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Original Article

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School Functioning Activity of Bengali Thalassemic Children Attending a Tertiary Care Hospital of Eastern India

Rajib Saha[1*], Raghunath Misra[2], Indranil Saha[3]

[1]Department of Community Medicine, Bankura Sammilani Medical College, Bankura, West Bengal, India
[2]Department of Community Medicine, Institute of Post-Graduate Medical Education and Research and Seth Sukhlal Karnani Memorial Hospital, Community Medicine, Kolkata, West Bengal, India
[3]Department of Community Medicine, IQ City Narayanahrudayala Hospital & Medical College, Durgapur, West Bengal, India

Corresponding Author: Rajib Saha, MBBS, MD, Department of Community Medicine, Bankura Sammilani Medical College AD-234, Rabindrapally, Krishnapur, Kolkata-700101, West Bengal, India. Tel: +919231857329; Email: dr.rajsaha@gmail.com

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Abstract

Introduction: The study was conducted to assess the school activity of thalassemic children and to reveal the relationship between school activity with the socio-demographic factors as well as clinico-therapeutic profile.

Methods: A total of 365 admitted thalassemic patients of Burdwan Medical College (ages 5 to 12 years) were participated in this cross sectional descriptive study conducted on from July 2011 to June 2012. Their parents were interviewed using school functioning domain of Paediatric Quality of Life Inventory 4.0 Generic Core Scale. Independent t test or Mann-Whitney U test, and analysis of variance (ANOVA) or Kruskal-Wallis test were applied to observe the difference between mean values in accordance to their applicability. Statistically significant factors in bivariate analysis were considered for binary logistic regression.

Results: Mean score of school activity was 49.42±15.30 out of 100. 49.3% thalassemic children had fair (50-74.9) school functioning score. Twenty percent of the children were presently not going to school, 11.8% never went to school and the remaining 8.2% were dropped out. Binary logistic regressions revealed that school activity worsened 4 times with the increase in frequency of blood transfusion single time per year. Patients belonging to joint family and family with no positive history of such disease, had 3.4 and 3.9 times worse school activity than nuclear family and family with positive child history respectively. Male children had 2 times more poor school activity than female.

Conclusion: School functioning activity of Bengali thalassemic children is generally poor, but counselling of parents and families can improve the situation.

Keywords: Blood transfusion, Logistic models, Quality of life, Student dropouts, Tertiary care centers

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Introduction

Thalassemia syndromes are a heterogeneous genetic disorder of blood, inherited to offspring autosomal recessively.[1] Globally, 15 million people are suffering from clinically thalassemic disorders apparently. Worldwide 240 million people are reported as β-thalassemia carrier, and among them 3.3% live in India.[2,3] Thalassemia is a chronic disease, where cure is not attainable due to limited resource and treatment may be prolonged, unpleasant and repetitive; thereby can affect a patient's general health, mental health and life satisfaction. Today's practitioners are more concern about the patient's quality of life and are trying to improve their life standards by introducing novel treatment options.[4-7]

Every child should have the opportunity to achieve his or her academic potential. Since thalassemic children are physically and mentally weak by birth due to the disease process, they should be properly educated in order to make their social identity and to confront with every situation in life, like ignorance etc.[8]

High treatment cost of the disease leads to financial burden that also results in poor maintenance of regular treatment as well as patient's physical inability. These issues also affect the educational process of the children.[9] So the school life and their activity in school is also considered as an important yardstick for their quality of life.[10-13]

However, our health care delivery system did not pay any attention and priority in this aspect. Research findings are also very limited in this regard.[10-13] In this background, this study was conducted to assess the school functioning activity of thalassemic children and to reveal any association or relationship between school functioning activity with social and demographic factors as well as clinico-therapeutic profile of them.

Methods

Study Design, Study Period & Place of Study

This cross-sectional epidemiological study was conducted in a tertiary care hospital of eastern India named Burdwan Medical College and Hospital from July 2011 to June 2012. Here patients are admitted not only from Burdwan district, but also from the surrounding districts of the West Bengal state.

