Editorial

Population-Based Developmental Outcomes Monitoring for High-Risk Infants Is Imperative

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Two recent reports from the United Kingdom and Ireland demonstrate the utility of the population-based approach to the study of long-term outcomes of high-risk neonates.^{1,2} A recent meta-analysis showed the paucity of information worldwide on this topic,³ while a commentary explored the sociopolitical, clinical, and health care environmental context that militates against similar studies in the United States.⁴ Wood et al.,¹ Costeloe et al.,² and their funding sources are to be commended for their foresight in organizing a nationwide project to follow extremely premature neonates into early childhood.

However, we should be cautious in applying the conclusions of this carefully designed and conducted project to the North American context. Neonatal intensive care practices, early intervention programs, and allied health services differ between the United Kingdom and the United States, just as health care systems are profoundly different. How, for example, are we to reconcile the extremely high mortality rates and developmental outcomes reported by Wood et al.¹ with North American data? Although truly comparable population-based data are unavailable, Bottoms et al.⁵ show survival to discharge for infants born in 1992 to 1993 of 24 weeks' gestation at 44% and of 25 weeks' gestation at 79%, compared to Woods et al., for 1995 at 26% and 44%, respectively. A recent review article comparing results of 10 North American studies shows survival rates for infants at 23 weeks' gestation ranging from 7% to 27%, at 24 weeks from 33% to 68%, and at 25 weeks from 60% to 70%.⁶ Does this contrast result from differences in definitions of vital events, neonatal resuscitation practices, maternal transport and access to tertiary perinatal services, failure to include extremely premature infants born outside tertiary perinatal centers in the Bottoms et al. study, or in the application of current viability rates by gestational age to neonatal resuscitation decision making? The answer is unknown, and, at least for the United States, unlikely to be forthcoming soon. Neither the NICHD Networks for maternal-fetal and neonatal research nor the Vermont-Oxford Neonatal Network are population

based, nor do they capture long-term developmental outcomes based on standards of care in the community. Although it may be a misnomer to refer to "standards of care" for community-based services and interventions for infants transitioning from the neonatal intensive care unit to the home, minimum expectations for the multidisciplinary professionals involved are now being defined, a necessary precondition to systematic measurement.⁷

The work of Wood et al., although excellent in describing the perinatal context of the United Kingdom, is not sufficient for neonatologists, other perinatal providers, public health professionals, or early intervention workers in the United States and Canada. Now it is time for a similar effort here in North America, lest we never know whether our efforts are continuing to make a difference in the lives of high-risk infants and their families.

References

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