

## ORIGINAL RESEARCH



# Quality of life of primary caregivers of children living with cerebral palsy at two clinics in Blantyre, Malawi

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## Abstract

### Introduction

In Malawi, Primary Caregivers (PCGs) of children living with Cerebral Palsy report challenges such as physical strain and lack of resources that affect care giving. Although such experiences affect the PCGs' Quality of Life (QoL), there is paucity of data for Malawi. Understanding their QoL would inform establishment of holistic intervention(s) tailored to meet their needs. Therefore, the purposes of this study were to determine QoL of PCGs of the children who were receiving rehabilitation at Queen Elizabeth Central Hospital (QECH) and Feed the Children (FtC), to identify PCG's and children's socio-demographic factors that may attribute to the perceived QoL, and to compare the PCGs' QoL between the sites.

### Methods

A cross-sectional study was conducted from January to April 2019 on 142 PCGs of children aged between 2 and 18 years of age. All PCGs who were employed for the child-care, or had a chronic sickness were excluded. QoL was assessed using the World Health Organization Brief questionnaire, with a cut-off point of <60% for poor QoL. The severity of children's impairments was assessed using Gross Motor Function Classification System. Descriptive and inferential statistics were conducted to analyze the data. The PCGs' age, sex, marital status and level of education, and child's severity of impairment were compared with QoL.

### Results

The majority of PCGs (61.30%) had poor QoL, and there was no significant difference in overall QoL of the PCGs between the sites ( $p < 0.31$ ). The PCGs at QECH had significantly higher physical domain mean scores than at FtC ( $U = 1906$ ,  $p < 0.01$ ). The overall QoL differed significantly across the marital statuses of the PCGs ( $p < 0.03$ ).

### Conclusion

The study has established that most PCGs at both sites possess poor QoL. However, there is need to investigate how the rehabilitation institutions and workers influence the QoL of the PCGs within and between the facilities.

**Key words:** Cerebral Palsy, Rehabilitation, Malawi, Quality of Life, Primary caregiver

## Introduction

Childhood disability is of concern in Malawi; 17 out of every 1000 children aged below 18 years in Thyolo and Ntcheu districts have an impairment, and physical impairment is the most common (39%)<sup>1</sup>. Although this occurrence is based on data from two districts only, this suggests that prevalence of disability among children is high. One leading cause of impairment that children present with in all Malawian pediatric rehabilitation centers is Cerebral Palsy (CP). The CP is defined as a heterogeneous group of movement and posture disorders caused by non-progressive damage to the immature brain<sup>2,3</sup>. Although the prevalence of CP in the country is unknown, literature shows that 10 out of every 1000 children born in Southern Africa have the condition<sup>4</sup>. This implies that there could be more cases of CP in Malawi. Caring for children living with a physical impairment becomes more challenging to Primary Caregivers (PCGs), defined as either a parent, family or any community member who primarily assists the children with activities of daily living without compensation, when a child grows. According to Wijesinghe et al. severity of child's impairment increases

burden of care<sup>5</sup>. Similar claims were made by Marron et al., who also reported that PCGs' depression further increases the burden<sup>6</sup>. Consequently, the care giving burden has also shown to increase depression and anxiety among the PCGs<sup>7</sup>; suggesting a bilateral causal effect. Additionally, child's functional limitations have shown to impair mental health and cause bodily pain among the PCGs<sup>8</sup>. Nevertheless, positive correlations were reported between the age of PCGs and various domains of Quality of Life (QoL)<sup>8</sup>. This suggests that the older the caregiver, the better the QoL, defined as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concern"<sup>9</sup>. Therefore, it is reasonable to postulate that socio-demographic factors of the PCGs, severity of child's impairment and functional limitations influence QoL of the PCGs. However, little is known regarding the QoL of the PCGs in African countries such as Malawi.

