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# Pediatric Cerebral Palsy in Africa: Where Are We?

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# Pediatric Cerebral Palsy in Africa: Where Are We?

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## Abstract

Cerebral palsy is the most common cause of physical disability in children worldwide. However, little is reported on this condition in the African context. Doctors from 22 countries in Africa, and representatives from a further 5 countries outside Africa, met to discuss the challenges in the evaluation and management of children with cerebral palsy in Africa and to propose service needs and further research. Basic care is limited by the poor availability of diagnostic facilities or medical personnel with experience and expertise in managing cerebral palsy, exacerbated by lack of available interventions such as medications, surgical procedures, or even regular therapy input. Relevant guidelines are lacking. In order to guide services for children with existing disabilities, to effectively target the main etiologies and to develop preventive strategies for the continent, research priorities must include multicenter collaborative studies looking at the prevalence, risk factors, and treatment of cerebral palsy.

## Keywords

cerebral palsy, etiologies, review, consensus

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Cerebral palsy is a common neurologic problem in children and is reported globally in approximately 2 to 2.5/1000 live births.<sup>1</sup>

Very little has been reported on this condition in the African context. A working group under the auspices of the African

Child Neurology Association (a subgroup of the International Child Neurology Association) addressed challenges in the management of children with cerebral palsy in Africa. The aim of the meeting was to develop an active group tasked with identifying strategic goals in the management of children with

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**Figure 1.** Cerebral Palsy in Africa meeting delegates.

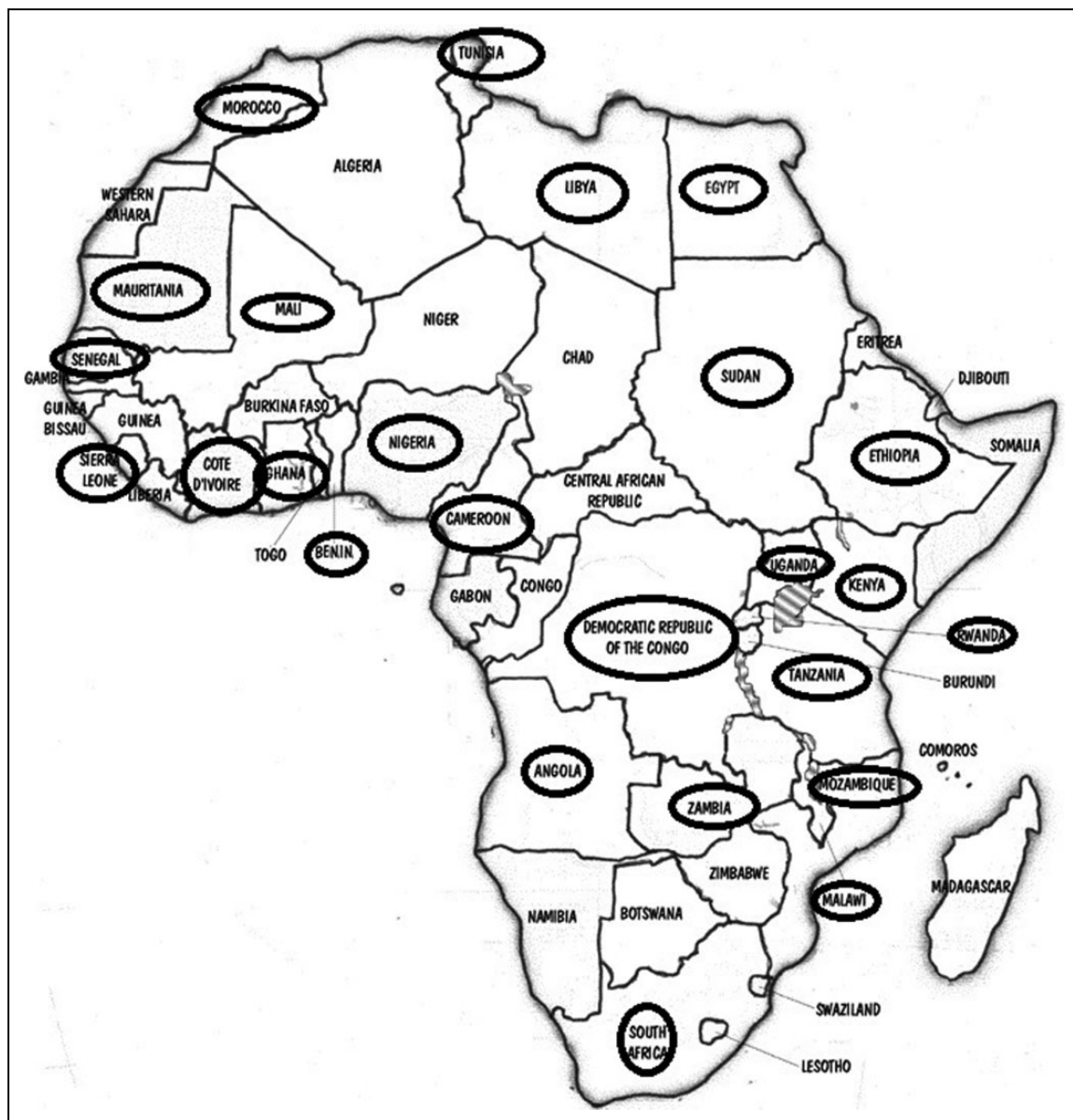
cerebral palsy in Africa. The following text summarizes the key findings from this meeting.

