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Original Research Article

A study on quality of life among thalassemic children aged 8 to 18 years

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ABSTRACT

Background: The assessment of quality of life in children, especially in those with chronic illness such as thalassaemia, is particularly important. It differs from other forms of medical assessment in that it focuses on the individuals' own views of their well-being and other aspects of life, giving a more holistic view of well-being.
Methods: Hospital based descriptive, observational study was conducted on 200 school-age children. Two tools were used to collect the necessary data. The first was a structured interview questionnaire sheet including socio-demographic data of children and their parents as well as medical history. The second tool was a standardized tool (Pediatric Quality of Life Inventory TM Version 4.0).
Results: The results of the present study revealed that the quality of life of school-age children with Thalassemia Major was affected. According to child's report regarding total QOL score 30% of children had good score compared to 35% in parent's report, while 65% had fair score compared to 60% in parent's report. Emotional functioning scored the lowest followed by physical then school and social functioning. Regarding compliance with treatment, 91% of the studied children had regular blood transfusion therapy. In addition, 81% of the studied children were compliant with iron chelation therapy.
Conclusions: Thalassemia has a negative impact on perceived physical, emotional, social and school functioning in thalassemia patients. There was a significant association between the total quality of life and compliance with blood transfusion and regular iron chelation therapy in both child and parent report.

Keywords: Quality of life, Thalassemia major, School-age

INTRODUCTION

Thalassemias are inherited disorders of Haemoglobin synthesis that result from an alteration in the rate of globin chain production. A decrease in the rate of production of a certain globin chain or chains (α, β, γ, δ) impedes Hb synthesis and creates an imbalance with the other, normally produced globin chains.[1]

The most severe form is the β-thalassemia major, which is characterized by a severe microcytic, hypochromic anemia (Cooley's anemia), whose symptoms appear usually within the first 2 years of life. Infants become pale and asthenic, have poor appetite, grow slowly, and often develop jaundice; spleen, liver, and heart may also be enlarged. Adolescents with the most severe form may experience delayed puberty.[2]

Significant advances in treatment modalities and improved clinical management have led to a substantially higher life expectancy of these patients.[3] Children with thalassemia major have good survival but little is known about their quality of life.[4] Children are less able to voice their concerns and are more vulnerable than adults (Ismail et al).[5]

The assessment of quality of life (QOL) in children especially in children with chronic illness such as thalassaemia is particularly important.[5] An assessment of QOL differs from other forms of medical assessment in that it focuses on the individuals' own views of their well-being and assesses other aspects of life, giving a more holistic view of well-being [6]

It is important to understand more about quality of life in pediatric population to evaluate and improve the care patients receive. Children with chronic physical illness exemplified thalassemia are vulnerable to emotional and behavioral problems leading to poor quality of their lives. The disease may cause a sense of stigmatization in the child leading to feeling of shame and rejection. It also may affect social relations, school interactions, and self-esteem. So, great attention has to be taken especially by the nurse during treatment, monitoring and follow up.[1]

As the state government declared all thalassemia's patient under the category of free treatment of this disease from 2 October 2011. After that there is significant improvement in the compliance of treatment. Due to these benefits more and more children are strictly adhere to treatment in form of blood transfusion or chelation therapy. Because of this policy of Rajasthan government economic burden over patients has decreased. So now it has been decided to conduct a study on quality of life among thalassemic children aged 8 to 18 years.

Objective of present study was to assess quality of life of school age children with thalassemia through PedsQL Measurement Model in term of physical, emotional, social and school functioning.

METHODS

This descriptive observational study was conducted in a tertiary care paediatric hospital attached with SMS Medical College, Jaipur from April 2013 to March 2014.The study was conducted on 200 school-age children (114 male children and 86 female) who fulfilled the following criteria:

Confirmed diagnosis of thalassemia major. Age: from 8 years old to 18 years old. Both sexes. Free from any other chronic diseases.

In this study 2 Tools were used for necessary data collection.

Tool I

Included structured interview questionnaire sheet which contains:

Biosocial data of the child as child's age, sex, birth order and the level of education. Information about disease history, any similar conditions in the family, number of blood transfusions per month, compliance with blood transfusion and compliance with chelation therapy. Socio-demographic data of child's parents such as age, educational level, occupation, family income as well as crowding index.

Tool II

The Pediatric Quality of Life InventoryTM Version 4.0 by Varni et al.[6]

The Peds QL Measurement Model is a modular approach to measure health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The Peds QL Measurement Model integrates seamlessly both generic core scales and disease- specific modules into one measurement system. This form included both child and parent report.