Studies done in Malawi have reported challenges such as social withdrawal, inadequate medical care, financial constraints and lack of physical strength as related to long-term care of children living with disabilities<sup>10,11</sup>. The

challenges negatively impair QoL of the PCGs<sup>11-14</sup>, and may contribute to unsuccessful rehabilitation or habilitation program of a child because of non-adherence of the PCGs to daily home-therapy program due to their ill-health. In Blantyre, such children mostly receive rehabilitation and habilitation care either at Queen Elizabeth Central Hospital (QECH) where there are Physiotherapists or at Feed the Children (FtC) where there are rehabilitation Technicians and Occupational Therapist. Understanding the QoL of the PCGs, at both facilities where the service providers have varying qualifications, is critical to the management of children living with CP. Such knowledge may inform health care workers of the need to deliver holistic care that would facilitate effective engagement of the PCGs in long-term rehabilitation (or habilitation) of the child, because the PCGs are part of the multidisciplinary team required. Consequently, this would facilitate attainment of the child's highest possible functional capacity. Therefore, the study aimed to determine the QoL of the PCGs of children living with CP at QECH and FtC, relate it to child's and PCGs' own socio-demographic factors, and compare it between the sites.

## Methods

### Study design

A descriptive cross-sectional study design was conducted from the 28th of January 2019 to 12th April 2019 at QECH and FtC Physiotherapy departments in Malawi. The two units constituted the major clinics in Blantyre that offered Physiotherapy services to more children living with CP. The PCGs of children aged 2-18 years living with CP who came for a Physiotherapy review appointment at each site and had been coming for physiotherapy over six months period at each site, constituted the target population. They were enrolled into the study if they were aged 18 years and above and had provided (i) consent for their voluntary participation, (ii) implied consent for their mentally challenged child, (iii) assent for their children aged above seven years, and (iv) parental permission for children under the age of seven. All PCGs who were employed to look after the children were excluded because they may choose to deliver care anyhow and may not always be available, hence the possibility of not experiencing the negative impact of such work. The PCGs with a chronic illness or any acute illness that lasted more than three weeks were also excluded because the illness may directly influence QoL regardless of care giving process.

With an estimated proportion of 10%, taken from literature<sup>4</sup>, confidence interval of 95%, a margin error of 0.05, and using the following sample size calculation formulae;  $n = (Z^2P(1-P))/M^2$ , a sample size of 139 was calculated. A total of 142 PCGs, each with his or her own child, were recruited using a systematic sampling method. While PCGs were sitting on benches, waiting for their appointment time, first participant was randomly selected from the first 10 participants who initially came to the facility on the first day of data collection. These participants were assigned a number between 1 to 10, and same count of numbers were written on pieces of paper that were folded and placed in a bag, and mixed thoroughly; one number, which became the first participant, was randomly selected in the bag by one research assistant, and from this number every second eligible client on the queue was then recruited until the closure of the clinics on that day. The process was repeated on each day of data collection until the sample size was met.

## Measurements

The independent variables for the current study were age, gender, marital status, level of education of the PCGs, children's age and severity of children's impairments. The PCGs were prompted to self-report their demographic details and their responses were recorded on the demographic section of the World Health Organization QoL Brief (WHO BREF) questionnaire, while the children's impairment severity was assessed using the Gross Motor Function Classification System (GMFCS) checklist. The GMFCS is a standardized observational instrument, designed and validated to rate the severity of motor function in children living with cerebral palsy<sup>15</sup>. It is a five-level classification system that describes the gross motor function of children and youth living with cerebral palsy based on their functional abilities, the need for assistive technology including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent quality of movement. The distinction between the class levels (I, II, III, IV and V) represent variations in gross motor function that are believed to be meaningful in children's daily lives. The higher the class, the more functional limitations a child face. Overall, the GMFCS group the children into four age bands: 2nd-4th birthday, 4th-6th birthday, 6th-12th birthday and 12th-18th birthday. The GMFCS considers the child's expected milestones to be achieved normally at each age group and classifies the severity of the impairment accordingly.

