Indian J Pediatr (October 2015) 82(10):909–916
DOI 10.1007/s12098-014-1670-6

ORIGINAL ARTICLE

Health Related Quality of Life and its Predictors among Bengali Thalassemic Children Admitted to a Tertiary Care Hospital

Rajib Saha · Raghunath Misra · Indranil Saha

Received: 10 April 2014 / Accepted: 18 December 2014 / Published online: 26 February 2015

Abstract
Objective To assess the quality of life among thalassemic children and to find out association of quality of life (QOL) with the socio-demographic factors, and clinico-therapeutic profile.
Methods This cross sectional descriptive epidemiological study was conducted from July 2011 through June 2012 on 365 admitted thalassemic patients of 5 to 12 y of age in the Burdwan Medical College and Hospital. Parents of the children were interviewed using Paediatric Quality of Life Inventory 4.0 Generic Core Scale. Statistically significant variables in bivariate analysis were considered for correlation matrix where independent variables were found inter related. So, partial correlation was done and statistically significant variables in partial correlation were considered for linear regression.
Results The mean age of 365 thalassemic children was 8.3± 2.4 y. Multiple linear regressions predicted that only 70.5 % variation of total summary score depended on duration since splenectomy (31.2 % variation), last pre transfusion Hb level (20.7 %), family history of thalassemia (17.3 %) and frequency of blood transfusions (1.3 %). After splenectomy, thalassemic children could lead a better quality of life upto 5 y only. The betterment of the quality of life needs maintaining pre transfusion Hb level above 7 g/dl. Previous experience of the disease among the family members enriches the awareness among them and helps them to take correct decisions timely about the child and that leads to better QOL.
Conclusions More awareness regarding the maintenance of pre transfusion Hb level should be built up among parents and families where such disease has occurred for the first time.

Keywords Thalassemia · Quality of life · Pre transfusion Hb level · Frequency of blood transfusion · Splenectomy

Introduction

Thalassemia syndromes are a heterogeneous group of single gene disorders, inherited in an autosomal recessive manner, prevalent among all ethnic groups and in almost every country around the world [1]. Worldwide, 15 million people have clinically apparent thalassemic disorders. Reportedly, there are about 240 million carriers of β-thalassemia worldwide, and among them 3.3 % in India alone [2, 3]. Among the different traits, hemoglobin (Hb) E/beta-thalassemia has been observed predominately among Bengalis in Eastern India.

Once a child has been diagnosed as thalassemia, he/she has to take lifelong treatment that can be availed by only 5–10 % thalassemic children in India. For chronic disease such as thalassemia, where cure is not attainable and treatment may be prolonged, quality of life is likely to be an essential

Electronic supplementary material The online version of this article (doi:10.1007/s12098-014-1670-6) contains supplementary material, which is available to authorized users.

R. Saha
Department of Community Medicine, Bankura Sammilani Medical College and Hospital, Bankura, West Bengal, India

R. Misra
Department of Community Medicine, Institute of Post-Graduate Medical Education and Research and Seth Sukhlal Karnani Memorial Hospital (IPGME&R and SSKM Hospital), Kolkata, West Bengal, India

I. Saha
Department of Community Medicine, IQ City Medical College and Narayana Hrudayalaya Hospitals, Durgapur, West Bengal, India

R. Saha (✉)
AD-234, Rabindrapally, Krishnapur, Kolkata 700101, West Bengal, India
e-mail: dr.rajsaha@gmail.com

outcome. Children are usually unable to express their concerns, thus the assessment of quality of life in children is essential for the provision of proper care, since it helps in identifying the impact of the disease and treatment from the child's perspective [4–7].

However, this aspect has not received due attention and priority from the relevant health care delivery system. Research findings in this regard are also very limited. Few studies [8–10] have examined the factors associated with quality of life in children and adolescents with thalassemia in other countries. But information in this aspect in our country [11], including West Bengal is scarce. A better understanding of the factors associated with quality of life among thalassemic children and adolescents is required for the development of more suitable clinical, counseling and social support programs to enhance treatment outcomes, especially in terms of quality of life of these patients.

