

A South African cerebral palsy registry is needed

Africa has undergone exponential population growth over the past decade, with children accounting for more than half of the entire population.^[1] It is estimated that Africa's population will more than double by 2050.^[1] Cerebral palsy (CP) remains the most common motor disability of childhood. The overall birth prevalence of CP is ~2/1 000 live births, ranging from 1.5/1 000 to >4/1 000 live births, according to population-based studies from around the world. In rural South Africa (SA), the prevalence of CP has been estimated to be as high as 10/1 000 live births.^[2]

In high-income countries, the prevalence, risk factors, distribution, frequency and severity of CP have been explored and defined through CP registers. Such registers are population databases from multiple sources, relying on a clear definition and inclusion and exclusion criteria of CP, and requiring a mix of skills with collaboration from obstetricians, paediatricians and epidemiologists. The collected dataset provides valuable information that can be used to monitor trends, motivate for interventions and calculate life expectancies.^[3]

The first CP registry was started >20 years ago in Europe.^[4] In 1998, a Surveillance of Cerebral Palsy in Europe (SCPE) registry was established, which incorporated data from 9 European countries with the aim of establishing collaborative research. Based on the Australian Cerebral Palsy Registry (established in 2007), Bangladesh was able to start their registry in 2015,^[5] New Zealand in 2016,^[6] and Sri Lanka in 2017.^[7] The CP registry in the USA began in 2006, from which a multi-institution database was later established.^[7]

Epidemiological data derived from CP registers of high-income countries may not be applicable to resource-constrained low- and middle-income countries (LMICs) if one considers differences in risk factors and challenges relating to provision of obstetric and neonatal care.^[8,9] In SA, a large proportion of children and adults with CP are assumed to have exposure to aetiological factors that are potentially preventable, including premature birth, intrapartum-related events (mainly intrauterine hypoxia), as well as congenital and postnatal infections.^[10] In terms of these risk factors, CP represents an important quantitative link, particularly with perinatal conditions. The main outcome measure most often used to assess standards of perinatal care is the perinatal mortality rate (PMR). It is uncertain whether decreases in perinatal mortality are associated with a parallel decrease in morbidity (i.e. childhood disability). To answer this question, prevalence rates of CP must be monitored. This can be done most effectively through the establishment of a regional or national CP registry.

Currently, the largest and most comprehensive CP mortality database globally, is the Life Expectancy Project in San Francisco.^[11] This database is often used to determine life expectancy in CP medicolegal litigation in SA. However, investigating the epidemiological differences between high-income and resource-constrained countries, it is logical that SA life expectancy should be calculated based on SA data. A local CP registry may ultimately be able to provide longitudinal mortality data that can allow estimation of relevant life expectancy reference data within the SA context.^[11]

In recent years, SA has seen an exponential rise in CP medicolegal litigations.^[12] Successful medicolegal claims come with recommended services that are stipulated for these patients by the courts. The huge patient load and scarcity of resources in the public health sector render the sector incapable of consistently and adequately providing the requirements specified for the care and support of children with CP. Therefore, a potential outcome of the proposed National

Health Insurance Bill may be the improvement of the public sector healthcare system to ensure adequate management of children suffering from CP.^[13] A CP registry in SA may enable the improved evaluation of current services that are being provided for children with CP, identify gaps in service provision (constrained resources for equipment and interventions, effects of the shortage of suitably trained and experienced staff, inequitable distribution of healthcare access across SA) and provide measures for the quality of life of children with CP and their families.

Children with CP are highly vulnerable, with few vocal advocates, and are frequently neglected in healthcare planning. This inevitably results in fewer resources allocated to children with disability by policymakers. It is, however, important that resource allocation by policymakers in all sectors, including health, should effectively even out the ethical criteria of cost effectiveness, equality and improved quality of life for all, regardless of one's level of function.^[14]

There is therefore an urgent need for SA to learn from and adapt already-established CP registries to develop a context-relevant tool with reference values drawn from the epidemiological profile of the country. This is an essential requirement if valuable data are to be acquired.^[15] Linking existing administrative health data to a well-established, population-based CP registry would assist in providing evidence-based motivations for significant policy-making, planning and managing of healthcare resources and preventive strategies for children with CP.^[16] CP registers are ideal for monitoring effectiveness of interventions and policy changes over time.^[17]

The establishment of a multi-institution CP registry would further facilitate the relationships between sectors that are involved in the holistic management of children with CP, i.e. the healthcare sector, and educational, rehabilitation and community settings.^[17]

The information-rich CP database that can be created through the registry would also provide a source from which novel research can be done to inform strategies for the prevention of and management strategies for CP in SA.^[17]

This calls for the combined efforts of government and other stakeholders to leverage and expand the clinical expertise in the SA healthcare system, invest in high-quality data management and curation infrastructure. This is a critical step in equitable and effective care for children with CP. Establishing a CP register will be the information backbone for being able to implement such initiatives within a relevant evidence-based framework, which is currently being planned for Western Cape Province, SA.

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