Cerebral palsy: why doesn't our knowledge advance more quickly?

Editorial

A while back I saw a 15-year-old youth in the spasticity clinic of our Neuromotor Program. She is a bright young lady who has been quite successful despite a very severe dystonic form of motor disturbance. We had tried a number of treatment approaches, none of which were of much benefit. With nothing more to offer her and with the visit ending I asked her if she had any questions. In an intense voice reflecting her years of struggle she asked me when we were going to find a cure because she wanted to walk. What I said was that we have researchers who were working to find answers and that, while we don't have effective treatments today, they would come in the future. I said that for now it was important to focus on her successes and the researchers would focus on finding the answer to her motor disorder. She left clearly not satisfied with my answer and she left me disturbed because she brought into focus something I have felt for some time now: we are not advancing our knowledge fast enough.

In 2000, Virginia Moyer and her colleagues published a textbook on evidence-based practice in pediatrics[1] within which a chapter on CP reviewed the evidence for some key questions related to early intervention, prognosis, and therapeutic options. Now, with the next edition of the book in final stages of preparation, we find very little new to say!

In fact, we seem to spend more time proving that fringe therapies don't work than rapidly advancing our knowledge in basic science, natural history, and therapeutic interventions. So why aren't we advancing as fast as we should and what can we do about it? Three strategies come to mind.

First, is an increased focus on basic science. Perhaps the hardest, most expensive, and yet potentially most important strategy is to focus increased attention on the biological processes involved in brain development, injury, and recovery as applied to children with CP. There are promising areas of development, such as the intrapartum factors influencing brain injury, but much more focus and attention is required. We must use the rapidly developing tools within basic science to understand the biology of CP.

We are seeing this investment occur in areas such as spinal cord injury where major efforts, spurred by high profile public figures, such as the actor Christopher Reeve, have established quality research efforts to repair the spinal cord after injury (reference). Such high profile is more difficult in CP but possible and necessary if we are going to take advantage of new technologies to get the results we need.

Second, multi-site collaboration is critical in bringing together the expertise and critical mass of patients to answer important questions in clinical research in a timely manner. We have learned this lesson from fields such as pediatric cancer and, more recently, neonatology.

Neonatology networks are increasing their sophistication in using multi-site standard collection of process and outcome measures to examine variation in outcomes across sites and to introduce large multi-site cohort studies and clinical trials, the results of which promise more rapid change than traditional approaches to research collaboration.

The creation of national and international collaborative groups provides a powerful means for answering critical questions in a timely way. These networks must capture large cohorts of children and have established agreements on measurement and classification as well as a structure for approving protocols and getting access to patients. Through a combination of randomized trials, cohort studies, and examining variations in outcome, the field could progress at a more appropriate pace.

We have had some success in this area with for example the six-centre North American Growth in Cerebral Palsy Project that was encouraged and supported through a grant from the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) and the United Cerebral Palsy Research and Education Foundation. CanChild in Ontario, Canada is another example of the value of a regional network in supporting research and application of new knowledge to practice. Overall though, the scale of collaboration has not yet approached its potential.

Third is measurement. In order for collaborative efforts to work we need the tools to be consistent in diagnosis and classification, to measure processes of care, and to measure outcomes. This is an area where there has been progress over the last several years: the Gross Motor Function Classification System[2] and Gross Motor Function Measure[3] are important standardized tools that are being used consistently across a broad range of studies.

Today we have the tools to collaborate in a way never before possible. We have the models in cancer and newborn care that demonstrate the power of such collaboration. With the AACPDM, the European Academy of Childhood Disability, and with other regions in the world establishing similar organizational structures we have a framework for changing the pace of advancement.

We should take up this challenge and develop a bold plan for moving forward. A plan that will truly give hope to the children, youth and families we seen in our clinics every day.

Robert Armstrong

DOI: 10.1017/S0012162203001063

References

1. Moyer VA, editor. (2000) *Evidence Based Pediatrics and Child Health*. London: BMJ Books.
2. Palisano RJ, Hanna SE, Rosenbaum PL, Russell DJ, Walter SD, Wood EP, Raina PS, Galuppi BE. (2000) Validation of a model of gross motor function for children with cerebral palsy. *Phys Ther* **80:** 974–985.
3. Russell DJ, Rosenbaum PL, Avery LM, Lane M. (2002) *Gross Motor Function Measure (GMFM-66 & GMFM-88) User's Manual. Clinics in Developmental Medicine. No 159.* London: Mac Keith Press.