Material and Methods

The present study is a hospital based cross sectional analytical epidemiological study which was carried out between July 2011 and June 2012 in the Burdwan Medical College and Hospital; a tertiary care hospital where patients are admitted not only from Burdwan district, but also from the neighboring districts within the West Bengal state, India. All the diagnosed major or intermediate thalassemic patients between 5 and 12 y of age, who were admitted either in Day Care Unit or In Patient Department (IPD) of pediatrics or General Medicine of the institute during the study period for only therapeutic blood transfusion and had been receiving blood transfusion regularly for at least 2 y or more, comprised the study population. Thalassemic children who had history of suffering from serious illness in the last month preceding the data collection, or had impaired cognitive function, delayed developmental milestone or suffering from any other chronic disease were excluded from the study. After reviewing of available previous year records, register and consultation with the head of the departments it was revealed that approximate 3285 number of thalassemic children of 5–12 y of age were admitted in Burdwan Medical College and Hospital in the previous year. It was calculated that a thalassemic patient aged 5–12 y received average nine times blood transfusion per year and this was also documented in the register and records. If the weightage is ignored from the year wise total number of thalassemic patient admissions, approximate estimate of yearly admitted thalassemic children of 5–12 y of age in the hospital can be found. This way it was estimated that approximate (3285/9)=365 thalassemic patients of 5–12 y of age admitted in a year in this hospital would be the required sample size. During the study period, data were collected in three alternate days of a week. Days of data collection were changed in consecutive weeks to reduce the bias for day specific hospital admission rate. All the thalassemic patients of that age group, who were admitted on the day of data collection in the respective departments, were included in the study and the data collection was continued until the required sample size was completed.

Parents of the children were interviewed using Paediatric Quality of Life Inventory 4.0 Generic Core Scale, parent proxy reports (age range: 5–7, 8–12) for obtaining data regarding socio-demographic characteristics and also for quality of life related data [12]. Relevant medical records (laboratory reports, bed head tickets, old prescriptions, discharge certificates *etc*.) were reviewed to collect data regarding clinico-therapeutic profile of the study subjects. Before application, reliability and validity of this scale was checked in this study setting by using the Cronbach's alpha test. Reliability analysis showed good reliability in case of physical, social and school functioning scale. Cronbach's α coefficient values in case of physical, social and school functioning scale were 0.873, 0.805 and 0.911 respectively. In case of emotional scale, reliability was found satisfactory (Cronbach's α coefficient=0.626).

Permission was obtained from Mapi Research Trust for the using of PedsQL 4.0 Generic Core Scale in this non-funded research.

All the statistical analysis was done in SPSS software, version 19.0 (Statistical Package for the Social Sciences Inc, Chicago, IL, USA). Difference between two mean values was tested by unpaired Student's t test, while analysis of variance (ANOVA) was used to compare more than two mean values. Degree and direction of relationship between two variables was computed by Pearson's correlation co-efficient (r). Partial correlation was also calculated to identify exclusive relationship between the two variables, by keeping other related variables constant. Significant correlated variables derived from partial correlation were further considered in multiple linear regression (stepwise approach) models to identify the change of dependent variable with one unit change of independent variables.

Results

Mean age of 365 thalassemic children was 8.3±2.4 y. Sex wise distribution was more or less equal (M:F=1.05). A large proportion of patients belonged to Muslim religion (40.3 %) and Scheduled Caste and Tribe families (73.9 %). Most of the study population (44.4 %) belonged to upper lower socio-economic status (according to modified Dr. B.G. Prasad socio-economic scale). Only 8.8 % parents of thalassemic children had history of consanguineous marriage and all of them were Muslims. About one fifth (22.7 %) of study population had family history of thalassemia. Most of the study populations (53.4 %) received blood transfusion last time when pre transfusion

Hb level was between 5 and 6 g/dl and majority (63.3 %) were receiving blood transfusion for >5 y. Majority of study population (53.4 %) received blood transfusion 7 to 12 times in the last year. Splenectomy was done only in 13.4 % cases. Among them in about half of the cases (51 %) splenectomy was done 3 to 5 y before. Only in 30.4 % cases (111/365) High Performance Liquid Chromatography reports were available. Among the available reports, most of the children (47.8 %) were suffering for beta thalassemia major. A good proportion of children (33.3 %) had HbE beta thalassemia.