## Methods

Doctors from 22 countries in Africa and representatives from a further 5 countries outside Africa participated in discussions around issues affecting the identification and management of children with cerebral palsy in Africa (Figure 1). African attendees who were identified as key opinion leaders in the field of child neurology in their country were invited to attend the meeting. In many settings, this was based on the doctor being the only child neurologist in the country or being recommended by the national pediatric neurology association. Each delegate completed a questionnaire relating to specific aspects of care for children with cerebral palsy in their country prior to the meeting. These findings were collated, and they guided the focus and discussion points addressed in the program. The scientific program consisted of a range of topics spanning from the state of the art in diagnosis and management to the challenges of basic care delivery in the context of resource-poor settings. Topics included the advances in the understanding of the neurobiology underlying the cerebral palsies, clinical and functional classification systems, theories around the relationship

between different factors in the causal cascade of this group of conditions, thoughts on the different spectrum of causes in resource-poor countries, management priorities, and cost-effective management strategies. In addition, specific topics such as vision, seating, and surgical interventions in cerebral palsy were discussed with emphasis on the appropriateness of different strategies in the African context.

Selected delegates from different regions across the continent gave concise presentations on a situational analysis and the specific challenges for their country or region. Focused time was allocated for the group to discuss how each presentation related to cerebral palsy in the African context. The final part of the meeting consisted of small working groups that discussed key themes that had arisen during the meeting and are discussed in more detail below, namely, capacity, definitions and etiology, guidelines, training, and education needs. Each theme was summarized by one of the African delegates who cofacilitated a working group. The videos of the presentations were made available on the ICNpedia website ([www.ICNpedia.org](http://www.ICNpedia.org)) along with the presentations themselves (after the patient and data confidentiality was addressed). The presentations were delivered by members of the International Child Neurology Association (ICNA), African Child Neurology Association, NeuroDevNet, the Japanese Child Neurology Society, local content experts, and the delegates.



**Figure 2.** African countries represented at the International Child Neurology Association Cerebral Palsy Meeting, 2013.

## Results and Discussion

Twenty-two African countries were represented and provided information on their services, capacity, and approach to diagnosing and managing children with cerebral palsy (Figure 2). The groups were multilingual and as a result languages were not a barrier.

Information on overall medical, pediatric, and neurology services in Africa were recently reported by our group and these data are not included again here.<sup>2</sup> This and the current report highlight how removed from the recommended WHO ratios for medical professionals to numbers of children most countries in Africa remain. In addition to personnel challenges in terms of numbers, professionals face severe lack of resources in general from diagnostic to interventional capacity even at a

basic level. Information specific to cerebral palsy in children are summarized in Tables 1 and 2.

