4-2024

# Quality of life in a cohort of Kenyan children with cerebral palsy

Pauline Samia

Melissa Tirkha

Amina Kassam

Richard Muindi

Wahu Gitakah

*See next page for additional authors*

## Authors

Pauline Samia, Melissa Tirkha, Amina Kassam, Richard Muindi, Wahu Gitakah, Susan Wamithi, James Orwa, Eugene Were, and Michael Shevell

Global Pediatrics 9 (2024) 100172

Contents lists available at ScienceDirect

Global Pediatrics

journal homepage: www.elsevier.com/locate/gpeds

# Quality of life in a cohort of Kenyan children with cerebral palsy

Pauline Samia [a,b,c,*], Melissa Tirkha [a,d], Amina-Inaara Kassam [a,e], Richard Muindi [a], Wahu Gitaka [a], Susan Wamithi [a], James Orwa [f], Eugene Were [a], Michael Shevell [g]

[a] Department of Paediatrics and Child Health, Medical College, Aga Khan University, Nairobi, Kenya
[b] Brain and Mind Institute, Aga Khan University, Kenya
[c] Department of Public Health and Primary Care, Ghent University, Belgium
[d] School of Public Health, University of Alberta, Canada
[e] Western University, Canada
[f] Department of Population Health, Medical College, Aga Khan University, Nairobi Kenya
[g] McGill University, Canada

ARTICLE INFO

*Keywords:*
Africa
Kenya
QoL
CP
Cerebral Palsy
East Africa
Pediatrics

ABSTRACT

*Aim:* The objective of the study was to evaluate the quality of life in Kenyan children (age 4–18 years) with cerebral palsy (CP).

*Methods:* A cross-sectional descriptive study was conducted. Children with CP were recruited from the pediatric clinics at the Aga Khan hospital Nairobi (AKUHN). Parent proxy-reports using CPQoL-child and CPQoL-adolescents were obtained. Clinical and demographic data were compiled from medical records and parent interviews. A Likert scale was utilized to determine QoL across several domains.

*Results:* One hundred and fourteen child–parent dyads with CP were recruited. The median age of study participants was 8 years (IQR 3–13 years), with males being the majority (57.02 %). Parent proxy-reports using CPQoL-child scale were obtained for $n = 93$ and CPQoL-adolescents for $n = 21$ respondents. Parents in both groups reported low domain QoL scores pertaining to function, family health and rehabilitation service accessibility.

*Interpretation:* Stigma, accessibility to services, therapies and schooling, particularly for children with severe functional limitations, remains a concern. Caregivers would benefit from awareness campaigns of available supports and from local community respite programs. Where national support systems exist, there are critical inefficiencies in service delivery to target population.

## Introduction

Cerebral Palsy (CP) describes a heterogeneous group of permanent early-onset disorders affecting movement and posture, which result from prenatal or perinatal insults to the developing infant brain.[1–4] In addition to non-genetic causes hereditary factors may predispose individuals to CP.[5] Genomic studies have identified clinically relevant copy number variants (CNV's) in approximately 10 % of cohorts of children with CP.[6] Children with de novo CNV's had a significantly poorer neurodevelopmental trajectory compared to those without such changes.[6,7]

Cerebral palsy is still considered one of the most common causes of physical disability during childhood and has ubiquitous effects on the child and family.[6] Studies indicate that the quality of life (QoL) in children with CP is usually low, and the degree of compromise depends on multiple factors including age and severity of the disorder.[8–10] Quality of life is broadly defined as a subjective multidimensional concept for assessing wellbeing including fulfillment of basic needs surrounding emotional, economic, and physical wellbeing and the presence of interpersonal relationships.[11] Studies from low and middle-income countries (LMICs) have generally suggested poor QoL in children living with CP and wide disparities relative to normally

*Abbreviations:* AKUHN, Aga Khan University Hospital, Nairobi; CFCS, Communication function classification system; CP, Cerebral Palsy; CNV's, Copy number variants; GMFCS, Gross Motor Function Classification System; HICs, High-income countries; LMICs, Low and middle-income countries; MACS, Manual ability classification system; PROMs, Patient-reported outcome measures; QoL, Quality of life; REDCap, Research Electronic Data Capture.

* Corresponding author at: Aga Khan University, 3rd Parklands Avenue, East Tower block, fourth floor. P.O BOX 30270 00100, Nairobi, Kenya
*E-mail address:* pauline.samia@aku.edu (P. Samia).

https://doi.org/10.1016/j.gpeds.2024.100172
Received 28 December 2023; Received in revised form 20 March 2024; Accepted 7 April 2024
Available online 16 April 2024

developing peers.[11]

Patient-reported outcome measures (PROMs) are increasingly incorporated into routine clinical practice. One of the most widely used tools to assess QoL is the CP Quality of Life Questionnaires for Children (CP QoL-Child) for ages 4–12 years and adolescents (CP QoL-Teen) for ages 13–18 years.[12] The metric is based on the assumption that QoL is an assessment of wellbeing across various domains including emotional life, service accessibility and family health.[13] The CP-QoL tool is consistently supported as a strong measure for evaluating QoL in school-aged children with CP[11,12,14] via self-report or proxy-perceptions.[15] Quality of life data for CP tends to be derived from proxy reports via the parent/primary caregiver due to concerns regarding the reliability of self-reports.[11,16,17]