Study Population

All 5-12 years confirmed major or intermediate thalassemic patients admitted either in day care unit or inpatient department (IPD) of Paediatrics or General Medicine of the institute during the study period for only therapeutic blood transfusion was considered as our study population. Among them only who were receiving blood transfusion regularly for at least 2 years or more, were ultimately included in our study. Thalassemic children who had history of suffering from serious illness in the last month preceding data collection, or had impaired cognitive function, delayed developmental milestone or suffering from any other chronic disease were excluded from the study. Eleven thalassemic children were excluded for serious illness in the last month and 6 were excluded for suffering from chronic diseases like diabetes, acquired immune deficiency syndrome (AIDS), tuberculosis etc.

Sample Size

In the year 2010, 3285 thalassemic children of ages 5-12 years were admitted in Burdwan Medical College and Hospital in day care unit or IPD of Paediatrics or General Medicine of the institute for therapeutic blood transfusion. In the case of chronic patient like thalassemia, a register is maintained in our institute and their medical history can be tracked easily from the register. From this register it was revealed that an admitted thalassemic child of that age group received an average of 9 times blood transfusion in a year and particularly from this institute. So it can easily be said that 3285 thalassemic children were not separate individual. Here, single child was admitted repeatedly in same institute for blood transfusion and same child was counted several times within the total admission estimate. So we have to divide the total thalassemic children admission in a year by average blood transfusion frequency, in order to estimate the actual number of yearly thalassemic children attendance in the hospital for blood transfusion. In our study, we targeted the covering of all those thalassemic patients. So estimated sample size for our study was (3285/9) = 365.

Sampling Technique

Here we followed complete enumeration method for the study.

Study Tools

School functioning domain of Paediatric Quality of Life Inventory 4.0 Generic Core Scale, parent proxy reports (age range: 5-7, 8-12) including investigator administered questionnaire were used to interview the parents of the children for data collection with respect to socio-demographic characteristics and also for the level of school functioning activity related data of school going children.[14] Clinico-therapeutic profile related data were collected by reviewing relevant medical records (laboratory reports, bed head tickets, old prescriptions, discharge certificates etc). The reliability and validity of this scale was checked by Cronbach α test before application in this study setting. Good reliability of school functioning scale reflected in Cronbach α coefficient values which was 0.911 and it is highly reliable.

Data Collection Method

Data of estimated sample size were collected by approaching those departments on 3 alternate days of every week during the one year study period. Data collection days were reversed in alternate week to reduce the bias for day specific hospital admission rate. All the thalassemic patients, who were admitted on the day of data collection in those departments and belonging to studied age group, were included in the study. The data collection was continued to cover the required sample size.

Inter-observer bias was nullified by appointing single interviewer for data collection purpose. Intra-observer bias was unavoidable but was reduced by using specific questionnaire and by completing the interview within the specified time which was 25 minutes. Prior to the commencement of data collection for the development of interviewing skill, interviewer applied the questionnaire on 30 parents of thalassemic child who were admitted into Lions Club Hospital (NGO). Though the assessment of parent's perception regarding their child's activity in school is a difficult task, we experienced that parents of thalassemic children were more responsible towards their child and answered the questions very well. Despite some personal bias which might be present in the study, the questionnaire is subjective.

Statistical Analysis

SPSS software, version 19.0 (SPSS Inc., Chicago, IL, USA) was used for all the statistical analysis. In bivariate analysis, independent *t* test or Mann-Whitney U test was performed in order to evaluate the statistically significant relationship between the two groups. Independent variables which showed homogeneity in variance in Levene test and their 2 subgroups were also found to be normally distributed, and were analyzed by independent *t* test. Independent variables which had no homogeneity in variance in Levene test, and their 2 subgroups were not normally distributed but their distribution had same shape and were analyzed by Mann-Whitney U test. One way analysis of variance or Kruskal-Wallis test was used to examine the statistically significant relationship between three or more subgroups. Independent variables which showed homogeneity in variance in Levene test and their 3 or more subgroups were also found to be normally distributed and were considered for one-way analysis of variance (ANOVA). Independent variables which had no homogeneity in variance in Levene test and their 3 or more subgroups had same variability and were analyzed by Kruskal-Wallis test.

Statistically significant factors in bivariate analysis were considered for binary logistic regression model to determine the important predictors of worse school activity, with school activity as dependent variable.