Mean score of social functioning domain (74.41) was found as highest among the mean scores in different quality of life domains and was worst in school functioning domain (49.42). Health related total quality of life score were fair (QOL score=50–74.9) among maximum study population (78.9 and 75.6 % respectively). Only 11.8 % population had good total QOL score (75–99.9) (Fig. 1).

Possible total quality score might range from 0 to 100; but in the index study it was found that score ranges from 41.87 to 83.33 (Mean > Median > Mode). Distribution of Total QOL score were slightly negatively skewed (−0.158) and platykurtic (−0.433). In Q-Q plot, authors found that observed actual data values adhered with the expected normal value line. In the present study, skewness value of all the dependent variables were within −0.5 to + 0.5 ranges that means these data were distributed approximately symmetric way.

In bivariate analysis, total summary scores were found significantly better among female thalassemic children, having family history of thalassemia, receiving blood transfusion for 5 y or less, <7 times frequency of blood transfusion in the last year and splenectomy done within last 3 y. Worst total summary scores were found among thalassemic children whose parents were married consanguineously and who were belonged to lower socio economic status, illiterate parents, 3rd or more issues by birth order. Worst total summary scores were also found among beta thalassemia major patients and whose in whom last recorded pre transfusion Hb levels were below 5 g/dl (Table 1).

In bivariate analysis, statistically significant relationship was found among 11 independent variables and total summary score; those variables were plotted in correlation matrix (Table 1).

In the correlation matrix, it was found that independent variables were inter related. So, to get the true relationship among independent variable and dependent variable, partial correlation was done. During partial correlation, one independent and one dependent variable were considered and remaining independent variables were kept in constant.

In partial correlation, total summary score positively correlated with education of parents, frequency of blood transfusion, duration since splenectomy and type of thalassemia and negatively correlated with consanguineous marriage of parents, family history of thalassemia, socio-economic status and last pre transfusion Hb level (Table 2).

