

ABSTRACT

POSTER TITLE: Parent Integrated Evidence-based Practice to Improve Quality (“Parent-EPIQ”): Meaningful outcomes for parents of very preterm children

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What is known: Children born very preterm are more likely to have developmental challenges. The Canadian Neonatal Follow-Up Network (CNFUN) collects and reports on the health and development of very preterm children when they are 18-24 months old so that health care providers and parents can plan for babies’ needs. CNFUN has used medical definitions to describe neurodevelopmental impairment (NDI) based on hearing, vision, cerebral palsy and developmental status. Parents have never been asked which outcomes they think are important.

Our question: How do parent perspectives of their child’s development compare with the current CNFUN medical classifications of impairment?

What we did: This is the first of a 4-step approach where parents will identify meaningful outcomes and co-create definitions of NDI. In this step, parents attending their child’s developmental assessment at 9 CNFUN sites, were asked whether they felt their child was developing normally or had a severe, moderate or mild impairment. Responses were compared to their child’s CNFUN developmental assessment using current NDI definitions using Cohen’s kappa statistic.

What we found: Parents of 237 children born on average at 26.1±1.5 weeks gestational age and birth weight 904±242 grams, were assessed at 19.2±2.7 months corrected for prematurity. The agreement between parents’ views and CNFUN definitions of NDI was only fair ($\kappa=0.22$; $p<0.01$). Parents tend to rate their child as less impaired. Of the 109 children with mild to significant NDI according to CNFUN, 52 (48%) were considered to have no NDI by their parents. Significant differences between CNFUN and parental categorization were found for hearing, thinking, moving and language abilities (all $p<0.01$) but not cerebral palsy.

What’s next: These results, combined with other ongoing studies capturing more indepth parental feedback, will be used to revise CNFUN reported outcomes and definitions. Proposed changes will be validated by CNFUN parents.

Why it matters: Understanding what outcomes are important to parents and co-creating definitions will improve care of very preterm infants and their families and guide future research.