Results

Background Characteristics

All 365 thalassemic children were belong to 8.3 ± 2.4 (mean ± standard deviation [SD]) years age and gender wise distribution was more or less equal (M:F = 1.05). A larger portion of patients belonged to Hindu religion (59.7%) and scheduled caste and tribe families (73.9%). According to modified Dr. BG Prasad socio-economic scale, socio-economic status IV class patients were found majority in number (44.4%) (Out of 5 categories of social classes, Social class I is richer & Social class V is poor).[15] History of consanguineous marriage was present only among 8.8% parents and all of them were found among Muslims. About one-fifth (22.7%) of the study population had thalassemia in their family. During last blood transfusion more than half of the patient's (53.4%) pre transfusion hemoglobin level was between 5 to 6 gm/dL. and majority (63.3%) were receiving blood transfusion for more than 5 years. Majority of them study population (53.4%) received blood transfusion for 7 to 12 times in the previous year. Splenectomy was done only in 13.4% cases. Among them, about half of the cases (51%) were done 3 to 5 years earlier. High performance liquid chromatography reports were available only in 30.4% cases (111/365). Among the available reports, most patients (47.8%) had beta thalassemia major. 33.3% cases were found HbE beta thalassemia.

Among the whole study population, 73 children (20%) were not presently attending school. Among them, 43 children (11.8%) never went to school and the others (8.2%) were dropped out from school. Eighty percent of dropped out children left their school due to physical inability and the rest left because of financial constrain.

School functioning activity was measured here only for school going children and it was expressed in out of 100 score. Mean score of school functioning activity was found to be 49.42 ± 15.30 (Figure 1). Majority of thalassemic children (49.3%) had fair (50-74.9) school functioning score and approximately 41.8% students had poor school functioning activity (25-49.9). Fair responses (50-74.9) were showed among major study populations in the field of paying attention in class, remembering study and keeping up with school work. But most of the children often missed school due to not feeling well and going to the physician or hospital (Table 1).

Possible scores of school functioning activity might range from 0 to 100; but in our study we found the score ranges from 25-90. School functioning score were distributed slightly positively skewed (0.070) and platykurtic (-0.789) pattern. Q-Q plot reflected that actual data values were closly adhered to expected normal value line. In our study, skewness value of

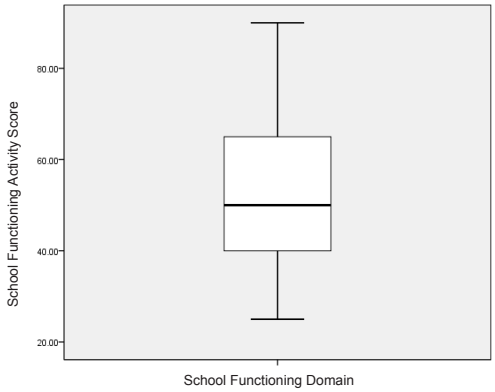

Figure 1. Box and Whisker Plot Showing School Activity Score of Thalassemic Children (n = 292).

dependent variables data distribution curve were within -0.5 to +0.5 ranges which implies that these data were distributed approximately in a symmetric way.

In bivariate analysis, statistically significant worst school activity was observed among those thalassemic patients who were aged participants (8-12 years), male child, Hindu religious, scheduled caste, belonging to joint family, children of no consanguineously married parents, belonging to family who previously have no history of such disease, receiving blood transfusion for more than 5 years and receiving blood transfusion for more than 12 times in the previous year (Table 2 and Table 3).

Statistically significant factors in bivariate analysis were considered in binary logistic regression.

Continuous independent variables showed a linear relationship with the logistic transformation of the dependent variables and dependent variable was coded dichotomously as worse as good school activity (mutually exclusive data: <50 score = worse school activity, ≥50 scores good school activity). The logistic regression model was justified as significant model, by the evidence of omnibus chi-square test ($\chi^2 = 61.507$, $P = .00$). Goodness to fit model was checked by Hosmer–Lemeshow test [χ^2 (8) = 37.997, $P = .37$]. Cox & Snell and Nagelkerke R square value revealed that all the independent variables collectively could explain 19% to 25.6% variance of the dependent variable (i.e. school activity). 63.9% of worse school activity and 81.2% of good school activity could be predicted by the regression model correctly. Generally, the model predicts 74% of school activity correctly as calculated in classification table of the logistic regression model. The statistical significant positive beta coefficients for male child, belonging to joint family child, belonging to family having no such disease initially and receiving blood transfusion for more

Table 1. Distribution of School Going Thalassemic Children According to School Functioning Activity (n = 292)[a]