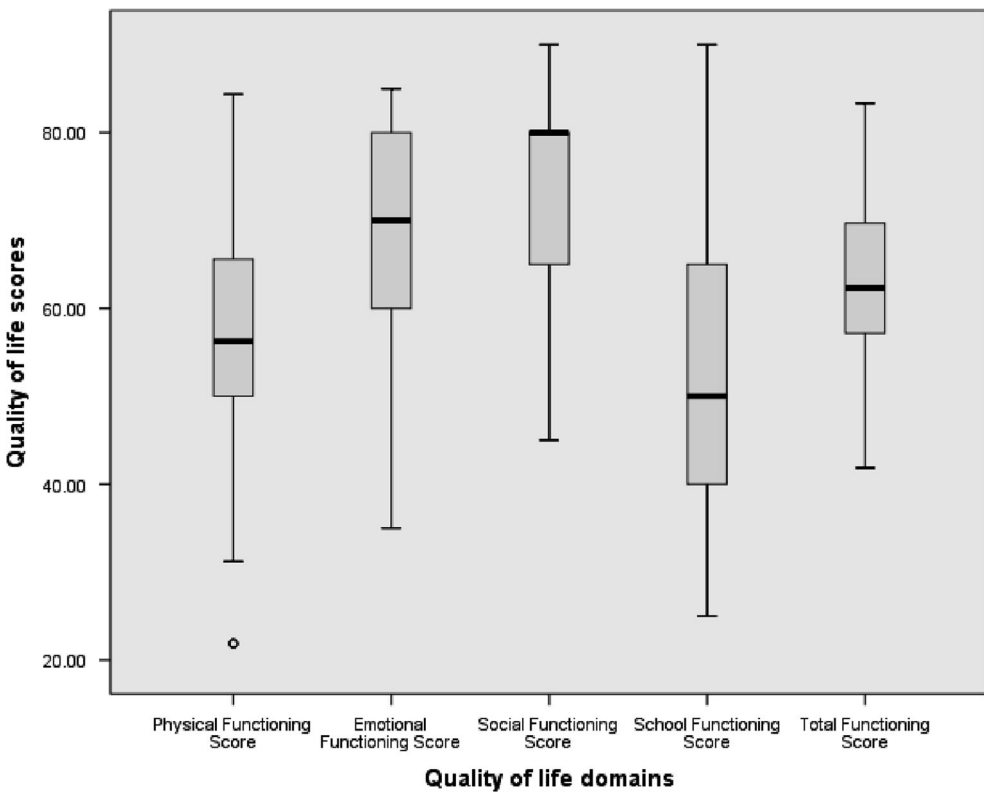

Fig. 1 Health related quality of life score in different domains and total score (n=365)

Table 1 Distribution of Quality of life score according to socio-demographic factors and clinico-therapeutic profiles of the patients

Variables	Sub variables	Total summary score (Mean ± SD)	Test of significance
Age (years)	5–7	63.94±10.06	t=1.717
	8–12	62.26±8.61	df=363, p=0.087
Sex	Male	61.38±8.69	t=−3.571
	Female	64.83±9.73	df=363, p=0.000*
Religion	Hindu	63.77±9.37	t=1.760
	Muslim	62.02±9.28	df=363, p=0.079
Caste	General & other backward caste (1)	63.81±8.83	F=0.165
	Scheduled caste (2)	63.49±9.14	df=2, p=0.848
	Scheduled tribe (3)	64.45±10.73	
Type of family	Joint	62.05±10.4	t=−1.311
	Nuclear	63.47±8.9	df=363, p=0.191
Residence	Rural	63.16±9.63	t=0.430
	Urban	62.63±8.15	df=363, p=0.668
History of consanguineous marriage of parents	Yes	59.8±8.89	t=−2.074
	No	63.38±9.35	df=363, p=0.039*
Family history of thalassemia	Yes	66.82±7.72	t=4.263
	No	61.96±9.52	df=363, p=0.039*
Socio-economic status	Lower (1)	59.96±10.79	F=7.681
	Upper lower (2)	62.72±9.76	df=3, p=0.000*
	Lower middle (3)	66.54±6.3	
	Upper middle (4)	64.25±6.14	
Education of the parents	Illiterate (1)	61.73±9.87	F=3.059
	Primary (2)	66.83±5.44	df=3, p=0.028*
	Middle school and secondary (3)	63.43±9.2	
	Higher secondary & graduates (4)	58±11.57	
Birth order	1st issue	62.74±10.25	F=4.995
	2nd issue	64.6±8.42	df=2, p=0.007*
	≥3rd issue	59.98±7.93	
Last pre transfusion Hb level (g/dl)	<5 (1)	59.45±9.42	F=12.005
	5–7 (2)	64.34±9.82	df=2, p=0.000*
	>7 (3)	65.15±5.42	
Duration of blood transfusion	2–5 y	64.96±9.21	t=2.982
	>5 y	61.96±9.28	df=363, p=0.003*
Frequency of blood transfusion in the last year	1–6 times/year	69.5±7.95	F=39.274
	7–12 times/year	64.68±8.68	df=2, p=0.000*
	>12 times/year	57.95±8.44	
History of hospitalization in the last year other than blood transfusion	Yes	60.86±10.85	t=−1.752
	No	63.4±9.08	df=363, p=0.081
History of splenectomy	Yes	64.90±7.33	t=1.477
	No	62.78±9.61	df=363, p=0.141
Duration since splenectomy	≤2	70.16±2.17	F=13.481
	3–5	67.15±8.07	df=2, p=0.000*
	>5	58.75±1.39	
H/O receiving chelating agent	Yes	62.56±9.29	t=−0.583
	No	63.22±9.39	df=363, p=0.560
Duration of receiving of chelating agent (mo)	≤12 (1)	64.1±8.61	F=1.502
	13–24 (2)	60.35±10.63	df=2, p=0.229
	>24 (3)	61.06±9.23	
Type of thalassemia	HbE—beta (1)	66.69±7.7	F=3.280
	Beta thalassemia major (2)	61.29±11.21	df=2, p=0.041*
	Beta thalassemia intermediate (3)	62.2±10.68	
Thalassemia related complication	Yes	62.12±11.25	t=−1.276
	No	63.48±8.38	df=363, p=0.203

