

REVIEW ARTICLE

Perspectives on cerebral palsy in Africa: Exploring the literature through the lens of the International Classification of Functioning, Disability and Health

Sandra Abdel Malek^{1,2}  | Peter Rosenbaum^{1,2,3}  | Jan Willem Gorter^{1,2,3} 

¹School of Rehabilitation Science, McMaster University, Hamilton, Ontario, Canada

²CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario, Canada

³Department of Paediatrics, McMaster University, Hamilton, Ontario, Canada

Correspondence

Sandra Abdel Malek, School of Rehabilitation Science, McMaster University, Hamilton, ON, Canada.

Email: abdels11@mcaste.ca

Abstract

Background: The prevalence of cerebral palsy (CP) in countries in Africa is suggested to be higher than in Western countries. Research in Western resource-rich contexts has demonstrated the importance of environmental factors in the activities and participation of individuals with CP, as illustrated by the International Classification of Functioning, Disability and Health (ICF). Although the domains of the ICF are often acknowledged in research on CP in western contexts, the extent to which these domains have been explored in resource-limited areas is unknown. The current review aims to describe the nature of the current published literature on CP in African countries and how it aligns with the domains of the ICF.

Methods: Key informants familiar with the literature on CP in Africa were consulted, and a literature search was conducted to identify articles on CP originating from countries in Africa. Identified articles were assessed to determine the ICF domains that align with the studies. Themes relating to each domain were identified.

Results: Twenty-seven studies were included. The majority of studies were quantitative (70.3%) and focused on children or caregivers. Most studies included a body functions and structures component (70.4%), focusing on impairment rather than functioning. Activities and participation domains were addressed, but often focused solely on mobility. Environmental factors typically related to resources and policies and personal factors were often unexplored.

Conclusions: Research on CP in Africa tends to be grounded in a biomedical approach to disability and does not explicitly use the ICF as a guiding framework. Studies exploring body function and structures tend to be descriptive in nature, whereas activities and participation, and environmental and personal factors, represent modifiable factors that may be addressed with interventions. Knowledge translation activities that promote the ideas of the ICF in an African context should therefore be considered.

KEYWORDS

Africa, cerebral palsy, disability, ICF

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2019 The Authors. Child: Care, Health and Development published by John Wiley & Sons Ltd

1 | INTRODUCTION

Cerebral palsy (CP) is a diagnosis that refers to “a group of permanent disorders of the development of movement and posture causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain” (Rosenbaum et al., 2007). The way in which CP manifests varies greatly between individuals and often includes impairments in “sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum et al., 2007). CP displays heterogeneity in “presentation, etiology, evolution, severity, medical and rehabilitation needs, comorbidities, and outcomes” (Shevell, Miller, Scherer, Yager, & Fehlings, 2011); however, various medical and rehabilitative interventions throughout development have the potential to help children with CP engage in meaningful life activities. The prevalence of CP in Western developed countries has been estimated to be approximately 2–2.5 per 1,000 children (Oskoui, Joseph, Dagenais, & Shevell, 2013). Despite concerns of underreporting, this prevalence has been suggested to be even higher in developing countries throughout Africa (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014).

Views of childhood disability have typically been grounded in a biomedical approach, with an emphasis on “fixing” impairments and achieving normality (Rosenbaum & Gorter, 2012). This traditional approach has been challenged in recent years, given that this model largely ignores society's contribution to the construction of disability and often discounts social and legal barriers (Wiat & Darrah, 2002). Disability as a sociopolitical movement has emerged in the Western world over the last several decades with the aim of redefining “disability” in terms of shortcomings of the community resulting in limitations to participation, rather than viewing disability as a problem inherent to the individual, as has usually been done (Wiat & Darrah, 2002). This movement mirrors the transition from the World Health Organization's (WHO) 1980 International Classification of Impairment, Disability and Handicap (ICIDH) to the 2001 International Classification of Functioning, Disability and Health (ICF). The ICIDH was a hierarchical framework consisting of impairment (organ level), disability

Key Messages

- Research on CP in African countries tends to focus on impairment rather than functioning.
- Activities and participation, beyond mobility, and personal factors are often unaddressed.
- Research rarely addresses perspectives of adolescents and adults with CP.
- Only one study was found to explicitly use the ICF. This review identifies a need to increase the acknowledgment of all ICF domains in research on CP in an African context.

(functional abilities), and handicap (disadvantages experienced as a result; Wood, 1980). However, the ICIDH focused on impairments rather than functioning and failed to address factors external to the individual. To address these shortcomings, the WHO released the ICF and its framework for health (Figure 1) in 2001.

The multidimensional ICF framework conceptualizes functioning and disability across four interconnected domains: body functions and structures, activities and participation, environmental factors, and personal factors. The domains of the ICF emphasize the biopsychosocial nature of functioning, providing an alternative way of viewing disability (WHO, 2001) and forming a valuable framework for the assessment and management of children and youth with CP (Rosenbaum & Stewart, 2004). For example, when considering treatment outcomes, parents, medical professionals, and youth with CP discussed several concepts that align with all domains of the ICF (Vargus-Adams & Martin, 2011). The diversity of these goals across the ICF may be expected, given that the domains of the ICF have been suggested to be interdependent, with relationships between domains likely to be influenced by other factors within the framework. Environmental factors have specifically been thought to play a role in the relationship

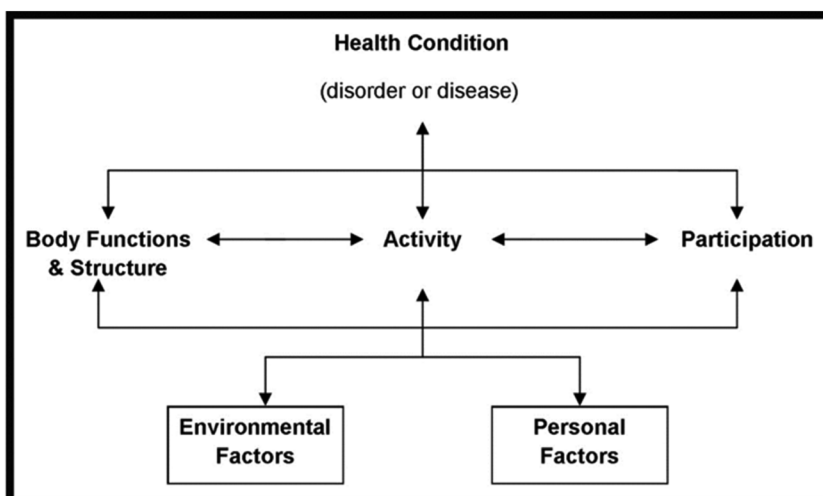


FIGURE 1 International Classification of Functioning, Disability and Health (World Health Organization, 2001)

between body function and structure and activities and participation (Wright, Rosenbaum, Goldsmith, Law, & Fehlings, 2008).

