EDITORIAL

Cerebral palsy care in South Africa: a paradigm shift

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The word 'paradigm', derived from the Greek *paradeigma*, refers to a 'framework' or 'a very clear and typical example of something'.[1] A paradigm shift thus signifies a change in the demand for certain competencies and/or expertise within a specific framework.

This certainly applies to patients affected by cerebral palsy (CP) in a developed world context. The domain of childhood CP has entered a new paradigm which entails significant changes regarding patient profile, treatment approach, outcomes and expectations. After an initially slow uptake, the developed world has now successfully adjusted to a broader biopsychosocial approach. Most of the developing world, however, still lacks a structured framework with the ability to accommodate and address the needs of this changing cohort of patients.

So, what exactly has changed?

A significant number of CP patients have reached adulthood.

A meta-analysis, conducted by Oskoui *et al*. between 1985 and 2011, concluded a global CP prevalence of 2.11 per 1 000 live births,[2] which is in keeping with the most commonly quoted global prevalence of 2–3 per 1 000 live births.[3,4]

It is generally acknowledged that developing countries would have a higher prevalence of CP, but multiple confounding factors, along with a lack of relevant literature, make an accurate estimation difficult. South Africa[3] reports a prevalence of 10/1 000 live births, India and China[5] 1.5–2.5/1 000 and Uganda 1.8–2.3/1 000.[6]

These statistics, along with the encouraging trend that death due to CP has become a much rarer occurrence,[7] contribute to the startling revelation that we will soon be treating large groups of patients with CP in the unique categories of adolescent, young adult, mature and even geriatric populations.

Currently, there is a paucity of literature regarding the prevalence of adult CP. In Sweden, a highly developed country, the prevalence of CP in the adult population is 1.14 per 1 000.[8] Although this number is slightly lower than the childhood prevalence for the same group, i.e. 1.7 per 1 000 at birth, it is clear that most of these children are, in fact, reaching adolescence and adulthood.[8]

Mortality in children with CP is centred on infancy. Eventual life expectancy, or progression into adulthood, shows a linear relationship with the number of major disabilities which co-occur in an infant, or young child, with CP.[9] Children with CP and no major disability have a 99% probability of surviving to the age of 30 years and beyond. However, only 33% of children will survive into adulthood if they have four or more co-occurring disabilities.[7,9]

The survival of 47 259 children receiving CP care in California was evaluated over a 20-year period (1983–2002). Researchers ascertained that life expectancy recorded in earlier studies should be increased by approximately 5 years and that mortality in children with severe disabilities should be decreased by 3.4% per year.[10]

Unfortunately, very few studies have evaluated the survival and mortality of CP patients in developing countries. The higher prevalence of CP in South Africa, however, strongly suggests that we can expect a large adult CP population group.

Why is this important?

The profile of the adult CP patient should take note of comorbidities, above and beyond motor disorders, which could affect these individuals. These factors may include depression, anxiety, intellectual disability, visual impairment, eating and swallowing disorders, language and speech disorders, dysarthria, gastrointestinal disorders, urinary disorders, auditory limitations as well as cardiovascular problems.

When compared to the general population, an adult with CP might display a significant increase in general pain, premature symptoms of ageing, spinal deformities and back pain, osteoporosis and arthritis, sarcopenia, cardio-metabolic and pulmonary morbidity, nutritional challenges (such as dysphagia and general malnutrition) as well as global functional limitations.[11] Up to 70% of young adults with CP struggle to perform activities associated with daily living.[12] These individuals experience a slow and progressive decline in their functional reserve and overall strength.[13] In addition, psychological issues and depression are also more commonly found in adults with CP.[14]

It is, unfortunately, abundantly clear that CP patients' health-related quality of life consistently rates lower than that of the general population, and that the factors which impact upon these individuals extend far beyond motor disabilities.[15]

Why do we need to shift our paradigm?

'I suppose it is tempting, if the only tool you have is a hammer, to treat everything as if it were a nail' – Abraham Maslow (1966)

Children with CP are traditionally cared for by a multidisciplinary team. The paediatric orthopaedic surgeon constitutes an integral cog within this framework as we are called on to mainly address the motor abnormalities of these children. Unfortunately, the care of CP adolescents, young adults, adults and geriatric patients becomes much more fragmented and, as a result, in most cases the individualised approach is once again adopted. For example, when an adult CP patient presents with osteoarthritis of the hip, more often than not the arthroplasty surgeon will address this problem. Said arthroplasty surgeon will frequently, and without addressing the numerous additional problems as previously noted, perform a total hip replacement. The additional problems may involve other musculoskeletal (*bio*psychosocial) as well as the so called 'soft' (bio*psychosocial*) aspects of comprehensive care for an adult with CP. The next consultation may be with a spinal surgeon, and so the individualised and fragmented cycle repeats itself. This cyclical repetition of fragmented care can, primarily, be ascribed to insufficient multidisciplinary support for the adult CP

patient and his/her treating orthopaedic surgeon, and should not be attributed to the treating physician's lack of attention to detail.

What should we do about the status quo?