The group formed the following conclusions based on their experiences, the results from the situational analyses, and the subsequent small group workshops.

### Terminology

*Cerebral palsy* is a term often used in African contexts to describe all motor disability syndromes. Delegates reported that in many countries cerebral palsy is considered synonymous with birth asphyxia/neonatal encephalopathy. Internationally accepted consensus definitions are relevant in resource-poor countries but the lack of diagnostic facilities

**Table 1.** Information by Country for Professional Neurology Organizations and First Contact for Children With Cerebral Palsy.

Country	National paediatric neurology group	Pediatrics group	National Medical Group	First point of contact	Who makes diagnosis	System for at-risk babies	Specialist services
<b>North Africa</b>							
Egypt	Yes	Yes	Yes	Tertiary center	Pediatrician	Yes	Yes
Libya	No	No	No	Health clinic/ regional hospital	Pediatrician	Yes	Yes
Morocco	Yes	Yes	Don't know	Health clinic	Pediatrician	Yes	Yes
Sudan	Yes	Yes	Yes	Tertiary center	Medical officer	Yes	Yes
Tunisia	Yes	Yes	Yes	Local hospital	Primary health care worker	Yes	Yes
<b>West Africa</b>							
Benin	No	Yes	Yes	Regional hospital/ tertiary center	Primary health care worker/ pediatrician	No	No
Cameroon	Don't know	Don't know	No	Community health teams	Primary health care worker	No	No
Co'te d'Ivoire	No	Yes	No	Regional hospital	Primary health care worker	No	No
Ghana	No	Yes	Yes	Health clinic	Pediatrician	Yes, tertiary center	Yes, tertiary centers
Mali	No	Yes	Yes	Traditional healer	Nurse or pediatrician	No	No
Mauritania	No	No	Yes	Regional hospital	Medical officer	No	No
Nigeria	Yes	Yes	Yes	Health clinic	Medical officer	Yes	Yes
Senegal	No	Yes	Yes	Traditional healer	Primary health care worker	No	Yes (tertiary)
Sierra Leone	No	No	Yes	Depends on where child resides	Medical officer	No	No
<b>East Africa</b>							
Ethiopia	No	Yes	Yes	Traditional healer	Medical officer	No	No
Kenya	No	No	Yes	Tertiary center	Primary health care worker	Yes	Yes
Rwanda	No	Yes	Yes	Traditional healer	Primary health care worker	No	No
Tanzania	No	Yes	Yes	Health clinic	Primary health care worker	Yes (local pockets)	Yes
Uganda	No	No	Yes	Health clinic	Primary health care worker	Yes	Yes
<b>Central Africa</b>							
Angola	No	Yes	Yes	NR	NR	NR	NR
DRC	No	Yes	NR	Could be at any level	Could be primary care worker through to pediatrician	No	No
<b>Sub-Saharan Africa</b>							
Malawi	No	Yes	Yes	Tertiary center	Pediatrician/medical officer	Yes	Yes
Mozambique	No	Yes	Yes	Regional hospital	Medical officer	Yes	Yes
South Africa	Yes	Yes	Yes	Tertiary center	Pediatrician	Yes	Yes
Zambia		No	Yes	Tertiary center	Medical officer	Yes	Yes

Abbreviation: DRC, Democratic Republic of Congo.

makes excluding some of the “non-cerebral palsy” conditions or mimics more difficult (Table 2). Because of the perceived greater number of children with cerebral palsy secondary to postnatal complications in Africa (such as meningitis, cerebral malaria, traumatic brain injury), the “ceiling” age at which one can call a postnatal insult “cerebral palsy” may be more important in this group than in developed countries where postnatal etiology makes up a small proportion of reported cerebral palsy populations. Some groups in Africa include children who acquired brain injury up to the age of 5 years. The group concluded that using the international consensus definition age of 2 years was the most useful way to achieve consistency on the

reporting of the topic. There was also a robust discussion on whether certain acquired conditions should be included in the cerebral palsy group. The consensus was that congenital infections such as cytomegalovirus and rubella should be included, as well as traumatic brain injury and neurologic sequelae of meningitis (occurring at less than 2 years of age), providing they also met the other inclusion criteria for the diagnosis. Conditions that are included by some centers in Africa, such as neurologic impairment secondary to human immunodeficiency virus (HIV) encephalopathy, as well as disorders of muscle and peripheral nerves, should be excluded. The inclusion of these conditions in “motor disability” rather than “cerebral palsy”