The importance of environmental factors in the activities and participation of individuals with CP has been demonstrated in a variety of contexts, including at home, school, and within the community (Anaby et al., 2014; Law et al., 2013). Research has generally focused on the role of environmental factors in Western resource-rich contexts, such as Canada, the United States, the United Kingdom, Australia, and Sweden (Anaby et al., 2013; Imms, 2008). However, environments in resource-limited contexts differ markedly from those of the Western world. There is a paucity of literature regarding the extent to which environmental factors, activities, and participation have been explored in resource-limited African countries, despite the likelihood of a higher prevalence of CP in these regions. A systematic review on CP in Africa revealed that research typically focuses on prevalence, aetiology, classification, treatment and management, and comorbidities (Donald et al., 2014). That review also revealed many gaps in the literature such as a lack of qualitative and mixed methods studies exploring individual and family understanding of CP, a lack of studies addressing access to resources and barriers to care, and a lack of longitudinal studies assessing outcomes (Donald et al., 2014). Additionally, although the ICF has been available since 2001, the acknowledgement and application of its domains across cultural contexts, particularly in African countries in both research and practice, remains to be explored.

The purpose of this literature review is therefore to explore the current published literature about CP in African countries. Specifically, this review aims to answer the following questions:

- 1) What is the nature and extent of the current published literature on cerebral palsy in countries in Africa?
- 2) How does the research focus of the published literature align with the domains of the ICF?

Applying the ICF framework to the current research will provide information regarding the recognition and endorsement of the domains of the ICF in varying cultural contexts and the need for knowledge translation activities to promote these ideas of functioning and disability.

2 | METHODS

A literature review was conducted in order to explore the scope of the literature regarding CP in Africa and to categorize the literature according to the corresponding ICF domains. To identify relevant studies, key informants who are familiar with the literature in Africa were contacted and provided the names of several prominent researchers who focus on CP in an African context. An author search was conducted through Google Scholar and the PubMed database to identify relevant articles. Additionally, a search of the PubMed database was conducted using medical subject heading terms. Specifically, “cerebral palsy” and “Africa, northern” OR “Africa, south of the Sahara” were used. These terms encompass studies pertaining to cerebral palsy across all African countries.

Reference lists were hand searched to identify other relevant articles.

2.1 | Inclusion/exclusion criteria

Title and abstracts of articles were screened, and relevant articles underwent a full-text review. Articles were included if they were peer-reviewed and published within the last 5 years (2014–present) and if the full text was available. Articles published prior to 2014 were excluded given that the only systematic review (to the author’s knowledge) on CP in Africa was published in 2014 and encompassed research from several databases, African and international disability organizations, commercial search engines, and local journals. The present literature review therefore provides an update to the information presented in 2014. Only articles that explicitly reported on CP (rather than other neurodisabilities or developmental disorders in general) in any setting (e.g., hospitals, schools, out-patient centres) were included. Additionally, only articles that reported results for an African country or region were included; articles that reported on “low-resource settings” or “low-income countries” without explicitly providing information relating to an African context were not included. Correspondences, commentaries, and editorials were not included, and no restrictions were placed on language.

2.2 | Data extraction

The purpose and outcomes of each included study were assessed to determine the ICF domains that align with the study. The ICF domains were determined according to the perspective of the individual with CP, rather than the participants of the study (e.g., caregivers’ mental health was reported as the individual with CP’s environment rather than as the caregiver’s body function and structure). The results were analysed, and themes relating to each ICF domain were identified.

3 | RESULTS

Using the inclusion criteria described above, 34 studies were identified. Following title and abstract screening, removal of duplicates, and the inclusion of articles found through the reference search, 27 full-text articles were included in the review (Table 1). Of the included studies, three were published in 2014, seven in 2015, six in 2016, seven in 2017, and four in 2018. All included articles were in English, with no studies meeting inclusion criteria found in other languages.

The included articles originated from 10 African countries, whereas one paper looked at Africa as a continent. Of studies looking at specific countries, one was conducted in each of the following: Ghana (3.7%), Zambia (3.7%), Malawi (3.7%), and Ethiopia (3.7%). Three studies were conducted in Egypt (11.1%), Nigeria (11.1%), and Zimbabwe (11.1%). Four studies were conducted in Botswana (14.8%) and South Africa (14.8%), and five in Uganda (18.5%). Of the included

