

Cerebral palsy in Australia: optimism and challenges

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In this issue of the *MJA*, Smithers-Sheedy and colleagues¹ report that rates of cerebral palsy in Australia are declining in a sustained and significant manner, and are among the lowest in the world. During 1995–2016, the overall cerebral palsy incidence rate declined by about 40%.¹ This change was accompanied by a reduction in the severity of the condition; the incidence of children who required assistive mobility equipment declined from 0.8 per 1000 live births in 1997–1998 to 0.5 per 1000 live births in 2015–2016.² Not only is this incredibly exciting, but the major improvements in the rates and severity of cerebral palsy will have a substantial economic benefit: in 2018, the financial costs of cerebral palsy in Australia were \$3.03 billion, not including \$2.15 billion in lost wellbeing.³

The strength of the study by Smithers-Sheedy and colleagues stems from its basis in data from population-based cerebral palsy registers with near complete case ascertainment. The power of such registers to capture the current status of the condition cannot be overstated. Epidemiologists and clinician scientists rely on registry data to inform effective research, stimulating questions about interventions for optimising outcomes for those at greatest risk of specific medical conditions. The researchers who manage registers spend vast amounts of time seeking funding for the ongoing employment of qualified staff to enter, manage, and analyse the data. The potential of registers to improve patient outcomes is enormous. For example, guidelines for hip screening and early interventions to reduce hip displacement in children with cerebral palsy were developed because register data identified risk factors and the natural history of this painful and debilitating condition.⁴ Funding for these valuable registers must be secure and sustained so that those managing them can undertake the research that will further improve treatment and patient outcomes.

Smithers-Sheedy and colleagues note that a major limitation of their study was that their birth prevalence analysis included data from only three state registers; data from New South Wales were excluded from the birth prevalence analyses, but will be included in future analyses as complete case ascertainment data become available.¹ That said, it is unlikely that the situation in South Australia, Victoria, or Western Australia (the included registers) differ significantly from that in NSW or the Australian Capital Territory. State-based cerebral palsy registers often operate ethically with an opt-out arrangement, whereby families are automatically included but are offered the choice of opting out. When families do opt out, ethics may still allow for a small minimum dataset to be collected from which prevalence can be estimated. Smithers-Sheedy and colleagues did not report the opting out rate, but register custodians reassure us that the rates are very low. Nevertheless, complete ascertainment of cases of cerebral palsy in Australia is not guaranteed, and this could bias the analysis, particularly if families in remote areas opt out more frequently than those in large cities.

While a 40% reduction in the incidence of cerebral palsy is exciting, it still leaves us with more than half of the journey toward complete prevention and cure ahead. Perinatal vulnerability

is the most significant contributor to cerebral palsy risk. It is largely associated with cerebral injury related to pre-term birth, with smaller contributions by birth asphyxia and other causes of neonatal encephalopathy, such as stroke and perinatal central nervous system infections. Only about 5% of cases of cerebral palsy result from post-natal causes, such as cerebral infections, hypoxic injury (smothering or near drowning), and non-accidental injury. Smallest in number are the cases in extremely pre-term infants (born earlier than 28 weeks' gestation), the babies most vulnerable to cerebral injury and maldevelopment; as the limit of viability is now as low as 22 weeks,⁵ their numbers are increasing. Newborn intensive care is improving, but expected improvements in outcomes are offset by the increase in risk that accompanies the active management of infants born at 22–23 weeks' gestation. Advances in neonatology, such as the administration of antenatal corticosteroids to avert pre-term lung disease⁶ and magnesium sulphate as a tocolytic for women in pre-term labour,⁷ have been accompanied by reductions in the incidence of cerebral palsy.⁸

High rates of cerebral palsy among infants born at the earliest gestational ages mean we need to expand our neuroprotective strategies to reduce rates further. The most frequent pre-term brain injury is diffuse white matter injury caused by inflammation; targeted anti-inflammatory therapies are now being investigated to see whether they also reduce the rate of cerebral palsy.⁹ For infants born at term but affected by hypoxic-ischaemic encephalopathy, the declining rate of cerebral palsy is driven in part by the widespread implementation of therapeutic hypothermia, most effective when commenced within six hours of birth.¹⁰

The real challenge posed by the exciting findings of Smithers-Sheedy and her colleagues arises from the awareness that nearly one-third of people with cerebral palsy in Australia are born or reside in regional and remote communities. The severity of illness in these areas seems to have increased, as a larger proportion of children require wheelchair assistance with mobility.¹ Given the geographic challenges of distance and the relative paucity of culturally appropriate health and early intervention services, we must consider how both preventive and disease-modifying therapies can be provided in remote areas. Neuroprotective strategies are often time-critical; the equipment required to actively administer therapeutic hypothermia has precluded its use except in cities, and transporting infants from remote areas to a tertiary centre within hours of birth is rarely possible.

Health workers providing health care in regional and remote Australia must be supported so that can confidently recognise infants at risk of cerebral palsy. In the era of telehealth, we have the infrastructure to support our colleagues in remote centres with delivering elements of newborn intensive care. Targeted education, mindful of cultural sensitivities, is required so that they can confidently identify and manage those at greatest risk of cerebral palsy.

We have come a long way, but we are not there yet!

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