There are few studies centered on QoL in low and middle-income countries (LMICs) particularly within Africa.[2,8,13,18–23] A study done in Sudan found low QoL scores among children with CP attending a tertiary care center in Khartoum.[24] In addition to the physical impairments, low socioeconomic status and lack of basic health services contributed to a further decline in QoL. Relative to High Income Countries, the burden of CP in LMICs is noted to be higher due to a myriad of factors including, a poor socioeconomic structure.[17,25,26] This is a major concern as low childhood QoL is a consistent predictor of poor QoL in adolescence.[16] The objective of our study was to provide a deeper understanding into the QoL for a cohort of children with CP attending clinics at a tertiary hospital in Kenya. Over the past three decades, there has been a significant evolution in our understanding of CP. These changes have been driven by advancements in medical research, increased awareness, and a shift towards more inclusive approaches to healthcare and education. In Kenya, where resources for managing child disabilities may be limited, it is crucial to leverage these evolving understandings and approaches to improve the care and support available to children with CP and other disabilities.

Data from this study can play a vital role in informing healthcare policies, guiding the allocation of resources, and developing effective interventions tailored to the needs of children with disabilities in the region. By adopting a holistic, inclusive, and evidence-based approach, it is possible to enhance the quality of life and opportunities for children with CP in Kenya and ensure they reach their full potential.[27]

## Method

### *Study design and setting*

This was a cross sectional survey, undertaken at the neurology and developmental pediatrics clinics at the Aga Khan University Hospital, Nairobi (AKUHN), a not-for profit referral teaching hospital located in Nairobi County. The study included children with CP who had attended pediatric neurology clinic or pediatric developmental clinic at AKUH, Nairobi during the period January 2011-December 2019.The participants were required to be between age 4–18 years at the time of the study and informed consent was sought from the parents/guardians. Approval to conduct the study was given by the AKUHN's Institutional Ethics Review Committee reference number: IERC_140. Research assistants explained the nature of study and proxy method of data collection to parents/guardians and written consent was obtained on behalf of children via guardians prior to interviews.

### *Data collection*

Quality of life (QoL) data were collected using the parent-proxy report versions of CP-QoL-child (ages 4–12) and CP-QoL-adolescent (ages 13–18) while demographic and clinical data were retrieved from medical records.[28,29] The QoL questionnaires were administered by research assistants who had been trained to maintain standard procedure and consistency. Research assistants followed a pre-determined script which guided parent-interviewer interaction and stipulated clear instructions for questioning and data collection. The participants were uniquely identified by anonymous codes different from the hospital numbers and all the information collected was held confidential, with access granted to the investigators only. The data were managed using Research Electronic Data Capture (REDCap) software hosted at AKUH.

### *Measures*

The CP-QoL questionnaires assess feelings around various domains including social wellbeing, access to services, pain, and impact of disability. Scoring was carried out as directed by the tool developers.[28,29] Items in the domains have a 1–9-point rating scale, where meaning varied depending on the context of the question (e.g. 1 = very unhappy and 9 = very happy). Questions pertaining to respite care, special equipment and school for children (ages 4–12) were dropped due to lack of relevance in the study settings. Other variables of interest were selected based on the literature and clinical knowledge. Motor function was assessed using GMFCS, manual ability classification system (MACS) levels and communication function classification system (CFCS). Information on socio-demographic characteristics, pregnancy, birth history, parental medical history and family characteristics were also recorded.

### *Statistical analysis*

Analysis was performed using R 4.0.3, a free statistical analysis software environment for computing and graphics. The analysis was stratified for the two groups (group-1: ages 4–12; group-2: ages 13–18). Questions with low response rates (>50 % missing) were dropped due to lack of relevance to participants (e.g. school-related variables for children 4–12 since majority are not enrolled). As a result, out of a possible 66 questions in CP-QoL-child questionnaire, 55 questions were included and, for the CP-QoL-adolescents' questionnaire, 82 out of 88 questions were included. A complete list of dropped questions is available in Table 4 in the appendix. Sample population characteristics were described using descriptive statistics. Domain specific standard Cronbach's alpha scores were tabulated for subscales to assess consistency since the questionnaires have not been validated in Kenya. Domain specific means, standard deviations and confidence intervals for the subscales were calculated.

## Results

### *Participant characteristics*

Around 230 children with CP attended pediatric neurology clinic and pediatric developmental clinic at AKUH. Among those children who attended the clinics, 114 were eligible and enrolled into the study. The median age for the study participants was 8 years (Q1 = 5; Q3 = 10 years), majority of the participants were males (57.02 %) and (77.42 %) resided in urban areas. This data is presented in Table 1.

For group-1 ($n$ = 93), the median age was 7 years (Q1 = 5; Q3 = 9). Males represented the majority (56.99 %) The median age at diagnosis was 6 months (Q1 = 4, Q3 = 10) and about one in six (16.13 %) resided

**Table 1**
At a glance: socio-demographic details for a cohort of Kenyan children with Cerebral Palsy (n=114)

| Age (years) | |
|---|---|
| median (Q1, Q3) | 8.00 (5.00, 10.00) |
| range | 4.00-18.00 |
| Gender (male) n (%) | 65 (57.02%) |
| Diagnosing age (months) | |
| median (Q1, Q3) | 7.00 (4.00,12.00) |
| Weight (kg) mean (SD) | 25.89 (16.33) |
| Residence (rural) (n %) | 21 (22.58%) |

in rural areas. Majority (96.77 %) of the children were born in a hospital, 6.45 % of the mothers did not receive antenatal care during their pregnancies, and two out of five (39.78 %) delivered through a cesarian section. Most mothers (62.37 %) presented with some complications during pregnancy or at delivery, with birth asphyxia (74.13 %) being the most common complication. The majority of children in group- 1 presented with spastic CP (89.25 %) and around half of them presented with GMFCS level≥4 (47.31 %). The most common score for MACS and CFCS was level 4 (25.81 %) and level 3 (31.18 %) respectively. This data is summarized in Table 2A.

