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Original Research Article

Assessment of quality of life and its predictors in thalassemic children

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ABSTRACT

Background: In India, approximately 10,000 children are being born with thalassemia per year contributing to 10% of the total world incidence of thalassemia affected children. With the advancement in medical therapy resulting in early diagnosis and initiation of blood transfusion at an early age, and management of complications, survival rates have improved and such child can survive till second and third decades.
Methods: This study was conducted among 100 children in the age range of 2 to 14 years registered with the Thalassemia clinic, department of paediatrics, Gandhi Medical College and associated Kamla Nehru hospital, Bhopal. All patients underwent routine investigation and other relevant investigations as required. To assess the quality of life of children with thalassemia, pediatric quality of life inventory (PedsQL4) scale was used.
Results: Mean age of children belonging to the age range of less than 4 years- 38±11.38 months whereas that of children in the age range of 5-7 years and 8 to 12 years was 71.08±8.93 month's and120.32±23.44 (95%CI 112.51-128.12) months respectively. The emotional domain of quality of life was significantly associated with compliance to chelation therapy among children in the age range of less than 4 and 8 to 12 years.
Conclusions: Thalassemia significantly affects negatively on the quality of life of all individuals irrespective of the age of the child. Though, all the domains i.e. physical, emotional, school and social are affected in these patients, physical and school domain are most commonly affected.

Keywords: Thalassemia, QOL, Children, Quality of life

INTRODUCTION

Thalassemia affects approximately 4.4/10,000 live births globally whereas, in India, approximately 10,000 children are being born with thalassemia per year contributing to 10% of the total world incidence of thalassemia affected children.[1,2]

With the advancement in medical therapy resulting in early diagnosis and initiation of blood transfusion at an early age, and management of complications, survival rates have improved and such child can survive till second and third decades. But these gains in terms of survival rates will be of little value if they are associated with poor quality of life (QOL).[3]

To measure the quality of life in pediatric patients, a multidimensional tool PedsQL4.0 is used. Literature assessing the quality of life amongst children with chronic disease such as thalassemia are scarce. The present study was thus conducted at a tertiary care centre to assess the quality of life in patients presenting with thalassemia.

Objectives

The objectives of this study were to find (a) out the quality of life among children suffering from thalassemia using PedsQL4 scale; and (b) association of QOL with serum ferritin levels.

METHODS

Study design

The study was facility-based cross-sectional study.

Study area

The study was carried out at Department of Pediatrics, Gandhi Medical College and Associated Kamla Nehru Hospital, Bhopal, Madhya Pradesh.

Study population

All the thalassemic pediatric patients between the age group of 2-14 years attending the department of pediatrics.

Study period

The study period was carried out in one year (1st June 2019 to 31st May 2020).

Study tool

The study tool was semi-structured questionnaire and PedsQL4.

Inclusion criteria

All the patients in the age range of 2 to 14 years registered with the thalassemia clinic, department of paediatrics, Gandhi Medical College and associated Hamidia or Kamla Nehru hospital, Bhopal.

Children whose parents/guardian consent for the study.

Exclusion criteria

Any debilitating disorders unrelated to thalassemia and first-time diagnosed patients were excluded from the study.

Sampling

All the patients fulfilling the inclusion criteria were selected using purposive sampling.

Methodology

After obtaining informed consent, all patients and their parents/guardian included in the study were interviewed and information was recorded on a predesigned, pretested and semi-structured questionnaire. The questionnaire included socio-demographic variables such as age, gender, education, occupation, monthly income, number of a family member etc. The detailed history of each patient was obtained with emphasis on age at diagnosis, details of the siblings, consanguinity, splenectomy, frequency of blood transfusion, dose and duration of iron chelation, serum ferritin and mean haemoglobin level. General examination to assess the complications if any, along with anthropometric measurements to assess growth was also recorded and entered in the questionnaire. Further, all patients underwent routine investigation and other relevant investigations as required. For the assessment of the quality of life of children with thalassemia, Pediatric Quality of Life Inventory (PedsQL4) scale was used. This tool consists of 23 items in four domains and three summary scores.