**Table 2.** Available Services, Investigations, and Long-Term Management for Children With Cerebral Palsy by Country.

Country	Chronic care of cerebral palsy	Home disability program	Guidelines	Medications available	Hearing and vision	CT	PT	OT	SLT	Orthotics	Orthopedic interventions
North Africa											
Egypt	Pediatrician	No	Yes	Baclofen	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Libya	Pediatrician/pediatric neurologist	No	No	Diazepam, Baclofen, piracetam	Yes	Yes	Yes	No	No	Yes	Yes
Morocco	Pediatrician/pediatric neurologist	No	No	Baclofen	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sudan	Pediatrician	Yes	No	Baclofen	Yes	Yes	Yes	No	No	No	Yes
Tunisia	Pediatrician/pediatric neurologist	Yes	No	Baclofen	Yes	Yes	Yes	Yes	Yes	Yes	Yes
West Africa											
Benin	Pediatrician and paramedics	No	No	Diazepam	Yes	Yes	Yes	Yes	No	Yes	No
Cameroon	Specialized treatment center in Mambu Bafut	Yes	No	None	No	No	Yes	Yes	Yes	Yes	No
Co.te d'Ivoire	Few specialists	No	No	Baclofen	No	Yes	Yes	No	No	No	No
Ghana	Pediatrician	No	No	baclofen	Yes (tertiary)	Yes	Yes	No	Only private	Yes	Yes
Mali	Nurses or medical officer	No	No	Diazepam, baclofen	Yes	Yes (tertiary)	Yes	Yes	Yes	Yes	No
Mauritania	Primary health care worker	No	No	Baclofen	No	Yes	Yes	Yes	Yes	No	Yes
Nigeria	Pediatrician/pediatric neurologist	No	No	Diazepam	Yes	Yes	Yes	No	No	Yes	Yes
Senegal	Pediatrician/neuropediatrician	No	No	clonazepam	Yes	Yes	Yes (tertiary)	No	No	Yes	No
Sierra Leone	Depends on child's residence	No	No	Diazepam	No	Yes	Yes	No	No	Yes	Yes
East Africa											
Ethiopia	Primary health care worker	no	no	Diazepam	(only at 1 tertiary center)	3 in country	Yes	No	No	orthoses only	No
Kenya	Pediatrician	No	No	Baclofen	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Rwanda	NGOs	No	No	none	Yes (vision, hearing, no hearing), dependent on local services	yes	Yes	No	No	No	No
Tanzania	Pediatrician/pediatric neurologist	NGO sometimes	No	Baclofen	Yes (vision), no hearing), dependent on local services	not at the center (100 km away)	Yes	Yes	Yes	Yes	Yes
Uganda	Physiotherapist/occupational therapist or clinical officer/nurse if with concurrent epilepsy	No	No	None	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Central Africa											
Angola	NR	No	No	NR	NR	NR	NR	NR	NR	NR	NR
DRC	Medical officer	No	No	Diazepam	Yes (tertiary)	Yes	Yes (NGO)	No	No	No	No
Sub-Saharan Africa											
Malawi	Pediatrician/pediatric neurologist	No	No	Baclofen, Diazepam	Yes	Yes	Yes	Yes	No	Yes	Yes
Mozambique	Pediatrician	No	No	Diazepam	Yes	Yes	Yes	Yes	Yes	Yes	Yes
South Africa	Pediatrician and network of therapists and specialists	No	Yes	Diazepam	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Zambia	Pediatrician/pediatric neurologist	Yes	No	Diazepam	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Abbreviations: CT, computed tomography; DRC, Democratic Republic of Congo; NGO, nongovernmental organization; NR, no response; OT, occupational therapy; PT, physiotherapy; SLT, speech and language therapy.

clinics for service purposes was proposed. The use of definitions in cerebral palsy as highlighted above remain contested in environments outside of those with the specific challenges faced by professionals in the African context. The different understandings in the terminology used to define cerebral palsy will have implications on published prevalence and incidence studies and ensuring a common understanding was considered essential to move forward.