There are four domains in each report. The PedsQL version 4.0 consists of 23 items including the following:

Physical functioning (eight items), emotional functioning (five items), social functioning (five items) and school functioning (five items)

Statistical analysis

The collected data was coded and entered in a data base file using the Foxpro for windows program. After complete entry, data were transferred to the Statistical package for social sciences (SPSS) version 14.0 program by which the analysis was conducted applying frequency tables with percentages and cross tabulations. The chi-square test was used to find the significant associations between the demographic and clinical data and the outcome measures.

Informed consent was obtained from all the parents of the patients. The study was approved by the Ethical Committee of the Institution.

RESULTS

There were 114 male and 86 were female children in the study. Among these children 56% were from rural and 44% were from urban areas. Those who ranked the first birth order constituted 41.5%, the second 36.5%, while 13% were the third. As regard to crowding index, 33% of families of the studied children were with crowding index of <2, while 35% were with crowding index of 2-3, as well as 32% had crowding index of >3 (Table 1). Children who were diagnosed as β-thalassemia major by the first year of life constituted 70%, while 30% were diagnosed by the second year. Consanguinity was found among 20% of the parents. It was also found that 44% had similar conditions in the family.

Regarding compliance with treatment, 9% of the studied children had irregular blood transfusion therapy, while 91% were regulars. In addition, 81% of the studied

children were compliant with iron chelation therapy, while 19% were not compliant. Among these 33% children come to the hospital once per month for transfusion therapy, while 67% come twice per month.

Table 1: Demographic characteristics of thalassemic children.

Birth order	No.	%
The first	83	41.5
The second	73	36.5
The third	26	13.0
The fourth	12	6.0
The fifth and more	6	3.0
Crowding index		
<2	66	33.0
2-3	70	35.0
>3	64	32.0
Residence		
Urban	88	44.0
Rural	112	56.0
Sex		
Male	114	57.0
Female	86	43.0

Table 2 shows the total QOL score and its domains. According to child's report, 30% of children had good score compared to 35% in parent's report, while 65% had fair score compared to 60% in parent's report.

Regarding physical QOL 48% had good score according to child's report compared to 24% in parent's report while 47% had fair score compared to 70% in parent's report. In relation to emotional QOL 35% had good score according to child's report compared to 24% in parent's report. On the other hand 18% had bad score compared to 20% in parent's report while 42% had fair score compared to 50% in parent's report. Regarding social QOL 60% had good social score compared to 62% in parent's report while 30% had fair social score compared to 28% in parent's report. Regarding school QOL 40% had good score according to child's report compared to 24% in parent's report. 42% of children had fair score compared to 68% in parent's report while 12% of children had bad score compared to 10% in parent's report.

The same table reveals that the emotional functioning scored the lowest followed by physical then school and social functioning according to both child and parent's report. Table 3 shows the QOL scores of the studied thalassemic children regarding the physical functions. There were 8 domain included in physical functions. Among these taking bath alone (80%) and walking (70%) had very good score according child report. On the other hand 32% of the studied thalassemic children had bad score regarding running and 12% had very bad score according to child's report, while in parent's report, 39 % had bad score and 31% had very bad score. As regarding activities and exercises according to child's report 36% had very good score and 45% had fair score. In comparison with parent's report 34% had very good score and 48% had fair score.

Table 2: The Total QOL Scale and QOL subscales of the thalassemic children.

QQL scale	Very good =100%		Good 75-99.9		Fair 50-74.9		Bad 25-49.9		Very bad 0-24.9		Mean±SD
	N	%	N	%	N	%	N	%	N	%	
Child report											
Total QQL	0	0.0	60	30.0	130	65.0	10	5.0	0	0.0	73.3±12.6
Physical	4	2.0	96	48.0	94	47.0	6	3.0	0	0.0	61.8±17.5
Emotional	0	0.0	70	35.0	84	42.0	36	18.0	10	5.0	60.2±19.6
Social	10	5.0	120	60.0	60	30.0	10	5.0	0	0.0	82.2±7.5
School	8	4.0	80	40.0	84	42.0	24	12.0	4	2.0	67.3±12.8
Parent report											
Total QQL	0	0.0	70	35.0	120	60.0	10	5.0	0	0.0	70.8±13.0
Physical	0	0.0	48	24.0	140	70	10	5.0	2	2.0	67.6±14.7
Emotional	0	0.0	48	24.0	100	50.0	40	20.0	12	6.0	51.4±22.2
Social	12	6.0	124	62.0	56	28.0	8	4.0	0	0.0	79.6±17.2
School	12	6.0	48	24.0	136	68.0	20	10.0	4	2.0	63.6±17.3

Table 3: Distribution of the physical functioning of the thalassemic children.