For group-2 ($n = 21$), the median age was 15 years (Q1 = 13, Q3 = 17). Similar to group-1, males were the majority (57.14 %) (Table 2B). The median at diagnosis was 10 months (Q1 = 3, Q3 = 36), and 71.43 % resided in an urban area. Although all patients in this group reported delivery at a hospital, only 66.67 % received antenatal care. Around 71.43 % mothers had complicated deliveries, with prolonged labor being the most common (80.95 %). Unlike group-1, most (66.67 %) presented with GMFCS levels 1–2. The most common motor type disorder for group-2 was spastic CP (85.71 %).

### *Quality of life*

All QoL data presented were collected by proxy reports from parents/guardians, who were also the primary caregivers of the children. Overall, the children presented with emotional and wellbeing scores in the good range, however QoL was reportedly lower with regards to family health, functioning, pain and accessibility to services (Table 3B).

Mean scores for group-1 indicate that the children presented with good ('happy') emotional wellbeing and self-esteem (72.95 SD 16.34) (Table 3B). Social wellbeing and acceptance QoL scores (72.77 SD 11.92) were also good. However, QoL scores were low with regards to participation and physical health (58.45 SD 19.24), feelings about functioning (58.14 SD 17.28), and family health (66.90 SD 20.38). Areas of pain and impact of disability (42.97 SD 21.76) and access to services (51.69 SD 21.24) were severely compromised relative to other domains (Table 3B). Additionally, since most of the children in group-1 were not enrolled in school (53.76 %), all variables pertaining to school were dropped (Table 4).

**Table 2A**
Socio-demographic and clinical variables for Kenyan children (age 4-12) with Cerebral Palsy (n=93)

| | |
|---|---|
| Age (years) median (Q1, Q3) | 7.00 (5.00, 9.00) |
| Gender (male) (n) % | 53 (56.99%) |
| Weight (kg) mean (SD) | 21.19 (10.17) |
| Diagnosing age (months) median (Q1, Q3) | 6.00 (4.00, 10.00) |
| Number of comorbidities – mode (n, %) | 1 (48, 51.61%) |
| Verbal, vision \|\| Epilepsy (n %) | 57 (61.29%) \|\| 26 (27.96%) |
| In school (no) (n %) | 50 (53.76%) |
| **Details pertaining to birth history** | |
| Place of birth (hospital) (n %) | 90 (96.77%) |
| Received antenatal care (n %) | |
| (no \| unknown) | 6 (6.45%) \| 3 (3.23%) |
| Caesarean section (CS) (n %) | 37 (39.78%) |
| CS (urgent) (n %) | 26 (70.27%) |
| **Complications during pregnancy/delivery (comorbid)** | **58 (62.37%)** |
| (If yes, involving asphyxia\| diabetes, hypertension, prematurity \| Other (n%) | 43 (74.13%) \| 16(27.59% \|15 (25.86%) |
| Induced labour (n %) | 35 (37.63%) |
| Gestation | 11 (11.82%) \| 60 (64.52%) \| |
| Post-term \| term \| premature (n %) | 22(23.66%) |
| Birth weight (kg) | |
| mean (SD) | 2.87 (0.81) |
| **Family characteristics** | |
| Maternal age (years) median (Q1, Q3) | 28.24 (25.00, 34.00) |
| Residence (rural) (n %) | 15 (16.13%) |
| **Clinical Characteristics relating to Cerebral Palsy** | |
| Spastic (n %) | 83 (89.25%) |
| (If yes, unilateral \| bilateral) | 36 (43.37%) \| 47 (56.63%) |
| dyskinetic \| ataxic \| mixed pattern \| unknown (n%) | 3 (3.23%) \| 1 (1.08%) \| 2 (2.15%) \| 4 (4.30%) |
| **Scores regarding functionality and therapies** | |
| GMFCS level (1\|2\|3\|4\|5) (n %) | 12 (12.90%) \| 13 (13.98%) \|24 (25.81%) \| 24 (25.81%) \| 20 (21.51%) |
| MACS level (1\|2\| 3\|4\|5) (n %) | 13 (13.98%) \| 23 (24.73%)\| 20 (21.51%) \| 24 (25.81%) \|13 (13.97%) |
| CFCS level (1\|2\| 3\|4\|5) (n %) | 8(8.60%)\|17(18.28%)\|29(31.18%)\| 23(24.73%) \|16(17.20%) |
| **Parental response to question: how has medical treatment impacted QoL?** | |
| (n %) (1 - Significantly worsened, 2 - worsened, 3 -neutral, 4 - modest, 5- significant improvements) | 0 (0%)\| 2 (2.15%) \| 17 (18.28%) \| 41 (44.09%) \| 33 (35.48%) |