This tool comprised of self-report and parent proxy report formats. Child self-report is for children in the age group of 5-7 years, 8-12 years and 13-18 years whereas parent proxy report includes following ages- 2-4 years (toddler), 5-7 years (young child), 8-12 years (child) and 13-18 years (adolescent). For child self-report in the age group of 8 to 14 years and parent proxy report, a five-point Likert response scale was utilized. Similarly, for child self-report in children less than 8 (5-7) years, a three-point pictorial scale was used. Reversed scoring was used on a 0-100 scale (i.e. 0=100, 1=75, 2=50, 3=25, 4=0) for all the item. Scale scores was calculated by the sum of all the items divided by the number of items answered. A higher score indicates better HRQOL: Data was compiled using MS excel and analysed by using SPSS version 20.0 for Windows.

Table 1: Description of the questionnaire.

Dimensions	Number of items	Custer of items	Reversed scoring	Direction of dimensions
Physical functioning	8	1-8	1-8	Higher score indicates better HRQOL
Emotional functioning	5	1-5	1-5	
Social functioning	5	1-5	1-5	
School functioning	5	1-5	1-5	

RESULTS

The present study was conducted on a total of 100 children presenting with thalassemia to assess the quality of life among children suffering from thalassemia using PedsQL4 scale. PedsQL4 scale has a different set of questionnaire-based upon age. Mean age of children belonging to the age range of less than 4 years- 38±11.38 months (95%CI-34.15-41.85) whereas that of children in the age range of 5-7 years and 8 to 12 years was 71.08±8.93 (95%CI-57.47-74.68) months and120.32±23.44 (95%CI 112.51-128.12) months respectively.

In the present study, physical and total quality of life was significantly better in children compliant to chelation therapy across all age ranges as compared to non-compliant children ($p<0.05$). However, the emotional domain of quality of life was significantly associated with compliance to chelation therapy among children in the age range of less than 4 and 8 to 12 years ($p<0.05$). However, school and social domain of quality of life were significantly better in elder children (8-12 years) compliant to chelation therapy as compared to non-compliant children ($p<0.05$). The present study documented statistically significant negative correlation of physical (r2=-0.496; p=0.001), emotional (r2=-0.460; p=0.001), social (r2=-0.538; p=0.001), school (r2=-0.266; p=0.001) and total score (r2=-0.678; p=0.001) with serum ferritin levels, i.e. as the serum ferritin level increased, quality of life decreased significantly in children belonging to age group of less than 4 years).

Similarly, serum ferritin levels correlated significantly with physical, emotional, social and total quality of life in children belonging to 5 to 7 years of age group. However, no such correlation was noted between the school component of quality of life and serum ferritin levels in these children ($p>0.05$). Among children in the age range of 8 to 12 years, a statistically significant negative correlation between serum ferritin levels and all the components of quality of life was observed i.e. as serum ferritin level increase, quality of life was affected in all dimensions ($p<0.05$).

There is no statistically significant correlation of quality of life with hemoglobin levels in children less than 4 years of age ($p>0.05$). Mean pre-transfusion hemoglobin levels correlated significantly with emotional, school and total quality of life in children belonging to 8 to 12 years of age groups.

Table 2: Association of quality of life with compliance to chelation therapy.

QOL	Compliance	Age group (in years)					
		≤4 (n=36)		5-7 (n=26)		8-12 (n=38)	
		Mean	SD	Mean	SD	Mean	SD
Physical	Yes	60.98	19.95	64.31	15.12	58.09	9.18
	No	29.68	15.47	43.30	25.01	34.57	17.58
	T test	2.167		2.079		5.367	
	P value	0.038		0.045		0.001	
Emotional	Yes	75.76	19.61	75.00	23.56	75.68	15.53
	No	40.00	21.21	1.67	27.53	49.06	15.52
	T test	2.497		1.572		5.219	
	P value	0.018		0.131		0.001	
Social	Yes	71.67	21.09	73.50	13.19	74.55	10.23
	No	62.50	24.75	53.33	32.15	61.56	13.63
	T test	0.593		2.037		3.359	
	P value	0.557		0.054		0.002	
School	Yes	69.94	18.27	69.00	13.24	54.32	9.29
	No	45.83	17.68	58.33	20.21	39.37	17.21
	T test	1.814		1.226		3.449	
	P value	0.079		0.234		0.001	
Total	Yes	68.31	16.68	69.68	12.44	64.67	8.46
	No	42.26	19.36	50.76	24.37	44.63	11.42
	T test	2.133		2.180		6.222	
	P value	0.040		0.041		0.001	

Table 3: Correlation of serum ferritin levels and quality of life.

