LETTER TO THE EDITOR

Severe cerebral palsy survival is similar in California, USA and Victoria, Australia

EDITOR—The recent article by Hinwood et al. is the largest Australian study of survival in cerebral palsy.1 The authors stratified children according to severity of motor impairment and the number of additional impairments (lack of speech, epilepsy, intellectual impairment, blindness, and deafness), and suggested this stratification scheme could be used to compare survival in different countries. However, the authors also acknowledged limitations of this scheme, a key example being the inability to distinguish between orally-fed and gastrostomy-fed children. The importance of this distinction is well-documented.2–4

The present letter compares Hinwood et al.’s survival estimates for children with severe motor impairment with those from the large Californian Department of Developmental Services (CDDS) registry, and provides additional stratification by tube-feeding status which has been systematically collected since the 1980s. We restrict attention to children with severe motor impairment, as tube-feeding is unusual in children with mild or moderate motor impairment. This study received approval from the relevant institutional review board.

Our matched cohort includes CDDS children whose gross motor function, speech, epilepsy, cognition, sight, and hearing were assessed at approximately age 5 years using the Client Development Evaluation Report. At present the CDDS cerebral palsy data spans a 37-year period. These data have been previously described.2

We computed Kaplan–Meier curves with follow-up beginning at age 5 years, corresponding to the typical age at assessment in the Victorian register. Table S1 presents survival probabilities up to age 40 years (i.e. 35 years of longitudinal follow-up).

There were 11,477 5-year-old children with severe motor impairment in the CDDS cohort. Roughly half of the Californian survival probabilities at ages 10, 20, 30, and 40 years were higher than the 95% confidence intervals reported by Hinwood et al.; all others were within their confidence intervals. Overall, however, our matched cohort analyses did not find major survival differences between California and Victoria (Table S1).

The need for tube-feeding proved to be a major adverse factor for survival that was highly significant even within Hinwood et al.’s stratifications. In the ‘Severe + 2’ group, for example, only 18% of 5-year-old tube-fed children survived to age 40, whereas 58% of orally-fed children did so. In the ‘Severe + 3–5’ group the figures were 18% and 44% respectively (Figure S1).

While the comparisons here are somewhat limited by differences in data collection between the Victorian and Californian registers, they nonetheless provide evidence that survival of children with cerebral palsy with severe impairment in both places is similar. We note that survival in California has also been shown to be remarkably similar to that in other high-income settings including the UK, Sweden, and Western Australia.2–5

Additionally, the comparisons highlight the importance of considering key factors such as the mode of feeding. As demonstrated, tube-feeding status has a larger impact on survival than the additional impairments separating the ‘Severe + 2’ and ‘Severe + 3–5’ groups.

DATA AVAILABILITY STATEMENT
Participant data is not available from the authors.

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REFERENCES
Table S1. Survival of Persons with Cerebral Palsy and Severe Motor Impairment in Victoria, Australia and California from age 5 years to ages 10, 20, 30, and 40 years

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*Survival percentage is significantly higher than the corresponding Australian figure, according to the 95% Confidence Intervals from Hinwood Table 4.1

Figure S1. Abbreviations: TF, tube-fed; NT, not tube-fed.