



HEALTH RELATED QUALITY OF LIFE IN BILIARY ATRESIA IN MALAYSIA: A COMPARATIVE STUDY

Ong SY, Khoh KM, Ng RT, Omar A, Lee WS
 Division 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) is a progressive obliterative cholangiopathy.
- The population incidences varies: 1:9600 in Japan;¹ 1: 16,700 in UK.²
- Children with BA rarely survived beyond 3 years without surgery.³
- With improved survival after surgery, the quality of survival has emerged as a fundamental focus of comprehensive healthcare.

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

- PedsQL TM 4.0 Generic core scales.
- 23-question instrument, validated with reference to normal children aged 2 to 18 years old.
- Age appropriate forms were used for different age groups comprised of 2-4, 5-7, 8-12, and 13-18 years old.
- Forms were completed by both the children and the either parent.
- HRQoL domains measured included:
 - Physical (8 items)
 - Emotional (5 items)
 - Social (5 items)
 - School Functioning (5 items)

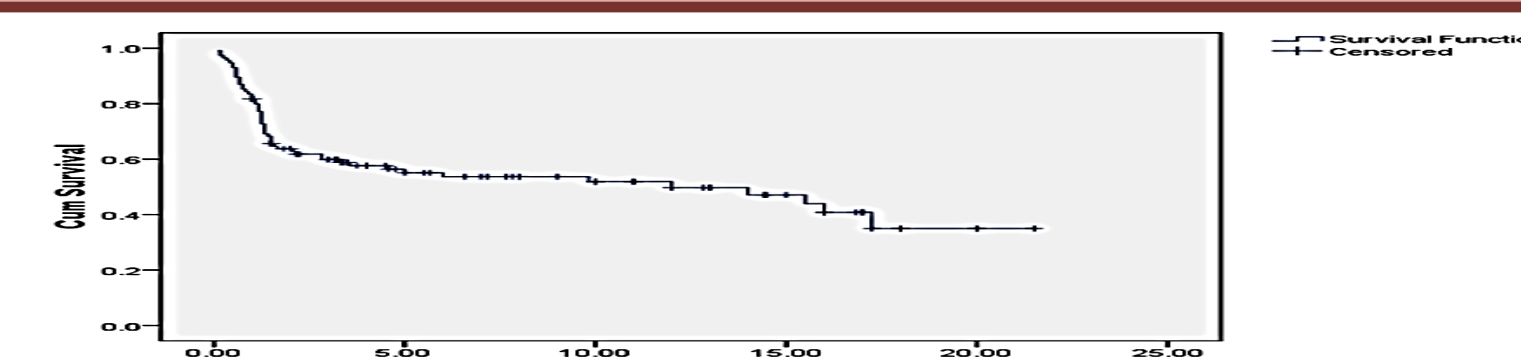
Statistical analysis

- SPSS version 16.
- Chi square test for categorical variables.
- HRQoL were reported as mean score (S.D.) and $p < 0.05$ as significant value.
- Multivariate analysis performed by conducting linear regression to identify significant demographic and clinical data that may influence HRQoL