Age (years)	QOL	R	R^2	Adjusted R^2	SE of the estimate	F	Sig.
≤4 (n=36)	Physical	-0.704	-0.496	-0.481	15.496	33.478	0.001
	Emotional	-0.678	-0.460	-0.444	16.077	28.954	0.001
	Social	-0.733	-0.538	-0.524	14.297	39.584	0.001

Continued.

Age (years)	QOL	R	R^2	Adjusted R^2	SE of the estimate	F	Sig.
	School	-0.516	-0.266	-0.245	16.941	12.350	0.001
	Total	-0.823	-0.678	-0.669	10.000	71.594	0.001
5-7 (n=26)	Physical	-0.558	-0.312	-0.283	14.844	10.874	0.003
	Emotional	-0.417	-0.174	-0.140	22.889	5.065	0.034
	Social	-0.463	-0.215	-0.182	15.171	6.564	0.017
	School	-0.271	-0.074	-0.035	14.079	1.905	0.180
	Total	-0.535	-0.286	-0.256	13.112	9.616	0.005
8-12 (n=38)	Physical	-0.792	-0.628	-0.617	10.924	60.666	0.001
	Emotional	-0.805	-0.648	-0.638	12.204	6.323	0.001
	Social	-0.440	-0.194	-0.171	12.105	8.652	0.006
	School	-0.631	-0.399	-0.382	11.795	23.855	0.001
	Total	-0.843	-0.711	-0.703	7.588	88.693	0.001

Table 4: Correlation of pre transfusion hemoglobin levels and quality of life.

Age (years)	QOL	R	R^2	Adjusted R^2	SE of the estimate	F	Sig.
≤4 (n=36)	Physical	0.040	0.002	-0.028	21.813	0.054	0.818
	Emotional	0.072	0.005	-0.024	21.820	0.178	0.675
	Social	0.183	0.033	0.005	20.678	10.176	0.286
	School	0.211	0.069	0.044	18.037	10.891	0.213
	Total	0.158	0.025	-0.004	17.403	0.869	0.358
5-7 (n=26)	Physical	0.298	0.089	0.051	17.081	20.336	0.139
	Emotional	0.006	0.000	-0.042	25.189	0.001	0.976
	Social	0.084	0.007	-0.034	17.060	0.172	0.682
	School	0.001	0.000	-0.042	14.627	0.000	0.995
	Total	0.144	0.021	-0.020	15.356	0.506	0.484
8-12 (n=38)	Physical	0.317	0.100	0.075	16.978	40.021	0.052
	Emotional	0.360	0.130	0.106	19.194	50.366	0.026
	Social	0.226	0.051	0.025	13.131	10.946	0.172
	School	0.432	0.187	0.164	13.715	80.267	0.007
	Total	0.402	0.162	0.138	12.931	60.938	0.012