*Statistically significant ($p \leq 0.05$)

Table 2 Correlation matrix and partial correlation between different independent variables and total summary score

	A	B	C	D	E	F	G	H	I	J	K	S
A	1	−0.070	−0.032	0.130*	−0.117*	−0.086	0.005	−0.033	−0.153**	0.022	0.097	0.184** **[−0.206]**
B		1	−0.076	−0.011	−0.109*	0.059	−0.028	−0.163**	0.028	−0.032	0.071	−0.108* **[−0.547**]**
C			1	0.264**	0.053	−0.003	0.112*	0.062	−0.286**	0.131*	0.238*	0.218** **[−0.791**]**
D				1	0.194**	−0.117*	0.226**	0.271**	−0.129*	0.222**	0.026	0.210** **[−0.309**]**
E					1	−0.398**	0.189**	0.166**	−0.094	0.036	−0.184	0.023 **[0.508**]**
F						1	0.010	−0.087	0.195**	0.191**	0.051	−0.119* **[−0.175]**
G							1	0.130*	−0.359**	0.551**	−0.229*	0.269** **[−0.485**]**
H								1	0.114*	0.595**	−0.136	−0.198** **[0.060]**
I									1	−0.011	−0.147	−0.425** **[0.220*]**
J										1	0.177	−0.313** **[0.561**]**
K											1	−0.185 **[0.762**]**
S												1

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed) Figures within parenthesis [ ] indicates Partial correlation

Score assigned to different categorical variables for multifactorial analysis

Discrete variables	Scores assigned			
	1	2	3	4
Sex	Male	Female		
Religion	Hindu	Muslim		
Type of family	Joint	Nuclear		
Education of parents	Illiterate	Primary	Secondary	Higher secondary & graduate
Consanguineous marriage among parents	No	Yes		
Family history of thalassemia	No	Yes		
Socio-economic status	Lower	Upper lower	Lower middle	Upper middle
Hospitalization except the purpose of blood transfusion in the last year	No	Yes		
Splenectomy	No	Yes		
History of thalassemia related complication	No	Yes		

Independent variables were used in correlation matrix

A = Sex	B = Consanguineous marriage of parents of thalassemic children	C = Family history of thalassemia
D = Socio-economic status	E = Education of parents	F = Birth order
G = Last pre transfusion Hb level	H = Duration of blood transfusion	I = Frequency of blood transfusion
J = Duration since splenectomy	K = Type of thalassemia	S = Total summary score

Factors were found statistically significant in partial correlation considering for linear regression.

From multiple linear regressions it can predict that only 70.5 % variation of total summary score depended on four independent variables like duration since splenectomy, last pre transfusion Hb level, family history thalassemia, frequency of blood transfusions and rest 29.5 % remain unexplained. Out of total variation, duration since splenectomy alone contributed 31.2 % and pre transfusion Hb level contributed (51.9–31.2 %) 20.7 %. Family history of thalassemia and frequency of blood transfusion were responsible for (69.2–51.9 %) 17.3 % and (70.5–69.2 %) 1.3 % variation of total summary score respectively (Table 3).

F value reveals that variation of total summary score in the different independent variables was statistically significant ($p \leq 0.05$).

