20	urnal or Pa OR	IGINAL RESEARCH PAPER	Gastroenterology					
Q E		ALITY OF LIFE IN CHILDREN WITH RAHEPATIC PORTAL VENOUS OBSTRUCTION IN RTIARY HOSPITAL	KEY WORDS: Portal, Splenomegaly,Quality ,Life,Varices					
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ABSTRACT	Objectives : There are very few studies on health related quality of life(HRQOL) in children with Extrahepatic Portal Venous Obstruction(EHPVO)9. This study evaluated the QOL in children with EHPVO ,before variceal eradication ,after variceal eradication and post surgery in comparison with healthy controls. Methods : Children with EHPVO and varices were divided in to 3 groups :Group 2, before variceal eradication (n=40) ,Group 3 ,after variceal eradication by endoscopic sclerotherapy(n=40) , and Group 4, children with their varices eradicated by surgery(n=9) . Group 1 consisted of healthy children (n=40).The Paediatric Quality of life Inventory Parent Proxy HRQOL Questionnaire which was prepared in Tamil language was used for assessment of QOL. Results: Compared with controls children with EHPVO had lower mean total and individual scores (physical, psychosocial, emotional, social and school functioning. Both total and individual scores were high among children in post variceal eradication group (95.9) compared to prevariceal eradication groups (89.3) and post surgery (94.3) though it was not statistically significant. The emotional scores of post surgery group were higher compared to prevariceal eradication group and it was statistically significant Conclusions: Children with EHPVO on treatment irrespective of whether varices are eradicated or not, have low total and individual scores was noted in children after EST.							

INTRODUCTION

In children, extra hepatic portal venous obstruction (EHPVO) is an important cause for non-cirrhotic portal hypertension. 85-92 % of these children manifest with bleeding varices. Variceal bleeding in EHPVO is managed successfully by obliteration of varices using endoscopy, which is associated with low morbidity but repeated visits are needed. Good control of bleeding is achieved by porto systemic shunt surgery, which may be useful in prevention of hypersplenism growth retardation, and also protects against development of portal biliopathy. (1) A holistic therapy has to be found to overcome all the problems of children with EHPVO to offer a chance of cure to these children.(7) Quality of life (QOL) is an established end result of medical care(8).

AIMS AND OBJECTIVES

The aim of this study was to assess health related parent perceived Quality of Life (QOL) among children with EHPVO before variceal eradication, after variceal eradication and also post-surgical in comparison with healthy age matched controls.

MATERIALS AND METHODS

STUDY DESIGN

Descriptive

STUDY PLACE

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STUDY PERIOD

December 2012- November 2013

CASE DEFINITION

EHPVO is defined as an obstruction of extra hepatic portal vein with/without history of upper GI bleeding and splenomegaly on examination with normal liver functon tests, presence of esophageal and /or gastric varices on upper GI endoscopy and demonstration of blocked or recanalised portal vein on abdominal Ultrasound

INCLUSION CRITERIA

All stable children in the age group of 2-12 years with EHPVO

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attending the Paediatric Gastroenterology Out Patient Department of Institute of Child Health during the study period were enrolled in the study

EXCLUSION CRITERIA

- 1. Parents not giving consent
- 2. Children with significant development delay
- 3. Psychological issues impeding the ability to complete the study.
- 4. Children on medications for other chronic illness

SAMPLE SIZE

40 children were enrolled in each group attending Gastroenterology OPD satisfying the criteria

ETHICS

Written informed consent was obtained from the parents and Institution review board clearance was obtained.

MANOEVRE

Cases were categorised into 3 groups

Group 2 –Children who are stable and are undergoing elective secondary prophylactic endoscopic therapy i.e., before variceal eradication

Group 3 - Children who had undergone endoscopic therapy and variceal eradication on surveillance

Group 4- Children who had undergone corrective surgery for their disease

Group 1 -Healthy children who belonged to the family of children with EHPVO were chosen as controls.

- Esophageal varices were graded from I to IV according to classification of Pacquet (ref)
- Gastric varices were graded according to Sarin and Kumar (Ref).
- Eradication of esophageal varices was defined as the absence of any visible varices on the endoscopy.

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Children were examined and palpable spleen was classified as mild, moderate and moderate depending on the size. Anthropometric measurements were taken in patients and controls at the time of evaluation. Height and weight were measured and expressed in Standard Deviation scores (SD)/(z scores), calculated from the reference data (10, 11). Patients having a height standard deviation score (HSDS) of < -2 were classified as having growth retardation.

After obtaining consent, parent proxy Paediatric Quality of Life Inventory (Peds QL) in local language was administered to the parents. Parents completed the Peds QL at the Gastroenterology OPD. Peds QL was read verbatim to the parents who were unable to read and scored. Parents of patients with EHPVO and healthy controls belonging to the same families were asked to complete the PedsQL questionnaire in two different occasions, once for the EHPVO patient and another for healthy control at an interval of minimum 4-6 wks.