TABLE 1 Articles meeting inclusion criteria and included in review

Authors	Title	Year	Journal	Country
Abd El-Kafy, E. M.	The clinical impact of orthotic correction of lower limb rotational deformities in children with cerebral palsy: A randomized controlled trial.	2014	<i>Clinical Rehabilitation</i>	Egypt
Adepoju, F., Hamzat, T., & Akinyinka, O.	Comparative efficacy of progressive resistance exercise and biomechanical ankle platform system on functional indices of children with cerebral palsy.	2017	<i>Ethiopian Journal of Health Sciences</i>	Nigeria
Adolfsson, M., Johnson, E., & Nilsson, S.	Pain management for children with cerebral palsy in school settings in two cultures: Action and reaction approaches	2018	<i>Disability and Rehabilitation</i>	South Africa
Bearden, D. R., Monokwane, B., Khurana, E., Baier, J., Baranov, E., Westmoreland, K., ... & Steenhoff, A. P.	Pediatric cerebral palsy in Botswana: etiology, outcomes, and comorbidities	2016	<i>Pediatric Neurology</i>	Botswana
Chikwanha, T. M., Chidhakwa, S., & Dangarembizi, N.	Occupational therapy needs of adolescents and young adults with cerebral palsy in Zimbabwe: Caregivers' perspectives.	2015	<i>Central African Journal of Medicine</i>	Zimbabwe
Chiluba, B. C., & Moyo, G.	Caring for a cerebral palsy child: A caregivers perspective at the University Teaching Hospital, Zambia.	2017	<i>BMC Research Notes</i>	Zambia
Coker-Bolt, P., DeLuca, S. C., & Ramey, S. L.	Training paediatric therapists to deliver constraint-induced movement therapy (CIMT) in sub-Saharan Africa.	2015	<i>Occupational Therapy International</i>	Ethiopia
Conchar, L., Bantjes, J., Swartz, L., & Derman, W.	Barriers and facilitators to participation in physical activity: The experiences of a group of South African adolescents with cerebral palsy	2016	<i>Journal of Health Psychology</i>	South Africa
Dambi, J. M., & Jelsma, J.	The impact of hospital-based and community based models of cerebral palsy rehabilitation: a quasi-experimental study.	2014	<i>BMC Pediatrics</i>	Zimbabwe
Dambi, J. M., Jelsma, J., & Mlambo, T.	Caring for a child with Cerebral Palsy: The experience of Zimbabwean mothers.	2015	<i>African Journal of Disability</i>	Zimbabwe
Dambi, J. M., Mandizvidza, C., Chiwaridzo, M., Nhunzvi, C., & Tadyanemhandu, C.	Does an educational workshop have an impact on caregivers' levels of knowledge about cerebral palsy? A comparative, descriptive cross-sectional survey of Zimbabwean caregivers.	2016	<i>Malawi Medical Journal</i>	Zimbabwe
Donald, K. A., Kakooza, A. M., Wammanda, R. D., Mallewa, M., Samia, P., Babakir, H., ... & Chugani, H.	Pediatric cerebral palsy in Africa: Where are we?	2015	<i>Journal of Child Neurology</i>	Africa
El-Tallawy, H. N., Farghaly, W. M., Shehata, G. A., Rageh, T. A., Metwally, N. A., Badry, R., ... & Kandil, M. R.	Cerebral palsy in Al-Quseir City, Egypt: Prevalence, subtypes, and risk factors.	2014	<i>Neuropsychiatric Disease and Treatment</i>	Egypt
Johnson, A., Gambrah-Sampaney, C., Khurana, E., Baier, J., Baranov, E., Monokwane, B., & Bearden, D. R.	Risk factors for malnutrition among children with cerebral palsy in Botswana.	2017	<i>Pediatric Neurology</i>	Botswana
Johnson, E., Nilsson, S., & Adolfsson, M.	Eina! Ouch! Eish! Professionals' perceptions of how children with	2015	<i>Augmentative and Alternative Communication</i>	South Africa

(Continues)

TABLE 1 (Continued)

Authors	Title	Year	Journal	Country
	cerebral palsy communicate about pain in South African school settings: Implications for the use of AAC.			
Kakooza-Mwesige, A., Andrews, C., Peterson, S., Mangan, F. W., Eliasson, A. C., & Forssberg, H.	Prevalence of cerebral palsy in Uganda: A population-based study.	2017	<i>The Lancet Global Health</i>	Uganda
Kakooza-Mwesige, A., Forssberg, H., Eliasson, A. C., & Tumwine, J. K.	Cerebral palsy in children in Kampala, Uganda: Clinical subtypes, motor function and co-morbidities.	2015	<i>BMC Research Notes</i>	Uganda
Kakooza-Mwesige, A., Byanyima, R. K., Tumwine, J. K., Eliasson, A. C., Forssberg, H., & Flodmark, O.	Grey matter brain injuries are common in Ugandan children with cerebral palsy suggesting a perinatal aetiology in full-term infants.	2016	<i>Acta Paediatrica</i>	Uganda
Kakooza-Mwesige, A., Tumwine, J. K., Eliasson, A. C., Namusoke, H. K., & Forssberg, H.	Malnutrition is common in Ugandan children with cerebral palsy, particularly those over the age of five and those who had neonatal complications.	2015	<i>Acta Paediatrica</i>	Uganda
Monokwane, B., Johnson, A., Gambah-Sampaney, C., Khurana, E., Baier, J., Baranov, E., ... & Bearden, D. R.	Risk factors for cerebral palsy in children in Botswana.	2017	<i>Pediatric Neurology</i>	Botswana
Munyumu, K., Idro, R., Abbo, C., Kaddumukasa, M., Katabira, E., Mupere, E., & Kakooza-Mwesige, A.	Prevalence and factors associated with sleep disorders among children with cerebral palsy in Uganda; a cross-sectional study.	2018	<i>BMC Pediatrics</i>	Uganda
Nilsson, S., Johnson, E., & Adolfsson, M.	Professionals' perceptions about the need for pain management interventions for children with cerebral palsy in South African school settings.	2016	<i>Pain Management Nursing</i>	South Africa
Ogoke, C. C., & Iloeje, S. O.	Severity of motor dysfunction in children with cerebral palsy seen in Enugu, Nigeria.	2017	<i>Pan African Medical Journal</i>	Nigeria
Patel, P., Baier, J., Baranov, E., Khurana, E., Gambah-Sampaney, C., Johnson, A., ... & Bearden, D. R.	Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study.	2017	<i>Child: Care, Health and Development</i>	Botswana
Polack, S., Adams, M., O'banion, D., Baltussen, M., Asante, S., Kerac, M., ... & Zuurmond, M.	Children with cerebral palsy in Ghana: malnutrition, feeding challenges, and caregiver quality of life.	2018	<i>Developmental Medicine & Child Neurology</i>	Ghana
Schiariti, V., Longo, E., Shoshmin, A., Kozhushko, L., Besstrashnova, Y., Król, M., ... & Mwale, M.	Implementation of the International Classification of Functioning, Disability, and Health (ICF) core sets for children and youth with cerebral palsy: Global initiatives promoting optimal functioning.	2018	<i>International Journal of Environmental Research and Public Health</i>	Malawi
Shehata, A. I., Hassanein, F. I., & Abdul-Ghani, R.	Seroprevalence of <i>Toxoplasma gondii</i> infection among patients with non-schizophrenic neurodevelopmental disorders in Alexandria, Egypt.	2016	<i>Acta Tropica</i>	Egypt

studies, one was a comparative study between South Africa and Sweden, and one was a cross-cultural study in Malawi, Russia, Poland, and Brazil. This cross-cultural study was the only one that explicitly used the ICF.