The dependent variable was QoL of the PCGs; it was assessed using standardized WHO BREF QoL questionnaire<sup>9</sup>. The standardized Chichewa version of this questionnaire<sup>16</sup> was administered by trained research assistants, who had 3-5 years' experience of using the tool and 4-13 years' experience working in rehabilitation field. The questionnaire has 26 questions altogether; the first two questions asked about an individual's overall perception of QoL, and an individual's overall satisfaction with own health, respectively. These two questions were examined separately from the remaining 24 which are categorized into four domains. The 4 main domains, include physical, psychological, social relationships and environment. Table 1 displays the facets that are incorporated in each domain. Likert scale scores of 1-5 were used by participants to rate their perceived judgement of QoL using the facets in each domain. Domain scores were calculated by taking the mean of all items included in each domain and multiplying by a factor of four. The calculated scores were transformed into a linear scale between 0 and 100 using the WHO BREF scoring guidelines<sup>9</sup>. The domain scores were scaled in a positive direction, higher scores denoting higher QoL. Overall, a cut-off point of 60% was used to classify the PCGs as having either a poor (<60) or good (>60%) QoL as suggested by Silva et al.<sup>17</sup>.

### Data management and quality control

At the end of each day, the Principal Investigator (PI) checked the questionnaires for data recording errors and referred any need for amendment or completion of missing data, that did not require participants' presence, back to the data collectors for correction. Thereafter, the PI completed coding of all relevant fields on the questionnaire. Data was then double entered into an excel sheet, checked for errors, and cleaned. The final database was exported into IBM SPSS version 26.0 for analysis.

**Analysis**

Descriptive statistics such as means, and standard deviations have been reported for continuous demographic characteristics data. Frequencies, proportions, and percentages have been reported for categorical data. Pearson Chi-Square tests were used to assess if there were any differences in the socio-demographic characteristics of the PCGs and children between the two study sites.

The data on physical, social, psychological, and environmental domains of QoL was not normally distributed between the study sites, PCG’s gender and children’s classes of impairment. Therefore, independent t-tests were only conducted in assessing the differences in overall QoL between gender and sites, while Mann-U test was used to assess the differences in each domain of QoL between gender. One-way independent groups Anova and post-hoc analysis was conducted to assess the differences in overall QoL across levels of education and marital statuses, whereas Kruskal Wallis H test (and post-hoc analysis) was conducted to assess the differences in each domain scores across the levels of education and marital status. Pearson correlation coefficient was used to assess the presence of linear relationships between the overall QoL and each domain of QoL, and both PCGs and children’s ages and children’s impairment level. The alpha level was set at 0.05.

**Table 1: The four main domains and their facets used to determine QoL**

DOMAINS	FACETS	
PHYSICAL	<ul style="list-style-type: none"> <li>• Activities of daily living</li> <li>• Dependence on medicinal substances and medical aids</li> <li>• Work Capacity</li> </ul>	<ul style="list-style-type: none"> <li>• Energy and fatigue</li> <li>• Mobility</li> <li>• Pain and discomfort</li> <li>• Sleep and rest</li> </ul>
PSYCHOLOGICAL	<ul style="list-style-type: none"> <li>• Bodily image and appearance</li> <li>• Negative feelings</li> <li>• Positive feelings</li> <li>• Self-esteem</li> </ul>	<ul style="list-style-type: none"> <li>• Spirituality / Religion / Personal beliefs</li> <li>• Thinking, learning, memory and concentration</li> </ul>
SOCIAL	<ul style="list-style-type: none"> <li>• Personal relationships</li> <li>• Social support</li> </ul>	<ul style="list-style-type: none"> <li>• Sexual activity</li> </ul>
ENVIRONMENT	<ul style="list-style-type: none"> <li>• Financial resources</li> <li>• Freedom, physical safety and security</li> <li>• Health and social care: accessibility and quality</li> <li>• Transport</li> </ul>	<ul style="list-style-type: none"> <li>• Home environment</li> <li>• Opportunities for acquiring new information and skills</li> <li>• Participation in and opportunities for recreation / leisure activities</li> <li>• Physical environment (pollution / noise / traffic / climate)</li> </ul>