The PedsQL is a health related QOL tool using generic core scales comprising of parent proxy reports. The 23 –item PedsQL generic score scales encompasses physical, emotional, social and school functioning.

1. It consists of 8,5,5,3 items (for age group 2-4 years and 5-7 years) 2. 8, 5, 5,5 items (age group 8-12 years) respectively in the physical, emotional ,social and school function domains A Tamil version of the questionnaire was prepared for each age group. A 5-point response scale was used where

0 - Indicated never a problem

4 - Almost always a problem.

Items were reverse scored and transformed linearly to a scale of 0-100 where 0=100, 1 = 75, 2 = 50, 3 = 25 and 4 = 0, with higher scores indicating better HRQOL.

To create the psychosocial health summary score, the mean is computed as the sum of the items answered in the emotional, social and school functioning scales. The physical health summary score is the same as the physical functioning scale score.

		Group 1	Group2	Group3	Group4
No.		40	40	40	9
Age (mean years)		7.663	8.425	9.163	10.056
Sex (M:F)		26:14	21:19	28:12	5:4
Splenomegaly	Mild	0	6(16)	5(16)	1(33)
	Moderate	0	12(32)	8(24)	2(67)
n(%)	severe	0	20(52)	20(60)	0
Hypersplenism	Hypersplenism n (%)		6(50)	6(50)	0
Growth retardation n (%)		0	9(75)	2(17)	1(8)

OBSERVATION AND RESULTS Table 1. Clinical parameters in both cases and controls.

The mean age of children in group 1 - 7.663 years, group 2- 8.4 years,

group 3 - 9.16 years and group 4 - 10.06 years.

M: F incidence in group 1 -26:24 Group 2- 21:19 Group 3-28:12Group 4- 5:4

Out of the total of 89 children, 74 children had splenomegaly (65.8%). Mild splenomegaly was noted in group 2- 6 cases (16% of total 38 cases) Group 3-5 (16% of total 33cases) Group 4 - 1(33% of total 3cases). Moderate splenomegaly was noted in group 2 -12(32% of 38 cases) Group 3 -8(24% of 33 cases) group 4 -2(67% of 3 cases).

Incidence of hypersplenism – hypersplenism was noted in 6 cases (50 % of total 12 cases) in group 2 Group 3 – 6 cases (50% of total 12 cases) Hypersplenism was not noted in 3 children with splenomegaly in the post-surgery group who had not undergone splenectomy along with corrective surgery The incidence of hypersplenism was equal in groups 2(50%) and in group 3(50%).

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Growth retardation was commonly noted in group 2 - 9(75%) of total of 12 cases with growth retardation) Group 3 - 2(17%) Group 4 - 1(18%). Test of significance showing Growth retardation was commonly noted in group 2 but it was not statistically significant(P=0.071).

TABLE 2 showing total and individual scores in each group

QOL SCORE	Group 1	Group 2	Group	Group 4
mean(%)			3	
Total score	99.8	89.3	95.9	94.3
physical	99.8 89	89.1	95.2	93.9
psychosocial	99.9	89.6	95.5	94.6
emotional	100	90	95.4	95.6
social	100	93.4	95.9	95
School function	99.6	84.2	95.5	93.3

Total scores in group 1 (controls) - 99.8 Group 2- 89.3 Group 3-95.9 Group 4- 94.3. Total scores were high in group 3 compared to groups 2 and 4.

A total of 129 children were included in the study with 40 children each in control group, children before variceal eradication and after variceal eradication 9, children were included in the post surgery growth.

- 1. The mean age of children in control group is 7.7 years, prevariceal group is 8.4 years , Post variceal eradication group is 9.2 years and post-surgical group is 10.1 years.
- M: F in control group -26:24, Prevariceal eradication group -21:19, Post variceal eradication group - 28:12 and Post surgery group - 5:4
- 3. Out of the total of 89 children , 74 children had splenomegaly, mild splenomegaly- was noted in prevariceal eradication group in- 6 cases (16% of total 38 cases) Post variceal eradication group -5(16% of total 33cases) Post surgical group -1(33% of total 3cases), moderate splenomegaly was noted in prevariceal eradication group -12 (32% of38 cases) Post variceal eradication group-8(24% of 33 cases) Post surgery group -2(67% of 3 cases) and Massive splenomegaly was noted in prevariceal eradication group -20 (52% of38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (52% of 38 cases) post variceal eradication group -20 (50% of total 33 cases) post variceal eradication group -20 (50% of total 33 cases) post variceal eradication group but it was not statistically significant.
- Incidence of hypersplenism hypersplenism was noted in 6 cases (50 % of total 12 cases) in prevariceal eradication group. Post variceal eradication group – 6 cases (50% of total 12 cases) hypersplenism was not noted in 3 children with splenomegaly in the post-surgery group who had not undergone splenectomy along with corrective surgery. The incidence of hypersplenism was equal in prevariceal eradication groups (50%) and in Post variceal eradication group (50%) 8)