DISCUSSION

In our study, 36% children belonged to the age group of less than 4 years, whereas 26% and 38% children belonged to age ranged of 5 to 7 years and 8 to 12 years respectively. Mean age in the present study was 76.5. months (6.4 years). Majority of children across all age ranges were diagnosed as thalassemia major whereas few patients were diagnosed as thalassemia minor and sickle thalassemia in our study. Mean age of patients in a study by Dhirar et al was 8.69±4.98 years and about 63.5% were boys.[4] Mean serum ferritin in children belonging to the age range of less than 4years was 1401.39±619.87 which was significantly less as compared to children belonging to 5 to 7 years (1906±689.77) and 8 to 12 years (2484.05±976.87). This could be due to the significantly higher number of transfusions in elder children as compared to children of the younger age group. The findings of the present study were supported by findings of Hakeem et al in which the authors documented significantly higher serum ferritin levels amongst children with thalassemia on transfusion (975±22.1) as compared to control group (43±3.7).[5] Our findings were concordant with the findings of Rathaur et al in which mean serum ferritin in thalassemia were 1,560.9.[6] In the present study, the overall quality of life was significantly affected as the age of child increased. Mean quality of life score in children of less than 4 years was 66.9±17.4 whereas that of children 5 to 7 years and 8 to 12 years was 66.7±15.2 and 56.2±51.7 respectively. These findings were concordant with the findings of Hakeem et al.[5] Devarshi et al documented findings similar to present study i.e. quality of life of children with thalassemia was significantly lower as compared to healthy controls ($p<0.05$).[7] The findings of the present study were also supported by findings of Mikael et al in which advancing age was significantly correlated with negative impact on the quality of life of patients with thalassemia.[8] Based upon PedsQL4 scale, physical functioning of quality-of-life score was 60.2±21.5, 61.7±17.5 and 48.2±19.9 in children belonging to the age range of less than 4, 5 to 7 and 8 to 12 years respectively. Our study documented a significantly lower mean physical score in children of higher age as compared to the younger age of children($p<0.01$). Similar to the present study, Hakeem et al also documented that mean physical functioning score was lower in children belonging to 8 to 12 years of age (40.3±22.6) which furthered deteriorated in adolescents of 13 to 18 years of

age (31.6±17.1).[5] In contrast, to present study, mean physical functioning score observed by Shakib et al in children belonging to 8 to 12 years of age was much higher i.e. 70.6±24.7.[9] In our study, emotional quality of life score was 72.8±21.6, 71.4±24.7 and 64.5±20.3 among children belonging to the age range of less than 4, 5 to 7 and 8 to 12 years of respectively. Emotional aspect was equally affected in all age range (p>0.05). Nashwan et al observed findings similar to the present study.[10] The emotional score was more than 70 in a study by Shakib et al among children belonging to 8 to 12 years of age.[9] In our study, the social score of quality of life was 70.1±20.7 in children of less than 4 years, 70.1±16.8 in 5 to 7 years and 69.1±13.3 in children of 8 to 12 years. However, the difference in social score of quality of life between children of different age range was statistically insignificant (p>0.05). These findings were supported by findings of Devarshi et al in which mean social function in thalassemia children was 62.14 that was significantly lower as compared to healthy controls (92.85) but the authors did not stratify the quality based upon age.[7] However, mean social functioning scores in thalassemia children observed by Ayoub et al was slightly in better range (78.5±24.0) as compared to the present study.[11] School functioning score were 67.6±19.5, 65.8±14.3 and 48.1±15.0 in children belonging to less than 4, 5 to 7 and 8 to 12 years of age respectively. As age increased, school functioning was significantly affected (p<0.01). The mean range of school functioning score obtained in the present study was similar to a study by Thavorncharoensap et al i.e. 67.89±15.92.[12] The overall quality of life showed a significant negative correlation with pre- transfusion haemoglobin levels in children belonging to more than 8 years of age (p<0.05). In contrast to the present study, Shakib et al and Hakeem et al documented no significant association between haemoglobin levels and quality of life.[5,9]

Limitations

Though life expectancy of children with thalassemia has improved, but it has a significant negative impact on the quality of life. Thus, efforts must be made to improve the overall quality of life of such children.

CONCLUSION

Based upon the study findings, it could be concluded that thalassemia significantly affects negatively on the quality of life of all individuals irrespective of the age of the child. Though, all the domains i.e. physical, emotional, school and social are affected in these patients, physical and school domain are most commonly affected. Factors which are important predictors of quality of life in such patients are the age of the patient, serum ferritin levels, compliance with chelation therapy. Pre transfusion haemoglobin levels affected emotional and school domain of quality of life. However, serum ferritin and compliance with chelation therapy affected the quality of life across all domains.

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