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Pediatric Cerebral Palsy in Africa: A Systematic Review

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Cerebral palsy is a common neurologic problem in children and is reported as occurring in approximately 2-2.5 of 1000 live births globally. As is the case with many pediatric neurologic conditions, very little has been reported on this condition in the African context. Resource-limited settings such as those found across the continent are likely to result in a different spectrum of etiologies, prevalence, severity as well as management approaches. This review aims to establish what has been reported on this condition from the African continent so as to better define key clinical and research questions.

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Introduction

The term cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture causing activity limitation, which are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain. It is an umbrella term encompassing a range of different etiologies and phenotypes as well as associated with a variety of comorbid conditions (including epilepsy, intellectual disability, sensory disorders, and behavioral problems).¹ CP is a common neurologic problem in children and is reported as occurring in approximately 2-2.5 of 1000 live births globally.² As is the case with many pediatric neurologic conditions, very little has been reported on this condition in the African context. This review aims to establish what has been reported on this condition from the African continent so as to better define key clinical and research questions.

Methods

We performed a systematic review of available literature to identify data on the prevalence, etiology, comorbidities, outcomes, screening tools, and treatment of CP in Africa. Abstracts from any study from or involving an African country were reviewed for possible inclusion. Studies reporting more general neurodevelopmental disabilities were included only if they specifically mentioned CP as an outcome. Studies that focused on a subgroup of children with CP (eg, premature infants or children with genetic disorders) were excluded.

Search Strategy

Online databases were searched using specific search strategies to identify relevant articles published in English. Ovid Medline, PubMed, and the Cochrane database were searched using combinations of the terms “cerebral palsy,” “Africa,” “developing countries,” “developmental disabilities,” “neurological impairment,” and “childhood disability.” Web sites from African and international disability organizations as well as the World Health Organization were scanned for further references missed through the aforementioned search. The abstracts of any articles identified in this search strategy were screened for relevance, and electronic or hard copies of the full text were obtained for all relevant articles. References from each relevant article were scanned for further relevant articles and a snowballing search was performed. Commercial search engines Google and Bing were then used to check for any missing publications. Additional local journals not on the PubMed database (such as the East African Medical Journal) were searched for relevant articles. For the final analysis, only original research publications published after 1980 were

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included. When multiple publications existed on the same study cohort, only the most recent or most relevant publication was included, and studies were included only if they had some special relevance to the African setting.

Results

We identified 16 publications on prevalence or etiology or both of cerebral palsy in Africa (4 from Nigeria,³⁻⁶ 4 from South Africa,⁷⁻¹⁰ 2 from Ethiopia,^{11,12} Ghana,^{13,14} and Tanzania,^{15,16} and 1 each from Egypt¹⁷ and Kenya¹⁸). A summary of key prevalence and etiology studies is presented in Table 1.

There were 6 studies that examined screening instruments and strategies in an African setting for developmental disabilities including CP.¹⁹⁻²⁴ In addition, 2 articles provided an overview of screening strategies in low-resource settings for neurodevelopmental disabilities including CP.^{25,26}

A total of 4 studies assessed the effect of caring for children with CP on the caregiver,²⁷⁻³⁰ and 10 studies assessed specific aspects of treatment of children with CP³¹⁻³⁶ and comorbidities.³⁷⁻⁴⁰ There were no studies that addressed broad longitudinal outcomes in children with CP in Africa.

Prevalence

Methodologies for determining prevalence varied widely between studies, varying from door-to-door surveys to hospital-based record reviews. Almost all studies were cross-sectional. A common technique was a 2-phase design using the World Health Organization Ten Questions screen administered by a community health worker to identify possible cases followed by confirmation by a clinician.²⁶ Prevalence varied widely from country to country from approximately 2-10 per 1000^{9,25,41} children in community-based samples, although owing to heterogeneity between studies, it is difficult to

attribute this to true differences in prevalence or to differences in methodology (Table 1).

Etiology or Risk Factors

The most common reported etiologies identified in African cohorts were birth asphyxia, kernicterus, and neonatal infections, with prematurity or low birth weight identified as a major etiology in only 2 studies (Table). This is in contrast with most studies in the United States and Europe in which prematurity or low birth weight is one of the major risk factors identified in almost all studies.⁴²

Identification and Classification

Several studies on prevalence attempted to assess the sensitivity and specificity of their screening methodology and found that the Ten Questions Screen followed by clinician confirmation had good sensitivity and reasonable specificity. A study conducted in Uganda and Sri Lanka attempted to develop and validate a screening “portfolio” (short battery of tests) that could be used by community health workers, though the study is limited by minimal information about how the screen was used and did not report sensitivity or specificity.¹⁹ Two studies, one in Malawi (the Malawi Developmental Assessment Tool) and another in Kenya (Kilifi Developmental Inventory), have developed developmental screening tools aimed at identifying children with neurodevelopmental disabilities including CP.^{21,22} A Zimbabwean group described the use of the Neonatal Neurological Examination based on Prechtl’s general movements to identify neonates at risk for developmental disabilities including CP.⁴³