The spectrum of etiologies appears to be different to the well-described European and North American cohorts.<sup>3</sup> There are very little published data either on prevalence or etiology in African countries. Published reports presented and discussed by delegates were largely discreet cohorts often drawn from hospital clinics and therefore not population-based studies. The most common reported etiologies identified in African cohorts were birth asphyxia (neonatal encephalopathy), kernicterus, and neonatal infections, with prematurity or low birth weight only rarely identified as major contributors to cerebral palsy in Africa.<sup>4-15</sup> By contrast, almost all studies published out of the United States and Europe report prematurity and low birth weight as major risk factors for cerebral palsy.<sup>16</sup>

Delegates reported seeing a larger proportion of severely disabled (Gross Motor Function Classification System IV and V) children in their cohorts compared to European and North American cohorts. This is in keeping with the majority of studies from the African continent published to date.<sup>3</sup> This was postulated to be due to a combination of selection bias (hospital cohorts versus community), lack of access to medical services (resulting in only the most severe children who really need medical input to survive being brought to medical attention), and powerful stigma against disabled children (resulting in children being “hidden” when medical attention is not considered essential). Delegates felt that there may be overall a greater proportion of children with more severe disability in resource-poor countries because of delayed presentation of a range of disorders as well as the lack of early intervention services. However, this hypothesis needs to be tested across population-based epidemiologic studies. This was identified as a key research priority going forward.

Basic care levels and capacity in Africa are limited by the poor availability of medical personnel with experience and expertise in managing cerebral palsy as well as medication shortages and limited diagnostic testing. In addition, several participants noted lack of available interventions such as medications, surgical procedures, or even access to regular therapy input, with very few of even the tertiary centers having allied therapy services other than physiotherapy (Table 1). Participants noted a lack of consistently available drugs for managing spasticity and comorbidities such as epilepsy. This was especially notable in rural clinics, where it was common to run out midmonth, leaving no available treatments. This was often due to inefficient administrative controls, lack of standard operating procedures for managing supply chains, and limited supplier options necessitating utilization of unreliable government recommended suppliers. Limited access to health care facilities and specialists, as well as a lack of adaptive equipment such as

wheelchairs and other ambulation aids are likely to contribute to the treatment gap for children with cerebral palsy. In addition, high levels of social stigma toward children with neurologic disorders were repeatedly reported as reasons for families failing to seek treatment even when it was available in many African countries.

Further contributing to difficulties in accessing health care facilities for children with cerebral palsy is a lack of wheelchair-accessible transport. This represents a particular challenge for families with older nonambulant children with cerebral palsy. This impression reported by delegates is supported by a multisite-country study conducted by the African Child Policy Forum on the lives of children with disabilities in Africa, which noted that poverty powerfully affected caregivers’ ability to provide for the basic needs of their disabled children.<sup>17</sup> Caregivers found the financial costs attached to medical care, rehabilitation, assistive devices, and transportation a significant barrier to seeking care. Community-based rehabilitation programs were reported by parents as being effective in increasing access to education and assistive devices, but none of these have been evaluated systematically.

In relation to the medical complications of cerebral palsy, spasticity occurs in the majority of children with this condition and may significantly hamper mobility and fine motor function.<sup>18</sup> There is no published information on the accessibility of treatment options for spasticity in Africa, and based on the feedback from delegates about availability, it appears to be very poor except for a few tertiary and private facilities (Table 2). Medical interventions such as oral benzodiazepines seem to be most widely accessible. However, the use of medications such as this with significant cognitive side effects can only be considered appropriate for the most severe functional categories of cerebral palsy. There is limited access to several other supportive procedures reported in isolated centers across Africa, which include botulinum toxin, musculotendinous release for spastic hips, and selective dorsal rhizotomy. The reality of the management of this most common complication of cerebral palsy reflects how far removed from current global guidelines the management of cerebral palsy in Africa remains.<sup>19</sup>

Key themes that arose repeatedly centered on resources, training needs, education, and innovative approaches that are needed to maximize initial and sustained access to health care for children with cerebral palsy. Although some countries have dedicated child neurology clinics, this is often only the case for 1 or 2 teaching hospitals in an entire country. The group highlighted the need to improve early recognition of cerebral palsy among medical practitioners and to improve the capacity to provide basic management approaches for spasticity and other comorbidities.

