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Challenges of neurodevelopmental follow-up for extremely preterm infants at two years

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ABSTRACT

Aim: This study examined the rates of follow-up for a cohort of extremely preterm (EP —<28 weeks gestation) and/or extremely low birthweight (ELBW —<1000 g) children at two years with related perinatal and geographical factors. The secondary aim was to determine the rates of developmental delay and disability.
Methods: A retrospective review of two year follow-up data for all EP and/or ELBW infants born in a large tertiary neonatal hospital over a two year period was undertaken. Neurodevelopmental outcome was assessed using the Bayley Scales of Infant and Toddler Development Scale — 3rd edition (Bayley-III) and neurosensory disability was assessed by a paediatrician using a standard proforma. Rates of delay (composite score ≥ 1SD below mean) were determined using the Bayley-III test norms and a local cohort normative group. Attrition rates and reasons for loss to follow-up were determined.
Results: Only 50% (109/219) of eligible children participated in the follow-up. The follow-up rate for children engaged in an ongoing research project was excellent at 98% (58/59), however it was only 32% (51/160) for children following the clinical pathway. The main reason for not attending the follow-up was loss of contact. Factors associated with attendance included a lower gestation, sepsis and living in the metropolitan areas. The rates of delay in this cohort were greater with reference to local cohort normative data compared to Bayley-III test norms with an overall rate of delay of 72% (95%CI, 63% to 81%) compared to 38% (95%CI, 29% to 50%).
Conclusions: Follow-up of EP/ELBW infants to two years is an important part of clinical care, however the high rate of attrition in routine clinical follow-up and consequent difficulty in accurately determining rates of delay highlight challenges for centres providing ongoing care.

1. Introduction

Preterm birth (<37 weeks gestation) in Australia increased from 6.6% in 2003 to 8.2% in 2009 [1,2]. The group at highest risk of developmental problems continues to be the extremely low birth weight (ELBW) (<1000 g BW) or extremely premature (EP) (<28 weeks gestation) infants, contributing to 1.3% of preterm births within the state of Victoria [3]. Whilst rates of neurosensory impairments or developmental delays can vary depending on the country and cohort being studied, ELBW or EP infants have higher rates when compared to term born infants. The rate of cerebral palsy (CP) in a geographic cohort in Victoria, Australia, has been found to be approximately 10% [4], and cognitive, motor or behavioural problems have been demonstrated in a range of studies to be present in up to 50% of EP/ELBW children [5–8].

The longitudinal follow-up of EP/ELBW infants is increasingly viewed as a required standard of care [9–11] with the American Academy of Pediatrics (AAP) recommending ongoing regular assessment for very preterm infants with intervention as needed [12]. In Australia the care of EP/ELBW infants predominantly occurs in tertiary centres, and their clinical follow-up programmes vary in how they are structured. Developmental surveillance is considered an important part of long-term management of children born early and the Australian and New Zealand Neonatal Network (ANZNN) recommends that a minimum data set of developmental and neurosensory outcomes is collected at two years (corrected for prematurity) [13] and submitted in order to measure the outcomes of all Australia and New Zealand. This two year assessment provides an important safety net for monitoring of the child's development allowing for timely referral to intervention if needed. It also provides important quality data for individual hospitals to benchmark the outcomes of their healthcare provision. Two years of age is well recognised as an important time-point to assess children as development can be more reliably assessed than at earlier ages [14,15]. Within the literature, follow-up studies that provide outcome data for preterm infants are predominantly the result of large funded research trials that achieve higher rates of retention [4,16,17]. However, it is also important to examine the follow-up and outcomes that occur via routine clinical care as opposed to funded research, as there may be potential for bias in research studies.

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Thus, the primary aim of this study was to examine the rates of follow-up of EP/ELBW infants over a two year period from a tertiary hospital and identify reasons for loss to follow-up, including a comparison of demographic and neonatal characteristics of those children who did and did not attend.