School Functioning Activity	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	%	
School Function	0	0	26	8.9	144	49.3	122	41.8	0	0	292 (100)
1. Paying attention in class	2	0.7	115	39.4	132	45.2	43	14.7	0	0	292 (100)
2. Forgetting things	8	2.7	115	39.4	122	41.8	47	16.1	0	0	292 (100)
3. Keeping up with school work	2	0.7	111	38	126	43.1	53	18.2	0	0	292 (100)
4. Missing school because of not feeling well	0	0	26	8.9	116	39.7	146	50	4	1.4	292 (100)
5. Missing school to go to the doctor or hospital	0	0	26	8.9	116	39.7	146	50	4	1.4	292 (100)

[a] 292 patients were going to school and rest were either drop out or never went to school.

Table 2. Distribution of School Activity Score According to Socio-Demographic Factors (n=292)

Variables	Subvariables	Number of Cases	School Activity Score (Mean ± SD)	Test of Significance
Age (years)	5-7	122 (41.8)	52.79 ± 14.5	$P = .001^a$
	8-12	170 (58.2)	47.00 ± 15.44	
Sex	Male	159 (54.5)	47.33 ± 13.53	$P = .010^a$
	Female	133 (45.5)	51.92 ± 16.89	
Religion	Hindu	174 (59.6)	47.21 ± 14.43	$P = .003^a$
	Muslim	118 (40.4)	52.67 ± 16.00	
Caste	General & other backward caste (1)	167 (57.2)	48.27 ± 13.98	$P = .037^a$ Test of homogeneity variance Levene statistics: 2.47, $P = .086$
	Scheduled caste (2)	101(34.6)	46.53 ± 15.16	
	Scheduled tribe (3)	24 (8.2)	47.92 ± 12.42	
Type of family	Joint	80 (27.4)	44.75 ± 13.91	$P = 0.001^a$
	Nuclear	212 (72.6)	51.18 ± 15.46	
Residence	Rural	235 (80.5)	49.64 ± 14.84	$P = .618$
	Urban	57 (19.5)	48.51 ± 17.16	
History of consanguineous marriage of their parents	Yes	24 (8.2)	58.75 ± 10.64	$P = .001^a$
	No	268 (91.8)	49.31 ± 15.30	
Family history of Thalassemia	Yes	70 (24)	56.34 ± 12.48	$P = .001^a$
	No	222 (76)	47.19 ± 15.48	
Socio-economic status	Lower (1)	57(19.5)	46.67 ± 13.47	$P = .368$ Test of homogeneity variance Levenes statistics: 1.706, $P = .166$
	Upper lower (2)	134 (45.9)	49.29 ± 15.56	
	Lower middle (3)	77 (26.4)	50.97 ± 16.40	
	Upper middle (4)	24 (8.2)	51.67 ± 14.04	
Education of the parents	Illiterate (1)	49 (16.8)	47.76 ± 16.8	$P = .174$ Test of homogeneity variance Levene statistics: 2.183, $P = .09$
	Primary (2)	20 (6.8)	47 ± 13.99	
	Middle school and Secondary (3)	214 (73.3)	50.4 ± 14.97	
	Higher secondary & Graduates (4)	9 (3.1)	40.56 ± 15.5	
Birth order	First issue	134 (45.9)	49.89 ± 15.21	$P = .832$ Test of homogeneity variance Levene statistics: 0.066, $P = .936$
	Second issue	126 (43.1)	49.25 ± 15.71	
	≥Third issue	32 (11)	48.13 ± 14.35	
	No	208 (71.2)	49.13 ± 15.02	

[a]Statistically significant <.05.

Table 3. Distribution of School activity score according to clinico-therapeutic profiles of the patients (n=292)