In an effort to fully understand the outcomes of different treatment options we should rethink our traditional approach to measuring said outcomes. In 1980 the World Health Organization (WHO) proposed the International Classification of Impairments, Disabilities and Handicaps (ICIDH) which classified *consequences of disease*. This comprehensive classification was developed to address a wide range of various health aspects and was consequently revised and adjusted in the early 1990s. After nine years of intensive research and input, the WHO published a new classification system, the International Classification of Functioning, Disability and Health, or ICF.[16] The ICF emphasises *components of health* rather than *consequences of disease* and has proven to be an extremely useful classification and model to adopt when dealing with CP patients.

The ICF model, as per *Figure 1*, provides a balanced perspective within which the spectrum of *functioning* and *disability* across the patient's lifespan can be appreciated. It seeks to identify and classify abnormalities across two components, namely: 1) body function and structure; and 2) activities and participation.

These components can be defined as follows:

- Body structures: anatomical parts of the body such as organs, limbs and their components
- Body functions: physiological functions of body systems including psychological functions
- Activities: execution of a task or action by an individual
- Participation: involvement in a life situation

In addition, the ICF recognised the importance of *contextual factors,* including personal and environmental factors which may obstruct, or facilitate, the level of functioning and disability. *Environmental factors* denote the physical, social and attitudinal environment in which people live, while *personal factors* describe factors unique to the individual (e.g. education, social background, life events, lifestyle and race/ethnicity) which impact upon his/her functioning.

The ICF model thus provides a biopsychosocial framework according to which clinical identification and quantification can take place while considering body function/structure and activities/participation as well as other relevant contextual data. This approach has proven useful in the CP domain, especially in the case of adolescents transferring into adulthood, as well as the adult CP patient.[17-19]

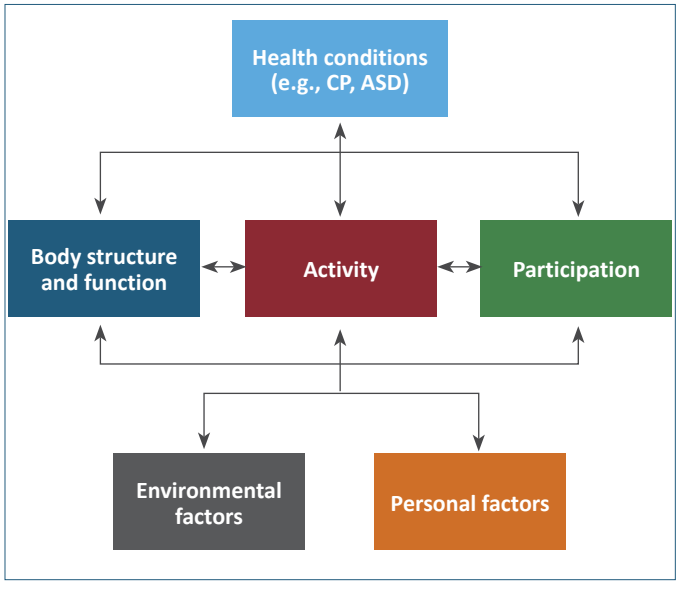

Figure 1. International Classification of Functioning, Disability and Health (ICF) (policyoptions.irpp.org-Source World Health Organization 2001)

If we wish to successfully implement this line of action, we need to *reinvent* our approach by creating different multidisciplinary groups which function within the broader scope of healthcare for adults with CP. In addition, groups within South Africa which are already utilising this approach should be embraced to facilitate knowledge transfer. Our aim should be to include a paediatric orthopaedic surgeon, well versed in CP care, to reassess general mobility, supply institutional memory, and treat reversible aspects that would normally have been addressed in childhood. Active participation of an upper limb, spinal, arthroplasty and foot and ankle surgeon will add immense value by facilitating a balanced approach to addressing the motoric abnormalities in addition to promoting an earlier recognition of the sequence and effect of one type of surgery on another, e.g. spinal and arthroplasty surgery. The psychosocial team will re-emphasise those day-to-day challenges which affect these individuals most, thus imbuing the orthopaedic surgeon with deeper insight regarding the possible implications of surgery as well as treatment plan options.

How should we approach CP care in the future?

To render appropriate and balanced care for this emerging patient group, we need to:

- better understand the prevalence of adults with CP in South Africa. We need to seriously contemplate the question: How large is this cohort of patients?
- identify the unique challenges which will be experienced by the adult population of CP patients in the South African developed/developing country context
- avail ourselves with the current structures which care for this group within South Africa
- reinvent and implement a multidisciplinary team which can address the unique challenges of this cohort
- utilise and implement the ICF
- set up research avenues that will assess, address and audit our past, present and future initiatives with regard to adults with CP
- become champions for the cause of this vulnerable group of patients.

This shifting landscape creates a unique opportunity to develop what can arguably be considered the first multidisciplinary team within South Africa, and Africa, to address the needs of a very special, and ever-growing group of patients, thus enabling us to render global and balanced care within an evidence-based framework.

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Erratum

The article, 'Proximal humerus fractures – Part 1: Conservative management' by Anley C, Vrettos BC, Rachuene P and Roche SJL, published in the *South African Orthopaedic Journal August* 2019 Vol 18 No 3 pp 63–71, inadvertently contained the incorrect version of an algorithm regarding the treatment of proximal humerus fractures, as well as the incorrect reference (Figure 4, page 68). These have both now been updated on the online version of the article.