Discussion

Chronic disease like thalassemia, where cure is not attainable and treatment is prolonged; quality of life becomes an essential parameter of treatment outcome for individual patient, as well as for the allocation of health care resources. In this background the present cross sectional descriptive epidemiological study was conducted from July 2011 through June 2012 on 365 admitted thalassemic patients of 5 to 12 y of age in the Burdwan Medical College and Hospital to assess the quality of life and to find out any association or relationship between quality of life with the socio-demographic factors, and clinico-therapeutic profile.

Overall quality of life score (63.06±9.36) of thalassemic children were found fair (50–74.5) as described in Dakhakhny et al. [13] study and far lower than best possible quality of life

Table 3 Regression coefficients and their significance in step wise multiple linear regressions for total summary score among the study subjects

Model summary

Model	R	R square	Adjusted R square	Std. error of the estimate	*F*	Sig.
1	0.559[a]	0.312	0.306	8.55934	49.530	0.000
2	0.720[b]	0.519	0.510	7.19244	46.367	0.000
3	0.832[c]	0.692	0.684	5.78036	60.211	0.000
4	0.840[d]	0.705	0.694	5.68571	4.592	0.034

Coefficients[e]

Model		Unstandardized coefficients		Standardized coefficients	*t*	Sig.	95.0 % confidence interval for B	
		B	Std. error	Beta			Lower bound	Upper bound
1	(Constant)	77.622	2.196		35.347	0.000	73.270	81.975
	Duration since splenectomy	−3.877	0.551	−0.559	−7.038	0.000	−4.969	−2.785
2	(Constant)	56.936	3.555		16.018	0.000	49.890	63.981
	Duration since splenectomy	−4.553	0.473	−0.656	−9.617	0.000	−5.492	−3.615
	Pre transfusion Hb Level	3.964	0.582	0.465	6.809	0.000	2.810	5.118
3	(Constant)	44.111	3.300		13.366	0.000	37.568	50.653
	Duration since splenectomy	−4.955	0.384	−0.714	−12.904	0.000	−5.717	−4.194
	Pre transfusion Hb level	4.305	0.470	0.505	9.162	0.000	3.374	5.237
	Family history thalassemia	9.696	1.250	0.421	7.760	0.000	7.219	12.173
4	(Constant)	49.591	4.132		12.000	0.000	41.398	57.784
	Duration since splenectomy	−4.546	0.423	−0.655	−10.743	0.000	−5.385	−3.707
	Pre transfusion Hb level	3.914	0.497	0.459	7.874	0.000	2.928	4.899
	Family history thalassemia	8.645	1.323	0.375	6.533	0.000	6.022	11.269
	Frequency of blood transfusion	−0.253	0.118	−0.136	−2.143	0.034	−0.488	−0.019

[a] Predictors: (Constant), duration since splenectomy

[b] Predictors: (Constant), duration since splenectomy, pre transfusion Hb level

[c] Predictors: (Constant), duration since splenectomy, pre transfusion Hb level, family history thalassemia

[d] Predictors: (Constant), duration since splenectomy, pre transfusion Hb level, family history thalassemia, frequency of blood transfusion

[e] Dependent Variable: Total Summary Score

In multiple regression analysis, relationships between dependent and independent variables were derived from different models and expressed in equations as follows:

$$Y = 77.622 - 3.877\,X_1 \text{(Model 1)}$$

$$Y = 56.936 - 4.553\,X_1 + 3.964\,X_2 \text{(Model 2)}$$

$$Y = 44.111 - 4.955\,X_1 + 4.305\,X_2 + 9.696\,X_3 \text{(Model 3)}$$

$$Y = 49.591 - 4.546\,X_1 + 5.205\,X_2 + 8.645\,X_3 - .253\,X_4 \text{(Model 4)}$$

[Y = Total Summary Score; X_1 = Duration since Splenectomy, X_2 = Pre transfusion Hb level, X_3 = Family history Thalassemia, X_4 = Frequency of blood transfusion]

standards (QOL score=100). In comparison with other studies, total summary score of this study was lowest, though the differences were not so large with Dakhakhny et al. [13] (64.8±13.8) and Torcharus et al. [14] (68.41±13.67) study; except Thavorncharoensap et al. study [15] (76.67±11.40). [PedsQL™ 4.0 Generic Core Scale were used in all those studies].