Participants of the studies varied. In the majority of the studies (12; 44.4%), participants were children ranging from 0 to 18 years of age. Six (22.2%) of the studies used caregivers of individuals with CP as participants—five (18.5%) of these studies were interested in those

providing care to children, whereas one study (3.7%) explored the perspectives of caregivers of adolescents. Five studies (18.5%) were conducted with professionals (teachers, clinicians, etc.), and two (7.4%) used an adult population. One study (3.7%) used both caregivers and children with CP as participants, whereas another study recruited individuals of all ages with CP.

Four studies (14.8%) were conducted in rehabilitation centres, four (14.8%) in school settings, and four (14.8%) in the community. Six (22.2%) of the studies occurred in a hospital (inpatient and outpatient sites) and nine (33.3%) took place in a referral centre (inpatient and outpatient, paediatric neurology clinics, and tertiary referral centres).

Nineteen (70.3%) of the studies were quantitative in nature, two (7.4%) used mixed methods, and six (22.2%) were qualitative studies. Of the six qualitative studies, one explored the perspectives of adolescents with CP, one explored caregiver perspectives, three explored perspectives of professionals (teachers, occupational therapists, physical therapists, social workers) in a school setting, and one described a meeting of physicians across Africa related to the evaluation and management of children with CP.

3.1 | ICF domains

In terms of ICF domains, some studies focused solely on one domain. For example, a study investigating neuroimaging patterns, specifically grey matter brain injuries, of children with CP aligns solely with the body functions and structures domain (Kakooza-Mwesige et al., 2016). However, the majority explored multiple domains, such as a study exploring the clinical subtypes, motor function, and comorbidities of children with CP (Kakooza-Mwesige, Forssberg, Eliasson, & Tumwine, 2015). This study aligns with body functions and structures (clinical subtype; speech, visual, and hearing impairments as comorbidities) as well as activities (motor function; learning impairment as a comorbidity). Table 2 outlines the ICF domains addressed by each included study.

Most studies (20; 74.1%) included a body functions and structures component. Studies that addressed body functions and structures were found to fall into three categories: those exploring comorbidities, those exploring risk factors, and those that are descriptive in nature. Activities were addressed by 11 (40.7%) studies, with the majority (9; 81.8%) focusing solely on mobility and the remaining two addressing self-care and learning. Participation was the least addressed of the domains, with only one of five studies addressing more than one area of participation. Participation focused on recreation and leisure, religion, education, and interpersonal interactions. Environmental factors were explored by 16 (59%) of the included studies. Environmental factors were related to the resources and policies in different settings, the support available to the individual, and attitudes of family and society in general. Three studies addressed products/technology, and three explored aspects of the natural environment. Personal factors were explored in two of the included studies. Table 3 indicates concepts addressed within each ICF domain by the included studies.

4 | DISCUSSION

This review reveals the nature of the current literature about CP in African countries and how the focus of the published research aligns with the domains of the ICF. The literature appears to be grounded in a biomedical approach to disability, with the majority of studies exploring some aspect of body functions and structures and a minority exploring activities and participation beyond mobility.

Studies included in this review indicate that the published research is not representative of all African countries, given that the included studies originate from 10 countries out of a possible 54. This may be due to a lack of resources in many African countries to support this kind of research. According to the WHO, the African Region (excluding countries in the Eastern Mediterranean Region such as Egypt and Morocco) accounts for 24% of the international burden of disease while having access to only 1% of the world's financial resources for health (WHO, n.d.-a). Additionally, resources are more often allocated to curative services that tend to be high-cost, rather than to prevention and health promotion measures (WHO, n.d.-a). These services are often focused on infectious diseases rather than noncommunicable diseases, including disabilities. This reality is likely attributable to a variety of factors, such as weak health systems, inadequate training for healthcare providers, lack of financial resources, and a perception that infectious diseases should be the primary health focus of the region (WHO, n.d.-a). This may explain, at least in part, some of the cross-continental underrepresentation of conditions like CP in the literature. Additionally, differences in education levels may play a role in which countries are represented in the literature. The 10 countries from which research was identified have an average literacy rate of 72.2%, with the majority of the unrepresented countries having a lower percentage, ranging as low as 22% in Chad and 14% in Niger (United Nations, 2018). Lower resources may therefore be a barrier to conducting research in these areas, posing a challenge in painting an accurate picture of the understanding of CP across Africa.

Participants in the included studies were generally children with CP or individuals interacting with children with CP, such as professionals or caregivers. Very few studies explored CP in adolescence or adulthood. This may be due to the lower life expectancy observed across Africa (average 61 years) compared with the global life expectancy (72 years; WHO, n.d.-b). In Western contexts, children with CP are likely to have a life expectancy similar to that of the general population, provided that appropriate healthcare is available (Koman, Smith, & Shilt, 2004; Strauss & Shavelle, 1998). However, this may not be the case in African countries where healthcare resources are often limited (Donald et al., 2015). Infants are at a higher risk of prematurity, low birth weight, and complications such as birth asphyxia (WHO Regional Office for Africa, 2014), all of which may contribute to an increased risk of CP (Odding, Roebroek, & Stam, 2006). Although infant mortality rates have been decreasing (WHO Regional Office for Africa, 2014), countries in sub-Saharan Africa have the lowest improvements in child survival (WHO, n.d.-a), which may contribute to CP being perceived as a childhood disorder and thus being researched as such. However,

TABLE 2 International Classification of Functioning, Disability and Health domains addressed by each article

