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Low rates of motor-related healthcare for 5-year children born extremely preterm with movement difficulty: Where to next?

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Children born extremely preterm (<28 weeks' gestation) are at increased risk of a range of poor health and developmental outcomes compared with children born at term.[1] While research on motor outcomes for children born extremely preterm has previously focused on cerebral palsy (CP), a broader trend in the literature is now exploring non-CP motor impairment, such as developmental coordination disorder (DCD). Consistent with this trend, Costa et al. highlight the high rates of non-CP motor impairment for children born extremely preterm.[2] Their study also draws attention to the proportion of children receiving motor-related health care, such as physiotherapy, occupational therapy, or early intervention services, which was both concerningly low and highly variable between and within the 11 European countries included in the study.[2]

As children born extremely preterm with non-CP motor impairment are not consistently accessing motor-related health care,[2] the next question should be 'why?'. This paper discussed some hypotheses that provide possible future research directions worth pursuing, including the extent to which clinical practice guidelines are being met, as with a better understanding, services can be adapted to provide better outcomes for this cohort.

Of particular interest, Costa et al. question whether the health beliefs of parents and health care providers, on movement difficulties and the need and/or availability of motor intervention, influenced rates of health care service use.[2] Further investigation into how health beliefs might influence access to therapy is warranted as motor impairment does not just influence motor skill performance, but has negative implications for physical activity participation (and health outcomes associated with inactivity), quality of life, education, and mental health.[3] Motor skills play an important role in facilitating participation in a range of activities, including self-care, educational-related tasks (such as handwriting), and play with friends. This is an important consideration for children born extremely preterm who are at increased risk of a range of poor outcomes across diverse domains, including cognitive, social, and behavioural outcomes,[1] which may compound the negative effects of motor impairment.

Intervention has shown promise for improving motor outcomes for young children with DCD.[3] However, children born extremely preterm with non-CP motor impairment likely present with more complex health and developmental outcomes compared with children with non-CP motor impairment who were born at term. For example, individuals born extremely preterm are at greater risk of impaired lung function throughout their lifespan, as well as poor cardiometabolic health and low bone density as they reach late adolescence and adulthood.[1] Children born extremely preterm are more likely to have cognitive impairment or behavioural challenges than children born at term.[1] While DCD research is important and informative in this area, we should not assume

This commentary is on the original article by Costa et al. on pages 1131–1144 of this issue.

that the outcomes and challenges for children with motor impairment are the same for children born extremely preterm and at term. The unique health outcomes associated with extremely preterm birth justify the need for future research into motor outcomes for this cohort throughout childhood, adolescence, and adulthood, to understand how motor impairment impacts physical and mental health outcomes. Research is also justified into targeted interventions for children born extremely preterm with motor impairment.

Finally, like many longitudinal cohort studies, children and families lost to follow-up were more likely to be from lower socioeconomic groups, and hypothesized to be less likely to have received motor-related health care.[2] It is worth noting that lower socioeconomic status is associated with greater risk of preterm birth in the first place.[4] Researchers and clinicians should continue to work to improve equitable access to clinical follow-up, timely intervention, and research participation for all children born extremely preterm and their families.

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Quality of life in people with intellectual and developmental disabilities

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The attitude of society towards people with intellectual and developmental disabilities (IDD) has changed dramatically in the last 50 years. The 2008 UN Convention on the Rights of Persons with Disabilities (CRPD) caused a revolution in international law concerning people with IDD and their recognition as full citizens. The CRPD protects and promotes the rights of people with IDD to have legal capacity, make their own decisions, live independently, access information and new technologies, and work and study in community and inclusive environments, among others.

Before the CRPD, the construct of quality of life (QoL) was the framework used for person-centered planning, guiding service delivery practices, and exploring the impact of individual and environmental factors for people with IDD. The main strength of the QoL model is its focus on context, measurement of person-valued outcomes, and the power to reflect the perspective of people with IDD and what is truly important to them. In parallel, the supports model was developed as a coincident and complementary approach to the

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