Among the individual domains, social functioning score was close with those study findings, but physical, emotional and school functioning scores varied too much than the other studies [13–15].

Ultimately multiple linear regressions predicted that only 70.5 % variation of total summary score depended on four independent variables like duration since splenectomy, pre transfusion Hb level, family history of thalassemia, frequency of blood transfusions and rest 29.5 % remain unexplained. Out of the total variation, duration since splenectomy alone contributed 31.2 % and pre transfusion Hb level contributed 20.7 %. Family history of thalassemia and frequency of blood transfusions were responsible for 17.3 and 1.3 % variation of total summary score respectively.

Hussain et al. [16] observed that majority of the patients (90.4 %) felt a definite improvement in the quality of life after splenectomy, but in this study no such significant relationship was observed. It is clearly notified here that QOL score worsened significantly after 5 y of splenectomy. Splenectomy decelerates extra corpuscular destruction of donor red cells that helps to maintain the Hb level of blood and gifts them a better QOL initially. But after splenectomy, chances of infection increased 30 times than normal populations that hampered their HRQOL [17]. Beside that in our country, post splenectomy care and follow up is poor and that also accelerates the worsening of QOL.

Patients maintaining pre transfusion Hb level >7 g/dl had better total QOL scores. This is similar to the finding of Thavorncharoensap [15] but not Torcharus et al. [14], both of whom reported on Thai children. This finding reflects how much thalassemic patients are dependent on blood transfusion. It could be explained by the fact that with the improvement of Hb level, a number of symptoms, such as fatigue, general weakness, and decreased mental alertness which might lead to impaired HRQOL of the patients in several domains, improves gradually.

In this study thalassemic children who received blood transfusions more than 12 times in a year had significantly lower total QOL scores. Frequent admission to the hospital for blood transfusion hits their self image and makes them realize that they are sick; that hampers their QOL badly. This finding is similar to Surapolchai et al. [18] who found that total QOL score were worse among Thai children who were receiving regular transfusion every 1–2 mo. However this is contradicted by Thavorncharoensap et al. [15] who reported that frequency of number of blood transfusions/ year is not related to QOL.

Children who had family history of thalassemia both or either in maternal or paternal side among first generation had significantly better QOL scores.

Thavorncharoensap et al. [15] found severity of disease as an important predictor of QOL score. They defined severity as age at onset <2 y, age at first transfusion <4 y, patients diagnosed with homozygous β thalassemia, patients with a pre transfusion Hb level <7 g/dl. Similar findings have been noted from the present study in which pre transfusion Hb level and duration of transfusion therapy had significant relation with total QOL score.

To improve the HRQOL of thalassemic children, Government should take active participation through implementation of country level national programme. Till now in developing countries etiology of the disease is not clear to common people, so thalassemic children are being neglected everywhere in the society. Grass root level awareness should be generated among all people using posters, electronic media *etc*. School environment should be friendly and helpful. They need psychological support and normal behavior from teachers and peer group. Sometimes they should interact with the other children affected with thalassemia to grow their self confidence. Thus, support group is very important part to treat the psychosocial issues. In developing countries, these issues are not receiving priority as treatment part. To improve the life expectancy, work efficiency and QOL, these issues should be highlighted also as well as medication. For that special training should be given to parents, teachers, caregivers, general practitioners and nurses.

Conclusions

HRQOL is the important parameter to assess the treatment outcome of thalassemic children. Through this cross sectional view authors observed several issues that might improve the HRQOL of patients. Thus to conclude, after splenectomy, thalassemic children could lead a better quality of life upto 5 y only. For better quality of life, pre transfusion Hb level should be maintained above 7 g/dl through regular blood transfusions and timely splenectomy.

