Impairments, functional limitations, and access to services and education for children with cerebral palsy in Uganda: a population-based study

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ABBREVIATIONS

HIC	High-income country
LMIC	Low- and middle-income country
MACS	Manual Ability Classification System
NGO	Non-governmental organization
PEDI	Paediatric Evaluation of Disability Inventory

AIM To describe the functional limitations and associated impairments of children with cerebral palsy (CP) in rural Uganda, and care-seeking behaviour and access to assistive devices and education.
METHOD Ninety-seven children with CP (42 females, 55 males; age range 2–17y) were identified in a three-stage population-based screening with subsequent medical examinations and functional assessments. Information on school and access to care was collected using questionnaires. The data were compared with Swedish and Australian cohorts of children with CP. We used the χ^2 test and linear regression models to analyse differences between groups.
RESULTS Younger children were more severely impaired than older children. Two-fifths of the children had severe impairments in communication, about half had intellectual disability, and one third had seizures. Of 37 non-walking children, three had wheelchairs and none had walkers. No children had assistive devices for hearing, seeing, or communication. Care-seeking was low relating to lack of knowledge, insufficient finances, and 'lost hope'. One-third of the children attended school. Ugandan children exhibited lower developmental trajectories of mobility and self-care than a Swedish cohort.
INTERPRETATION The needs for children with CP in rural Uganda are not met, illustrated by low care-seeking, low access to assistive devices, and low school attendance. A lack of rehabilitation and stimulation probably contribute to the poor development of mobility and self-care skills. There is a need to develop and enhance locally available and affordable interventions for children with CP in Uganda.

The large investments made in treating deadly infectious, nutritional, and neonatal conditions, in line with the Millennium Developmental Goals, have reduced child deaths worldwide by almost half between 1990 and 2015.[1] However, these efforts have largely neglected the challenges faced by children with developmental disabilities, who are not included in health, education, and social services in many low- and middle-income countries (LMICs).[2–4] The recent inclusion of disability in the Sustainable Development Goals recognizes that children with developmental disabilities have the right to be included in international and national health initiatives, but there is limited knowledge about what is needed to direct these efforts.

Cerebral palsy (CP) is a motor disorder caused by disturbances in the developing brain leading to lifelong functional limitations and associated impairments.[5] Affected children can benefit from multifaceted interventions and assistive devices such as wheelchairs and communication technologies.[6,7] In this study, we explored access to health services and education for children with CP in a rural part of Uganda. Although there are population-based studies on CP from high-income countries (HICs), such studies from LMICs are lacking, with existing reports entailing mainly clinical cohorts.[4,8] There are no published population-based studies on motor function and associated impairments of children with CP in sub-Saharan Africa. This lack of evidence results in many children not being identified and not receiving much-needed services. Our group recently published the first large population-based study from sub-Saharan Africa. It exposed a high prevalence (3 per 1000 children), altered spectrum of aetiologies, and increased mortality versus those reported from HICs.[9]

Here, we extend our initial study and describe the functional abilities and associated impairments, care-seeking practices, and access to assistive devices and education for children with CP in rural Uganda.

METHOD

Study design

This was a population-based cross-sectional study of the Iganga Mayuge Health and Demographic Surveillance Site, which includes 65 villages in a rural part of eastern Uganda. The three-stage screening performed in 2015 included: (1) door-to-door screening of all children living in the area; (2) follow-up by a trained CP team; and (3) clinical neurological assessment in combination with a triangulation of all villages using key village informants, as previously described.[9] The study was approved by the Higher Degrees Research and Ethics Committee of the School of Public Health, College of Health Sciences, Makerere University, and the Uganda National Council for Science and Technology (HS 1734 and 1787). All caregivers gave written informed consent, and assent was obtained from participants older than 8 years of age who understood the request and communicated adequately.

Participants and procedures

The screening of 31 756 children aged 2 to 17 years identified 97 with CP.[9] Children with CP were examined by a trained CP team, including a clinician, a physiotherapist or occupational therapist, a study nurse, and a nurse aid. The clinician and therapist performed standard neurology and medical examinations, including an assessment for associated impairments. The study nurse obtained information about the pregnancy, birth history, medical problems, development, and sociodemographic factors.

The children's functional abilities were assessed by a team of expert physiotherapists and occupational therapists at the child's home or a nearby health centre. The Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), and Communication Function Classification System were used to assess gross motor, fine motor, and communication ability respectively.[10–12] These classify ability on a 5-point ordinal scale, from level I (mild/independent) to level V (severe limitations requiring assistance for all activities). The Ugandan version of the Paediatric Evaluation of Disability Inventory (PEDI) was used to measure children's mobility, self-care, and social functioning.[13,14] Raw scores were converted to scale scores using a 0 to 100 scale.

Information on school attendance, care seeking, and mobility-assisting devices was collected using a pretested, semi-structured questionnaire with closed- and open-ended questions.

Information on associated visual, hearing, intellectual, and behaviour impairments and the presence of seizures was gathered from three different sources. Impairment was considered confirmed when reported by at least two sources and unconfirmed when reported by only one.

What this paper adds

- Development of mobility and self-care skills is lower in Ugandan than Swedish children with cerebral palsy (CP).
- Older children in Uganda with CP are less impaired than younger children.
- Untreated seizures and impairments of communication and intellect are common.
- Access to health services, assistive devices, and education is low.
- Caregivers lack knowledge and finances to seek care and often lose hope of their child improving.