Growth retardation was commonly noted in prevariceal eradication group - 9(75 %) of total of 12 cases with growth retardation) post variceal eradication group -2(17%) post surgery group 4 -1(18%)

7. Growth retardation was commonly noted in group 2 but it was not statistically significant

Primary outcome

All Children with EHPVO had lower mean total and individual scores (physical, psychosocial, emotional, social and school functioning) compared to control group. Total scores in controls-99.8 total scores were high among children in post variceal eradication group (95.9) compared to prevariceal eradication groups (89.3) and 4(94.3).

Physical scores of controls- 99.7% Physical score was high in post variceal eradication group (95.1) compared to prevariceal eradication group(89.1) and 4(93.9).

Psychosocial Scores in controls 99.9% Psychosocial scores were higher in children in post variceal eradication group (95.5)

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compared to prevariceal eradication group (89.6) and 4(94.6) Emotional scores of controls - 100% Emotional scores were higher in post-surgery group (95.6) compared to prevariceal eradication group (90) and post variceal eradication group (95.4).

Social scores of controls- 100% Social scores were higher in group 3(95.9) compared to prevariceal eradication groups (93.4) and post-surgery group(95).

School functioning scores in controls- 99% Compared to prevariceal eradication group (84.2) and post-surgery group (93.3) school functioning scores were higher in post variceal eradication group (95.9)

The scores in all the domains were lower in children with EHPVO compared to (controls) Children in prevariceal eradication group had lower scores in all the domains compared to children with varices eradicated either by EST or by surgery. Children in post surgery group had lower total scores and lower scores in physical, psychosocial ,social and school functioning domains compared to post variceal eradication group.

Total scores of post variceal eradication group is significantly higher in comparison with Prevariceal eradication groups (P=0.002) but among the children with EHPVO though the mean scores were higher in post variceal eradication group it was not significant statistically.

The mean physical scores of post variceal eradication group are higher compared to group 2 and it is statistically significant (P=0.004). Among the other groups it was not significant.

The psychosocial scores of post variceal eradication group is significantly higher (P=0.009) compared to prevariceal eradication group, but on comparison among the children with EHPVO group (2, 3, 4) it is not statistically significant

The emotional scores of post-surgery group are significantly higher (P=0.010). Compared to post variceal eradication group and also significantly higher compared to prevariceal eradication group (P=0.045) but among the groups the difference is not statistically significant.

The mean social scores of post variceal eradication group are higher compared to other groups but it is not significant statistically.

The school function scores of post variceal eradication group are significantly higher (P=0.000) compared to prevariceal eradication group but among the groups it is not significant statistically.

The total scores and individual scores (physical, psychosocial, emotional, social and school function) scores are lower in children with massive splenomegaly compared to children with mild and moderate splenomegaly, though it is not statistically significant.

The psychosocial and emotional scores in children with moderate splenomegaly are lower compared to children with mild splenomegaly, though it is not significant statistically.

Total and individual scores in all the domains (physical, psychosocial, emotional, social and school functioning) are all lower in children with hypersplenism than those children without hypersplenism. The low emotional scores and the social scores in children with hypersplenism are statistically significant. (p =0.029 and p= 0.023 respectively).

Hypersplenism is noted in total of 12 children out of 74 children with splenomegaly. 10 out of 12 cases of Hypersplenism occurred (83.3%)children with massive splenomegaly 2 out of 12 cases occurred in children(16.6%) with moderate splenomegaly Hypersplenism is commonly noted in children with massive splenomegaly ,though it is not statistically significant. Total and individual scores in all the domains (physical, psychosocial emotional, social and school functioning) are lower in children

with growth retardation., though it is not statistically significant. Growth retardation is noted in total of 10 children with splenomegaly. 2 out of 10 cases of growth retardation occurred in children with mild splenomegaly. 3 out of 10 cases with growth retardation occurred with moderate splenomegaly.5 out of 10 cases of growth retardation occurred with massive splenomegaly. Though growth retardation commonly occurred in children with massive splenomegaly is not statistically significant.

There is no correlation between the increasing spleen size and the height standard deviation score (HSDS).

Among splenomegaly, hypersplenism and growth retardation, splenomegaly is the major predictor of the Quality Of Life in Children (QOL) with EHPVO.