More awareness regarding the child health should be built up among parents and families, especially among families where such a disease has occurred for the first time. Support group approach, psychosocial counseling and emotional support are still not entertained as an important therapy part in government set up. But these are important issues that can improve HRQOL drastically. In the present study there was no scope to address these issues due to lack of such approach in our community. In future, we need to perform some interventional or experimental study in this regard that may help to set up a newer treatment guideline which may help to maintain good QOL among thalassemics.

Contributions RS: Primary researcher, planner, analysis of data and writing of article; RM: Guidance during article writing and will act as guarantor for this paper; IS: Guidance during article writing, statistical analysis.

Conflict of Interest None.

Source of Funding None.

References

1. Weatherall DJ, Clegg JB. The thalassemia syndromes. 4th ed. Oxford: Blackwell Scientific Publications; 2001.
2. Yaish HM. Thalassemia. Available at http://www.emedicine.com/PED/topic2229.htm. Accessed 6 Aug 2007.
3. Verma IC, Choudhry VP, Jain PK. Prevention of thalassemia: a necessity in India. Indian J Pediatr. 1992;59:649–54.
4. Forrest CB, Simpson L, Clancy C. Child health services research: challenges and opportunities. JAMA. 1997;277:1787–93.

5. Homer CJ, Kleinman LC, Goldman DA. Improving the quality of care for children in health systems. Health Serv Res. 1998;33:1091–109.
6. McGlynn EA, Halfon N, Leibowitz A. Assessing the quality of care for children: prospects under health reform. Arch Pediatr Adolesc Med. 1995;149:359–68.
7. Seid M, Varni JW, Segall D, Kurtin PS. Health-related quality of life as a predictor of pediatric healthcare costs: a two-year prospective cohort analysis. Health Qual Life Outcomes. 2004;2:48.
8. Ismail A, Campbell MJ, Ibrahim HM, Jones GL. Health related quality of life in Malaysian children with thalassemia. Health Qual Life Outcomes. 2006;4:39.
9. Pakbaz Z, Treadwell M, Yamashita R, Quirolo K, Foote D, Quill L, et al. Quality of life in patients with thalassemia intermedia compared to thalassemia major. Ann N Y Acad Sci. 2005;1054:460–1.
10. Shaligram D, Girimaji SC, Chaturvedi SK. Psychological problems and quality of life in children with thalassemia. Indian J Pediatr. 2007;74:727–30.
11. Sachdeva A, Yadav SP, Berry AM, Kaul D, Khanna VK. Assessment of quality of life in thalassemia major. Int J Hematol. 2002;76:4–76.
12. Varni JW. The PedsQL™ measurement model for the pediatric quality of life inventory™. Available at http://www.pedsql.org/index.html. Accessed 28 May 2013 at 11p.m.
13. El Dakhakhny AM, Hesham MA, Mohamed SE, Mohammad FN. Quality of life of school age thalassemic children at Zagazig city. J Am Sci. 2011;7:186–97.
14. Torcharus K, Pankaew T. Health-related quality of life in thalassemia treated with iron chelation. Royal Thai Army Med J. 2011;64:3–10.
15. Thavorncharoensap M, Torcharus K, Nuchprayoon I, Riewpaiboon A, Indaratna K, Ubol B. Factors affecting health-related quality of life in Thai children with thalassemia. BMC Blood Disord. 2010;10:1–10.
16. Hussain S, Anwer A, Ahmad A, Jaffery S. Improved quality of life in post splenectomized thalassemic patients. Pak J Surg. 2011;27:83–6.
17. Singer DB. Post-splenectomy sepsis. Perspect Paediatr Pathol. 1973;1:285–331.
18. Surapolchai P, Satayasai W, Sinlapamongkolkul P, Udomsubpayakul U. Biopsychosocial predictors of health-related quality of life in children with thalassemia in Thammasat University Hospital. J Med Assoc Thail. 2010;93:S65–75.