The three sources were: (1) interviews by a study nurse using questionnaires based on the Washington group extended question set of functioning.[15] These interviews included asking the caregiver about the child's medical history, seizures, difficulties in hearing, seeing, moving, behaving, or understanding; (2) Clinical officer/paediatric doctor performing a full clinical examination at the hospital, including asking the caregiver about medical history including checklist for seizures, behavioural abnormalities, and cognitive functions; and (3) Therapist assessment, including PEDI interview with the caregiver, and an interactive physical and motor assessment where the therapist engaged the child in play and following instructions.

Qualitative content analysis of interviews

The open-ended questions on seeking care and assistive devices were asked in the local language, Lusoga, and entered verbatim in English by a therapist fluent in both languages. The open-ended questions were analysed using qualitative content analysis in six steps inspired by Graneheim and Lundman:[16] (1) written material was first read several times to obtain a sense of the overall data; (2) the text was divided into meaning units; (3) the meaning units were condensed; (4) condensed meaning units were coded; (5) codes were compared, contrasted, and sorted into categories; and (6) categories were sorted into different themes. Quotations were used to further illustrate the themes.

Comparative analysis with other cohorts of children with CP

To investigate whether children with CP in Uganda developed similar skills and abilities as children in HICs, we compared the data from the present study with data from two CP cohorts in Sweden,[17,18] and from the Australian CP registry.[19] The pattern of functional classification levels was compared with data from a population-based CP cohort including 186 children with CP aged 4 to 8 years within a geographically defined area of western Sweden.[17] To compare the development of mobility and self-care skills over age, we used PEDI data from a convenient cohort of 116 children aged 3 to 15 years, collected to describe the development of functional ability over time.[18]

Statistical analysis

We double entered and verified data using Visual FoxPro version 9.0 (first visit) and spot checks (second visit). Stata

version 14.2 (Statcorp, College Station, TX, USA) and R software version 3.2.3 (R Foundation for Statistical Computing, Vienna, Austria) were used for statistical analyses. χ^2 tests compared three groups of GMFCS levels (I–II, III, and IV–V) and two groups of MACS levels (I–II and III–V) between two age groups (2–5y and 6–17y). For categories with few individuals, the *p*-value was calculated using a Monte Carlo simulation in R software.[20] Linear regression models were used with PEDI scores as the dependent variable and combinations of GMFCS or MACS levels, age, group (Sweden or Uganda), and interactions as independent variables. The model assumptions of normality of the residuals and homogeneity of the variance were assessed using diagnostic plots (Table S1, online supporting information).

RESULTS

Background demographics

Complete functional assessment was performed on 93 of 97 children with CP identified in 2015; two children died between the first and second examinations, and two children had moved out of the area. The background information on the 93 children and their household's socio-economic status is presented in Table 1. Most families were living in rural areas working as subsistence farmers, and most households lived in extreme poverty, with incomes below the national poverty level (<0.9 US dollars/person/day).[21]

Table 1: Background demographics of children with cerebral palsy and their main caregivers

Category	*n*=93
Age	
2–5y	33 (35)
6–17y	60 (65)
Sex	
Female	40 (43)
Male	53 (57)
Residence area	
Semi-urban	26 (28)
Rural	67 (72)
Main caregiver	
Mother	67 (72)
Grandmother	17 (18)
Father	4 (4)
Sister	3 (3)
Another relative	1 (1)
Missing	1 (1)
Education of main caregiver	
None	18 (19)
Primary	47 (51)
Secondary	19 (20)
Adult education	1 (1)
Certificate	1 (1)
University degree	1 (1)
Missing	6 (6)
Occupation of main caregiver	
Farmer	65 (70)
Petty trade	13 (14)
Unemployed	1 (1)
Teacher	2 (2)
Vocational	5 (5)
Traditional healer	1 (1)
Missing	6 (6)
Estimated monthly household income (USD/d)[a]	
<27 (<0.9 person/d)	57 (61)
28–51 (0.9–1.7 person/d)	20 (22)
52–133 (1.7–4.4 person/d)	5 (5)
>134 (>4.5 person/d)	2 (2)
Unknown	7 (8)
Missing	2 (2)

Data are *n* (%). [a]US dollars (USD)/person/day calculated from estimated household income. The international poverty line is 1.9 USD/day per person and the national Ugandan poverty line is 0.9–1 USD/person/day.[21] Mean number of persons living in each household is seven.

Functional classifications

The proportion of children aged 2 to 5 years with severe mobility impairment (GMFCS levels IV–V) was three times higher (36%) than for children aged 6 to 17 years (10%; p=0.002; Table 2). Similarly, severe hand function impairments (MACS levels IV–V) were more common among children aged 2 to 5 years (48%) than in children aged 6 to 17 years (10%; p=0.01). The difference in proportion between these two age groups (2–5y and 6–17y) were significant (GMFCS levels IV–V p=0.002 and MACS levels IV–V p=0.01). When the severity of motor impairments in this Ugandan population was compared with that in a cohort of children from Sweden,[17] there were significant differences for the younger age group in GMFCS levels (p<0.001), with proportionally more severe impairments in the Ugandan sample, but not in MACS (p=0.29). For the older age group there were differences between the populations in both GMFCS levels (p<0·001) and MACS levels (p=0.006), with less severe impairments in the Ugandan cohort.