Physical domain	Very good =100%		Good 75-99.9		Fair 50-74.9		Bad 25-49.9		Very bad 0-24.9		Total
	N	%	N	%	N	%	N	%	N	%	
Child report											
Walking	140	70.0	20	10.0	26	13.0	10	5.0	4	2.0	200
Running	24	12.0	18	9.0	18	9.0	64	32.0	76	38.0	200
Making activity	72	36.0	10	5.0	90	45.0	16	8.0	12	6.0	200
Lifting something	94	47.0	16	8.0	60	30.0	18	9.0	12	6.0	200
Taking a bath	160	80.0	10	5.0	20	10.0	6	3.0	4	2.0	200
Doing chores	112	56.0	16	8.0	52	26.0	14	7.0	6	3.0	200
No pain	70	35.0	18	9.0	92	46.0	12	6.0	8	4.0	200
Having energy	60	30.0	8	4.0	82	41.0	28	14.0	22	11.0	200
Parent report											
Walking	130	65.0	24	12.0	32	16.0	8	4.0	6	3.0	200
Running	20	10.0	16	8.0	24	12.0	78	39.0	62	31.0	200
Making activity	68	34.0	14	7.0	96	48.0	12	6.0	10	5.0	200
Lifting something	90	45.0	20	10.0	58	29.0	18	9.0	14	7.0	200
Taking a bath	154	77.0	8	4.0	22	11.0	10	5.0	6	3.0	200
Doing chores	106	53.0	18	9.0	60	30.0	8	4.0	8	4.0	200
No pain	82	41.0	28	14.0	78	39.0	12.0	6.0	0	0.0	200
Having energy	66	33.0	12	6.0	80	40.0	30	15.0	12	6.0	200

Table 4: Distribution of the emotional functioning of the thalassemic children.

Emotional domain	Very good =100%		Good 75-99.9		Fair 50-74.9		Bad 25-49.9		Very bad 0-24.9		Total
	N	%	N	%	N	%	N	%	N	%	
Child report											
Being afraid	90	45.0	8	4.0	56	28.0	18	9.0	28	14.0	200
Being sad	84	42.0	10	5.0	90	45.0	12	6.0	4	2.0	200
Being angry	28	14.0	16	8.0	54	27.0	70	35.0	32	16.0	200
Sleeping trouble	100	50.0	6	3.0	64	32.0	24	12.0	8	4.0	200
Being worried	120	60.0	22	11.0	36	18.0	12	6.0	10	5.0	200
Parent report											
Being afraid	92	46.0	6	3.0	60	30.0	20	10.0	22	11.0	200
Being sad	80	40.0	12	6.0	92	46.0	10	5.0	6	3.0	200
Being angry	30	15.0	18	9.0	52	26.0	60	30.0	40	20.0	200
Sleeping trouble	96	48.0	8	4.0	60	30.0	28	14.0	8	4.0	200
Being worried	110	55.0	16	8.0	40	20.0	26	13.0	8	4.0	200

According to parent's report 45% had very good score and 7% had very bad score regarding lifting something heavy. Regarding pain, 46% had fair score and 6% had bad score according to child's report. While in parent's report, 39% had fair score and 6% had bad score. Among studied thalassemic children, 56% had very good score regarding doing chores around the house in child's report compared to 53% in parent's report and 26% had fair score compared to 30% in parent's report.

Table 5: Distribution of the social functioning of the thalassemic children.

Social domain	Very good =100%		Good 75-99.9		Fair 50-74.9		Bad 25-49.9		Very bad 0-24.9		Total
	N	%	N	%	N	%	N	%	N	%	
Child report											
Getting along with kids	176	88.0	4	2.0	10	5.0	10	5.0	0	0.0	200
Other kids refuse him	140	70.0	10	5.0	30	15.0	10	5.0	10	5.0	200
Teasing from other kids	150	75.0	0	0.0	28	14.0	12	6.0	10	5.0	200
Can't do things as others	90	45.0	10	5.0	80	40.0	4	2.0	16	8.0	200
Keeping up when play	60	30.0	6	3.0	58	29.0	26	13.0	50	25.0	200
Parent report											
Getting along with kids	170	85.0	8	4.0	8	4.0	10	5.0	4	2.0	200
Other kids refuse him	150	75.0	12	6.0	20	10.0	8	4.0	10	5.0	200
Teasing from other kids	148	74.0	0	0.0	32	16.0	14	7.0	6	3.0	200
Can't do things as others	88	44.0	12	6.0	84	42.0	6	3.0	10	5.0	200
Keeping up when play	50	25.0	16	8.0	56	28.0	44	22.0	34	17.0	200

Table 6: Distribution of the school functioning of the thalassemic children.

