

Cerebral palsy and newborn care: I, II, and III (1981)

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Kiely JL, Paneth N, Stein Z, Susser M. Cerebral palsy and newborn care. I: Secular trends in cerebral palsy. *Dev Med Child Neurol* 1981; **23**: 533–38.

Kiely JL, Paneth N, Stein Z, Susser M. Cerebral palsy and newborn care. II: Mortality and neurological impairment in low-birthweight infants. *Dev Med Child Neurol* 1981; **23**: 650–59.

Kiely JL, Paneth N, Stein Z, Susser M. Cerebral palsy and newborn care. III: Estimated prevalence rates of cerebral palsy under differing rates of mortality and impairment of low-birthweight infants. *Dev Med Child Neurol* 1981; **23**: 801–07.

I chose these three historical papers by Kiely et al. for several reasons. I wanted to acknowledge the New York City Columbia University Gertrude Sergievsky group under Mervyn Susser, with his wife Zena Stein, and colleagues, Nigel Paneth and John Kiely because they made such outstanding contributions to neuroepidemiology (they still do!). They were particularly interested in causal pathways and in obtaining the best data to answer important questions in neurodevelopment. I remember that my first ever seminar in the US in 1981 was to their group and they were very encouraging of this young epidemiologist setting up the first population-based registers of the cerebral palsies and of birth defects in Australia.

In the early 1980s there was considerable concern about the impact of neonatal intensive care on the survival of low birthweight (LBW) brain-damaged newborns. In fact it was one of the major reasons we established our West Australian cerebral palsy (CP) registry. The major question was whether more aggressive interventions which seemed so effective in reducing mortality would result in more damaged infants surviving.

These three papers were rigorous in summarizing the best epidemiological studies at that time, relying heavily on the wonderful Swedish studies of Bengt and Gudrun Hagberg et al.¹ as well as other European studies. They included follow-up studies from Neonatal Intensive Care Unit (NICU) populations, the best being from Ann Stewart et al.² in London and Pam Fitzhardinge et al.³ in Toronto, and the work of Karin Nelson and Jonas Ellenberg⁴ from the National Institutes of Health and the famous US perinatal project.

Several of the methodological issues raised in these papers have influenced research around the world since then including: (1) the importance of obtaining total population data on deaths and impairments by birthweight and linkable back to NICU experience – they note in these papers how challenging it is to compare different follow-up data from newborn studies which have such different antecedents (e.g. proportions in- or out-born); (2) the consideration of ‘prevalence’

or ‘incidence’ rates for CP rates with the realization that true incidence is unattainable due to deaths of those before CP diagnosis; this led on to (3) the understanding that pathways to preterm cerebral damage can cause death and CP and that CP can only be ascertained if the child survives – and hence death and CP are competing outcomes; and (4) suggesting that various possible scenarios to explain how these pathways may be influenced by NICU included: (i) severely damaged infants who would previously have died were surviving to increase the rates of CP, (ii) good care may also shift infants from impairment to non-impairment, and (iii) increases in impairment could only be avoided if the rate of morbidity declined more rapidly than the rate of mortality. As deaths are more common an outcome than CP, large data sets are needed to monitor trends precisely. And of course population data on the patterns and trends of preterm and LBW infants was important to ascertain the extent to which any changes in mortality or CP might be due to falling rates of those births at high risk.

They correctly predicted from the limited epidemiological data they managed to obtain at that time, that CP rates in LBW infants would rise as survival increased. However, they also commented that the overall increase in survival of non-impaired children was also considerable. Since these careful and thoughtful reviews were published, we have better and more data on both deaths and impairments in larger populations of children with standard methods of ascertainment and diagnosis which these authors also suggested was important. We have shown that CP has increased along with increased survival and particularly so in those under 30 weeks’ gestational age. These papers left a legacy of better data and more rigorous analysis to enable us to continue perinatal neuroepidemiological analyses to achieve the best outcomes.

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References

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