Communication skills were assessed only in the older children (Table 2), of whom 38% could not communicate consistently even with familiar partners such as family members (Communication Function Classification System levels IV–V). The verbal ability from the PEDI social skills in the same age group of 6 to 17 years showed that 22 (37%) were non-verbal, three (5%) could say single words, six (10%) could say two-word sentences, one (2%) could say four- to five-word sentences, and 28 (47%) could tell a simple story.

Associated impairments

The prevalence of associated impairments in the present population and in children from Sweden and Australia are shown in Table 3.[17,21] Intellectual disability (confirmed) was common in both age groups (45% in younger, 58% in older). It was less prevalent in children with mild motor impairments (41% of those in GMFCS levels I–II vs 89% of those in GMFCS levels IV–V). Of the 33 Ugandan children with confirmed seizures, only 13 were currently on antiepileptic medication, giving an epilepsy treatment gap of 61%. Overall, roughly one-third (32%) had no associated impairments, one-third (37%) had one associated impairment, and one-third (31%) had two or more associated impairments. In addition, one child had bilateral clubfoot, and one child had features of Down syndrome.

Table 2: Functional classifications in children with cerebral palsy

Level	*n* (%) in Uganda		Sweden (%)[a]
	2–5y (*n*=33)	6–17y (*n*=60)	
GMFCS			
I–II	13 (39)	43 (72)	65[17]
III[b]	8 (24)	11 (18)	3[17]
IV–V	12 (36)	6 (10)	33[17]
MACS			
I–II	16 (48)	46 (77)	59[17]
III	1 (3)	8 (13)	9[17]
IV–V	16 (48)	6 (10)	32[17]
CFCS			
I–II		23 (38)	41[37]
III		14 (23)	21[37]
IV–V		23 (38)	38[37]

Distribution of children and severity levels categorized by Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), and Communication Function Classification System (CFCS) displayed in a younger (2–5y) and an older (6–17y) age group (CFCS only assessed in the older age group). [a]Data are derived for the entire age range from Swedish cohorts.[17,37] [b]Note that GMFCS level III was slightly adapted for the Ugandan environment. None of the children had access to assistive devices for walking; therefore, children who can sit independently and move shorter distances (crawling, etc.) but not walk (without assistive devices) were included.

Table 3: Most common associated impairments in cerebral palsy

Associated impairment	*n* (%) in Uganda		HIC (%)[a]
	2–5y (*n*=33)	6–17y (*n*=60)	
Intellectual disability			
Confirmed	15 (45)	35 (58)	33–45[17,19]
Unconfirmed	8 (24)	8 (13)	26[19]
Behaviour impairment			
Confirmed	4 (12)	12 (20)	
Unconfirmed	5 (15)	14 (23)	
Seizures			
Confirmed	10 (30)	23 (38)	29–44[17,19]
Unconfirmed	5 (15)	10 (17)	
Vision impairment			
Confirmed	5 (15)	6 (10)	17–35[17,19]
Unconfirmed	6 (18)	14 (23)	
Hearing impairment			
Confirmed	1 (3)	6 (10)	12[19]
Unconfirmed	6 (18)	9 (15)	

The presence of associated impairments are displayed for the younger and older age group. Confirmed means that two or more of the sources observed impairment; unconfirmed means that there was only observation from one source. [a]Comparative population-based data from high-income countries are derived for the entire age range from Sweden[17] and Australia.[19]

Mobility, self-care, and social skills

The PEDI functional skill scores in mobility, self-care, and social skills in the different age groups are presented in Table S2 (online supporting information). In general, mean performance increased with age, but we observed that the development with age in Ugandan children seemed to be lower than expected and therefore compared the developmental trajectories with similar data from Sweden.[18] Figure 1 shows PEDI mobility scores plotted as a function of age according to GMFCS levels in both populations. Mobility skills increased with age for children with milder forms of CP (GMFCS levels I–II) in both Uganda and Sweden. However, the interaction between mobility and age was different between the two cohorts ($p<0.001$), with a stronger positive correlation between mobility and age in the Swedish versus the Ugandan cohort. In the moderately affected group (GMFCS level III), the Swedish children, but not the Ugandan children, scored higher with age ($p<0.001$). In the severely affected group (GMFCS levels IV–V), PEDI mobility scores improved in the Swedish cohort ($p=0.015$) but not in the Ugandan cohort ($p=0.72$).

Similar differences between the Ugandan and Swedish cohorts were found when PEDI self-care functional skills scores were plotted as a function of age for different MACS severity levels (Fig. 2). In the mildest-affected group (MACS level I), both cohorts scored higher with age, but the increase was greater in the Swedish cohort ($p=0.02$). For MACS level II, the difference between cohorts was significant ($p<0.001$), with a positive correlation observed in the Swedish cohort but not in the Ugandan cohort, including 10 children over 10 years of age with low PEDI scores (<63), all of whom had intellectual disability. Likewise, for children in MACS levels III to V, PEDI scores increased with age in the Swedish cohort ($p=0.014$) but not in the Ugandan cohort ($p=0.09$).

Assistive devices

Three of 37 non-walking children had wheelchairs in working condition, and none had assistive devices for walking (canes, crutches, or walkers). Two children, who were neighbours, shared a locally made walker for knee walking. Only one child had a locally made special chair for sitting. Thirteen children with no mobility were dependent on being carried. Twenty-one non-walking children moved short distances by rolling, creeping, crawling, bottom shuffling, or walking while holding on to objects. Thirty-five of the caregivers (95%) with non-walking children wanted to have any/additional assistive devices for mobility, such as a wheelchair (*n*=20), walking device (*n*=9), special seat (*n*=6), standing frame (*n*=3), or ankle–foot orthotics (*n*=1).