The Bayley Scales of Infant and Toddler Development 3rd edition (Bayley-III) [18] is considered the gold-standard assessment for neurodevelopmental outcomes at two years for preterm infants [13]. This tool is widely used for determining delay or disability in cognitive, language and motor developmental domains [18–20]. The normative data for the Bayley-III is based upon a sample of 1700 children from across the USA [19] and several recent studies have shown that the Bayley-III normative data underestimates developmental delay, both in Australian children [21] and in those from other countries [22]. In order to more accurately determine rates of delay, comparison with a local reference or control group has been recommended when using this assessment [21]. Therefore, the second aim of the study was to identify rates of neurosensory disability and developmental delay using the assessment norms and a local cohort normative group.

2. Methods

2.1. Study design

The study is a retrospective review of two year follow-up data.

2.2. Participants

Participants were identified from the Royal Women's Hospital, Melbourne (RWH) database with the following inclusion criteria; a) infants born <28 weeks gestational age and/or <1000 g born or transferred to the RWH between 1st January 2008 and 31st December 2009 and who b) survived to discharge (or two years). There were no exclusions based on perinatal characteristics. The two year corrected age (CA) assessment needed to occur within an age range from 22–28 months CA and data from children assessed outside of that time period were excluded. The Human Research Ethics Committee (RWH and University of Melbourne) and the Clinical Audit Committee of the RWH approved the project.

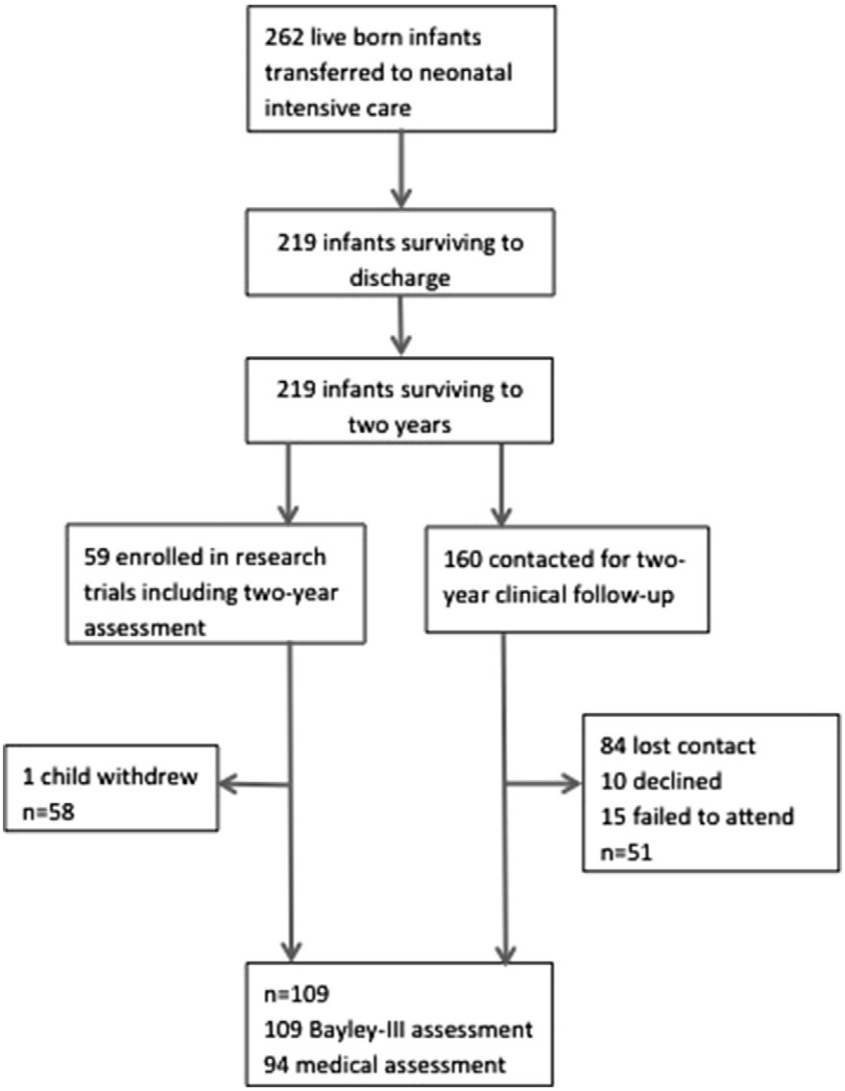

Fig. 1. Flow diagram for the pathway of extremely preterm or extremely low birth weight infants from the study cohort to two yeur assessment.