marital statuses ( $p < 0.01$ ) and the children’s classes of impairments ( $p < 0.01$ ) differed significantly between the sites. Table 2 shows a summary of comparisons made between the demographic characteristics of the PCGs and children at QECH and FtC.

**Determining quality of life of PCGs**

There were no significant differences in PCGs who were sick ( $p < 0.49$ ) and who had a chronic condition ( $p < 0.34$ ) between the sites. Overall, out of 9 PCGs who were sick at the time

**Ethical considerations**

Ethical approval was obtained from the College of Medicine Research and Ethics Review Board (P.05/18/2392). Permission to conduct the study in all respective sites was sought prior to conducting the study. Detailed information sheets regarding the study and their participation were handed out to the PCGs, informed and implied consent, assent and parental permission were sought thereafter.

**Results**

**Participants’ Profile**

All 142 enrolled PCGs completed the study, and the majority (97.20%,  $n=138$ ) were women compared to men (2.80%,  $n=4$ ). The mean age of the caregivers was  $32.78 \pm 7.20$  years. Regarding the children, their mean age in years was  $5.80 \pm 3.03$ . A large proportion (38%,  $n=54$ ) were categorized as falling under 2nd and 4th birthday GMFCS age group, and a minority (5.60%,  $n=8$ ) were under the 12th and 18th category. The 4th-6th and 6th-12th age bands had 23.24% and 33.10% of children, respectively.

**Distribution of participants’ characteristics at QECH and FtC**

The gender and highest level of education attained by the PCGs did not differ significantly ( $p < 0.62$ ,  $p < 0.54$ , respectively) between the two sites. However, the PCGs’

of study, four had upper back pain, two had flu, one had musculoskeletal leg pain, another asthma and the remainder complained of generalized headache. Also, out of the 38 PCGs who reported to have a chronic disorder or condition, 23 had HIV/AIDS while six, two, four, one and two had hypertension, diabetes, asthma, epilepsy and stomach ulcers respectively.

**Table 2: Comparison of the participants' characteristics between the study sites**

Characteristics	QECH	FTC	P-Value
	n(%)	n(%)	
PCGs			
Gender			
Female	70(98.60)	68(95.80)	<0.62
Male	1(1.40)	3(4.20)	
Qualification attained			
None	19(26.80)	12(16.90)	<0.54
Primary education	29(40.80)	31(43.70)	
Secondary education	21(29.60)	26(36.60)	
Tertiary education	2(2.80)	2(2.80)	
Marital Status			
Single	1(1.40)	5(7.00)	<0.01*
Married	29(40.85)	31(43.70)	
Cohabiting	25(35.20)	20(28.20)	
Divorced	1(1.40)	7(9.90)	
Separated	14(19.70)	4(5.60)	
Widowed	1(1.41)	4(5.60)	
CHILDREN			
Gender			
Female	34(47.89)	35(49.30)	<1.00
Male	37(52.11)	36(50.70)	
Level of education			
Not in school	52(73.23)	50(70.42)	<0.85
Primary school	19(26.76)	21(29.58)	
GMFCS Classes			
I	15(21.13)	6(8.45)	<0.01*
II	21(29.58)	16(22.54)	
III	14(19.72)	17(23.94)	
IV	9(12.68)	24(33.80)	
V	12(16.90)	8(11.27)	

**\*Significant**

On self-rating of overall QoL and satisfaction level with own health, the PCGs said it was neither good nor poor ( $3.38 \pm 1.06$ ), and they were neither satisfied nor dissatisfied ( $3.39 \pm 1.11$ ), respectively. In general, most of the PCGs (61.30%) had a poor QoL and the remainder (38.70%) reported a good QoL, and the mean score for overall QoL was  $56.15 \pm 12.20$ . The PCGs of children who received rehabilitation or habilitation care at QECH had significantly higher physical domain mean scores than the FtC group ( $U=1906.50$ ,  $P<0.01$ ).