Variables	Subvariables	Number of Cases	School Activity Score (Mean ± SD)	Test of Significance
Last pre transfusion Hb level (gm/dL)	<5 (1)	81 (27.7)	49.01 ± 14.09	Kruskal-Wallis test $P = .838$
	5-7 (2)	159 (54.5)	49.56 ± 16.25	
	>7 (3)	52 (17.8)	49.62 ± 14.34	
Duration of blood transfusion	2-5 y	76 (26)	53.42 ± 11.61	$P = .001^a$
	>5 y	216 (74)	47.4 ± 16.52	
Frequency of blood transfusion in the last year	1-6 times/y (1)	36 (12.3)	51.11 ± 17.2	Kruskal Wallis test $P = .001^a$
	7-12 times/y (2)	163 (55.8)	52.15 ± 12.84	
	>12 times/y (3)	93 (31.9)	43.98 ± 17.12	
History of hospitalization in the last year other than blood transfusion	Yes	256 (87.7)	47.78 ± 14.56	$P = .493$
	No	36 (12.3)	49.65 ± 15.41	
History of splenectomy	Yes	49 (16.8)	49.4 ± 15.07	$P = .993$
	No	243 (83.2)	49.42 ± 15.37	
Duration since splenectomy, n = 49	<5	21 (42.9)	54.52 ± 15.5	$P = .057$
	≥5	28 (57.1)	46.43 ± 13.5	
H/O receiving of chelating agent	Yes	80 (27.4)	49.44 ± 13.28	$P = .985$
	No	212 (72.6)	49.40 ± 16.04	
Duration of receiving of chelating agent (months) n = 80	<12 (1)	24 (30)	50 ± 14.74	Mann-Whitney U test: $P = .43$
	≥12 (2)	56 (70)	49.64 ± 12.43	
Type of thalassemia, n = 71	HbE – beta (1)	25 (35.2)	54.6 ± 17.07	F (2,68) = 2.588 $P = .083$ Test of homogeneity variance Levene statistics: 2.831, $P = .066$
	Beta Thalassemia major (2)	37 (52.1)	46.35 ± 17.39	
	Beta Thalassemia intermediate (3)	9 (12.7)	56.67 ± 7.91	
Thalassemia related complication	Yes	84 (28.8)	50.12 ± 16.04	$P = .619$
	No	208 (71.2)	49.13 ± 15.02	

[a]Statistically significant <.05.

than 12 times in the previous year; implies that the chances of worse school activity in a patient increases with the presence of one or more of these independent variables. We discovered that school activity of a thalassemic children worsened 4 times with increase in the frequency of blood transfusion single time per year (odds ratio [OR] = 4; 95% CI = 1.1–14.0; *P* = .03). Thalassemic children belonging to joint family and had no positive family history, were found to have 3.4 and 3.9 times worse school activity than nuclear family and family having positive history belonging to thalassemic child respectively (OR = 3.4, 95% CI = 1.7-6.6, *P* = .001; OR = 3.9, 95% CI = 1.9-8.0, *P* = .001). Male thalassemic children had 2 times more poor school activity than female (OR = 2.1, 95% CI = 1.1-3.9, *P* = .028) (Table 4).

Discussion

Overall school activity score was 49.42 ± 15.30 which was lower than best possible quality of life standards (QOL score = 100). It was the lowest observed score comparative to other related studies like Thavorncharoensap et al[10] (67.89 ± 15.92), Torcharus and Pankaew[11] (62.14 ± 15.84), El Dakhakhny et al[12] (66.55 ± 17.1), Ismail et al[16] (60.1 ± 16.4), Cheuk et al[17] (75.4 ± 19.5) [PedsQL™ 4.0 Generic Core Scale were used all those studies].

The adoption of modern and optimum treatment facilities could explain the high score in the above studies and to avoid school absenteeism, blood transfusion was scheduled on weekends in their countries. But our day care unit does not provide services during weekends and high cost modern effective treatment options (splenectomy, stem cell transfusion etc) are mostly out of reach for the general population. The low school functioning activity score in our sample could be explained by the high frequency of patient visits at hospital/clinics mainly for symptomatic anemia. Sometime patient may requires admission and children could not attend school on their admission days.

In our country particularly in rural districts, counselling and awareness program for thalassemic families is still deficient. Governments and international health agencies are not considering that the thalassaemia is a major health burden in developing countries comparable to other major diseases.[18] That is why neither generally accessible health program nor policy has been planned by Indian government for thalassemic children.

In this study, although all of the children were within the school going age but one-fifth were found not going to school. In another study of West Bengal conducted in Kolkata, it was discovered that 53.1% of thalassemic children were not going to school and it was much higher than that of the present study.[13] It might be as a result of the conduction of the previous study among wider age grouped patients (5-15 years) and dealing with more severe patients. In our study 8.2% children were observed as drop out from school in primary stage which is more than three times higher than state primary stage dropout rate (West Bengal primary stage dropout rate in year 2009-2010 = 2.5%).[19] This implies that thalassemia badly affects school life of the children.