Authors	Title	Body functions/ structures	Activities	Participation	Environment
Abd El-Kafy, E. M.	The clinical impact of orthotic correction of lower limb rotational deformities in children with cerebral palsy: A randomized controlled trial.	x			
Adepoju, F., Hamzat, T., & Akinyinka, O.	Comparative efficacy of progressive resistance exercise and biomechanical ankle platform system on functional indices of children with cerebral palsy.	x	x		
Adolfsson, M., Johnson, E., & Nilsson, S.	Pain management for children with cerebral palsy in school settings in two cultures: Action and reaction approaches	x		x	x
Bearden, D. R., Monokwane, B., Khurana, E., Baier, J., Baranov, E., Westmoreland, K., ... & Steenhoff, A. P.	Pediatric cerebral palsy in Botswana: Etiology, outcomes, and comorbidities	x	x		
Chikwanha, T. M., Chidhakwa, S., & Dangarembizi, N.	Occupational therapy needs of adolescents and young adults with cerebral palsy in Zimbabwe: Caregivers' perspectives.		x	x	x
Chiluba, B. C., & Moyo, G.	Caring for a cerebral palsy child: A caregiver's perspective at the University Teaching Hospital, Zambia.				x
Coker-Bolt, P., DeLuca, S. C., & Ramey, S. L.	Training paediatric therapists to deliver constraint-induced movement therapy (CIMT) in sub-Saharan Africa.	x			x
Conchar, L., Bantjes, J., Swartz, L., & Derman, W.	Barriers and facilitators to participation in physical activity: The experiences of a group of South African adolescents with cerebral palsy	x		x	x
Dambi, J. M., & Jelsma, J.	The impact of hospital-based and community based models of cerebral palsy rehabilitation: A quasi-experimental study.		x		x
Dambi, J. M., Jelsma, J., & Mlambo, T.	Caring for a child with Cerebral Palsy: The experience of Zimbabwean mothers.				x
Dambi, J. M., Mandizvidza, C., Chiwaridzo, M., Nhunzvi, C., & Tadyanemhandu, C.	Does an educational workshop have an impact on caregivers' levels of knowledge about cerebral palsy? A comparative, descriptive cross-sectional survey of Zimbabwean caregivers.				x
Donald, K. A., Kakooza, A. M., Wammanda, R. D., Mallewa, M., Samia, P., Babakir, H., ... & Chugani, H.	Pediatric cerebral palsy in Africa: Where are we?				x
El-Tallawy, H. N., Farghaly, W. M., Shehata, G. A., Rageh, T. A., Metwally, N. A., Badry, R., ... & Kandil, M. R.	Cerebral palsy in Al-Quseir City, Egypt: Prevalence, subtypes, and risk factors.	x			x
Johnson, A., Gambrah-Sampaney, C., Khurana, E., Baier, J., Baranov, E., Monokwane, B., & Bearden, D. R.	Risk factors for malnutrition among children with cerebral palsy in Botswana.	x	x		x
Johnson, E., Nilsson, S., & Adolfsson, M.	Eina! Ouch! Eish! Professional' perceptions of how children with cerebral palsy communicate about pain in South African school settings: Implications for the use of AAC.	x		x	

(Continues)

TABLE 2 (Continued)

Authors	Title	Body functions/			
		structures	Activities	Participation	Environment
Kakooza-Mwesige, A., Andrews, C., Peterson, S., Mangen, F. W., Eliasson, A. C., & Forssberg, H.	Prevalence of cerebral palsy in Uganda: A population-based study.	x	x		
Kakooza-Mwesige, A., Forssberg, H., Eliasson, A. C., & Tumwine, J. K.	Cerebral palsy in children in Kampala, Uganda: Clinical subtypes, motor function and co-morbidities.	x	x		
Kakooza-Mwesige, A., Byanyima, R. K., Tumwine, J. K., Eliasson, A. C., Forssberg, H., & Flodmark, O.	Grey matter brain injuries are common in Ugandan children with cerebral palsy suggesting a perinatal aetiology in full-term infants.	x			
Kakooza-Mwesige, A., Tumwine, J. K., Eliasson, A. C., Namusoke, H. K., & Forssberg, H.	Malnutrition is common in Ugandan children with cerebral palsy, particularly those over the age of five and those who had neonatal complications.	x			
Monokwane, B., Johnson, A., Gambah-Sampaney, C., Khurana, E., Baier, J., Baranov, E., ... & Bearden, D. R.	Risk factors for cerebral palsy in children in Botswana.	x			x
Munyumu, K., Idro, R., Abbo, C., Kaddumukasa, M., Katabira, E., Mupere, E., & Kakooza-Mwesige, A.	Prevalence and factors associated with sleep disorders among children with cerebral palsy in Uganda; a cross-sectional study.	x			
Nilsson, S., Johnson, E., & Adolfsson, M.	Professionals' perceptions about the need for pain management interventions for children with cerebral palsy in South African school settings.	x	x		x
Ogoke, C. C., & Iloeje, S. O.	Severity of motor dysfunction in children with cerebral palsy seen in Enugu, Nigeria.	x	x		
Patel, P., Baier, J., Baranov, E., Khurana, E., Gambah-Sampaney, C., Johnson, A., ... & Bearden, D. R.	Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study.				x
Polack, S., Adams, M., O'banion, D., Baltussen, M., Asante, S., Kerac, M., ... & Zuurmond, M.	Children with cerebral palsy in Ghana: Malnutrition, feeding challenges, and caregiver quality of life.	x	x		x
Schiariti, V., Longo, E., Shoshmin, A., Kozhushko, L., Besstrashnova, Y., Król, M., ... & Mwale, M.	Implementation of the International Classification of Functioning, Disability, and Health (ICF) core sets for children and youth with cerebral palsy: Global initiatives promoting optimal functioning.	x	x	x	x
Shehata, A. I., Hassanein, F. I., & Abdul-Ghani, R.	Seroprevalence of <i>Toxoplasma gondii</i> infection among patients with non-schizophrenic neurodevelopmental disorders in Alexandria, Egypt.	x			x
		20	11	5	17

Total number of studies addressing each ICF domain.

studies in Western contexts have shown the importance of addressing the needs of adolescents with CP (Gorter, Stewart, & Woodbury-Smith, 2011), particularly because participation seems to become more restricted as children transition into adolescence and adulthood (King et al., 2003), which may have a negative influence on health and well-being (Shikako-Thomas, Kolehmainen, Ketelaar, Bult, & Law, 2014). Therefore, future studies should aim to explore adolescents'

experiences and perspectives in an African context to promote well-being and functioning according to the ICF domains.

