The development of a multidisciplinary team to evaluate early developmental outcomes of infants with TOF/OA

Background

New South Wales, is a very large state, of over 800,000 square kilometres(20 times the size of Holland) and has a population of over 8 million. The neonatal unit, Grace Centre for Newborn Care at the Children’s Hospital at Westmead is one of these centres in New South Wales where surgical repair of oesophageal atresia and tracheo-oesophageal fistula is performed.

Survival following surgery is high and research is now focussing on long term morbidity, including neuro-developmental outcome.

Our previous data showed that infants who had expressive language delay and permitted the expansion of the Grace Developmental Assessment (GDA) to all infants with TOF/OA developed a multidisciplinary team.

The aim of this study was to determine and monitor subsequent developmental outcome of a cohort of children over the last three years.

Results

Of 29 possible infants, 18 were enrolled in the clinics, with 16 infants completing developmental assessments.

Developmental assessments showed that most infants were performing within the average range on each of the subtests, with the largest deviation found in gross motor with 33% scoring below average.

<table>
<thead>
<tr>
<th>Below average</th>
<th>Average</th>
<th>Above average</th>
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<tbody>
<tr>
<td>1 (6)</td>
<td>12 (75)</td>
<td>3 (19)</td>
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<tr>
<td>2 (13)</td>
<td>12 (80)</td>
<td>1 (67)</td>
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<td>1 (4)</td>
<td>13 (87)</td>
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<tr>
<td>1 (6)</td>
<td>13 (81)</td>
<td>2 (12.5)</td>
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<td>5 (33)</td>
<td>10 (67)</td>
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Of the 13 infants who were not assessed, the majority were for reasons such as: parental refusal, non-attendance, infants enrolled in other neurodevelopmental clinics and infants from overseas.

Methods

Infants diagnosed with TOF/OA were identified from the neonatal unit database and developmental outcomes from the clinic database.

Infants were assessed using the Bayley Scales of Infant and Toddler development (Version III). This assessment consists of five sub scales:

- Cognition
- Receptive Language
- Expressive Language
- Fine Motor
- Gross Motor

The scores for infants on each of the scales were then classified as above average, average and below average according to the assessment manual.

Conclusion

Due the size of NSW, the distance which parents have to travel makes standardised follow-up challenging.

We have commenced multi-disciplinary long term follow up clinics for TOF/OA infants where in the one clinic they see a surgeon and a respiratory paediatrician. It is planned to combine this with neurodevelopmental assessment to provide a one visit clinic assessment which will benefit the child and parents and potentially improve compliance. Although five infants were not enrolled, additional strategies to prevent this have resulted in no infants being missed since the beginning of 2013.