Table 3 shows the summary of comparisons made on QoL of the PCGs between the sites.

***Relationship and comparison between QoL and socio-demographic factors of the PCGs***

A significantly weak negative correlation was found between the classes of impairments and the environmental domain ( $r=-.19$ ,  $p<0.03$ ). Significant differences were observed between the marital statuses and the overall QoL ( $p<0.03$ ), physical ( $p<0.01$ ) and social ( $p<0.01$ ) domains of QoL.

**Table 3: Summary of QoL scores and their comparisons between QECH and FtC**

DOMAINS	MEAN SCORE (%)	QECH	FtC	U-VALUE	P-VALUE
PHYSICAL	54.05±16.13	80.15 <sup>‡</sup>	62.85 <sup>‡</sup>	1906.50	<0.01*
PSYCHOLOGICAL	63.37±14.52	72.56 <sup>‡</sup>	70.44 <sup>‡</sup>	2445.50	<0.76
SOCIAL RELATIONSHIPS	55.89±20.74	70.30 <sup>‡</sup>	72.70 <sup>‡</sup>	2435.00	<0.73
ENVRIONMENT	50.80±16.11	74.2 <sup>‡</sup>	68.79 <sup>‡</sup>	2328.00	< 0.42
OVERALL QoL	56.15±12.20	57.2±11.43	55.10±9.14	-	<0.31

\* Mean Rank; \*Significant; ‡Not applicable

**Table 4: The strength of correlations observed between the socio-demographic factors and QoL**

FACTORS	CORRELATIONS (coefficient, p-value)				
	Overall QoL	Physical	Psychological	Social	Environment
Age of Children	0.21, <0.06	0.24, <0.07	0.15, <0.08	0.14, <0.08	0.07, <0.08
Classes of Impairments	-0.30, <0.13	-0.10, <0.27	-0.03, <0.72	-0.06, <0.46	-0.19, <0.03*
Age of PCGs	-0.12, <0.15	-0.16, <0.06	-0.10, <0.24	-0.04, <0.62	-0.07, <0.41

\*Significant at 5% significant level

**Table 5: The statistical differences observed between the socio-demographic factors of the PCGs and their QoL domains**

FACTORS	DIFFERENCES				
	P-VALUE (POST-HOC RESULT)				
	Overall QoL	Physical	Psychological	Social	Environment
Gender	<0.45	<0.38	<0.76	<0.24	<0.84
Level of Education	<0.15	<0.37	<0.06	<0.51	<0.06
Marital status (Separated vs cohabiting)	<0.03*	<0.01* (Married versus Cohabiting)	<0.24	<0.01* (Separated versus Cohabiting)	<0.15

\*Significant at 5% significant level

**Table 6: The domain and overall QoL mean scores across the marital statuses of the PCGs of children**

MARITAL STATUS	DOMAIN MEAN SCORES (%)				
	Overall QoL	Physical	Psychological	Social	Environment
Married	54.42±11.40	48.54±16.31	63.43±13.53	56.35±18.68	48.72±16.27
Separated	51.50±8.49	60.28±13.30	57.28±13.42	38.83±19.53	49.50±13.89
Cohabiting	61.18±12.11	60.29±12.75	65.73±15.93	62.22±19.52	56.09±15.87
Widow	52.20±8.61	51.40±13.33	57.60±5.51	46.20±18.10	52.60±16.64
Single	55.33±15.06	52.00±20.10	64.83±18.82	55.33±19.17	48.00±15.90
Divorced	54.38±18.42	49.38±22.58	65.75±15.44	61.75±28.92	40.63±16.08

No significant differences in the domains and overall QoL were observed between PCG’s gender and across levels of education. Tables 4, 5 and 6 describe the strength of the correlations, differences between the socio-demographic factors and the domains of QoL, and the mean domain scores across marital statuses, respectively.