**Table 2B**
Socio-demographic & clinical variables for Kenyan adolescents (age 13 -18) with Cerebral Palsy (n=21)

| | |
|---|---|
| Age (years) median (Q1, Q3) | 15.00 (13.00, 17.00) |
| Gender (male) (n) % | 12 (57.14%) |
| In school (no) (n) % | 3 (14.29%) |
| Weight (kg) mean (SD) | 46.70 (21.76) |
| Diagnosing age (months) median (Q1, Q3) | 10.00 (3.00, 36.00) |
| Comorbidity count mode (n) | 1 (n=16) |
| **Details pertaining to birth history** | |
| Place of birth (hospital) (n) % | 21 (100%) |
| Caesarean section (CS) (n) % | 8 (38.10%) |
| CS (urgent) (n) % | 7 (33.33%) |
| **Complications during delivery (yes)** | **15 (71.43%)** |
| If yes, birth asphyxia/prolonged labour (n) % | 12 (57.14%) |
| Induced labour (n) yes \| unknown % | 10(47.62%) \| 1 (4.76%) |
| Antenatal care (n) (yes) % | 14 (66.67%) |
| Post term \| premature\| term (n) % | 2(9.52%)\|5(23.81%)\|14 (66.67%) |
| Birth weight (kg) | |
| mean (SD) | 3.08 (0.86) |
| **Family characteristics** | |
| Maternal age (years) median (Q1, Q3) | 28.55 (26.00, 32.00) |
| Residence (rural) (n) % | 6 (28.57%) |
| **Clinical Characteristics relating to Cerebral Palsy** | |
| Predominant motor type | |
| (dyskinetic, spastic, unknown) | 2 (9.52%), 18(85.71%), 1 (4.76%) |
| *(If spastic, unilateral)* (n) % | *15 (71.43%)* |
| GMFCS level (1\|2\|3\|4\|5) (n) % | 11 (52.38%) \| 3 (14.29%) \| 2 (9.52%) \|3(14.29%) \|2(9.52%) |
| MACS level (1\|2\| 3\|4\|5) (n) % | 13 (61.90%)\| 2 (9.52%) \| 2 (9.52%) \| 2 (9.52%) \| 2(9.52%) |
| CFCS level (1\|2\| 3\|4\|5) (n) % | 9 (42.86%) \| 6 (28.57%)\|3 (14.29%) \| 1(4.76%) \| 2 (9.52%) |
| **Parental response to question: how has medical treatment impacted QoL (%)** (1 - Significantly worsened, 2 - worsened, 3 -neutral, 4 - modest, 5- significant improvements) | 1 (4.76%) \| 0 (0%) \| 4 (19.05%) \| 6 (28.57%) \| 10 (47.62%) |

**Table 3A**
Group-2 Quality of life scores and Cronbach's alpha of subscales for CP-QoL-ADOLESCENT via proxy reports[ß] (n=21)

| Subscales | Standard Alpha | Mean domain score (SD) | 95% confidence interval of the mean |
|---|---|---|---|
| General wellbeing & participation | 0.89 | 71.47 (12.98) | 65.92, 77.02 |
| Communication & physical health | 0.85 | 70.38 (12.41) | 65.07, 75.69 |
| School wellbeing[ø] | 0.79 | 76.78 (10.56) | 72.26, 81.30 |
| Social wellbeing & family acceptance | 0.68 | 84.31 (9.59) | 80.22, 88.42 |
| Access to Services | 0.70 | 51.25 (16.68) | 44.12, 58.38 |
| Family health | 0.71 | 66.82 (20.05) | 58.24, 75.40 |
| Feelings about functioning | 0.86 | 64.85 (22.61) | 55.18, 74.52 |

[ß] scores calculated from proxy reports (parents)
[ø] for children enrolled (n=18)

**Table 3B**
Group-1 Quality of life scores and Cronbach's alpha of subscales for CP-QoL-CHILD via proxy reports[ß] (n=93)

| Subscales | Standard Alpha | Mean domain score (SD) | 95% confidence interval of the mean |
|---|---|---|---|
| Emotional wellbeing & self esteem | 0.74 | 72.95 (16.34) | 69.63, 76.27 |
| Participation & physical health | 0.82 | 58.45 (19.24) | 54.54, 62.36 |
| Pain and impact of disability | 0.66 | 42.97 (21.76) | 38.55, 47.39 |
| Social wellbeing and acceptance | 0.72 | 72.77 (11.92) | 70.35, 75.19 |
| Access to Services | 0.73 | 51.69 (21.24) | 47.37, 56.00 |
| Family Health | 0.76 | 66.90 (20.38) | 62.76, 71.04 |
| Feelings about functioning | 0.81 | 58.14 (17.28) | 54.63, 61.65 |

[ß] scores calculated from proxy reports (parents)

**Table 4**
List of dropped questions by domain due to lack of relevance (<50% response rates)

| CP-QoL Child | CP-QoL Adolescent |
|---|---|
| **Variables relating to school** | **Special equipment** |
| **Social wellbeing and acceptance** | the special equipment they have at home? (e.g. special seating, standing frames, wheelchairs, walkers, AFOs, visual aids, hearing aids, communication aids)? |
| the way they get along with other children at preschool or school? | the special equipment they have at school? (e.g. note takers, special seating, standing frames, wheelchairs, walkers, laptops, visual aids, hearing aids, communication aids)? |
| how they are accepted by other children at preschool or school? | the special equipment that is available in the community (ramps, escalators, wheelchair access)? |
| **Feelings about functioning** | **Access to services [none were available]** |
| their ability to keep up academically with their peers? | your access to respite care? |
| **Pain and bother** | the amount of respite care you receive? |
| Is your child bothered when they miss school for health reasons? | how easy it is to get respite care? |
| **Participation and physical health** | |
| their ability to participate at preschool or school? | |
| **Access to services** | |
| your child's access to extra help with learning at preschool or school | |
| the special equipment they have at their school? | |
| the special equipment that is available in the community? | |
| your access to respite care? | |
| the amount of respite care you receive? | |
| how easy it is to get respite? | |