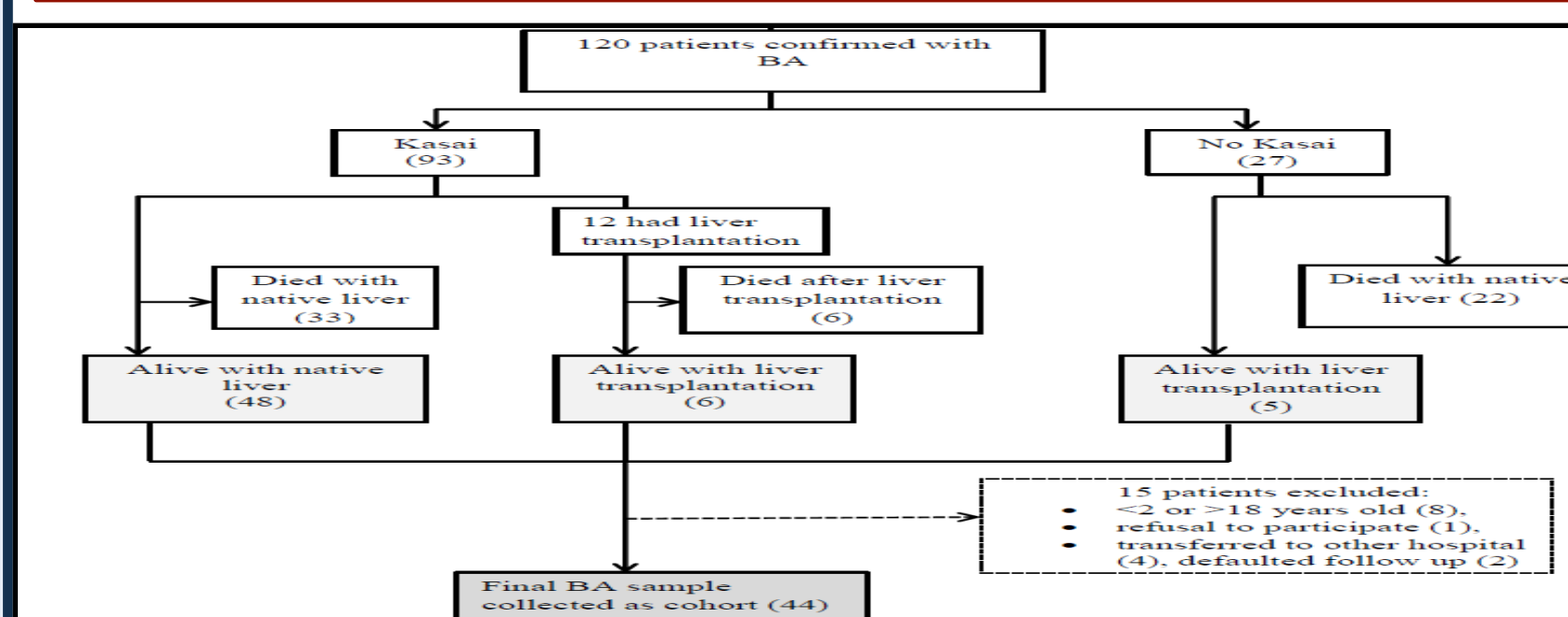
Conclusions

- The HRQoL of children with BA who had successful surgery are comparable with normal population as reported in previous study of similar nature.^{4,5}
- 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.

Overall 2-year survival rate (native and transplanted liver) of BA in UMMC from 1991-2013=47%



Patient selection



Comparison of clinical features of study sample:

- anthropometry measurements
 - presence of morbidities e.g. portal hypertension
 - laboratory assessment e.g. hemoglobin, platelet, bilirubin, ALT, AST, γ GT, coagulation profile
- showed no significant difference between children with BA and children with CLD.

Although there is a trend for children with BA to have a lower PedsQL score across all domains, none reach statistical significance.

- Comparison of Mean PedsQL Total score:
 - BA vs. healthy: 85.6 vs. 87.38, $p=0.465$
 - BA vs. CLD: 85.6 vs. 87.12, $p=0.613$
 - CLD vs. healthy: 87.12 vs. 87.38, $p=0.908$