Studies from the African continent published to date have reported a larger proportion of severely affected children or those with Gross Motor Functional Classification System IV

Table Summary of Key Studies Evaluating Prevalence and Etiology of Cerebral Palsy in Africa

Study	Country, Region, and Income Status	Design	Prevalence (per 1000)	Most common Etiologies
El-Tallawy et al ⁴¹	Egypt North Africa Lower middle income	Prospective Community based Cross-sectional	2	Birth asphyxia (34.6%) Preterm birth (17.3%) Kernicterus (15.4%)
Ogunlesi and Ogundeyi ³	Nigeria West Africa Lower middle income	Retrospective Case series Hospital based	Not measured	Birth asphyxia (57.6%) Kernicterus (36.9%) CNS infections (21.7%)
Couper ⁹	South Africa Southern Africa Upper middle income	Prospective Community based Cross-sectional	10	Not reported
Karumuna and Mgone ¹⁵	Tanzania Southern Africa Low income	Prospective Hospital based Cross-sectional	Not measured	Birth asphyxia (36%) Low birth weight (20%) CNS infections (15%)

CNS, central nervous system.

and V in their services compared with European and North American cohorts.^{4,9,15,17}

Management

Children with CP require multidisciplinary care for optimal management of their medical needs as well as support to maximize their developmental and educational potential.⁴⁵ Guidelines for the recommended investigation and management of specific aspects of CP are available through pediatric organizations such as the American Academy of Pediatrics.⁴⁶ However, little is known about either the availability of guidelines or the recommendations in practice across resource-poor countries in Africa. In the first instance, several studies identified barriers toward optimal care for children with CP in Africa. Limited access to health care facilities and specialists, as well as a lack of adaptive equipment such as wheelchairs and other ambulation aids, contributes to the treatment gap for children with CP.⁴⁰ In addition, high levels of social stigma toward children with neurologic disorders were reported as reasons for families failing to seek treatment even when it was available.⁴¹

Further contributing to difficulties in accessing health care facilities for children with CP is a lack of wheelchair-accessible transport.^{28,44} This represents a particular challenge for families with older nonambulant children with CP. A multisite country study conducted by the African Child Policy Forum on the lives of children with disabilities in Africa noted that poverty powerfully affected the caregivers' ability to provide for the basic needs of their disabled children.⁴⁴ Caregivers found the financial costs attached to medical care, rehabilitation, assistive devices, and transportation to be 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.

There are isolated reports on experience in specific aspects or approaches to management for children with CP in selected populations. These include a South African study in which an 8-week randomized controlled trial of a strength training program for adolescents with CP showed improved gait and body image perception.³⁵ Another study examined a video-based training model for providers working with children with CP.³⁴

In relation to the medical complications of CP, spasticity occurs in most children with this condition and may significantly hamper mobility and fine motor function. Spasticity is defined as a velocity-dependent increase in muscle tone and is one of the core impairments experienced by children with CP.⁴⁶ Although effective use of botulinum toxin has been described in a group from Egypt,⁴⁷ there is no information regarding how accessible this treatment option is across the continent as a whole. There is limited access to several other supportive procedures reported in isolated centers across Africa. These include musculotendinous release for spastic hips⁴⁸ and gait analysis assessments.⁴⁹⁻⁵¹ Finally, a study on selective dorsal rhizotomy provided long-term evidence for

safety and efficacy of this treatment for spasticity in CP in a resource-limited setting in South Africa, although the sample size was small.^{31,53}

Home- or community-based approaches to rehabilitation have been described as being well suited for low-resource settings as they often require relatively minimal infrastructure and resources to implement compared with alternative models, such as center-based interventions.⁵⁴ In addition, they have been described as providing opportunities for strengthening the parent-child bond.¹⁴ There is a lack of information regarding any intervention studies or evidence-based clinical studies on the efficacy of home-based interventions from Africa. Most of the information on home-based studies has been done in high-income countries using varying interventions and presents conflicting results.⁵⁴⁻⁵⁶

Comorbidities

Consistent with reports from North American and European groups,^{57,58} epilepsy is one of the most common comorbidities of CP in Africa. In the cohort studied in Dar Es Salaam in Tanzania, the most common comorbidities were epilepsy (in 35% of children with CP), followed by deafness, speech impairment, and visual impairment. In the study by Ogunlesi et al conducted in Nigeria, the most common comorbidities were seizures (in 46.7%), speech impairment (43.5%), visual impairment (25%), and cognitive impairment (24%). Although not specifically identified as a comorbidity in this study, malnutrition was also identified in 80.4% of children with CP. A second Nigerian study by Lagunju and Fatunde³⁸ also identified epilepsy as a common comorbidity of CP, occurring in 38% of children.

Seizure-related morbidity and mortality are comorbidities that could potentially be reduced by appropriate anticonvulsant use in children with CP.⁵⁹ Of those living with epilepsy, 80% globally reside in resource-poor regions like Africa⁶⁰; it is estimated that 23% of people with active epilepsy in Senegal and up to 100% of such patients in parts of Uganda, Togo, the Gambia, and Tanzania do not access the anticonvulsants they require.^{37,60} Untreated epilepsy is likely to contribute to increased mortality as well as loss of developmental potential in children with CP and epilepsy in Africa.

