

Fighting cerebral palsy in Africa

Cerebral palsy affects children across Africa. Prevention is difficult since we know little about its aetiology in African countries, and efforts to help those affected are hampered by a lack of resources. But individuals and organisations are rising to the challenge. Adrian Burton reports.

For more on cerebral palsy in Africa see *Semin Pediatr Neurol* 2014; 21: 30–35

For more on the facilities available in African countries see *J Child Neurol* 2015; 30: 963–71

For more on cerebral palsy in Botswana see http://www.neurology.org/content/82/10_Supplement/P4.297 and http://www.neurology.org/content/84/14_Supplement/17-1B (accessed July 9, 2015)

A child was born before dawn in a village in southern Africa. His birth was difficult, protracted: he was starved of oxygen for a while. His exhausted mother does not yet know that her son will be physically and intellectually disabled by cerebral palsy (CP). Had her baby's condition seemed immediately life-threatening, she might have made the 40-mile trip to the nearest hospital. Soon she will notice his symptoms and hear gossip of how she must have been unfaithful during her pregnancy; how else could she have had a son with such difficulties? Physiotherapy is available at that far-off medical centre, but no staff member is trained to deal specifically with CP, and they have little of the equipment that could help. It's a brutal scenario but, sadly, not uncommon. Some people, however, are trying to change that.

Little has been published on CP in Africa. Large gaps remain in our knowledge of its aetiology across the continent, its risk factors, even its prevalence—information vital to the development of prevention strategies. Even our knowledge of its most common comorbidities, essential to the development of systems needed to manage patients and support their families, is lacking.

"It seems, however, that birth asphyxia, kernicterus, and neonatal infections of the central nervous system are major culprits in resource-poor African settings", says Kirsten Donald, head of developmental paediatrics at the Red Cross War Memorial Children's Hospital, University of Cape Town, South Africa. "This is quite different to [CP] seen in industrialised nations, where prematurity and low birth weight are the major risk factors. Many cases of CP in Africa could therefore be prevented if the right human and

material resources were available. With a possible prevalence of up to 10 cases per 1000 births, that's a lot of children who are not able to reach their potential."

"Strengthening links between researchers, clinicians, therapists, and those providing specialist training and care is vital if we are to make headway against CP."

In February, 2013, a working group of the African Child Neurology Association met in Cape Town to try to build a picture of CP across the continent, to determine how well equipped different countries are to deal with it, and to identify the steps needed to improve the situation. Its findings reveal the scale of the problem. The delegates, from 22 African nations, reported that a large proportion of children seem to be affected through postnatal insults, such as meningitis or cerebral malaria, yet no system of surveillance of at-risk babies was available in nine of these countries. Specialist services were often absent. In some countries, traditional healers were still the first point of contact for medical help, and South Africa and Egypt were the only countries to have any guidelines for managing CP. And while all the countries represented reported physiotherapy to be available, about half could offer no occupational, speech, or language therapy, and many could provide no orthopaedic support.

"And remember, just because a country reports having certain facilities, that does not at all mean they are ubiquitously available or of the best quality", explains Jo Wilmschurst, head of paediatric neurology at the Red Cross War Memorial Children's Hospital.

"For example, even in South Africa, the most developed of the nations represented [in the working group], CP can be a huge burden in rural areas, where resources and help can be sorely limited. Indeed, in most African countries, the help available outside the major cities may be minimal. Staffing capacity and training are inadequate to support focused disability care, let alone multidisciplinary services, and equipment is typically lacking or outdated."

The delegates agreed that further research was needed to clarify aetiologies and outcomes, and 2 years later the results are beginning to come in. "In Botswana, we recently found perinatal hypoxia (28%), prematurity (21%), postnatal infections (15%), and prenatal TORCH [toxoplasmosis, rubella, cytomegalovirus, and herpes] infections (10%) to be the most common aetiologies", says David Bearden of the Division of Child Neurology, Children's Hospital of Philadelphia, PA, USA, who reported the results of a study of 68 children at the April, 2015, meeting of the American Academy of Neurology in Washington DC, USA. Co-investigator Baphaleng Monokwane, of the Department of Paediatrics, University of Botswana, Gaborone, Botswana, explains that CP was often the consequence of delayed referral to a tertiary hospital. "Unfortunately, we see cases of complicated meningitis due to delays in seeking medical interventions because of traditional beliefs. Addressing this could make a difference. In terms of prematurity, we could do a lot by working on prevention."