4.1 | ICF domains

This literature review revealed that the ICF is not explicitly addressed in research on CP in African countries. However, as the current work

TABLE 3 Concepts addressed within each International Classification of Functioning, Disability and Health domain among 27 studies

Body functions and structures	Number of studies
Descriptive	11
Comorbidities	11
Risk factors	4
Activities	
Mobility	11
Self-care	2
Learning	1
Participation	
Recreation and leisure	2
Education	2
Communication/interpersonal interactions	2
Religion	1
Environment	
Support	8
Resources and policies	7
Attitudes	6
Products and technology	3
Natural environment	3
Personal Factors	
Socioeconomic status	1
Personal preferences	1

illustrates, it is possible implicitly to align the findings of these studies analytically to a variety of concepts within each domain of the ICF. Each domain is discussed in further detail below.

4.1.1 | Body functions and structures

The majority of the studies included in this review had a body functions and structures component, with many exploring comorbidities such as malnutrition and visual, hearing, and speech impairments. Risk factors included infections and issues relating to birth, such as prematurity and neonatal infections. Descriptive studies focused on neuromusculoskeletal impairments and clinical subtype. Studies exploring components of body functions and structures tended to focus on impairments rather than functioning, which aligns with the biomedical view of disability (Rosenbaum & Gorter, 2012). However, research suggests that interventions targeting impairments do not necessarily increase functional independence and participation (Law & Darrah, 2014; Novak, 2012; Wright et al., 2008), indicating a need for interventions, and research, to go beyond the scope of physical impairment in order to benefit individuals with CP more effectively.

Additionally, only one study explored the mental health of individuals with CP by investigating depression and anxiety among adolescents in South Africa as it relates to their participation in physical activity (Conchar, Bantjes, Swartz, & Derman, 2016). Children with CP have been suggested to be at a higher risk of experiencing symptoms associated with mental illness (Downs et al., 2018), suggesting the need to investigate the extent to which these disorders affect adolescents and young adults with CP in an African context.

4.1.2 | Activities and participation

Mobility was the most reported activity and was addressed in 11 out of 14 studies that aligned with the activities domain, indicating a narrow focus of the current research. The majority of these studies used the Gross Motor Function Classification System (Palisano, Rosenbaum, Bartlett, & Livingston, 2008) to conceptualize mobility and classify participants according to motor functioning. Participation was the least reported domain—out of a total of five studies addressing components of participation, three were explicit in their aim to investigate this concept. Children and adolescents with CP in resource-rich contexts have been found to engage in a narrower range of activities compared with their typically developing peers, with more activities occurring at home, alone, or with family rather than peers (Engel-Yeger, Jarus, Anaby, & Law, 2009; King, Law, Hurley, Petrenchik, & Schwellnus, 2010; Shikako-Thomas, Majnemer, Law, & Lach, 2008). Groups of international researchers, as well as clinicians and consumers, have therefore identified participation as a priority for research and interventions (McIntyre, Novak, & Cusick, 2010; Schiariti, Masse et al., 2014). Given that environmental factors have been shown to play an important role in meaningful participation (Anaby et al., 2013; Shikako-Thomas et al., 2008), it is important to investigate the participation of individuals with CP in different cultural contexts, particularly in resource-limited African countries, where the environment differs significantly from resource-rich countries from which the majority of the literature on participation originates.

4.1.3 | Environmental factors

A scoping review of environmental factors influencing participation of children and youth with disabilities identified social support and geographic location as the most common facilitators of participation, whereas attitudes, physical environment, transportation, policies, and lack of support were the most frequently cited barriers (Anaby et al., 2013). Every category of the environment domain has been found to influence participation in some way, whether it be as a facilitator or as a barrier (Anaby et al., 2013). The main environmental contextual factors that were addressed by the studies included in this review are resources and policies, support and relationships, and attitudes. Resources and policies were described in the context of schools, transportation, and health services, as well as more broadly at the national level. Support was provided by two main sources, caregivers

and professionals. Familial and societal attitudes were also discussed. Importantly, although contextual factors were discussed in the literature, personal factors were rarely addressed. Although the social and cultural environment influences an individual's participation in daily activities (Law et al., 1999), it has been suggested that the effects of both environmental and personal factors on health and well-being should be equally explored (Rosenbaum & Stewart, 2004).

4.1.4 | Personal factors

Personal factors such as age and gender, as well as likes and interests, have been shown to play a role in the participation of children and youth with CP (Shikako-Thomas et al., 2008; Verschuren, Wiart, Hermans, & Ketelaar, 2012). Of the qualitative studies addressing environmental factors, only one considered the perspective of adolescents with CP; the remaining qualitative/mixed methods studies reported the perspectives of caregivers and professionals. The importance of considering the perspectives of both children and their caregivers has been described in the literature (Garth & Aroni, 2003), particularly because children and caregivers often have differing perspectives on the same topics (Schiariti, Suave et al., 2014). Individuals with CP may therefore perceive, experience, or value things differently than their caregivers, offering unique input in research and in the development of interventions. Future studies should therefore consider the perspectives of individuals with CP, and particularly their personal factors, and ways in which these factors can be incorporated in clinical practice.

This literature review has some potential limitations. First, only one database was searched by the first author (S. A.), so articles from other databases or from African journals not included in the database may have been missed. Additionally, articles published in other languages and not included in PubMed may have also been missed. However, this literature review was meant to be exploratory in nature in order to provide a sense of the current literature on CP in Africa, rather than trying to be exhaustive. Next steps therefore include creating a comprehensive search strategy for multiple databases and searching the grey literature in order to assess whether there may be a more accurate state of knowledge on CP in the African continent.