School domain	Very good =100%		Good 75-99.9		Fair 50-74.9		Bad 25-49.9		Very bad 0-24.9		Total
	N	%	N	%	N	%	N	%	N	%	
Child report											
Pay attention in class	118	59.0	6	3.0	62	31.0	10	5.0	4	2.0	200
Forgetting things	130	65.0	0	0.0	50	25.0	14	7.0	6	3.0	200
School work	160	80	10	5.0	20	10.0	6	3.0	4	2.0	200
Missing school due to illness	102	51.0	8	4.0	44	22.0	36	18.0	10	5.0	200
Missing school to go to hospital	4	2.0	2	1.0	20	10.0	14	7.0	160	80.0	200
Parent report											
Pay attention in class	120	60.0	4	2.0	60	30.0	12	6.0	4	2.0	200
Forgetting things	140	70.0	2	1.0	40	20.0	12	6.0	6	3.0	200
School work	174	87.0	2	1.0	22	11.0	2	1.0	0	0.0	200
Missing school due to illness	98	49.0	12	6.0	40	20.0	38	19.0	12	6.0	200
Missing school to go to hospital	8	4.0	6	3.0	10	5.0	16	8.0	160	80.0	200

Table 4 showed QOL Score of emotional functions. According to child's report, it was found that 45% of children had very good score regarding fear compared to 46% in parent's report. Those who had very bad score constituted 14% compared to 11% in parent's report. Regarding sadness, 45% of children had fair score compared to 46% in parent's report. In addition, 42% had very good score compared to 40% in parent's report. As regard anger, 16% of children had very bad score compared to 20% in parent's report. Only 14% had very good score compared to15% in parent's report. In relation to having sleeping trouble, 50% of children had no sleeping trouble and had very good score compared to 48% in parent's report. Regarding worry, 60% of the studied children had very good score as they had no worry about what will happen to them compared to 55% iparent's report. Six percent of children had bad score compared to 13% in parent's report.

Table 5 illustrated the social functioning of the studied thalassemic children. According to child's report, it was found that 88% had no problems with getting along with other kids so they had very good score compared to 85% in parent's report. Children who had very good score regarding acceptance of them from other kids as friends constituted 70% compared to 75% in parent's report. Children who were not teased from others and had very good score constituted 75%. In relation to the ability of doing things as other kids 45% had very good score and 40% had fair score. Regarding keeping up with other kids when playing 30% of children had very good score while 25% of children had very bad score.

Table 6 showed school functioning of these children. Regarding paying attention in class 60% of children had very good score in children report and 30% had fair score in parent's report. As regard to forgetting things, 70% of children had very good score in parent's report. Regarding keeping up with schoolwork, 87% of children had very good score in parent's report. In relation to missing school due to illness, 49% of children had very good score and 19% had bad score in parent's report.

DISCUSSION

The present study found that 81% of children had compliance with iron-chelation therapy. This finding is against the Amal et al who done his study at Zagazig university Hospitals and he found that most of his studied sample were not compliant with iron-chelation therapy.[1] It may be due to government providing free treatment to all thalassemia' patients and increasing awareness in public regarding disease.

Regarding the total QOL of children with thalassemia major, Shaligram et al found that three quadrants of the studied thalassemic children had poor QOL.[8] This goes against with the present study 65% of children had fair QOL and 5% had bad QOL. This is may be due to improvement in treatment options and improvement in adherence to therapy. The present study noticed that mothers related QOL of their children as fair in 60% of them and bad in 5%. This finding against the Shaligram et al who mentioned that caregivers related QOL of their children as poor in most children. This was due to sense of guilt toward those children as thalassemia is an inherited disease and due to the permanent comparison between them and the other healthy children or siblings.

The current study found that emotional functioning scored the lowest followed by school then physical and social functioning. This finding is in consistent with Cheuk's et al study that conducted in Hong Kong.[9] On other hand our finding is in contrast with both Thavorncharoensap et al and Ismail et al who found that school functioning scored the lowest, followed by emotional functioning and social functioning then physical functioning.[4,10] Ismail and Thavorncharoensap et al clarified their finding by the fact that frequent absenteeism from school for hospital visits, and lack of energy when performing academic activities, had a significant negative impact on the children's health related quality of life (HRQOL).

