

The Whitney Comorbidity Index for adults with cerebral palsy: A challenge for practice.

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There is growing evidence that adults with cerebral palsy (CP) are at risk of significant comorbidity that increases mortality rates. Compared to adults without CP, adults with CP are at increased risk for a variety of conditions, for example diabetes, hypertension, stroke and osteoporosis. Whitney and Basu [1] validated the recently developed Whitney Comorbidity Index (WCI) to predict mortality in adults with CP [2]. The authors presented a strong paper which is highly relevant for the adult CP population. The WCI was validated in 16,728 adults with CP with or without epilepsy and/or intellectual disability and proved to be a valid measure to predict mortality in (subgroups of) adults with CP, based on 27 different comorbidities. Not unexpectedly, adults with CP and epilepsy and/or intellectual disabilities died at younger age than the adults with only CP (7.8-11.1%, range mean age of death 55.1-62.0 years; 8.0%, mean age at death 67.3 years; respectively) while the WCI scores of the subgroups hardly differed.

The study stresses the importance of accessible preventive measures for this population. However, findings did not consider the heterogeneity of the adult CP population, while evidence shows marked differences in mortality rates between CP severity levels and types of CP. For example, higher GMFCS levels and dyskinetic CP are known to elevate the risk of mortality [3]. Nor did the findings relate to cause of death, which further complicates the clinical use of the WCI yet. Before the WCI can find its way in clinical practice, more evidence on mortality risk is needed for subgroups of adults with CP based on clinical presentation (and associated accompanying aspects such as sedentary behavior) to be meaningful for clinicians and adults with CP themselves.

Whitney and Basu [1] discussed the limitation of their measurement of the comorbidities. They rightly stated that claims-based data represents an underestimation of the comorbidity prevalences. But this underestimation seems not only a result of methodology. In practice, preventive care services often lack knowledge, accessibility and modifications of testing

procedures to properly serve adults with CP [4]. Diagnosing the comorbidities in adults with CP is sometimes difficult, especially in adults with more severe CP (GMFCS IV-V). For example, severe spasticity interferes with blood pressure measurements. For women with CP, having Pap smears or mammograms can turn into a rather adventurous and complex undertaking[5], to put it mildly.

The study of Whitney and Basu [1] contributes to the field of research on comorbidities and mortality in adults with CP. Not only by showing the substantial health issues and the alarming high two-year mortality rate in this population. The study emphasizes the need for accessible and disability-appropriate preventive care to ensure that adults with CP (and adults with disability in general) are granted equal access to healthcare services, as stated in the United Nations Convention of the Rights for People with Disabilities. As such, the study is also relevant for patient and advocacy organizations.

## References

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