Vision abnormalities have been identified in 58% of African children with CP in a study.³⁹ Strabismus occurred in 15%-34% of children in this group. This is a potentially a surgically correctible anomaly with resultant improvement in binocular alignment and fusion. Regular diagnosis and management of ocular anomalies in Africa is enhanced by several nongovernmental agencies, but access to intervention services remains suboptimal.^{39,40}

Other common comorbidities reported in high-resource settings, such as poor feeding, orthopedic complications, and cognitive impairment, are likely to be even more common in African cohorts given the high percentage of more severe forms of CP and limited access to health care. However, there are minimal data on the prevalence or management of these comorbidities in Africa.

Discussion

Despite concerns about underreporting of CP in many African communities, the prevalence estimates reported here were generally higher than the estimated 2-2.5 of 1000 in most studies conducted in the United States or Europe.⁶¹ These discrepancies may in part be because of methodological differences in the way these studies were conducted, but it is likely that the prevalence of CP is indeed higher in Africa because of the level of perinatal complications such as birth asphyxia and neonatal infections. However, variations in data collection methodologies between studies make direct comparisons between countries difficult.

As noted earlier, several major contributors to CP in Africa are potentially preventable and include birth asphyxia, central nervous system infections, and kernicterus. Prematurity and low birth weight are proportionally much smaller contributors to CP in Africa than in high-resource settings, likely because of relatively poor survival among these infants. However, it should be noted that most studies on etiology lacked a control group and few discussed issues of confounding and bias. Further, CP is a term often used in African contexts to describe all motor disability syndromes, and the term is considered synonymous with birth asphyxia in many countries. Thus, in the absence of a control group, studies reporting high rates of CP due to birth asphyxia should be viewed with a certain amount of caution.

What is clear is that there is a lack of structured and consistent screening policy for developmental disabilities amongst infants and preschool children in Africa. Families that can afford privately funded health care have access to pediatricians directly and may have access to some screening. However, even within these relatively well-resourced communities, programs are not standardized and no consistent strategy exists for referral lines or interventions when problems are identified. For most populations in Africa, recognition of a child with a disability relies on the parents or caregivers identifying a problem and presenting to medical facilities. On a continent where access to even the most basic health services is often poor and the burden of severe diseases high, this situation leaves many children with disabilities unrecognized and hence without appropriate intervention.

There may be 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. The relatively increased severity spectrum seen in reports of African cohorts may also be because of a combination of selection bias (hospital cohorts vs community- or population-based studies), lack of access to medical services (resulting in only those severely affected children requiring 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). Children with disabilities and their families in African countries are frequently excluded from society because of stigmatization. Most of these children consequently confront many challenges socially, economically, and politically because they are often

denied the basics of health care, education, socialization, and recognition.

Despite reports from a number of groups describing aspects of care for children with CP on the African continent, there appears to be very little information on the coordinated management of multiple impairments and associated comorbidities which these children may be affected with. There is a shortage of trained health workers and rehabilitation personnel across the continent, with few personnel specifically trained in the tools necessary to care for and to manage a child with CP in rural areas. In addition, when infrastructure exists, it is constrained by a lack of cultural- and language-specific validated clinical assessment tools, low literacy rates, and limited facilities for rehabilitative services and equipment. Initiatives that have emerged in some countries in the last 10 years have included a combination of nongovernmental organization-driven and government-subsidized community- and centre-based programs. Promotion of the use of adaptable low-cost materials, community health care workers, development of parent support groups, and multidisciplinary outreach programs may serve as means to manage CP in Africa. These need to be evaluated for effectiveness in the African context.^{44,52,62}

Limitations of a review such as this include the fact that there is likely to be much information on these topics that is not published in peer-reviewed English-language journals, such as conference abstracts, thesis dissertations, and other “gray literature.” In particular, the Francophone countries in West Africa represent a large subpopulation within the continent and are not well represented in this review because of the exclusion of non-English-language publications. In addition, owing to our emphasis on CP, we did not include studies on other neurologic disorders that might also have relevance for CP, for example, studies of community rehabilitation for children with visual impairment. Despite this, the available literature does highlight some useful points as described.

This review suggests several gaps of knowledge regarding CP in Africa. The lack of validated research criteria for identifying cases of CP in low-resource settings and the absence of standardized methodologies for assessing prevalence prevent meaningful comparisons between countries or assessing change in prevalence over time. Most studies are simple cross-sectional descriptive studies and there is a lack of appropriate control groups that would allow better assessment of risk factors. Large multicenter studies with a standardized methodology and appropriate control groups would help to address this gap. In addition, qualitative or mixed-methods studies assessing patient and family understanding of CP, access to resources, and barriers to care are virtually absent in Africa and would help in designing future interventions. Finally, there is a need for longitudinal studies that would assess outcomes over time for patients with CP as well as for randomized controlled trials of community-based treatment strategies that would be appropriate in an African setting.

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