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Article *in* Developmental Medicine & Child Neurology · February 2018

DOI: 10.1111/dmcn.13711

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Health-related quality of life in children with cerebral palsy in low- and middle-income countries: opportunities and next steps

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doi: 10.1111/dmcn.13711

This commentary is on the systematic review by Power et al. To view this paper visit https://doi.org/10.1111/dmcn.13681.

Over recent decades, children with cerebral palsy (CP) are living longer than ever before, prompting researchers from several high-income countries (HICs) to explore the relationship of health with quality of life.

In contrast, in the low- and middle-income countries (LMICs) where the burden of CP is higher compared to that in HICs and notably decreases with advancing age,[1] there is hardly any information on this subject. The data from the few studies available reported very poor outcomes in comparison to those in HICs, and particularly in the aspect of physical well-being.[2] These findings are disturbing but not surprising in view of the complexity of challenges which affect CP care and management in LMICs,[3] coupled with the limited access to assistive technology for mobility.[4]

Health-related quality of life (HRQoL) encompasses the impact that CP has on functional health status and well-being as perceived and reported by the child. While HRQoL measures have been developed and used in studies for children and adolescents with CP in HICs, there is a lack of culturally developed tools to address this issue in LMICs. Furthermore, since HRQoL is multifaceted, it is vital for clinicians to determine exactly what information is desired from the patients' assessment rather than make their own judgements based on implicit knowledge, acquired from professional training and values, or their own assumptions. As such, it may be inaccurate to assume that all the same measurements in adapted HRQoL tools from HICs will apply for the LMICs. A combination of generic and disease-specific HRQoL tools would be optimal to obtain complementary information; however, due to paucity of studies on this subject in LMICs, there may be an added challenge of lack of appropriate controls for the comparison group for the disease-specific HRQoL tool.

Another point of contention is the variability in agreement between children's self-reports and parent proxy-reports (especially for subjective domains). It has been recommended that issues like parental well-being and child pain also be taken into consideration in the interpretation of proxy reports.[5] Regrettably in this review,[2] three-quarters of the data was reported via proxies. The possible explanation for the dearth of studies on self-reported HRQoL could be due to high prevalence of intellectual disability in these children[1] which raises concerns regarding the reliability of proxy reports in this population.

The results of this systematic review[2] are relevant in that they contribute to a currently small body of empirical evidence on the HRQoL of children with CP in LMICs that can inform national disability policies and inform future data and research efforts on the subject. Unfortunately, the findings cannot be generalized for LMICs, given that the eight countries included in the study are not representative. Furthermore, a sizeable number of the children with CP stay at home and do not present to the health/rehabilitative facilities for care for varied reasons.[1] The small sample sizes in the analysed studies, the lack of characterized information for children and adolescents, and inclusion of studies only published in English also undermine the reliability of the results.

The findings do have implications for increasing our efforts to conduct additional research on HRQoL in LMICs which must be theory driven, well-designed, multi-sited, and utilize standardized measures with established protocols. These studies can: (1) help to gain a better understanding of predicting factors influencing HRQoL with different types of CP; (2) assist in the development of better and more reliably user-friendly strategies to evaluate HRQoL outcomes for those children who either do not or cannot respond for themselves; (3) determine the best times to measure HRQoL in relation to the critical events that are to be recorded; and (4) be used to monitor for HRQoL changes especially when self-reported and measured repeatedly over time in the same child.

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