None of the children with vision or hearing impairment had any kind of assistive devices, such as hearing aids or spectacles. None of the children with communication difficulties had any kind of assistive devices for communication, including low-tech devices such as communication boards.

School enrolment

One third (*n*=18/60) of the older children (aged 6–17y) with CP attended school. School attendance decreased with increasing GMFCS and Communication Function Classification System levels and with the presence of associated impairments and seizures (Fig. 3). Children in GMFCS levels IV to V did not attend school. Only three children with seizures (confirmed), and three children with intellectual disability (confirmed) were in school. Of the children that were attending school, all but one had mild

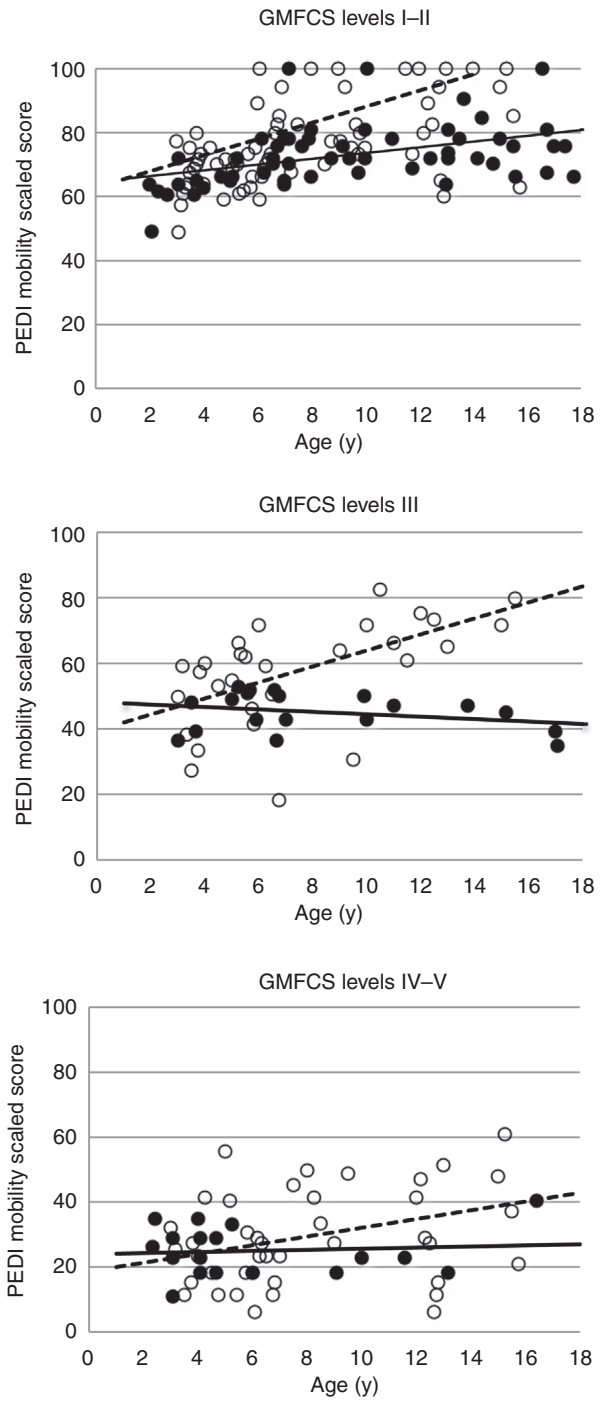

Figure 1: Scatter plots of Paediatric Evaluation of Disability Inventory (PEDI) scores for functional mobility plotted against age for children in Gross Motor Function Classification System (GMFCS) levels I–II, III, or IV–V in Uganda (filled circles) or Sweden (open circles).[17] Statistics for GMFCS levels I–II: difference, Uganda–Sweden, $p<0.001$; Uganda, $p<0.001$, Sweden, $p<0.001$. GMFCS level III: difference, Uganda–Sweden, $p<0.001$; Uganda, $p=0.2$, Sweden, $p<0.001$, GMFCS levels IV–V: difference, Uganda–Sweden, $p=0.18$; Uganda, $p=0.72$, Sweden, $p=0.015$. (Also see Table S2, online supporting information).