Fig 1: Mean PedsQL score for BA, CLD and Healthy controls

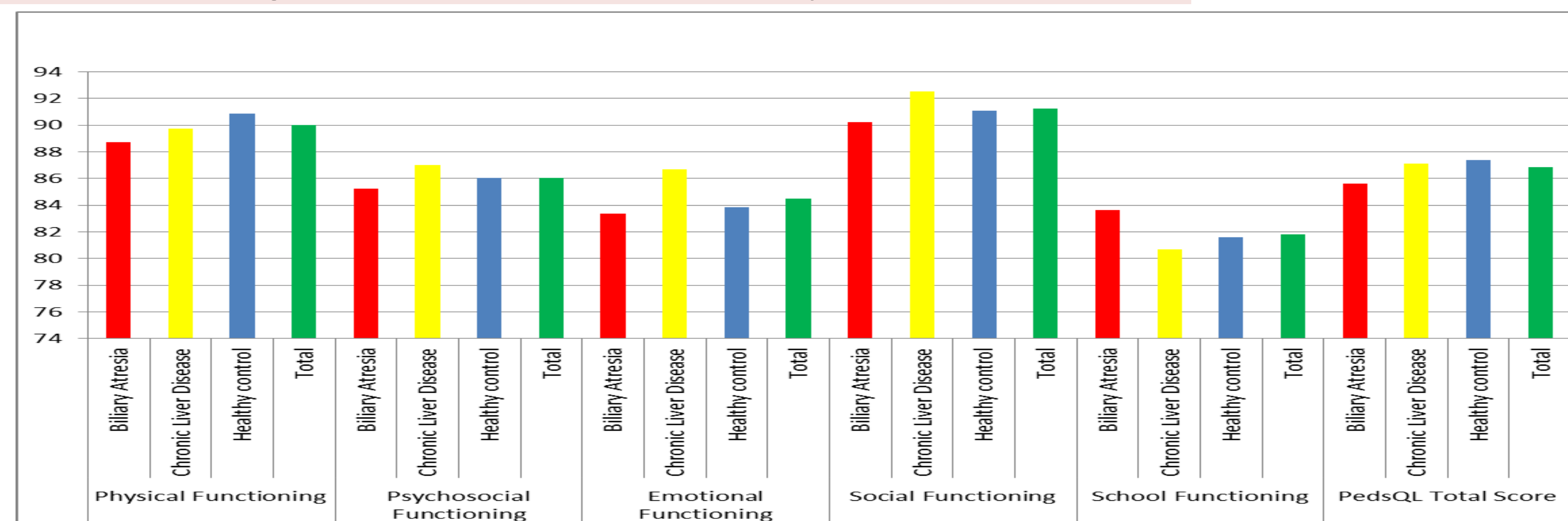


Table 2: Mean PedsQL score in BA and CLD in relation to portal hypertension

	Biliary Atresia	Chronic Liver Diseases	Healthy controls	Total
Age				
2-4 years old	17	11	26	54
5-7 years old	7	5	15	27
8-12 years old	8	19	19	46
13-18 years old	12	9	21	42
Gender				
Male	17	19	34	70
Female	27	25	47	99
Ethnic group				
Malay	7	12	48	67
Chinese	32	23	12	67
Indian	5	6	20	31
Others	0	3	1	4
Parents' marital status				
Married	42	40	79	161
Divorced/widowed	2	4	2	8
Number of siblings				
1	11	9	10	30
2	15	15	30	60
3	9	11	24	44
4	4	6	11	21
5	5	3	6	14
25	0	3	1	4
Parental education				
No formal education	0	3	1	4
Primary school	1	4	1	6
Secondary school	22	23	47	92
Tertiary	18	14	31	63
Postgraduate	3	0	1	4
Parent (as respondent)				
Father	11	17	16	44
Mother	33	27	65	125
Total household monthly income (RM)				
<1000	1	4	2	7
1000-1500	21	26	53	100
1500-2000	18	14	26	58
>2000	4	0	0	4

Results

Table 1: Demographic features of study sample

	Portal Hypertension	BA				CLD			
		N	Mean	Mean Difference	Sig. (2-tailed)	N	Mean	Mean Difference	Sig. (2-tailed)
Physical Functioning	yes	15	83.64	-7.71	0.255	8	76.56	-16.12	0.005
	no	29	91.34			36	92.67		
Psychosocial Functioning	yes	15	80.26	-7.53	0.176	8	72.92	-17.19	0.029
	no	29	87.79			36	90.11		
Emotional Functioning	yes	15	77.33	-9.18	0.079	8	63.75	-28.06	0.008
	no	29	86.51			36	91.81		
Social Functioning	yes	15	87.33	-4.45	0.459	8	87.50	-6.11	0.288
	no	28	91.79			36	93.61		
School Functioning	yes	11	79.24	-6.84	0.314	7	65.71	-18.12	0.014
	no	20	86.08			33	83.84		
Total PedsQL score	yes	15	80.88	-7.15	0.221	8	73.77	-16.32	0.036
	no	29	88.03			36	90.09		

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 tricep 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 anemia, thrombocytopenia, ascites correlating with lower HRQoL score in those with portal hypertension were unfruitful.
- 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

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