5 | CONCLUSION

The current published literature on CP in Africa originates from a handful of countries. The target population of these studies is largely children with CP, with very few studies looking at adolescents and adults. Additionally, the majority of the studies are quantitative in nature and primarily have a body functions and structures component focusing on impairment rather than on functioning. Studies addressing body functions and structures report comorbidities and risk factors and tend to be descriptive in nature. In contrast, studies that align with activities and participation, and environmental and personal factors, provide insight into modifiable factors that may be addressed

with interventions. Mobility was the most reported activity, suggesting the need for research regarding other activities. Participation was the least reported domain, although it has been shown to be closely linked to health and well-being. Interventions aiming to increase participation in all activities of life should therefore be considered. Participation may be increased by focusing interventions on environmental modifications. The most reported environmental factors were contextual, relating to resources and policies, support, and attitudes. Policy changes may be necessary to provide more support for caregivers and to reduce barriers to participation in schools and in the larger community. Personal factors should also be addressed when developing interventions by investigating the perspectives of individuals with CP and by exploring ways in which these factors can be applied to clinical practice. This literature review reveals the need for knowledge translation activities to promote the ideas presented by the ICF in an African context.

ACKNOWLEDGEMENTS

We would like to thank Dr. Robert Armstrong (Nairobi, Kenya) and Dr. Charles Newton (Oxford, UK) for providing their expertise as key informants and pointing us in the direction of the current literature. Dr. Gorter holds the Scotiabank Chair in Child Health Research.

ORCID

Sandra Abdel Malek  <https://orcid.org/0000-0002-8230-7879>

Peter Rosenbaum  <https://orcid.org/0000-0001-6751-5613>

Jan Willem Gorter  <https://orcid.org/0000-0002-3012-2119>

REFERENCES

- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: A scoping review. *Disability and Rehabilitation*, 35(19), 1589–1598. <https://doi.org/10.3109/09638288.2012.748840>
- Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M., Avery, L., & Teplicky, R. (2014). The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. *Archives of Physical Medicine and Rehabilitation*, 95(5), 908–917. <https://doi.org/10.1016/j.apmr.2014.01.005>
- Conchar, L., Bantjes, J., Swartz, L., & Derman, W. (2016). Barriers and facilitators to participation in physical activity: The experiences of a group of South African adolescents with cerebral palsy. *Journal of Health Psychology*, 21(2), 152–163. <https://doi.org/10.1177/1359105314523305>
- Donald, K. A., Kakooza, A. M., Wammanda, R. D., Mallewa, M., Samia, P., Babakir, H., ... Wilmshurst, J. M. (2015). Pediatric cerebral palsy in Africa: Where are we? *Journal of Child Neurology*, 30(8), 963–971. <https://doi.org/10.1177/0883073814549245>
- Donald, K. A., Samia, P., Kakooza-Mwesige, A., & Bearden, D. (2014). Pediatric cerebral palsy in Africa: A systematic review. *Seminars in Pediatric Neurology*, 21(1), 30–35. <https://doi.org/10.1016/j.spen.2014.01.001>
- Downs, J., Blackmore, A. M., Epstein, A., Skoss, R., Langdon, K., Jacoby, P., ... Cerebral Palsy Mental Health Group (2018). The prevalence of mental health disorders and symptoms in children and adolescents with cerebral palsy: A systematic review and meta-analysis. *Developmental Medicine and Child Neurology*, 60(1), 30–38. <https://doi.org/10.1111/dmcn.13555>

