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ORCIDGavin Clowry  <https://orcid.org/0000-0002-6489-8329>**REFERENCES**

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Describing functional skills in children with cerebral palsy close to age 5 years matters

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Children with cerebral palsy (CP) typically experience changes in motor function due to age and development, secondary impairments, or as a result of medications or interventions. Huroy et al. describe the evolution of gross motor function in children with CP between two time points: initial referral for diagnosis and confirmation of diagnosis.¹ The Gross Motor Function Classification System (GMFCS) was developed to rate a child's current and usual gross motor function performance by focusing on self-initiated movements.² Previous studies demonstrated its relative overall stability over time and acceptable prediction of walking ability in later age,³ which is a key consideration when discussing prognosis with parents. The GMFCS is also used in surveillance and research settings. In public health practice and epidemiological research, population-based registration is the criterion standard for the provision of information on CP and has been steadily contributing to the overall understanding of this condition. Beyond neurological findings, information regarding functional skills is necessary to fully document severity. Grading of the child's motor ability using the GMFCS has proven to be feasible, valid, and reliable, and allows for accurate classification even when the only medical information available is the medical records,⁴ which is a common situation in CP registration.

In CP registries, the identification and registration process generally occurs at two points in time: at first referral for diagnosis, usually before the age of 2 years, and at confirmation of diagnosis, optimally in 5-year-olds. For example, children are considered for inclusion in the Surveillance of Cerebral Palsy in Europe database if they fulfill the clinical and eligibility criteria after their 4th birthday.⁵ Referral of infants with suspected neurological conditions or at high risk of developing CP facilitates case identification and data collection. Confirmation of diagnosis is necessary to fully ascertain the entire population with CP, including milder cases, within a defined geographical area, thus allowing for accurate prevalences and descriptions. For both ages, information on functional status is captured. Thus, the databases may contain two levels of functional limitations that may, in some cases, be discordant as shown by Huroy et al. for gross motor function. Changes at the individual level affected 14.1% of children in the Canadian CP Registry.¹

The CP registry community has made considerable efforts to standardize the language used to define and classify CP and, to a lesser extent, describe functional status. This article reminds us that registry databases need be consolidated with data collected close to age 5 years to describe the distribution of variables likely to change over time, regardless of how the child is identified and the previous registration steps are organized. Thus, we can be

This commentary is on the original article by Huroy et al. on pages 1487–1493 of this issue.

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sure that we can compare results across studies or aggregate information for larger surveillance systems.

DATA AVAILABILITY STATEMENT

Not required

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Thinking about differences in the worldwide prevalence of cerebral palsy

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A gratifying development of recent decades is the increased attention to the descriptive epidemiology of cerebral palsy (CP). Counting the frequency of health events is among the least glamorous of biomedical research activities, and yet is central to understanding the impact of different health disorders on the population, providing metrics that underly all priority setting in public health.

With other members of the Global CP Prevalence Group, McIntyre et al.¹ have provided a careful and thoughtful summary of the current state of global CP prevalence. We have come a long way from the days when the only reliable population-based CP data and time trends came from Sweden² and Denmark.³ The 10 reports by Bengt and Gudrun Hagberg and colleagues from Gothenburg, authored over a span of 35 years (1975–2010), set the standard for the creative use of CP registries, and are linked to the present report through the authorship of Dr Himmelmann, first author of the final two Gothenburg studies.⁴ The paper by McIntyre et al. includes data from

registries from 27 countries, though not all could be mined for time trends.

The good news is that CP prevalence has decreased by about 25% over the past 20 years or so, but this is known only from data from high-income countries (HICs). The situation in low- and middle-income countries (LMICs) is not nearly so encouraging. Time trends are not available, but the best estimate of current CP prevalence in LMICs is over 3 per 1000 live births, about double the 1.6 per 1000 the authors estimate for HICs.

We must consider the slight possibility that the decline in CP prevalence in HICs may in part be a consequence of improvements in diagnostic testing in children with motor abnormalities and the clearer identification of specific genetic or metabolic conditions that may then be classified under their specific etiology and not under the broader descriptive rubric of CP. A careful study in one or more CP registries might be able to clarify this point. This minor caveat notwithstanding, two clear questions are generated by this exemplary piece of descriptive epidemiology: (1) why is CP prevalence higher in LMICs; and (2) why is prevalence declining in HICs?

This commentary is on the original article by McIntyre et al. on pages 1494–1506 of this issue.

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