For adolescents (group-2), mean social wellbeing and family acceptance scores were in the happy range (84.31 SD 9.59) The mean score for general wellbeing and participation was (71.47 SD 12.98). Good scores (70.38 SD 12.41) were also reported in communication and physical health. Scores for the domain on feelings about functioning (64.85 SD 22.61) and family health (66.82 SD 20.05) were depressed relative to social and general wellbeing scores. Scores for accessibility to services were also a point of concern (51.25 SD 16.68); they were the lowest scores among the evaluated domains. The majority of group-2 children were enrolled in school (85.71 %), and reported good mean school QoL scores (76.78 SD 10.56) This data is presented in Table 3A.

## Discussion

This study aimed to describe QoL for a cohort of Kenyan children with Cerebral Palsy (CP). As a general trend among the children and adolescents—accessibility to services, family health and feelings about functioning were notably lower relative to other domains.

Children (group-1) in particular reported low QoL in the pain domain and the impact of disability. It was the lowest mean score across all domains for group-1 with poor reported scores in participation and physical health. This could be due to the severity of disability indicating fairly severe functional limitation. This association needs to be formally tested. However, a Ugandan study reported a higher proportion of younger children with CP present with more severe limitation (bilateral spastic) but with increasing age, they present with less severe (unilateral) phenotypes, suggesting a high rate of mortality for children with severe limitations.[20] Low domain specific scores relating to pain and functioning may point to inadequate coping mechanisms for group-1, however, since this data is derived from proxy-reports, we cannot completely dismiss parental perception bias.[22]

During the interviews, parents shared their thoughts on their overall care experiences which help to contextualize QoL ratings, particularly in areas of function and access to services for children with disabilities. Several key themes came up: lack of knowledge of where to find appropriate schools or services; low funding, infrastructure, human resources with regards to general medical, school and specialized services— particularly pronounced for parents in rural areas, and for children with severe functional limitations; inability for children to improve mobility and function (e.g. dressing self) due to distance and financial stress impeding continuing care and access to physiotherapy; stigma in local communities; and a lack of respite for caregivers.

There is a scarcity of healthcare, school infrastructure and human resources in Kenya with regards to disability care.[27] With regards to services, parents pointed out a lack of accessible clinical care for their children. Many were unable to (due to cost or distance), or unaware of where to access consistent specialized medical care, equipment and appropriate schools for their children. Many were travelling from far counties or areas like Homa Bay, Kisumu, Nakuru or Kitale (ranging 4–8 h travel) to access specialized medical, physiotherapy and disability care at AKUH, one of the few tertiary care facilities with pediatric neurology services. Furthermore, in addition to travel costs, there are difficulties paying for repeated prescribed medication and specialized services like physiotherapy as well, which are critical to improve functioning. Hence some parents can only make the trip a few times a year. These concerns were particularly problematic for parents with children with more severe functional limitations, who in addition to consistent, specialized medical care require additional tools like wheelchairs, writing/communication aids, and crutches to improve QoL. Many parents pointed out that they were no locally available or affordable wheelchairs for their children. In Kenya, some families migrated abroad to access equipment and care, but this is not a readily available option for the most vulnerable.[30]

Regarding schools, many echoed the same issues around a scarcity of schools which provide tailored teaching. In group-1 the majority of patients were not in school which suggests that there may be a school accessibility issue for children with greater functional limitations. The lack of schooling is concerning since studies support an association between higher QoL and school enrollment. For instance a study by Mohammed and colleagues[24] found significantly better QoL in children (≤18 years) with CP attending school in Sudan, citing school as a critical medium to form social connections and gain new experiences.[24] Furthermore, parents report that schools often lacked sufficient instructors (numbers and training) and equipment to adequately support children, or were filled to capacity.

Other themes came up around stigma, lack of respite services, and the need for a reinforced national policy framework targeting children with disability. Parents shared during interviews that stigma continues to be of concern. The associated effects of stigma can be catastrophic if society attributes the child's impairment to a "curse" or moral punishment for parents' sins.[30] In extreme cases, parents may abandon their child, who in turn is sent to an orphanage in outskirt areas with less school and resource access.[30] This decision is often made to protect the child and family from harm, and further ostracization.[30] For children with severe functional limitations, this means they are less likely to

access specialized and follow-up care, and receive little or no social support from family members.

With regards to respite services, parents also shared that they would welcome any relief programs or community support programs, as many were solely responsible for providing full time care. They are not able to rely on any community supports or government subsidization. Although caregiving can be fulfilling, combined with experiences of stigma and financial stress, parents can experience overwhelming sense of burden, helplessness and isolation. A study examining caregivers of children with disabilities in Kilifi, Kenya, highlighted feelings of distress, social discrimination and exclusion in several areas of life.[31] Lastly, conversations implied larger structural problems like a poor national policy framework to support persons with disability and minimal resources to train healthcare and education personnel.

## Recommendations

With regards to access to services and functioning, at the local level, the first area of response requiring action concerns a lack of financial supports for families. There is a major disconnect between the study population's knowledge of available services, the actual services (although there is still a scarcity and poor quality of many services and facilities) and issues around the efficient, timely delivery of those services. Parents have noted that subsidization from government towards disability medical care or social assistance would reduce the level of financial burden. There are some benefits and grants available, provided through for example—the National Council for Persons with Disabilities (NCPWD), however individuals must first register with the NCPWD.[32] There is also a National Safety Net Programme - Cash Transfer for Persons with Severe Disabilities (PWSD-CT) which provides around KES 2000 *per household* per month, delivered every two months through appointed payment agents.[33] Only a handful of parents mentioned these benefits; most did not know of them or of the NCPWD.