**Discussion**

It is known that PCGs of children living with CP encounter various challenges<sup>10,11</sup>, which may eventually affect their QoL<sup>11-14</sup>. In this study, most of the PCGs reported poor QoL, and the affected domains included physical, social and environment. Surprisingly, our study findings suggest that the psychological well-being of the PCGs from both study sites was not impaired. Although no significant differences in

the overall QoL were observed between the sites, the PCGs at FtC presented with significantly lower physical domain scores than those at QECH. Briefly, a significant weak inverse correlation was only observed between the classes of children’s impairments and the environment domain scores, and significant differences in overall QoL, social and physical domain scores were only observed across the PCGs’ marital statuses.

Most of the PCGs in the current study reported (i) body pains, lack of strength to care for self and for the child, lack of sleep, (ii) stigma, inadequate support from hospitals, families and their communities, and(or) (iii) poor infrastructural design of their houses, hospitals and other facilities that limit their accessibility, which are negatively

associated with the physical, social and environment domains of QoL respectively<sup>9</sup>. Similar challenges were also reported by caregivers of children living with disabilities in previous studies done in Malawi, Kenya, Nigeria and Sudan<sup>10,11,18-20</sup>. Therefore, it is reasonable to postulate that the multifaceted attributes of the impaired QoL of the PCGs in Blantyre require a multidisciplinary coordinated approach to be managed. Thus, all relevant stakeholders involved in well-being of people, especially within such domains of life need to be engaged adequately. Contrary, Ahanotu et al. found that the PCGs had high overall QoL ( $3.91 \pm 0.71$ ), psychological ( $59.36 \pm 12.50$ ), physical ( $54.78 \pm 14.92$ ), social ( $71.76 \pm 17.26$ ) and environment ( $63.36 \pm 14.81$ ) domain scores<sup>21</sup>. Although Ahanotu et al. and our current study used the validated and reliable WHO BREF questionnaire, the former did not consider whether the caregiver was a primary carer or not. This might have affected their findings because someone who is fully committed to taking care of a child with disability may have different experiences with someone who commits a few months or days in a year to do this work. Ahanotu et al. also did not report their cut-off point, yet they reported "high" scores. Nevertheless, both studies did not use a control group and the assessment was done once, hence it is difficult to draw conclusions. In our study, the varying levels of competency among the rehabilitation workers might have affected the adequacy and quality of support they give to the PCGs, and that might have contributed to the PCGs inability to use appropriate body mechanics when giving care, hence the observed difference in physical domain scores between the sites.

In this study, the PCGs reported positive feelings, high self-esteem and confidence, and religious beliefs that promote their psychological well-being. It has been previously reported that caregivers of children living with disability engages in religious gatherings as a strategy to cope with the reality, which helps them to accept their child's condition easily<sup>22,23</sup>. It is not uncommon that in Malawi, some people also engage in religious activities through which people are conformed to believe in the supernatural powers in relation to their child's condition; hence able to think positively. On the other hand, Neves, Pietrovic and Claudio reported that PCGs in Brazil had lower psychological domain scores<sup>24</sup>. However, their study had a small sample size ( $n=55$ ) compared to the current ( $n=142$ ), and questionnaires were completed by the patients at home possibly in the presence of their spouses and other family members, who might have assisted them to respond to the questions. Literature suggests that the prevalence of psychological impairment is high (ranging 32 to 89%) among PCGs of children living with disability in Malawi, Kenya and Pakistan<sup>25-27</sup>. Although the impairment assessment tools used by the mentioned studies<sup>25-27</sup> differed to ours, their findings also indicated that caring for a child living with disability is distressful. Nevertheless, the children in the mentioned studies had intellectual disabilities, while our study focused on those with functional limitations with or without intellectual impairments; hence it is difficult to generalize the findings.