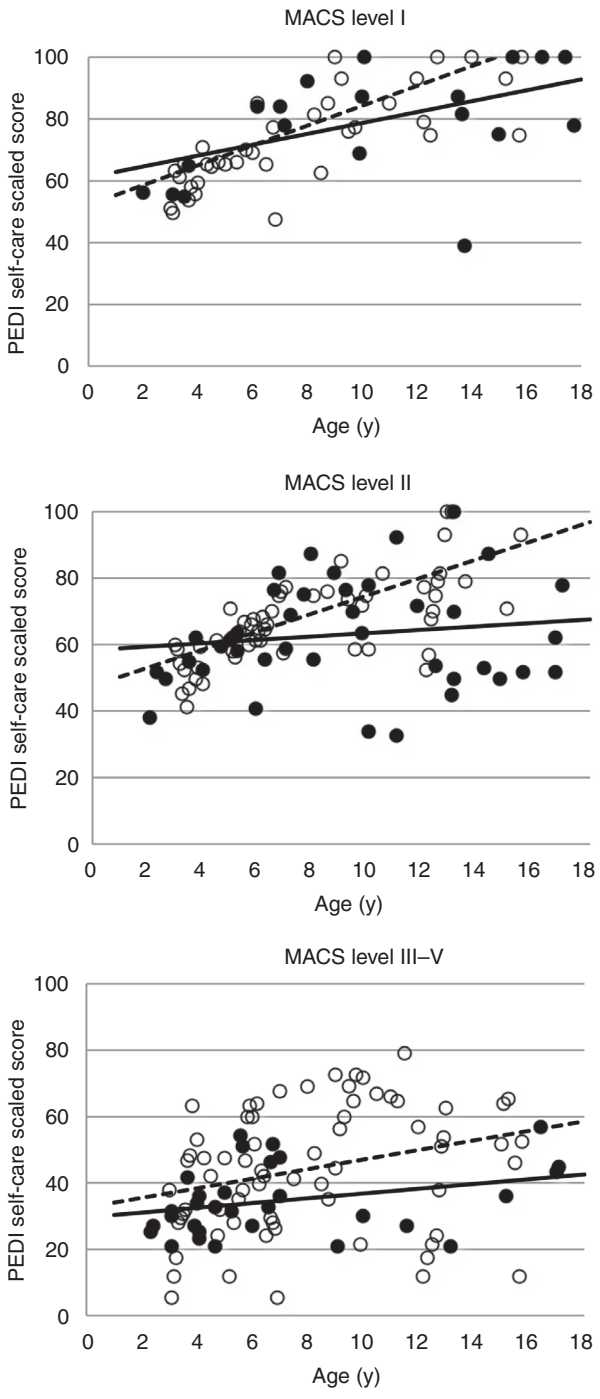

Figure 2: Scatter plots of Paediatric Evaluation of Disability Inventory (PEDI) score for self-care skills plotted against age for children in Manual Ability Classification System (MACS) levels I, II, or III–IV in Uganda (filled circles) or Sweden (open circles).[17] Statistics for MACS level I: difference, Uganda–Sweden, $p=0.02$; Uganda, $p=0.02$, Sweden, $p<0.001$. MACS level II: difference Uganda–Sweden, $p<0.001$; Uganda, $p=0.38$, Sweden, $p<0.001$. MACS levels III–V: difference, Uganda–Sweden, $p=0.38$; Uganda, $p=0.09$, Sweden, $p=0.014$. (Also see Table S2, online supporting information).

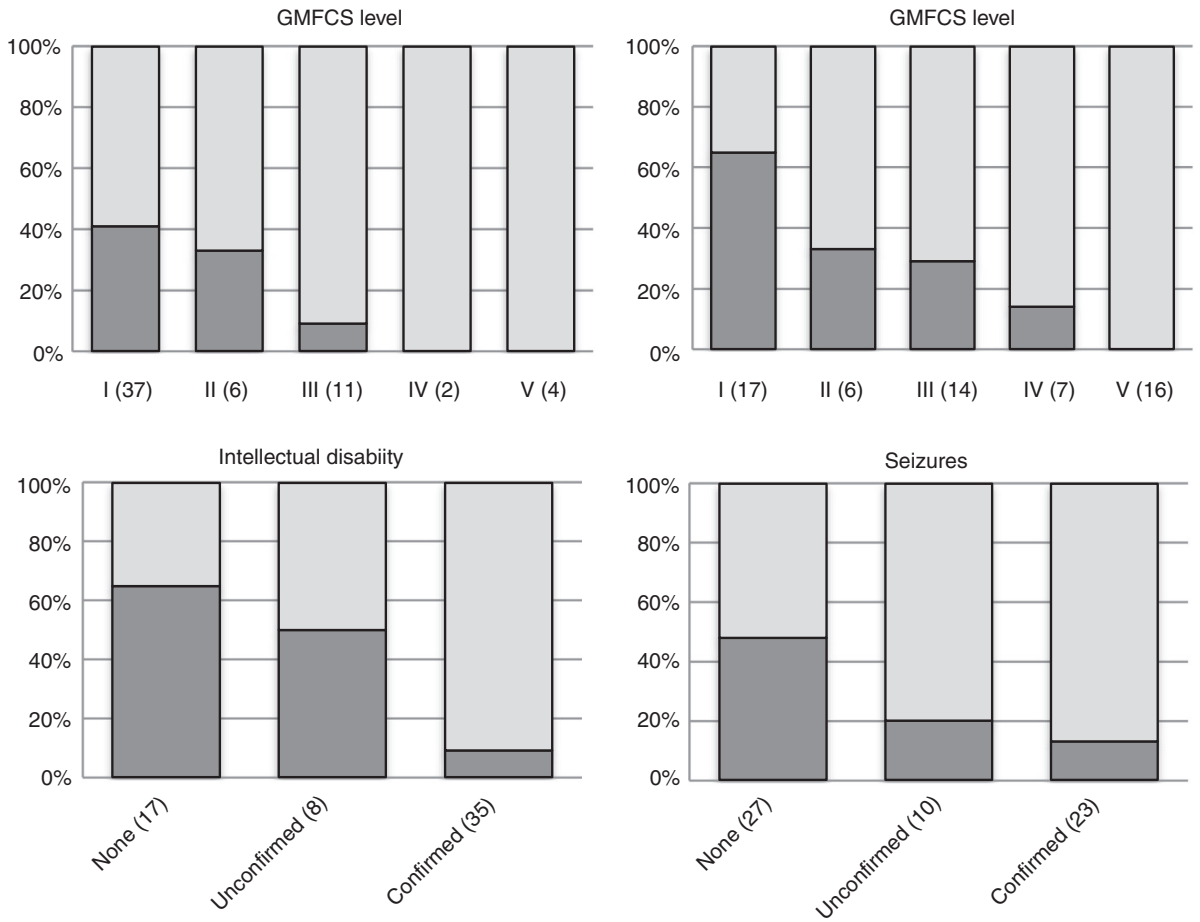

Figure 3: School attendance of children with cerebral palsy aged 6–17 years according to impairments: attending (dark grey; *n*=18); not attending (light grey; *n*=42). GMFCS, Gross Motor Function Classification System; CFCS, Communication Function Classification System.

functional impairments in motor function (GMFCS levels I–II and MACS levels I–II), one non-walking child attended school (GMFCS level III); this child had no assistive device but was young and light and was carried to school by the caregiver.

