27]. Reliance on proxy reports rather than self-reports was necessary due to developmental limitations and CP severity. Selection bias toward more severe cases may exist as milder cases may not attend clinics, our sample may underestimate QoL in milder CP (less connected to services) and overestimate challenges in accessing services (sample already engaged with healthcare). Future studies should aim for broader community-based sampling to capture a more representative spectrum of disability severity.

Strengths include being the first validation in sub-Saharan Africa, and providing a culturally appropriate tool for an underserved population. A further strength is the involvement of a diverse multidisciplinary team — including professional translators, an anthropologist, a cultural translator, and CP experts — in the translation and cultural adaptation process, strengthening the credibility and contextual appropriateness of the Chichewa version. The questionnaire was administered through structured face-to-face interviews, which is essential in contexts where written literacy cannot be assumed. In this study, administration took approximately 30–45 minutes per participant, slightly longer than self-completion versions reported in other validations, but feasible in most settings.

Conclusion

In conclusion, the available data indicates that the English version of the CP-QoL child for primary caregivers questionnaire has effectively been translated to Chichewa with an excellent internal consistency ($\alpha = 0.96$ overall; domain $\alpha = 0.65$–0.96) and a strong test–retest reliability, with ICCs ranging from 0.84 to 0.96. The Malawian CP-QoL Child provides a culturally appropriate and psychometrically sound tool to gain further understanding of the determinants of QoL of children with CP and their primary caregivers in this setting. Once responsiveness to change has been established in future studies, it may also serve to evaluate the effectiveness of interventions for children with CP. This is an important step forward for the research into this aspect of the life of children with CP and their families in Malawi. It could lead to a better understanding of the needs of these families and might help with policy for these disadvantaged and vulnerable children.

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