Regarding physical QOL, Shaligram et al found that the majority of children had no problems with self-care followed by usual activities, and mobility.[8] This finding is in agreement with the present study as 80% had no problems with self-care, and 70% had no problems with walking. Dahlui et al clarified that, the physical function scores were higher than the other domains because these patients had been having the disease since childhood, they were not working for a living and as such had not much expectation with regard to physical performance.[5]

The present study found that 32% had bad physical QOL regarding running while, 8% had bad physical QOL regard making activities and exercises. These findings are supported by Caro who found, less than one quadrant of conventionally treated thalassemia major patients had their activities very often stopped due to thalassemia, its complications or desferrioxamine treatment, and 20% had their physical activities limited at least a bit.[11] This may be due to the regular period of mild anemia before the scheduled transfusion which might limit their exercise capacity as thalassemia leads to low hemoglobin level resulting in fatigue and general weakness (Cheuk et al).[9]

The present study found that 46% of children had affected QOL regarding pain and 6% had bad and 4% had very bad QOL score. This finding is supported by Shaligram et al who clarified his result on the basis that iron chelating therapy produce arthritis, abdominal pain, diarrhea and vomiting which may have a bearing on the high score on the pain.

Regarding emotional QOL, the present study found that 46% of children had fair emotional QOL and only 20% had bad emotional QOL. These findings are in agreement with a subsequent multi-center European study conducted by Sadowski et al found the same results. In addition, Pradhan

et al found that more than two thirds of children had emotional problems.[12,13] Emotional QOL was affected because thalassemic children feel different from their peers and elaborate negative thoughts about their life. In addition, children may develop psychological and emotional problems early from the toddler stage. Toddlers want to become capable of satisfying some of their own needs to develop a sense of autonomy but, if caregivers refuse to let them perform these tasks due to their illness, they may develop shame and doubt about their ability to handle problems. Moreover, the treatment is emotionally demanding as transfusion and chelation therapy require repeated invasive procedures and hospital visits.

Regarding social functioning, Gharaibeh et al reported that stigmatization was significantly noticed among older children to younger children.[14] He also found that all children who were not currently at school experienced severe stigmatization due to thalassemia major. In consistent with Gharaibeh findings, the present study found that 75% of children, who had not teasing from others had very good social QOL. Only 11% of children, who had teasing from others had severe problems with social interaction. In addition, the majority of children had no problems with getting along with other kids and they related their social QOL as very good. Regarding being a member in a play team with other kids 70% of the studied thalassemic children had no problems as other kids didn't refuse them so they related their social QOL as very good. This may be due to the nearly absence of the disease complications at this age resulting in decreased feeling of stigmatization that causes limitations of social interaction.

Regarding school functioning, Saeed explored that having to go to hospital for blood transfusion and missing school is one of the most important factors affecting the QOL of conventionally treated thalassemic patients.[15] In addition, Gharaibeh et al reported that education was one of the greatest difficulties that affected children with thalassemia, as 42.7% of children with thalassemia experienced moderate to severe difficulties in their education.[14] Similarly, Cantaan et al mentioned that education of two thirds of children with thalassemia at school age was affected, mainly due to having attended hospital for investigations and transfusions.[16] Consistent with the previous studies, the present study found that 46% had fair school QOL while only 12% were bad. It may be due to pre booked and decrease hospital stay for blood transfusion and investigations helps in decrease missing school days. Improved compliance in treatment helped in physical and mental health.

Telfar et al discussed that QOL for non-chelated and fully chelated thalassemia patients differed.[17] The fully chelated patients had a QOL almost similar to that of normal children. In consistency, the present study revealed that 80% of children who were compliant with iron chelation therapy had good QOL. This may be clarified by the fact that chelation therapy can reduce complications, and improve survival and quality of life of transfused patients (Cianciulli, 2009).[18]

Despite showing various aspects of quality of life among thalassemia patients this study had some limitations. Small sample size was one of major limiting factor. Study was questionnaire based so chances of biases were more. In this study various socio economic groups of patients were not compared. Further larger multi centric studies may helpful for validation.

CONCLUSION

Based upon the results of the present study, it was concluded that thalassemia as a chronic disease had some negative impact on perceived physical, emotional, social and school functioning of school-age children resulting in impaired quality of life. The study reflected that emotional functioning was the most affected from the point of view of both children and parents but quality of life in these children significantly improved compared to previous studies. The study also demonstrated an association between compliance with treatment regimen and quality of life. Improvement in compliance reflected in better quality of life in thalassemia children.

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