Service seeking

Seventy-four of the 93 caregivers wanted their children to improve in activities, such as rolling, sitting, crawling, standing, walking, or using hands. Of these, one-third (31%) had searched for help during the previous year at the various sites as presented in Table 4. Help was most frequently sought at government hospitals or health centres, traditional medicine practitioners, and non-governmental organization (NGO)-led health programmes. Children visiting public health centres and hospitals had mainly received medicines, for example antiepileptic medication. Some NGOs provided advice and therapy, but their support was sporadic and dependent on the caregiver's time and transport possibilities.

Qualitative content analysis was performed from the open-ended questions with the 51 caregivers that had not sought help to improve their child's functioning. The analysis identified the following themes for not seeking care: lack of money; lack of knowledge; lost hope; thinking motor difficulties were not the major problem and would go away with time; their main concern were convulsions.

Examples

Lack of money to seek for help, for transport costs, to pay for services and to buy the needed equipment:

> 'Because I do not have the money to buy the equipment' (sibling of 7-year-old male, GMFCS level III and MACS level III).

Lack of knowledge of what is wrong with the child, what could be done, what kind of help could be received, and where to look for help or assistive devices:

> 'I didn't know even what to do to help my child, I don't know where to begin from' (mother of 4-year-old male, GMFCS level V and MACS level V).

Lost hope and given up on the child improving. This could sometimes be related to having previously sought

Table 4: Summary of care

	Help received for child's motor impairment[a]	
Places where help was sought in the last 12mo	*n*	Services provided (*n*)
Government hospitals and health centres	13	Unspecified medicine (2), topical medicine to smear on hands (1), antiepileptic medication (3), advice (1), eye surgery (1), advice and passive stretching (1), sought assistive devices and got no help (2), missing (2)
Traditional medicine practitioners (Sheiks, witch doctors, herbal medicine men)	9	Herbs (5), asked for money and white chicken for ritual (1), herbs and exercises (1), prayer and Arabic medicine (1), missing (1)
NGO-driven outreach programs or centres	4	Motoric and vision assessment (1), toys for hand training (1), physical exercises and advice (1), ankle–foot orthotics (1)
CURE children's hospital of Uganda in Mbale, non-governmental non-profit organization	2	Epilepsy medicine and advice (1), caregiver training in passive stretching and sitting exercises (1)
District disability/parish councillor to seek assistive devices	2	Sought assistive devices and got no help (2)
Private hospital	1	Unspecified medicine (1)
Church	1	Praying (1)
Private person to seek financial help	1	None (1)
Private shops to seek assistive devices	1	None (1)

Caregivers seeking help to improve the motor impairment and to get assistive devices for mobility for their child in the last 12 months.
[a]Twenty-three caregivers had sought help 34 times (range 1–3 episodes per caregiver). NGO, non-governmental organization.

help and not seeing an improvement or not receiving the help they wanted:

> 'Whenever we take her to hospital/clinics, we are always told that there is nothing much they can do to make her condition improve. . .I have given up any hope of her ever improving, and we are just waiting for her to die' (sister of 6-year-old female, GMFCS level V and MACS level V).

DISCUSSION

An unexpected, and principally important, finding of this study was the slow development of mobility and self-care skills over age in children with CP in a rural part of Uganda. In the cohort of children in GMFCS levels III to V there was no increase in PEDI mobility skills with age, which is in contrast to children in the same GMFCS levels in Sweden. Likewise, while there was an increase in PEDI self-care skills with age in children in MACS level II to V in Sweden, there was no such increase in the Ugandan cohort. At the lowest levels (GMFCS level I and MACS level I) the Ugandan children increased in both mobility and self-care skills with age but not at the same rate as in the Swedish cohort. As GMFCS and MACS levels are supposed to be stable over time, these results suggest that children in Uganda with the same original impairments as those in Sweden do not reach their developmental potential toward independent mobility and self-care. These findings suggest that the enabling environment in Sweden stimulates children's development, in contrast to the conditions in Uganda. The Swedish environment includes several factors such as parental training, activity-based interventions, medical/surgical treatment, assistive devices, and active inclusion in schools, all aiming to improve function, abilities, and participation of children with CP.[22] This corresponds with research on activity-driven neural plasticity for skill acquisition,[23] and with clinical trials showing that therapies, including active learning and training, drive plasticity and improve function.[6,24]

Most of the children in the study lacked access to rehabilitation services, assistive devices, and education. None of the children had any assistive devices for seeing, hearing, or communication. Only one child received regular therapy, and the only assistive devices were a few wheelchairs donated from NGOs. The absence of devices for mobility prevented children from developing independent mobility or constrained them to a lying position, leaving the caregivers to carry them from place to place. This restricted their participation in family and community life, and often resulted in the children being neglected and left alone at home. Some children used rolling or creeping techniques to move around, but this requires a large amount of energy and induces discomfort.