A recent report assessing the impact of the PWSD-CT in 2024 showed that a significant number of persons with severe disabilities are not registered persons with disabilities. This means they are likely missing out on all government services for persons with disabilities including any cash transfer due to this lack of registration.[34] The report also indicated payment is not sufficient to adequately cover all supports (e.g. transportation), however, it is a vital means accessible to families who are typically engaged in precarious employment.[34] The report also revealed service delivery inefficiencies. At the time of the assessment, the beneficiaries of the program had not been paid for over six months resulting in financial struggles and an inability to adequately care for their persons with severe disabilities.[34] With regards to awareness of NCPWD services, only 36 % of surveyed households ($n = 351$) were aware of its existence.[34] Hence from a national level, the report recommends increasing the monthly stipend, implementing monitoring and evaluation programs, regularizing payment to beneficiaries to ensure access to funds in a timely manner, and increasing awareness of the NCPWD by strengthening the link between the Beneficiary Welfare Committee and program officers at the local and county level.[34] With regards to educational services, the NDFPWD educational fund covers up to 75 % of course fees. In exceptional circumstances the Fund may pay 100 % of fees but the applicant has to provide evidence of extreme poverty.[32] Increasing funding in this arena is important – but critically, delivery inefficiencies need to be addressed in addition to increasing awareness in the target population. Sustained access to these supports would likely support improved Qol.

Awareness campaigns (for example, by engaging local and national media programmes, social media, and clinical spaces) are means which could be used to increase awareness. However for persons in rural areas without consistent internet access, there remain issues around increasing awareness and accessibility to local offices. Equipping local community networks, for example, Community Health Workers (CHWs) or local NCPWD program officers, might be a better strategy, as there is evidence to suggest that CHW can help to fill community knowledge gaps.[35] Other key recommendations are provided in the report.[34]

From a clinical standpoint, subsidization of certain costs (e.g. physiotherapy (PT) accessibility) and medical check-ups would be beneficial to improve QoL. The NDFPWD supports the provision of Assistive Devices (e.g. wheelchairs) and Services to Persons with Disabilities (PWDs) ,[32] however awareness and accessibility remains poor.[34] Improving access to PT and mobility supports like wheelchairs would increase functioning QoL. With regards to robust medical care, there needs to be investments into a robust disability healthcare policy framework to guide action. For example, patients might benefit from investments into a care model with multidisciplinary teams in one location to reduce costs associated with travel.[27] Additionally, investment should be made into the training and retention of medical personnel (CHWs, physicians, nurses) with knowledge on providing culturally competent and specialized disability care. Generating a list of relevant resources by county (school and healthcare facility list) for parents (in the form of pamphlets, brochures etc.) and sharing this with families would be helpful.

Additionally allocating funding into local communities to educate the local population, and increasing awareness and understanding of disabilities is pertinent to reduce stigma. Providing more community driven services to help children gain a sense of integration, or aid with finding meaningful ways to socially participate or bolster economic wellbeing would improve quality of life. Many parents shared that there were no community services available to help their child find any employment support. The NCPWD provides a community assistance grant to established groups of Persons with Disabilities to help towards self-sufficiency in generating income[36] – but again, many community stakeholders are likely not aware of this grant.

With respect to caregivers - although many practice adaptive coping strategies, their responsibilities have physical and psychological consequences.[30] Caregivers would benefit from nationally sponsored community respite services, parent support groups or local caregiver skill training. They also require adequate financial support if unable to engage in income generating activities. Further studies can look into piloting programs or strategies to improve wellbeing. For example World Health Organization (WHO) has a Caregiver Skills Training (CST) program with modules on caregiver wellbeing in addition to providing training for families to provide care for children with disabilities.[37] This type of resource could help to reduce reliance on the more formal healthcare services as well.

## Limitations

This study utilized a cross sectional design, consequently we cannot infer about trends of QoL in children with CP across time. Although AKUHN receives patients from across the country, the study used convenience sampling restricted to children receiving treatment at AKUHN, therefore it is difficult to generalize the findings. The study questionnaire was administered in English (an official language of Kenya) and the design utilized simple language. We cannot rule out bias due to language, although most of the parents/guardians were proficient in English.

## Conclusion

Both children with CP and their families reported low QoL scores, especially in areas related to function, access to services, accessibility, and family health. This indicates that there are significant barriers to accessing necessary services and supports, which can impact the overall well-being of children with CP and their families. Additionally, more than half of children under 12 years of age in this sample were not enrolled in school, particularly those with severe phenotypes of CP, which is concerning since schooling has been associated with improved QoL scores. There is poor availability of respite support for caregivers, as

the majority in the study were ready to be enrolled in any relief programs available. Given these findings, there is a clear need for further research and interventions to improve the QoL for children with CP in Kenya. A large multicenter longitudinal study focusing on QoL evaluation in children with CP could help identify trends, barriers, and priority areas for intervention over time, leading to more targeted and effective support programs for children with CP and their families. Overall, increasing caregiver's knowledge of available supports, further subsidizing medical care, funding multidisciplinary healthcare teams, increasing trained medical workers and teachers, bolstering community respite and employment service programs, and generating a healthcare service/school resource list would all help to improve QoL. For existing programs, there are major inefficacies with regards to financial and overall support delivery. From an infrastructural perspective, major systemic changes are needed to connect and integrate services so that grants or services are streamlined and delivered in a timely manner. Establishing monitoring and evaluation programs to assess and fix inefficiencies in the existing network of support programs and hold governing bodies accountable are critical as well.