DISCUSSION

Extra hepatic portal venous obstruction (EHPVO) is an important cause of non-cirrhotic portal hypertension in children. Mortality due to variceal bleeding is uncommon, but however morbidity due to massive splenomegaly with hypersplenism, growth failure ,ectopic varices like rectal varices, portal biliopathy abnormal mental function with impaired neurocognitive ability is significant and of concern due to the sequelae. Hence it is important to manage acute bleed and to prevent recurrence.

The two methods of variceal bleeding control which are very effective are endoscopic variceal sclerotherapy (EST) and endoscopic variceal ligation (EVL) The issue of optimal therapy is not settled. Whether shunt surgery can be done after variceal bleed control with endotherapy or further endotherapy and surveillance is needed for variceal eradication is still not clear. Long term studies after endotherapy show that there is no mortality. The risk of bleeding reduces with increasing age, but with increasing age of survival these children are likely to have long term consequences in nutrition and mental function. In children with EHPVO the quality of life is affected due to the following reasons.

- 1) Repeated episodes of bleeding
- 2) Associated complications and morbidities
- 3) Growth retardation
- 4) Undergoing diagnostic and therapeutic procedures

They may have psychological issues that impede their ability and the physical, emotional, social, academic and other extracurricular segments are also affected.

The primary outcome measure of this study is to assess the Quality Of Life (QOL) in children with EHPVO before and after variceal eradication and postsurgical group, compared with a control population of healthy children.

The secondary outcome measure is to determine the effects of splenomegaly, hypersplenism and growth retardation on QOL in children with EHPVO.

The male incidence is higher compared to female children. Children in the prevariceal eradication group had a lower mean age and the mean age in the post-surgery group is higher.

Recurrence of bleeding was not noted in any child with varices eradicated by EST or surgery Varices did not recur in children who had undergone EST. It is noted that massive splenomegaly commonly occurred in children with varices eradicated by endoscopic sclerotherapy but it was not significant statistically. Hypersplenism was equally found in prevariceal eradication and postvariceal eradication group. Growth retardation was commonly noted in children with varices but it is not significant, which was similar to that of study by Y.Radhakrishnan et al.

Compared to healthy controls the total and individual scores were significantly lower in all the 3 group of children with EHPVO .The most affected domain in these children was school functioning, which is similar to the study by Y,Radhakrishnan et al. On comparison of total and individual scores between the groups,

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children with varices had lower scores compared to those with varices eradicated by EST or surgery, similar to the Y.Radhakrishnan et al study. Unlike in the above mentioned study where children after surgery had better QOL scores (both total and individual), our study showed that children after variceal eradication had higher scores compared to the post surgery group though it was not significant statistically. Children with massive splenomegaly had lower total and individual scores though it was not significant, and the most affected domain was school functioning.

Children with hypersplenism had lower total and individual scores compared to those children without hypersplenism, similar to the study by Y.Radhakrishnan et al. The low emotional and social scores were significant statistically. Similar to the Y.Radhakrishnan et al study, hypersplenism was seen most commonly in children with massive splenomegaly, but it was not statistically significant. The total and individual scores were lower in children with growth retardation similar to the above mentioned study. But it was not significant statistically. Growth retardation was commonly noted in children with massive splenomegaly and there was no correlation between mean splenic sizes and height standard deviation score, similar to Y.Radhakrishnan et al study.

Regression coefficient analysis showed that among splenomegaly, hypersplenism and growth retardation, splenomegaly is an independent predictor of the QOL and it is statistically significant, where in the study by Y.Radhakrishnan et al study both spleen size and growth retardation were predictors for QOL.

CONCLUSIONS

- 1. EHPVO is the commonest cause of portal hypertension and variceal bleeding in children but the long term sequelae that results from EHPVO are hypersplenism, growth retardation and reduced neurocognitive functions which affect the Quality Of Life (QOL).
- 2. Growth retardation was common in children with varices.
- 3. Hypersplenism was common in children with massive splenomegaly.
- Children with EHPVO on treatment irrespective of whether varices are eradicated or not, have low total and individual scores compared to healthy children.
- Children who had their varices eradicated by EST had better scores compared to that of post surgical group and prevariceal eradication group
- Of all domains school functioning was affected more, probably due to the frequent visits made by the children with EHPVO for sake of follow up endoscopy regardless of the variceal status.
- Children who had their varices eradicated by either EST or surgery did not have recurrence of gastrointestinal bleed, but had recurrence of varices, though it was of grade II or lesser grade.
- The children with splenomegaly, hypersplenism and growth retardation had lower total and individual QOL scores due to the limited physical activity, and due to the parental concern of persisting disease. The school functioning was most affected among them.
- The spleen size did not correlate with height, though growth retardation commonly occurred in children with massive splenomegaly.
- 10. Splenomegaly is an independent predictor of QOL among splenomegaly, hypersplenism and growth retardation .this may be due to the easy fatigability, early satiety, and abdominal discomfort which limits the physical activity and is of constant concern to the parents.

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