One-third of caregivers had sought some sort of care the previous year, while the majority had not owing to lack of money; lack of knowledge; lost hope; and thinking motor difficulties were not the major problem or would go away with time. Previous studies in Uganda have shown that caregivers spend much of their time and finances visiting different service providers in the quest for a cure for their child.[25] The only public facility that offers specialist neurology services in Uganda is the national referral hospital, but long distances, delays at health facilities, poor quality of services, and poverty make it difficult for caregivers to go to the hospital for specialized care.[3] At the time of the study, no NGOs were providing regular services for children with disabilities in the area. Travel costs pose a barrier towards accessing services as most families in our study were subsistence farmers living well below national poverty levels. This may be why most caregivers had given up searching for assistance. To increase the access to services for children with CP in Uganda, locally available and affordable interventions are needed. Community-based interventions are cost-effective for providing large-scale

services to local populations and have shown promising results.[26] However, further studies are needed to properly evaluate these and other methods for low-income settings, such as training programmes for parents of children with developmental disabilities, which are under development by the World Health Organization.[27] A community-based training programme for parents of children with CP was recently evaluated in Ghana that improved caregivers' quality of life and knowledge and their confidence in caring for their child.[28]

School attendance can be used as a proxy measure of participation for children with disabilities. We found that only 30% of the children with CP attended school, although Uganda is promoting inclusive education,[29] and 74% to 87% of children in the general population attend school.[30] None of the children in this study with severe mobility limitations (GMFCS levels IV–V) were in school. The present findings are in agreement with a previous report showing that children with disabilities from LMICs are less likely to attend school and have less education than persons without disabilities,[2] despite the 'inclusive and quality education for all' called for by Sustainable Development Goal 4.

The results of the present study show that intellectual disability is more common in children with CP in Uganda than in those in HICs.[17,19] Although this may reflect differing patterns of brain injury,[9] it is possible that the lack of stimulation during the first years and low school attendance may have played a role. We previously reported that severe forms of CP were more prevalent in younger children than in the older age groups.[9] The present study extends this to reveal there are twice as many non-walking children, and a five-fold larger proportion of children with poor hand function (MACS levels IV–V), in the younger cohort. Unlike previous reports from LMICs and HICs,[17,19,31–35]] the associated impairments reported here varied between age groups. As any age differences would likely have been noticed in registers and population-based studies performed in HICs, this phenomenon may be unique to LMICs, reflecting an increased mortality among children with severe forms of CP,[9] which was previously unrecognized due to the lack of population-based studies.[4,36] This finding underscores the importance of conducting population-based studies and indicates that subsequent studies on neurodevelopmental disorders from LMICs consider and present results for different age cohorts.

Strengths and limitations

This study is the first population-based study in Africa describing functional limitations, associated impairments, and care-seeking for children with CP. Another strength is that we used contemporary international methods for diagnoses and to assess functions and disability, enabling comparisons with results from leading CP registries in HICs and with subsequent population-based studies in LMICs. A limitation is that we did not use standardized methods to assess associated impairments. However, the questionnaires we used were based on the Washington group extended question set of functioning,[15] which is recommended for screening in low-income countries where appropriate specialists and equipment are lacking. It is also important to recognize that the study was performed in a rural area of Uganda and is therefore not representative of urban areas, for example Kampala, the capital of Uganda.

CONCLUSION

Children with CP in Uganda lack access to health care, assistive devices, and education, which probably contributes to their poor development of mobility and self-care skills. Changing the situation for these children will require development and evaluation of low-cost near-client services, as most families are poor subsistence farmers that do not have resources for transport and health and social services, which are, at present, inadequate.[3]

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SUPPORTING INFORMATION

The following additional material may be found online:

Table S1: Linear regression models PEDI scores.

Table S2: PEDI functional skills scaled scores.

Appendix S1: Detailed descriptions of statistical methods and results.

REFERENCES

1. Kassebaum N, Kyu HH, Zoeckler L, et al. Child and adolescent health from 1990 to 2015: findings from the Global Burden of Diseases, Injuries, and Risk Factors 2015 Study. *JAMA Pediatr* 2017; **171**: 573–92.
2. UNESCO. Education and Disability: Analysis of Data from 49 Countries. 2018; Information Paper No. 49. Available at: http://uis.unesco.org/en/news/education-and-disability-analysis-data-49-countries (accessed 14 October 2019).
3. Wilmshurst JM, Badoe E, Wammanda RD, et al. Child neurology services in Africa. *J Child Neurol* 2011; **26**: 1555–63.
4. Donald KA, Kakooza AM, Wammanda RD, et al. Pediatric cerebral palsy in Africa: where are we? *J Child Neurol* 2015; **30**: 963–71.

5. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl* 2007; **109**: 8–14.
6. Novak I, McIntyre S, Morgan C, et al. A systematic review of interventions for children with cerebral palsy: state of the evidence. *Dev Med Child Neurol* 2013; **55**: 885–910.
7. Henderson S, Skelton H, Rosenbaum P. Assistive devices for children with functional impairments: impact on child and caregiver function. *Dev Med Child Neurol* 2008; **50**: 89–98.
8. Maulik PK, Darmstadt GL. Childhood disability in low- and middle-income countries: overview of screening, prevention, services, legislation, and epidemiology. *Pediatrics* 2007; **120**(Suppl. 1): S1–55.
9. 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 Global Health* 2017; **5**: e1275–82.
10. Palisano RJ, Rosenbaum P, Bartlett D, Livingston MH. Content validity of the expanded and revised Gross Motor Function Classification System. *Dev Med Child Neurol* 2008; **50**: 744–50.
11. Eliasson AC, Krumlinde-Sundholm L, Rösblad B, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Dev Med Child Neurol* 2006; **48**: 549–54.
12. Hidecker MJ, Paneth N, Rosenbaum PL, et al. Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Dev Med Child Neurol* 2011; **53**: 704–10.
13. Kakooza-Mwesige A, Tumwine JK, Forssberg H, EliassonAC. The Uganda version of the Pediatric Evaluation of Disability Inventory (PEDI). Part I: cross-cultural adaptation. *Child Care Health Dev* 2018; **44**: 552–61.
14. Amer A, Kakooza-Mwesige A, Jarl G, et al. The Ugandan version of the Pediatric Evaluation of Disability Inventory (PEDI-UG). Part II: psychometric properties. *Child Care Health Dev* 2018; **44**: 562–71.
15. Washington Group. Washington Group - Extended Question Set on Functioning. Available at: http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/WG_Extended_Question_Set_on_Functioning.pdf (accessed 14 October 2019).
16. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; **24**: 105–12.
17. Himmelmann K, Uvebrant P. Function and neuroimaging in cerebral palsy: a population-based study. *Dev Med Child Neurol* 2011; **53**: 516–21.
18. Öhrvall AM, Eliasson AC, Löwing K, Ödman P, Krumlinde-Sundholm L. Self-care and mobility skills in children with cerebral palsy, related to their manual ability and gross motor function classifications. *Dev Med Child Neurol* 2010; **52**: 1048–55.
19. Australian Cerebral Palsy Register Group. Australian Cerebral Palsy Register Report 2016. Available at: https://cpregister.com/wp-content/uploads/2018/05/ACPR-Report_Web_2016.pdf (accessed 14 October 2019).
20. Hope ACA. A simplified Monte Carlo significance test procedure. *J R Stat Soc* 1968; **30**: 582–98.
21. World Bank Group. The Uganda poverty assessment report 2016. Available at: http://pubdocs.worldbank.org/en/381951474255092375/pdf/Uganda-Poverty-Assessment-Report-2016.pdf (accessed 14 October 2019).
22. Degerstedt F, Wiklund M, Enberg B. Physiotherapeutic interventions and physical activity for children in Northern Sweden with cerebral palsy: a register study from equity and gender perspectives. *Global Health Action* 2016; **10**(Suppl. 2): 1272236.
23. Steele CJ, Zatorre RJ. Practice makes plasticity. *Nat Neurosci* 2018; **21**: 1645–6.
24. Diaz Heijtz R, Almeida R, Eliasson AC, Forssberg H. Genetic variation in the dopamine system influences intervention outcome in children with cerebral palsy. *EBioMedicine* 2018; **28**: 162–7.
25. Hartley S, Ojwang P, Baguwemu A, Ddamulira M, Chavuta A. How do carers of disabled children cope? The Ugandan perspective. *Child Care Health Dev* 2005; **31**: 167–80.
26. World Health Organization. Community based rehabilitation guidelines. Available from: http://www.who.int/disabilities/cbr/guidelines/en/ (accessed 14 October 2019).
27. Reichow B, Kogan C, Barbui C, Smith I, Yasamy MT, Servili C. Parent skills training for parents of children or adults with developmental disorders: systematic review and meta-analysis protocol. *BMJ Open* 2014; **4**: e005799.
28. Zuurmond M, O'Banion D, Gladstone M, et al. Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS One* 2018; **13**: e0202096.
29. Abimanyi-Ochom J, Mannan H. Uganda's disability journey: progress and challenges. *Afr J Disabil* 2014; **3**: 108.
30. Uganda Bureau of Statistics. National population and housing census 2014. Available at: https://unstats.un.org/unsd/demographic/sources/census/wphc/Uganda/UGA-2016-05-23.pdf (accessed 14 October 2019).
31. Sellier E, Platt MJ, Andersen GL, et al. Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003. *Dev Med Child Neurol* 2016; **58**: 85–92.
32. Van Naarden Braun K, Doernberg N, Schieve L, Christensen D, Goodman A, Yeargin-Allsopp M. Birth Prevalence of cerebral palsy: a population-based study. *Pediatrics* 2016; **137**: e20152872.
33. El-Tallawy HN, Farghaly WM, Shehata GA, et al. Cerebral palsy in Al-Quseir City, Egypt: prevalence, subtypes, and risk factors. *Neuropsychiatr Dis Treat* 2014; **10**: 1267–72.
34. El-Tallawy HN, Farghaly WM, Shehata GA, Metwally NA, Rageh TA, Abo-Elfetoh N. Epidemiology of cerebral palsy in El-Kharga District-New Valley (Egypt). *Brain Dev* 2011; **33**: 406–11.
35. Couper J. Prevalence of childhood disability in rural KwaZulu-Natal. *S Afr Med J* 2002; **92**: 549–52.
36. Donald KA, Samia P, Kakooza-Mwesige A, Bearden D. Pediatric cerebral palsy in Africa: a systematic review. *Semin Pediatr Neurol* 2014; **21**: 30–5.
37. Himmelmann K, Lindh K, Hidecker MJ. Communication ability in cerebral palsy: a study from the CP register of western Sweden. *Eur J Paediatr Neurol* 2013; **17**: 568–74.