## CRediT authorship contribution statement

**Pauline Samia:** Writing – review & editing, Validation, Supervision, Methodology, Investigation, Data curation, Conceptualization. **Melissa Tirkha:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Amina-Inaara Kassam:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Investigation, Data curation. **Richard Muindi:** Writing – review & editing, Resources, Project administration, Investigation, Data curation. **Wahu Gitaka:** Writing – review & editing, Validation, Supervision, Data curation. **Susan Wamithi:** Writing – review & editing, Supervision, Methodology, Investigation, Formal analysis. **James Orwa:** Writing – review & editing, Supervision, Methodology, Formal analysis, Data curation. **Eugene Were:** Writing – review & editing, Supervision, Investigation, Data curation. **Michael Shevell:** Writing – review & editing, Validation, Supervision, Resources, Project administration, Conceptualization.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Acknowledgements

We would like to thank the children, parents/guardians of children and adolescents with cerebral palsy who participated in the study, the staff at Aga Khan University hospital, Nairobi who facilitated study, Procedures and the Research Institute of the McGill University Health centre for a donation of USD 800 to facilitate the study. One research assistant was funded in part by a Queen Elizabeth II Diamond Jubilee Scholarship, no other funding was provided and the authors supported the study in kind.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.gpeds.2024.100172.

## References

1. Bax M, Goldstein M, Rosenbaum P, et al. Proposed definition and classification of cerebral palsy, April 2005. *Dev Med Child Neurol.* 2005;47(8):571–576. https://doi.org/10.1017/S001216220500112X.
2. Donald KA, Samia P, Kakooza-Mwesige A, Bearden D. Pediatric cerebral palsy in Africa: a systematic review. *Semin Pediatr Neurol.* 2014;21(1):30–35. https://doi.org/10.1016/j.spen.2014.01.001.
3. Wimalasundera N, Stevenson VL. Cerebral palsy. *Pract Neurol.* 2016;16(3):184–194. https://doi.org/10.1136/practneurol-2015-001184.
4. Shevell MI, Bodensteiner JB. Cerebral palsy: defining the problem. *Semin Pediatr Neurol.* 2004;11(1):2–4. https://doi.org/10.1016/j.spen.2004.01.001.
5. Bearden DR, Monokwane B, Khurana E, et al. Pediatric Cerebral palsy in Botswana: etiology, outcomes, and comorbidities. *Pediatr Neurol.* 2016;59:23–29. https://doi.org/10.1016/j.pediatrneurol.2016.03.002.
6. Oskoui M, Coutinho F, Dykeman J, Jetté N, Pringsheim T. An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. *Dev Med Child Neurol.* 2013;55(6):509–519. https://doi.org/10.1111/dmcn.12080.
7. Zarrei M, Fehlings DL, Mawjee K, et al. De novo and rare inherited copy-number variations in the hemiplegic form of cerebral palsy. *Genet Med.* 2018;20(2):172–180. https://doi.org/10.1038/gim.2017.83.
8. Das S, Aggarwal A, Roy S, Kumar P. Quality of life in Indian children with cerebral palsy using cerebral palsy-quality of life questionnaire. *J Pediatr Neurosci.* 2017;12(3):251. https://doi.org/10.4103/jpn.JPN_127_16.
9. Namaganda LH, Almeida R, Kajungu D, et al. Excessive premature mortality among children with cerebral palsy in rural Uganda: a longitudinal, population-based study. *PLoS ONE.* 2020;15(12), e0243948. https://doi.org/10.1371/journal.pone.0243948.
10. Young NL, Rochon TG, McCormick A, Law M, Wedge JH, Fehlings D. The health and quality of life outcomes among youth and young adults with cerebral palsy. *Arch Phys Med Rehabil.* 2010;91(1):143–148. https://doi.org/10.1016/j.apmr.2009.08.152.
11. Power R, King C, Muhit M, et al. Health-related quality of life of children and adolescents with cerebral palsy in low- and middle-income countries: a systematic review. *Dev Med Child Neurol.* 2018;60(5):469–479. https://doi.org/10.1111/dmcn.13681.
12. Davis E, Mackinnon A, Davern M, et al. Description and psychometric properties of the CP QOL-Teen: a quality of life questionnaire for adolescents with cerebral palsy. *Res Dev Disabil.* 2013;34(1):344–352. https://doi.org/10.1016/j.ridd.2012.08.018.
13. Power R, Akhter R, Muhit M, et al. Cross-cultural validation of the Bengali version KIDSCREEN-27 quality of life questionnaire. *BMC Pediatr.* 2019;19(1):19. https://doi.org/10.1186/s12887-018-1373-7.
14. Marwa G, Mtawaa S, Toulgui E, et al. Quality of life and its predicting factors for Tunisian children with cerebral palsy. *Afr J Disabil.* 2022;11:1046. https://doi.org/10.4102/ajod.v11i0.1046.
15. Mpundu-Kaambwa C, Chen G, Huynh E, Russo R, Ratcliffe J. A review of preference-based measures for the assessment of quality of life in children and adolescents with cerebral palsy. *Qual Life Res.* 2018;27(7):1781–1799. https://doi.org/10.1007/s11136-018-1837-0.
16. Colver A, Rapp M, Eisemann N, et al. Self-reported quality of life of adolescents with cerebral palsy: a cross-sectional and longitudinal analysis. *The Lancet.* 2015;385(9969):705–716. https://doi.org/10.1016/S0140-6736(14)61229-0.
17. Kakooza-Mwesige A. Health-related quality of life in children with cerebral palsy in low- and middle-income countries: opportunities and next steps. *Dev Med Child Neurol.* 2018;60(5):437. https://doi.org/10.1111/dmcn.13711.
18. Burton A. Fighting cerebral palsy in Africa. *Lancet Neurol.* 2015;14(9):876–877. https://doi.org/10.1016/S1474-4422(15)00189-1.
19. Donald KA, Kakooza AM, Wammanda RD, et al. Pediatric cerebral palsy in Africa: where are we? *J Child Neurol.* 2015;30(8):963–971. https://doi.org/10.1177/0883073814549245.
20. Kakooza-Mwesige A, Andrews C, Peterson S, Wabwire Mangen F, Eliasson AC, Forssberg H. Prevalence of cerebral palsy in Uganda: a population-based study. *Lancet Glob Health.* 2017;5(12):e1275–e1282. https://doi.org/10.1016/S2214-109X(17)30374-1.
21. Khandaker G, Muhit M, Karim T, et al. Epidemiology of cerebral palsy in Bangladesh: a population-based surveillance study. *Dev Med Child Neurol.* 2019;61(5):601–609. https://doi.org/10.1111/dmcn.14013.
22. Snehal I, Kumar A. A questionnaire based study of the quality of life of children with cerebral palsy aged 4–12 years. *Indian J Child Health.* 2019:229–233. https://doi.org/10.32677/IJCH.2019.v06.i05.009.
23. Namanja A, Phiri VS. Quality of life of primary caregivers of children living with cerebral palsy at two clinics in blantyre, Malawi. *Malawi Med J.* 2022;34(3):176–183. https://doi.org/10.4314/mmj.v34i3.6.
24. Mohammed FMS, Ali SM, Mustafa MAA. Quality of life of cerebral palsy patients and their caregivers: a cross sectional study in a rehabilitation center Khartoum-Sudan (2014 –2015). *J Neurosci Rural Pract.* 2016;07(03):355–361. https://doi.org/10.4103/0976-3147.182778.
25. Dan B, Paneth N. Making sense of cerebral palsy prevalence in low-income countries. *Lancet Glob Health.* 2017;5(12):e1174–e1175. https://doi.org/10.1016/S2214-109X(17)30420-5.
26. Salie R, Eken MM, Donald KA, Fieggen AG, Langerak NG. Pain, health-related quality of life, and mental health of adolescents and adults with cerebral palsy in urban South Africa. *Disabil Rehabil.* 2022;44(17):4672–4680. https://doi.org/10.1080/09638288.2021.1916101.
27. Samia P, Wamithi S, Kassam A, et al. Child disability and family-centred care in East Africa: perspectives from a workshop with stakeholders and health practitioners. *Afr J Disabil.* 2022;11:931. https://doi.org/10.4102/ajod.v11i0.931.
28. Davis E, Davern M, Waters E, et al. *Cerebral Palsy Quality of Life Questionnaire For Adolescents (CP QOL-Teen) Manual.* University of Melbourne; 2013:25.
29. Waters E, Boyd R, Reddihough D, et al. *Cerebral Palsy Quality of Life Questionnaire For Children (CP QOL-Child) Manual.* University of Melbourne; 2013:26.

