

The long-term view for cerebral palsy research and care

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This commentary is on the original article by Jonsson et al. on pages 839–845 of this issue.

The long-term objective of the pediatric health care provider should be to help individuals develop into high functioning adults with as few medical complications as possible. The long-term outcome data presented by Jonsson et al.¹ raises several important issues related to clinical care and research of adults with cerebral palsy (CP) which are barriers to this goal. The data presented come from the Swedish Population Register, which was founded in the 1950s, and provide fascinating information about functional and health status. The authors report on a decrease in ambulatory function that relates to distribution and type of CP, and note an increase in the prevalence of intellectual disability and seizures as the participants moved into their adult years.

First, the paper shows the power of a registry, specifically a population-based registry. As the authors note, population-based registries can gather data from individuals who do not go to a clinic. Clinic-based studies are necessarily biased toward individuals who have problems that lead them to seek medical care. A population-based registry allows a truer picture of the scope of the issue under study. However, even clinic-based registries, such as the Cerebral Palsy Research Network,² are sorely needed to provide long-term outcome information based on clinical characteristics and, more importantly, interventions. Registries are complex and require extensive infrastructural support, but they are an excellent vehicle for moving clinical research forward, especially for relatively uncommon diagnoses such as most pediatric-onset disabilities.

Second, as Jonsson et al. observe, there is a major need for clinicians that are interested in becoming knowledgeable about adults with CP and the challenges they face. Along with the well documented problem of loss of mobility function as described in this paper, this population faces increased risk of many chronic diseases which occur at an earlier point in life than seen in their typically developing peers.³ Managing these problems is complicated by physiological alterations that lead to different approaches to screening and monitoring, as well as treatment. Adults with CP need informed, coordinated care, but there is currently a lack of clinicians interested in both individuals with pediatric-onset problems and adult populations.⁴

Finally, this study reminds us of the need to investigate and understand health and functional changes in adults with CP. When these changes are seen, they should not be attributed to ‘progression of CP’ or ‘early aging’. There are many neurological issues that arise in adults with CP that can affect function, such as undiagnosed stroke, spinal stenosis, pain, changes in tone, and mental health issues which should be diagnosed and appropriately treated.⁵ The high prevalence of multimorbidity of chronic illnesses certainly plays a role in functional loss, and must be properly identified and managed. Decreased physical activity or poor quality of equipment may be involved as well.

This remarkable long-term outcome study is a valuable addition to the literature, defining the problems and issues adults with CP face. As a medical community, we must advocate for the development of better infrastructure (such as registries) to create similar studies that will allow broad analysis of interventions with extensive follow-up. We must continue to increase our knowledge, including developing new interventions and care pathways to address the unique problems of this population. We must also disseminate this knowledge and take necessary steps to increase the capacity of high-quality care for adults with CP.

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