- Engel-Yeger, B., Jarus, T., Anaby, D., & Law, M. (2009). Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*, 63(1), 96–104. <https://doi.org/10.5014/ajot.63.1.96>
- Garth, B., & Aroni, R. (2003). "I value what you have to say." Seeking the perspective of children with a disability, not just their parents. *Disability & Society*, 18(5), 561–576. <https://doi.org/10.1080/0968759032000097825>
- Gorter, J. W., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: Care, health and development. *Child: Care, Health and Development*, 37(6), 757–763. <https://doi.org/10.1111/j.1365-2214.2011.01336.x>
- Imms, C. (2008). Children with cerebral palsy participate: A review of the literature. *Disability and Rehabilitation*, 30(24), 1867–1884. <https://doi.org/10.1080/09638280701673542>
- International Classification of Functioning, Disability and Health. (2001). Geneva.
- Kakooza-Mwesige, A., Byanyima, R. K., Tumwine, J. K., Eliasson, A.-C., Forsberg, H., & Flodmark, O. (2016). Grey matter brain injuries are common in Ugandan children with cerebral palsy suggesting a perinatal aetiology in full-term infants. *Acta Paediatrica*, 105(6), 655–664. <https://doi.org/10.1111/apa.13352>
- Kakooza-Mwesige, A., Forsberg, H., Eliasson, A.-C., & Tumwine, J. K. (2015). Cerebral palsy in children in Kampala, Uganda: Clinical subtypes, motor function and co-morbidities. *BMC Research Notes*, 8(1), 166–175. <https://doi.org/10.1186/s13104-015-1125-9>
- King, G., Law, M., Hurley, P., Petrenchik, T., & Schweltnus, H. (2010). A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *International Journal of Disability, Development and Education*, 57(1), 77–107. <https://doi.org/10.1080/10349120903537988>
- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, 23(1), 63–90.
- Koman, L. A., Smith, B. P., & Shilt, J. S. (2004). Cerebral palsy. *The Lancet*, 363(9421), 1619–1631. [https://doi.org/10.1016/S0140-6736\(04\)16207-7](https://doi.org/10.1016/S0140-6736(04)16207-7)
- Law, M., Anaby, D., Teplicky, R., Khetani, M. A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children and youth with and without disabilities. *British Journal of Occupational Therapy*, 76(2), 58–66. <https://doi.org/10.4276/030802213X13603244419112>
- Law, M., & Darrah, J. (2014). Emerging therapy approaches. *Journal of Child Neurology*, 29(8), 1101–1107. <https://doi.org/10.1177/0883073814533151>
- Law, M., Haight, M., Milroy, B., Wilms, D., Stewart, D., & Rosenbaum, P. (1999). Environmental factors affecting the occupations of children with physical disabilities. *Journal of Occupational Science*, 6(3), 102–110. <https://doi.org/10.1080/14427591.1999.9686455>
- McIntyre, S., Novak, I., & Cusick, A. (2010). Consensus research priorities for cerebral palsy: A Delphi survey of consumers, researchers, and clinicians. *Developmental Medicine and Child Neurology*, 52(3), 270–275. <https://doi.org/10.1111/j.1469-8749.2009.03358.x>
- Novak, I. (2012). Evidence to practice commentary: Is more therapy better? *Physical & Occupational Therapy in Pediatrics*, 32(4), 383–387. <https://doi.org/10.3109/01942638.2012.726894>
- Odding, E., Roebroeck, M. E., & Stam, H. J. (2006). The epidemiology of cerebral palsy: Incidence, impairments and risk factors. *Disability and Rehabilitation*, 28(4), 183–191. <https://doi.org/10.1080/09638280500158422>
- Oskoui, M., Joseph, L., Dagenais, L., & Shevell, M. (2013). Prevalence of cerebral palsy in Quebec: Alternative approaches. *Neuroepidemiology*, 40(4), 264–268. <https://doi.org/10.1159/000345120>
- Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine and Child Neurology*, 50(10), 744–750. <https://doi.org/10.1111/j.1469-8749.2008.03089.x>
- Rosenbaum, P., & Gorter, J. W. (2012). The "F-words" in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, 38(4), 457–463. <https://doi.org/10.1111/j.1365-2214.2011.01338.x>
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., ... Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology. Supplement*, 109, 8–14.
- Rosenbaum, P., & Stewart, D. (2004). The World Health Organization International Classification of Functioning, Disability, and Health: A model to guide clinical thinking, practice and research in the field of cerebral palsy. *Seminars in Pediatric Neurology*, 11(1), 5–10. <https://doi.org/10.1016/j.spen.2004.01.002>
- Schiariti, V., Mâsse, L. C., Cieza, A., Klassen, A. F., Sauve, K., Armstrong, R., & O'Donnell, M. (2014). Toward the development of the International Classification of Functioning Core Sets for children with cerebral palsy: A global expert survey. *Journal of Child Neurology*, 29(5), 582–591. <https://doi.org/10.1177/0883073813475481>
- Schiariti, V., Sauve, K., Klassen, A. F., O'Donnell, M., Cieza, A., & Mâsse, L. C. (2014). "He does not see himself as being different": The perspectives of children and caregivers on relevant areas of functioning in cerebral palsy. *Developmental Medicine and Child Neurology*, 56(9), 853–861. <https://doi.org/10.1111/dmcn.12472>
- Shevell, M., Miller, S. P., Scherer, S. W., Yager, J. Y., & Fehlings, M. G. (2011). The Cerebral Palsy Demonstration Project: A multidimensional research approach to cerebral palsy. *Seminars in Pediatric Neurology*, 18(1), 31–39. <https://doi.org/10.1016/j.spen.2011.02.004>
- Shikako-Thomas, K., Kolehmainen, N., Ketelaar, M., Bult, M., & Law, M. (2014). Promoting leisure participation as part of health and well-being in children and youth with cerebral palsy. *Journal of Child Neurology*, 29(8), 1125–1133. <https://doi.org/10.1177/0883073814533422>
- Shikako-Thomas, K., Majnemer, A., Law, M., & Lach, L. (2008). Determinants of participation in leisure activities in children and youth with cerebral palsy: Systematic review. *Physical & Occupational Therapy in Pediatrics*, 28(2), 155–169. <https://doi.org/10.1080/01942630802031834>
- Strauss, D., & Shavelle, R. (1998). Life expectancy of adults with cerebral palsy. *Developmental Medicine and Child Neurology*, 40(6), 369–375.
- United Nations (2018). *African statistical yearbook 2018*. New York, NY: United Nations. <https://doi.org/10.18356/197757d1-en-fr>
- Vargus-Adams, J. N., & Martin, L. K. (2011). Domains of importance for parents, medical professionals and youth with cerebral palsy considering treatment outcomes. *Child: Care, Health and Development*, 37(2), 276–281. <https://doi.org/10.1111/j.1365-2214.2010.01121.x>
- Verschuren, O., Wiart, L., Hermans, D., & Ketelaar, M. (2012). Identification of facilitators and barriers to physical activity in children and adolescents with cerebral palsy. *The Journal of Pediatrics*, 161(3), 488–494. <https://doi.org/10.1016/j.jpeds.2012.02.042>
- WHO. (n.d.-a). Comprehensive Analytical Profile: WHO African Region.
- WHO. (n.d.-b). Global Health Observatory (GHO) Data. Retrieved March 19, 2019, from https://www.who.int/gho/mortality_burden_disease/life_tables/situation_trends_text/en/
- WHO Regional Office for Africa (2014). In M. Harris, & M. Beveridge (Eds.), *The health of the people: What works—The African Regional Health Report 2014*. Luxembourg: World Health Organization.
- Wiart, L., & Darrah, J. (2002). Changing philosophical perspectives on the management of children with physical disabilities—Their effect on the use of powered mobility. *Disability and Rehabilitation*, 24(9), 492–498. <https://doi.org/10.1080/09638280110105240>

- Wood, P. (1980). *International classification of impairments*. Geneva: Disabilities and Handicaps.
- Wright, F. V., Rosenbaum, P. L., Goldsmith, C. H., Law, M., & Fehlings, D. L. (2008). How do changes in body functions and structures, activity, and participation relate in children with cerebral palsy? *Developmental Medicine and Child Neurology*, 50(4), 283–289. <https://doi.org/10.1111/j.1469-8749.2008.02037.x>

How to cite this article: Abdel Malek S, Rosenbaum P, Gorter JW. Perspectives on cerebral palsy in Africa: Exploring the literature through the lens of the International Classification of Functioning, Disability and Health. *Child Care Health Dev.* 2020;46:175–186. <https://doi.org/10.1111/cch.12733>