Our study findings also suggest that having a child with severe forms of impairment negatively influence how the PCG interacts with the environment at home, in the community, at health and social care facilities, and markets or credit facilities. Although this suggests that there is need to adjust the stated environment, the suggestions to modify environment such as infrastructure or physical terrain take

longer to be adopted or implemented in Malawi. Equipping the PCGs with suitable and appropriate assistive devices such as mobility and sitting aids, and skills on how to use the assistive devices could benefit the PCGs most, whilst waiting for infrastructure or terrain modification.

While our findings suggest that the PCGs who were married and separated received inadequate support from their spouses and co-parents, respectively, compared to the cohabiting PCGs, Arasu et al. reported that PCGs who were married had adequate support from their spouses<sup>28</sup>. Because the majority of PCGs in this study were women, it is reasonable to allude the observed differences to familial and community support. Although it is a common practice that men in Malawi provide material needs of their families, women are custodians of families and communities. Culturally, they are responsible for preparing meals, and performing other chores including assisting children with activities of daily living such as bathing, toileting, washing and feeding, and mobility. Consequently, they may experience an increased workload that may prevent them from interacting socially in their communities. The increased workload and possible fatigue may also affect the PCGs' relationships with their spouses. Matrilineal family practice, which is mostly practiced in the southern part of Malawi where the study was conducted, encourages maternal ownership and responsibility for child-care. This might have also contributed to the lack of support among the PCGs who were on separation, hence having the lower scores in the social relationships and overall QoL.

Lastly, our findings suggest that PCGs' age, gender, and literacy levels did not significantly affect the QoL. Similar non-significant results were reported in studies done in Sudan and Brazil<sup>20,24</sup>. However, the non-significant negative correlations of age and QoL in our study suggest that caring for a child with a disability require PCGs to have a stable mind. This is because the mean age of the PCGs in this study indicates that they were still younger and probably at an age that would propel them to socialize more. Nevertheless, further investigations should be done to understand the independent role of each socio-demographic factor on the QoL of the PCGs.

### Strengths and limitations

Our inability to compare QoL of PCGs of children living with CP and healthy children, to ascertain if the observed poor QoL is not a common experience of PCGs of all children in Blantyre, limit the generalizability of the findings. We also compared QoL of PCGs who were exposed either to a private or government rehabilitation centre with varying operation and management systems, which may affect the QoL differently. Therefore, there is need to investigate factors, at institutional level, which may affect the QoL within and between the facilities. Nevertheless, this is the first study to be conducted in Malawi on QoL of PCGs of children living with CP.

### Conclusion

Conclusively, the study has established that the PCGs from both sites had a poor QoL. While social relationships and environment components of QoL of the PCGs at both sites were equally affected, the physical component was greatly affected among PCGs at FtC. The severity of child's impairments informs a challenging interaction of the PCG and the environment in which they live and function, hence the need to offer realistic and feasible solutions that would

foster this interaction. Both parents of the child living with CP, and the communities in which they live need to be engaged in the provision of child-care and creation of an enabling support system, respectively. Future research should explore the role of rehabilitation workers and institutions on QoL of PCGs to inform improved care delivery practices.

## Declaration

Data sets for this study are available from the corresponding author on a reasonable request.

## Competing interests

The authors declare no competing interests.

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## Authors' contributions

AN designed the study, facilitated the training of the research assistants, collected, and analyzed data, drafted the manuscript, and reviewed all drafts. VSP facilitated the training of research assistants, supervised data collection process, analyzed data, revised, and approved all drafts. Both authors read and approved the final manuscript.

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