Recommendations for the investigation and management of specific aspects of cerebral palsy are available through recent systematic reviews and pediatric organizations such as the American Academy of Pediatrics.<sup>18,20</sup> However, even in relatively well-resourced environments, consensus on clinical recommendations for the management of cerebral palsy remains



**Table 3.** Training Priorities for Africa.

Objective	Action
Introduce standardized and relevant training for neurodisability	Undergraduate level: Increased time in the curriculum dedicated to the concepts of prevention, recognition, multidisciplinary care, the role of early intervention Postgraduate level: focused modules targeting effective intervention across all levels of health care, eg, epilepsy and cerebral palsy
Expanding training across disciplines	Identify training centers across the continent with the capacity to train in pediatric neurodisability Recruit strategically placed health care workers inclusive of medical officers, nurses, community workers, rehabilitation therapists, to traditional healers Expand the training capacity in these centers
Encourage training and trainees to remain in Africa <a href="http://www.scah.uct.ac.za/scah/apfp">http://www.scah.uct.ac.za/scah/apfp</a>	“Africans training Africans for Africa”—this improves the relevance of the training and increases the retention of staff. Identify trainee from centers with the foundations to deliver specialized care, eg, other tertiary institutions Liaise with the training center of the specific training goals for the trainee Support the training in the home center in developing a structure to successfully implement a health care plan through the ongoing collaboration, the identification of working teams (nurses and rehabilitation staff), and the establishment of standard operating procedures that can be carried through to other levels of health care Collaborations with overseas experts who assist with the on-site training and establishment of services.

difficult to achieve. Reasons for this include the fact that cerebral palsy remains an umbrella concept that, though having an early static brain lesion and motor disability at its core, remains a heterogeneous condition in reality with a multitude of potential associated disorders and medical complications. The consequent involvement of many different disciplines and professions further inhibits consistent approaches.<sup>21</sup> Little is known about either the availability of guidelines, or recommendations, in practice across resource-poor countries in Africa, and certainly the delegates attending this meeting were not aware of guidelines in use locally. This was a similar finding to that described in the report from the 2012 meeting on epilepsy in Africa held in Uganda.<sup>2</sup> Lack of locally relevant guidelines is likely to be a transversal issue with respect to neurologic conditions in pediatrics across the continent. Delegates reported that guidelines from high-resource settings were often poorly accessible to them, both in content and relevance to the reality of practicing in countries with overburdened medical systems and where many patients live in remote and widely scattered settlements with poor road and transport infrastructure and limited access to investigations and medications. Home-based or community approaches to rehabilitation are described as being well suited for low-resource settings as it often requires relatively minimal infrastructure and resources to implement compared to alternative models, such as center-based interventions.<sup>22</sup> There is a lack of information regarding any intervention studies or evidence-based clinical studies on the efficacy of home-based interventions from Africa for children with cerebral palsy. However, some success has been reported using this approach in high-risk infants, and it remains an approach that should be explored further.<sup>23</sup>