Binary logistic regressions indicated that school activity became worsened with the increase in blood transfusion requirement per year. Risk of hamper of their school activity increased 4 times with the increment of single frequency blood transfusion requirement per year. During therapeutic blood transfusion, children cannot attend their school properly. Children whose requirement of blood transfusion in a year is more, they are usually more physically unable than other child. All these collectively hamper their school activity. Thalassemic child who were growing up in the environment of joint family, had 3.4 times more risk to develop worse school activity. The school activity of the child is hampered possibly as a result of diverse opinion of different family members or their extra protective nature towards the child caring. Families where the disease was notified for first time had 3.9 times poor school activity than others. Previous experience of such disease may help the family members to handle the situation and they realized it from previous experiences that only good schooling can gift their child recognition. The finding of our study did not correlate with the results of the study presented by Ayoub et al,[20] because they did not find any significant relationship between family history and school activity. Surprisingly, we found that male children were 2 times worse than female in case of school activity. This was discovered during interview. Most of the family thought that unexpected accidents may occur during school hours or children may not receive proper care or behavior from peers and teachers. So they restrain their children's school activity. Extra care towards male child may justify the findings of our study.

Table 4. Logistic Regression Model for the Predictors of Worse School Activity of Thalassemic Children

Variables in the Equation		B	SE	Wald	df	*P*	Exp (B)	95% CI for EXP (B)	
								Lower	Upper
Step 1[a]	Age	0.099	0.089	1.234	1	.267	1.104	0.927	1.313
	Gender (Male = 1, Female = 0)	0.726	0.330	4.833	1	.028[b]	2.067	1.082	3.949
	Religion (Hindu = 0, Muslim = 1)	-0.337	0.422	0.635	1	.426	0.714	0.312	1.635
	Caste (General = 0, SC&ST = 1)	-0.243	0.389	0.389	1	.533	0.785	0.366	1.682
	Family Type (Joint = 1, Nuclear = 0)	1.225	0.340	12.992	1	.001[b]	3.404	1.749	6.626
	Consanguineous marriage (Yes = 0, No = 1)	0.146	0.077	3.562	1	.059	1.157	0.994	1.345
	Family history of thalassemia (Yes = 0, No = 1)	1.358	0.366	13.766	1	.001[b]	3.889	1.898	7.969
	Duration of blood transfusion in years	0.027	0.026	1.021	1	.312	1.027	0.975	1.082
	Frequency of blood transfusion in last year	1.390	0.639	4.726	1	.030[b]	4.013	1.146	14.046
	Constant	-5.338	1.091	23.926	1	.001	0.005		

[a]Variable(s) entered on step 1: Age, gender, religion, caste, family type, consanguineous marriage, family history of thalassemia, duration of blood transfusion in years, frequency of blood transfusion in last year.
[b]Statistically significant <.05.

Borhani et al[21] found that family centered empowerment model of counseling significantly improve the school activity of thalassemic children. The study of Allahyari et al also supported their findings.[22] If we can adopt family centered empowerment model of counseling in our settings, the school activity might be improved.

Conclusion

At the end of the study, it can be said that reduction of the frequency of blood transfusion by adopting modern alternative techniques like splenectomy, and stem cell transfusion can improve the school activity of thalassemic children. Side by side family centered empowerment approach should be introduced for counseling of parents including all family members. Then we can gift them a better school life as well as better quality of life.

Authors Contributions

Planner, data collection, compilation, analysis, article writing by RS, review the article & give valuable suggestions by RM and data analysis by IS.

Conflict of Interest Disclosures

No conflict of interest.

Ethical Approval

Mapi Research Trust provided the permission for the using of PedsQL 4.0 Generic Core Scale in this non-funded research.[14]

Institutional ethics committee of Burdwan Medical College & Hospital approved the study ethically and provided necessary permission for conduction of the study. The synopsis was scrutinized by West Bengal University of Health Sciences (WBUHS) review board after obtaining approval from the institutional review board. The study was conducted after obtaining clearance from the university review board.

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Research Highlights

What Is Already Known?

Thalassemia is a chronic disease which affects patient's quality of life very badly as well as their school functioning activity.

What This Study Adds?

This study not only reestablishes the fact but also identifies the factors which are responsible for worse School functioning activity of thalassemic children. The increasing of blood transfusion requirement per year worsened the school activity of those children. Patients belonged to joint family and family experienced the disease for the first time and male child had experience of poor school functioning activity.

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