30. Chabeda-Barthe J, Wambua T, Chege WL, Hwaga D, Gakuo T, Rotich GC. Child developmental disabilities, caregivers' role in Kenya and its implications on global migration. *Int J Environ Res Public Health*. 2019;16(6):1010. https://doi.org/10.3390/ijerph16061010.
31. Gona JK, Mung'ala-Odera V, Newton CR, Hartley S. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child*. 2011;37(2):175. https://doi.org/10.1111/j.1365-2214.2010.01124.x.
32. Kenya Disability Resource. *Kenya Government Disability Services*. Kenya Disabiliy Resource; 2017. Accessed March 14, 2024. http://www.kenyadisabilityresource.org/Kenya-Government-Disability-Services
33. Social Protection. *Persons With Severe Disability Cash Transfer, PWSD–CT*. socialprotection.org; 2024. Accessed March 14, 2024. https://socialprotection.org/discover/programmes/persons-severe-disability-cash-transfer-pwsd%E2%80%93ct
34. National Council for Persons with Disabilities (NCPWD). *Persons with severe disabilities Cash Transfer (PWSD-CT) Programme. Kenya*. 2024. Impact Assessment Report.
35. Mbugua RG, Karanja S, Oluchina S. Effectiveness of a community health worker-led intervention on knowledge, perception, and prostate cancer screening among men in Rural Kenya. *Adv Prev Med*. 2022;2022, 4621446. https://doi.org/10.1155/2022/4621446.
36. National Council for Persons with Disabilities. *Economic Empowerment*. NCPWD; 2022. Accessed March 14, 2024. https://ncpwd.go.ke/economic-empowerment/
37. Salomone E, Pacione L, Shire S, Brown FL, Reichow B, Servili C. Development of the WHO caregiver skills training program for developmental disorders or delays. *Front Psychiatry*. 2019;10:769. https://doi.org/10.3389/fpsyt.2019.00769.