Health Related Quality of Life in Biliary Atresia in Malaysia: A Comparative Study

Ong SY, Khoh KM, Ng RT, Omar A, Lee WS
Department of Gastroenterology and Nutrition, Department of Paediatrics
University Malaya Medical Centre, Kuala Lumpur Malaysia
(All the authors have no conflict of interest to declare)

Introduction

- Biliary atresia (BA): a progressive obstructive cholangiopathy.
- The population incidence varies: 1:9,600 in Japan, 1:16,700 in UK.
- Children with BA rarely survived beyond 3 years without surgery.1
- With improved survival after surgery, the quality of survival has emerged as a fundamental focus of comprehensive healthcare.
- Important factors affecting the HRQoL in children with BA include:
  - The presence of portal hypertension.
  - Number of hospital admissions.

Objectives

- To measure the Health-related Quality of Life (HRQoL) in children with BA with or without surgery who survived beyond 2 years of age.
- To determine the demographic and clinical factors affecting the HRQoL in children with BA.
- To compare the HRQoL in survivors of BA with that of normal population and children with other chronic liver diseases (CLD).

Study Design

Cross sectional study (Dec 2011- March 2013) of HRQoL in children in Paediatric Hepatology unit, UMMC.
- Children with BA and CLD, aged 2 to 18 years old, were included.
- Normal/healthy children attending Paediatric general clinic in UMMC were recruited as control.

Survey instrument

PedQL TM 4.0 Generic core scales.
- 23-question instrument, validated with reference to normal children aged 2 to 18 years old.
- PedsQL 4.0 Generic core scales.
- 23-question instrument, validated with reference to normal children aged 2 to 18 years old.
- Child/parent forms were completed by both the children and the either parent.
- Normal/healthy children attending Paediatric general clinic in UMMC were recruited as control.

Statistical analysis

- SPSS version 18.
- Chi square test for categorical variables.
- HRQoL were reported as mean score (S.D.) and p < 0.05 as significant value.

Conclusions

- The HRQoL of children with BA who had successful surgery are comparable with normal population as reported in previous studies of similar nature.1,2
- Important factors affecting the HRQoL are the presence of portal hypertension and number of hospital admissions.
- It is important to incorporate HRQoL as routine assessment during medical review in children who survived BA to have a more comprehensive evaluation of the well being of these children.

Results

Overall 2-year survival rate (native and transplanted liver) of BA in UMMC from 1991-2013 is 1:9,600 in Japan; 1:16,700 in UK.

Discussion

Factors affecting HRQoL:
- We were unable to identify any significant differences between age group, ethnicity and gender in the HRQoL of various study group.
- Nutritional parameters such as tripel skin fold thickness, presence of failure to thrive and laboratory parameters of nutrition also did not show any significant difference.

Sub-analysis in importance of presence of comorbidities:
- In the presence of portal hypertension, children in both BA and CLD group reported lower mean score across all domains (Table 2). However, only CLD group score were statistically significant. Further analysis looking into contributing factors such as anaemia, thrombocytopenia, ascites correlating with lower HRQoL score in those with portal hypertension were unfulfilling.
- Higher number of hospitalisations has resulted in lower score in both BA and CLD.
- There is no significant difference in reported HRQoL comparing native and transplanted liver in BA.

Table 1: Demographic features of study sample

<table>
<thead>
<tr>
<th>Age Group</th>
<th>BA (N=23)</th>
<th>CLD (N=33)</th>
<th>Healthy (N=57)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-4 years old</td>
<td>5</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>5-7 years old</td>
<td>8</td>
<td>24</td>
<td>30</td>
</tr>
<tr>
<td>8-12 years old</td>
<td>11</td>
<td>23</td>
<td>38</td>
</tr>
<tr>
<td>13-18 years old</td>
<td>9</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>---------</td>
<td>------</td>
<td>-------</td>
<td>------</td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>13</td>
<td>30</td>
</tr>
<tr>
<td>Female</td>
<td>13</td>
<td>10</td>
<td>27</td>
</tr>
</tbody>
</table>

Table 2: Mean PedsQL score in BA and CLD in relation to portal hypertension

<table>
<thead>
<tr>
<th>Domain</th>
<th>BA (N=23) Mean (S.D.)</th>
<th>CLD (N=33) Mean (S.D.)</th>
<th>Healthy (N=57) Mean (S.D.)</th>
<th>t-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning</td>
<td>79.24 (7.35)</td>
<td>73.77 (8.24)</td>
<td>87.50 (4.87)</td>
<td>5.12</td>
<td>0.0001</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>77.33 (6.84)</td>
<td>65.71 (7.28)</td>
<td>87.50 (6.46)</td>
<td>4.48</td>
<td>0.0001</td>
</tr>
<tr>
<td>School Functioning</td>
<td>87.79 (7.53)</td>
<td>72.92 (9.26)</td>
<td>92.67 (7.21)</td>
<td>2.65</td>
<td>0.008</td>
</tr>
<tr>
<td>Total score</td>
<td>80.26 (7.71)</td>
<td>72.92 (9.26)</td>
<td>92.67 (7.21)</td>
<td>2.65</td>
<td>0.008</td>
</tr>
</tbody>
</table>

References