It is clear that there is inadequate training at both undergraduate and postgraduate levels in pediatric neurology in

most medical schools across the African continent. Even for particularly prevalent conditions such as epilepsy and cerebral palsy, which constitute a significant burden of disease among the pediatric population, there is very little formal training in many centers. There are significant challenges in establishing training centers and addressing the training needs of specialists across Africa. Motivated medical personnel who seek training from specialist centers outside of their own countries often return to overwhelming workloads and an experience of isolation because of the scarcity of colleagues with similar expertise. The lack of a network of colleagues within a country is an underappreciated barrier to retention of these experts. Safety, financial considerations, and political instability also play a role in loss of scarce skills from countries across the continent. These are ongoing challenges that have to be addressed within each country. Training should be promoted within Africa by Africans to ensure that the training is relevant to the health needs of the region. Training in well-resourced, international centers should be focused on the acquisition of a relevant skill-set as well as assisting trainees in building relationships with both global and regional colleagues with similar interests in order to create a broader scaffold for support and collaboration. Visiting specialists can provide valuable focused input into African training programs, especially if they are from centers that are actively involved with training specialists from resource-limited settings (Table 3 for key training priorities).

## Conclusions

This meeting gave an excellent body of both academic and practical content around the topic of Cerebral Palsy in the African context. All the lectures were recorded and will be

available as podcasts (and pdf's) on the ICNApaedia website and are widely and freely available as a resource. Discussions following the didactic lectures are included in the material available.

Key points identified by the groups included the following:

- Longer-term training programs, which foster both clinical training and research collaborations, are a key priority. Existing networks already exist to a limited extent but need to be developed further.
- Research projects with a focus on prevalence, spectrum of cerebral palsy, and main etiologies in the African context using multisite, collaborative designs should be prioritized. This is key in order to inform policy, not only for services for children with existing disabilities but also in order to effectively target the main etiologies to develop preventive strategies for the continent.
- The value of this meeting included connecting a group of individuals, who often work as isolated professionals (as they may be the only such specialist in the country), driving the care of children with cerebral palsy in their region/country together to address challenges, which in many respects are similar across the continent. This is a forum that can be grown and expanded in order to focus the needs of children with neurodisability in Africa.

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### Author Contributions

KAD designed and collated the questionnaire data, coordinated the scientific program and was the main author of the manuscript. AK, PS, RW, HB, MM, AM, DB, MS, and HC all collated data from local sources to contribute to the workshops and participated in manuscript preparation. JMW coordinated the meeting with KAD and assisted with manuscript preparation.

### Author's Note

Attendees from Africa:

Dr Angelina Kakooza (Uganda), Dr Pauline Samia (Kenya), Prof Haydar Babakir (Sudan), Prof Robinson Wamanda (Nigeria), Prof Chanez Triki (Tunisia), Dr Kirsty Donald (South Africa), Prof Jo Wilmschurst (South Africa), Dr Reneva Petersen (South Africa), Dr Mac Mallewa (Malawi), Dr Judy Orikiiriza (Rwanda), Dr Eben Badoe (Ghana), Dr Kindu Woldemichael (Ethiopia/Botswana), Dr Tinsae Alemayehu (Ethiopia), Dr Stella Langa (Mozambique), Dr Alao Jules (Benin), Dr Celestin Caputu (DRC), Dr Amadou Toure (Mali), Dr Nuri Shembesh (Libya), Dr Ngozi Ojiinaka (Nigeria), Dr Sami Lemine (Mauritania), Dr Evans Mpabalwani (Zambia), Dr Marieke Dekker (Netherlands/Tanzania), Dr Dalila Sulemane (Mozambique), Dr Alusine Jalloh (Sierra Leone), Dr Edward Kija (Tanzania), Dr Wadzanai Zvavamwe (Zimbabwe), Dr Muhamed

Salisu (Nigeria), Prof Graham Fieggen (South Africa), Shona MacDonald (South Africa), and Dr Chris Tinley (South Africa)

Attendees from outside Africa:

Prof Michael Shevell (Canada), Prof Annette Majnemer (Canada), Prof Darcy Fehlings (Canada), Prof Pratibha Singhi (India), Prof Hans Forsberg (Sweden), Dr Pam Follett (USA), Prof Kazuhiro Haginoya (Japan), Dr David Bearden (USA/Botswana), Dr Nelleke Langerak (South Africa/Netherlands), and Prof Helen Cross (UK)

In addition, 20 local (SA) pediatric neurologists (or pediatricians working with neurologic conditions in children) and pediatric neurology trainees attended the conference and took part in the discussions.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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