The same research group also reported that 41% of affected children fell into the most severe motor impairment category, while

84% suffered intellectual disability, 77% had epilepsy, 46% were visually impaired, 16% had hearing problems, 31% had contractures, and 28% showed orthopaedic complications. Reflecting the delegates' recognition of the need for innovative solutions to maximise access to health care, Bearden emphasises the potential of "appropriate, low-cost, community-based classes in which we could teach parents basic rehabilitation techniques for these problems. This, in combination with regular check-ups by community health workers, may be better than a system that demands parents regularly bring children to a hospital, which can be very challenging for families in most parts of Africa."

Malamulele Onward, a non-governmental organisation based at the Children's Memorial Institute, Braamfontein, South Africa, may be ahead of the game in this respect. "Many dedicated therapists and mid-level staff work at hospitals across the continent, but don't have specialised training in CP", explains Gillian Saloojee, the organisation's executive director. "Over the past 9 years, our work with over 700 children and their families in deeply rural areas of South Africa, Lesotho, and Rwanda has shown that a sustainable intervention model not only has to include training for rehabilitation therapists, but also for parents and families, along with the provision and fitting of postural equipment, hands-on therapy, and regular mentoring visits."

"Parents are an untapped resource in rural areas", adds Misty Weyer, Malamulele Onward's training co-ordinator, "one that we mobilise through our Carer-2-Carer Facilitator Course or through blocks of residential intensive therapy. We developed the Carer-2-Carer programme...with 20 parents representing five languages and cultures, and it's now the first CP programme in South Africa to be taught by rural parents themselves. Parents are trained in CP care, shown how to support other parents and

facilitate peer-learning, and work in partnership with their local CP clinics. This provides other families [with] access to information about CP in ways they understand, in their own language, from someone living similar experiences."

"We assess our programmes through feedback from the parents, plus annual follow-up visits to the rural hospitals, where we have trained therapists and mid-level workers, and through home visits to children we've treated", explains Saloojee. "As we've learned about the realities of daily life for caregivers and families, the more appropriate our training courses have become. The burden remains huge, but we've seen that the strategies we follow can change the quality of care children with CP receive in rural areas."

Malamulele Onward, however, is not alone in its efforts. Cerebral Palsy Africa, a non-governmental organisation based in Duns, Scotland, UK, is involved in similar projects in Ghana, Zambia, Malawi, Kenya, and Uganda. "We provide training to rehabilitation workers [involved in] community-based projects, which allows access to children and families and helps win their trust", explains co-founder Archie Hinchcliffe. "In addition, we train specialist therapists in [guaranteed] long-term paediatric employment; this boosts the efforts of rehabilitation workers, [to] help avoid children developing contractures, and ensures their continued progress. And we help set up self-sustaining workshops in which the workers we train make assistive, supportive devices from waste paper and cardboard available at hospital pharmacies. Using appropriate paper-based technology methods, chairs and standing frames can be made to measure, facilitating each child's development and social participation."

Other organisations are working on the ground too, such as the Cheshire Foundation (Botswana), Benola (Nigeria), Handicap International (Burundi), and the Ronald Trust for



Malamulele Onward

Cerebral Palsy and Autism Children (Zimbabwe). The African Paediatric Fellowship Program at the University of Cape Town is also offering special training for African doctors, nurses, and rehabilitation practitioners. "We've trained doctors in Ghana, Kenya, Tanzania, and Zimbabwe in neurology patient care", explains Wilmshurst, "and training courses have been run in Ghana and Zimbabwe, developing rehabilitation awareness in these regions".

"Strengthening links between researchers, clinicians, therapists, and those providing specialist training and care is vital if we are to make headway against CP", concludes Donald. "Our meeting in Cape Town brought together clinicians often working in isolation who can now support each other. Creating links with organisations like Malamulele Onward can only increase our chances of taking on this problem that makes life so difficult for all who are touched by it. African nations may be hampered by low resource levels for years to come, but by pooling our minds and hearts, and by pulling together, we can begin to make a difference."

Adrian Burton

*In memory of Bafokeng Mohamoe
March 18, 2010–June 10, 2015*

For more on **Malamulele Onward** see <http://www.malamuleleonward.org>

For more on the **Carer-2-Carer course** see http://www.malamuleleonward.org/index.php?option=com_content&view=section&layout=blog&id=20&Itemid=171

For more on the **paper-based supportive devices** see <http://www.paperfurnitureenterprise.com>

For more on the **Cheshire Foundation** see <http://www.info.bw/~cheshire.bots>

For more on **Benola** see <http://www.benola.org>

For more on **Handicap International** see <http://www.handicap-international.us/burundi>

For more on the **Ronald Trust** see <https://www.facebook.com/ronaldtrust4cp>

For more on the **African Paediatric Fellowship Program** see <http://www.paediatrics.uct.ac.za/scah/apfp/programme/overview>