Quality of life, Family Impact and Parental Satisfaction with Multidisciplinary Care in Children with Oesophageal Atresia

Background
Significant long-term morbidity including gastro-oesophageal reflux disease (GERD) and recurrent lower respiratory tract infections (LRTIs) occur commonly in children with oesophageal atresia (OA). Despite improvement with age, quality of life (QOL) may be impaired and negatively impact on family functioning. Multidisciplinary care may improve health outcomes and increase parental satisfaction.

Aims
To assess QOL, family impact and healthcare satisfaction scores in children with OA and their families.

Methods
Prospective evaluation of 45 children and their families attending a multidisciplinary OA clinic. QOL, family impact, and healthcare satisfaction were assessed using the PedQL 4.0: Paediatric Generic Quality of Life Inventory (QOL), PedQL: Family Impact Module (FIM), and PedQL: Healthcare Satisfaction Generic Module (HCSM), respectively. For the QOL, 37 children aged 6 or above self-reported their QOL, while 17 children aged 6 or above had their scores reported via parent proxy. These scores were compared to published age-appropriate reference populations.

Results
A retrospective audit was performed to obtain demographic, history of surgical intervention, history of gastrostomy tube placement, and current respiratory and gastrointestinal symptoms. The presence of negative health behaviors, as determined by the doctor, were also assessed.

Table 1. Patient Demographics (n = 45)

<table>
<thead>
<tr>
<th>Type</th>
<th>Mean (SD)</th>
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<tbody>
<tr>
<td>Sex</td>
<td>Male: 26 (58%), Female: 19 (42%)</td>
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<tr>
<td>Age, years</td>
<td>6.2 (4.9)</td>
</tr>
<tr>
<td>Current weight</td>
<td>18.7 (3.6)</td>
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<tr>
<td>Current height</td>
<td>128.4 (7.8)</td>
</tr>
<tr>
<td>BMI</td>
<td>18.4 (2.5)</td>
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<tr>
<td>Weight category</td>
<td>Normal (39.1%), Overweight (15.6%)</td>
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</tbody>
</table>

Figure 1. A child with OA/MTO, 34 weeks post-maturity, EXTREME electrolyte imbalance and failure to thrive on gastrostomy feeds.

Figure 2. PedQL 4 Quality of Life Scores

Conclusions
- Children with OA experience many comorbidities, require frequent interventions and have long-term morbidities.
- Both parental-proxy HR-QOL and child self-reported QOL measures were significantly lower in children with OA, especially in the domains of Emotional Functioning and Psychosocial Health.
- Family Impact scores were significantly lower compared to a healthy reference group, indicating a high impact on families especially in the domains of Communication and Worry. Gastrostomy feeds and lengthening/challenging feeding behaviors were associated with significant family impact.
- Parent Healthcare Satisfaction scores were generally high indicating that many domains were identified as areas that could be improved upon.

References
- Children with OA experience many comorbidities, require frequent interventions and have long-term morbidities.
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Mean Total QOL scores and several domain scores were reduced in children with OA and their parents when compared to healthy reference populations reported in the literature. Using mean differences and effect size (d) calculations (t-test for 2 small, 0.2 moderate, 0.5 large) between our findings and published healthy data, we found significant differences for Parent-Proxy Total QOL score (mean diff. -1.13, p < 0.05) and all subcategories with the greatest mean difference and effect size seen in Emotional Functioning (mean diff. -1.43, p < 0.05) and Psychosocial Health (mean diff. -1.13, p < 0.05).

For child self-reported scores, clinically significant differences were found in Social Functioning (mean diff. -0.8, p < 0.05), Psychosocial Health (mean diff. -0.8, p < 0.05), and Total QOL scores (mean diff. -0.8, p < 0.05).

Only 1 respiratory admission in the previous 12 months was significantly associated with reduced Total self-reported QOL scores, p < 0.04.

Family Impact
The PedQL Family Impact Module (FIM) is reversed scored with higher scores indicating less impact on the family.

Compared to published reference data, we found significantly reduced scores across all domains with large effect sizes indicating lower family functioning. Total Impact score mean diff. (d) -0.8, p < 0.05, Emotional -0.8, p < 0.05, Cognitive -0.8, p < 0.05, Communication -0.8, p < 0.05, Daily Activities -0.8, p < 0.05, Family Relationships -0.8, p < 0.05.

Challenging mealtime behaviors (p < 0.05), lengthening meals (p < 0.05) and current feeding problems (p < 0.05) were factors affecting Family Impact score.

Healthcare Satisfaction
Parent satisfaction with healthcare received was high. Median Total score for the PedQL Parental Satisfaction Module was 89.4. Median subscores from highest to lowest were: Gastrostomy Care (89.4), Communication (89.1), and Emotional Well-being (88.9). These were high compared to the only other published values of 854 Chinese parents of children with chronic diseases (2013) in which median scores for all categories were 75.