



# Is the Management of Children with Cerebral Palsy Tyrannized by Evidence?

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It seems we have arrived at a place where no management strategy is acceptable unless there is published data that support its effectiveness. The systematic review process reveals a reverence for randomized controlled trials (RCTs) while failing to recognize that the RCT model is based in the medical management of a single disorder using a single drug and tests for a single outcome comparing treated and control groups.

Systematic reviews are shining a light on a real shortfall of evidence of interventions for children with cerebral palsy (CP) that meets the criteria for all levels of quality described by the Centre for Evidence-Based Medicine (<http://www.cebm.net>). Short-term, single-focus, clinical studies comprise the primary body of literature that is considered “evidence,” whether or not they ask or answer science-based questions about the effectiveness of an intervention. The effects of aiming a single treatment at a single issue for four, eight, or 12 weeks loses relevance when considered in the context of the diversity, complexity, scope, ongoing changes, and life-long duration of challenges faced by - and management options offered by - all concerned with each child’s welfare. *“Evidence based guidelines often map poorly to complex multimorbidity.” (Greenhalgh T 2014, p. 2)*

In my opinion, the current demand for “evidence” as a justification for intervening overlooks the shortfall of evidence and discourages the emergence of clinical evaluation, skill building, and science-based innovation.

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*“Good doctors [and clinicians] use both individual clinical expertise and the best available external evidence, and neither alone is enough. Without clinical expertise, practice risks becoming tyrannized by evidence, for even excellent external evidence may be inapplicable to or inappropriate for an individual patient.”*

- D.L. Sackett

*“Evidence based medicine: what it is and what it isn't”*

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The achievement of virtuoso-level skills reportedly requires ~10,000 hours of deliberate practice with typical daily practice sessions of ≤4 hours (*Ericsson KA 1996; Krampe RT 1996, Ericsson KA 1993, Sloboda J1996, Gladwell M 2008, Jabusch HC 2009*). If so, virtuosity would be achieved in 7 years of daily practice sessions of four hours, and in 10 years of daily sessions of three hours. Typically developing (TD) children can be expected to spend three to four hours per day standing and walking after the first year of development.

At this rate of practice, children show a measure of maturity in walking kinematics and muscle recruitment between ages 2.5 and 3.5 years of age (*Okamoto T 1972, Sutherland DH 1988 & 1984*). Preschoolers lack full hip extension range of motion (10° past 0° (*Kendall FP 2005*)) and remain immature in kinetic development – energy generation and conservation mechanisms. All differences between children and adults in gait skills - in normalized mechanical work and energy efficiency - diminish significantly after age 7 years and disappear after age 10 years (*Hillman SJ 2009, Ganley KJ 2005, Schepens B 2004*). Dierick (2004) reported that the TD children they studied gained full control of immature displacements of the body center of mass after six years of walking. These observations suggest to me that fully mature walking can be considered to be a virtuoso-level skill.

This long-term acquisition of typical walking expertise has escaped the attention of most researchers of effectiveness of rehabilitative interventions for children with cerebral palsy (CP). While TD children practice walking for hours daily for seven to 10 years, a therapy session can last 30 to 60 minutes, and offered at intervals of one/month to three/week to two/day in “intensives” of four weeks occurring once or twice yearly. Therapists depend upon caretakers and teachers to “carry-over” their treatment successes and support the goals at home and at school, regardless of their time constraints or abilities.

One wide-ranging<sup>1</sup>, long-term study of the effects of the intensity of therapy services on GMFM scores determined that intensive training, ≥3 sessions per week and/or participation in an intensive program, was the only intervention factor associated with enhanced gross motor progress. *“Intensive training was associated with enhanced gross motor progress over an average of 2.9 years in children with CP. Intellectual disability was a strong negative prognostic factor.”* (*Størvold GV 2018, p. 548*)

Garment therapy grew out of the clinical experience of discovering two things: 1) a child’s potential to use his or her body more effectively and efficiently with manual facilitation and enhanced somatosensory input, and 2) the inability of that child to sustain those gains without massed practice. The sciences of kinesiology, biomechanics, motor learning, and physiologic adaptation of all tissues, including the cortex, all support routine use for many years to achieve lasting effects. Learning by experience to use a body that is better aligned for several hours per day can be expected to require many thousands of hours of practice – i.e. several years of routine use – to see the effects on functional skills and participation.

In my experience, foot alignment is so influential on limb and body alignment that I align them before introducing a garment system for use in standing and walking. If the AFOs and the garment system improve functioning alignment immediately and effectively, then the intervention “works” and so it needs to be implemented for as long as it is needed. The only RCT of the effects of garment use on crouch posture in school-aged children with CP illuminated this point by assessing the use of TheraTogs without foot alignment, then introducing ankle foot orthoses with TheraTogs (*Abd El-Kafy EM 2014*). The combination was more effective than TheraTogs alone, but the effects of the AFOs were not established first.

As DL Sackett made these statements in 1996, pp 71-72: *“Good doctors use both individual clinical expertise and the best available external evidence, and neither alone is enough. Without clinical expertise, practice risks becoming tyrannized by evidence, for even excellent external evidence may be inapplicable to or inappropriate for an individual patient.”*

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<sup>1</sup> A Norwegian prospective cohort study based on 2048 assessments of 442 children (256 boys, 186 girls) aged 2-12 years.

*“By individual clinical expertise we mean the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice.”*

*“Evidence based medicine is not "cookbook" medicine. Because it requires a bottom up approach that integrates the best external evidence with individual clinical expertise and patients' choice, it cannot result in slavish, cookbook approaches to individual patient care. External clinical evidence can inform, but can never replace, individual clinical expertise, and it is this expertise that decides whether the external evidence applies to the individual patient at all and, if so, how it should be integrated into a clinical decision.”*

In the context of the existing and typical therapy services and schedules, GMFCS-related functional skills of children with CP are reported to be stable. Progress between levels (e.g. from level III to Level II) does not occur (Rosenbaum PL 2002, Alriksson-Schmidt A 2017). This functional stability data serves as a control group for RCTs and eliminates the need to consider maturation as a factor in measuring the gains made with long-term and combined interventions. It seems we can track GMFM scores over years of living in improved foot and body alignment as an adjunct to the therapy program and challenge the notion of functional stability by implementing known scientific principles.

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