

Quality of life among parents of Thalassemic Children in Eastern India

Daliya Biswas¹, Aditya Prasad Sarkar^{2*}, Dibakar Haldar²,
Gautam Narayan Sarkar² and Indrajit Saha²

¹Department of Community Medicine, North Bengal Medical College, Sushruta Nagar, Darjeeling-734012 West Bengal, India and ²Department of Community Medicine, Bankura Sammilani Medical College, Kenduadihi, Bankura-722102, West Bengal, India

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Abstract: *Background:* Thalassaemia imposes persistent stress on the parents of thalassemic children because of realization of the adverse consequences with resultant psychological problems. *Objectives:* To assess the quality of life (QOL) in respect of physical, psychological, social and environmental domains among parents of thalassemic children and to identify the factors related to their QOL. *Methods:* An institution-based descriptive cross-sectional study was conducted in Thalassaemia clinic of Bankura Sammilani Medical College and Hospital, West Bengal, during July 2016 - June 2017. Ninety six study participants were selected by systematic random sampling. WHO Quality of Life (WHOQOL) Bref Version was used for assessment of Quality of life. Pearson correlation coefficient, unpaired *t*-test, ANOVA, multiple linear regressions were performed using SPSS 22.0 version. *Results:* Most of the participants (55.2%) belonged to 21-30 years age group, were female, Hindu, from rural area and of lower socio-economic status. The mean score of overall QOL was 78.57 ± 9.8 (Mean \pm SD). Median score in psychological domain was the lowest domain. Overall QOL score was positively associated with educational level, occupation and SES. *Conclusion:* Along with medical management for thalassemic children, the psychological well-being of their parents should also be taken care of.

Keywords: Thalassaemia, Quality of life, WHOQOL-Bref

Introduction

Thalassaemia imposes persistent stress on the children and their caregivers, which in fact, affects the caregivers more than the diseased children themselves because of better realization of the adverse consequences relating to the enormity of the illness with resultant increased risk of anxiety and mood disorders [1]. The sufferings in the family end only with death of the affected children or the latter just might create another vicious cycle of awaited psychopathology in parents [2].

The impact on the caregiver's QOL may also be determined by the burden of care that the condition possesses like amount of physical stress associated with caring for the child and the amount of time and money that are required to care for the child's medical, physical and social needs [3]. Serious illness and disability often have a devastating impact on caregivers and

family members [4]. However, the caregiver's QOL aspect has not received due attention and priority from the relevant health care delivery system. Information in this aspect in India, including West Bengal is scarce. A better understanding of the factors associated with quality of life among parents of thalassemic children is required for the development of more suitable clinical, counselling and social support programs to enhance treatment outcomes, especially in terms of quality of life of them [5-6].

With this background the present study was conducted to assess the quality of life in respect of physical, psychological, social and environmental domains among parents of thalassemic children attending Thalassaemia clinic of Bankura Sammilani Medical College and Hospital (BSMC & H) in Bankura district, West Bengal and to identify the factors related to their quality of life, if any.

Material and Methods

An institution-based descriptive cross-sectional study was conducted in Thalassemia clinic of BSMC & H from July 2016 to June 2017. The clinic was held once in a week i.e. Tuesday. Around 20-25 thalassaemic children and their caregivers were attending the clinic per clinic day with their caregivers. Either of the parents attending the Thalassemia clinic with the thalassaemic children who were diagnosed at least one year back constituted the study population. Parents of thalassaemic children who were suffering from severe illness themselves (e.g. severe anaemia, Hepatitis B, Hepatitis C etc.) were excluded from the study.

For the purpose of sample size calculation, prevalence of poor quality of life of caregivers in India was considered 50% [1]. Sample size was calculated using the formula $n = (Z^2 \times pq) / d^2$, where $Z=1.96$ (considering 95% confidence interval, two tailed), d =absolute precision of 10% and q was the complement of p . Applying finite population correction (as $n/N=0.25$ which is >0.05) the sample size was revised as per the following formula of finite population correction, $fpc = \sqrt{\{(N-n)/(N-1)\}} = \sqrt{\{(400-100)/(400-1)\}} = 0.8671$ [N =Finite population size =400] and assuming 10% non-response rate, the final sample size was $(87+9) = 96$.

The study subjects were selected by systematic random sampling and data were collected once in a week (Thalassemia clinic day i.e. Tuesday) for six months. After obtaining ethical clearance from Institutional Ethics Committee of BSMC & H and finalizing the study tool, informed written consent was taken from all participants before beginning the study. Either of the parents of thalassaemic children was approached once on the scheduled day of data collection as nobody refused to participate in the study. The interview was done maintaining privacy and confidentiality.

As in most of the situation mothers of the thalassaemic children accompanying them to the clinic we could not include both parents in this study. Baseline characteristics included participants' age, sex, religion, caste, education, occupation, type of family, socioeconomic status (SES) etc. and age, sex, birth order, age at diagnosis, frequency of blood transfusion of thalassaemic children, educational level, average

monthly treatment cost for thalassemia etc. SES was assessed by Modified and Updated BG Prasad Scale 2016 [7]. For assessment of Quality of life among parents WHO Quality of Life (WHOQOL) Bref Version [8] was used. Four domains of QOL were measured: physical, psychological, social and environmental. Items were arranged in a 5-point Likert format. The four domains were scaled in positive direction and the scale has 26 items, with total score ranges from 26 to 130.

Two items in physical domain and 1 item in psychological domain had reverse scoring. There were 2 items based on participants' quality of life as they feel and satisfaction with their health, which were not included in these 4 domains. The overall quality of life was assessed based on these 4 domains including the 2 items. The total scores of each domain (raw scores) were converted into transformed scores as per the WHOQOL Bref version instruction which ranged from 0 to 100.

Interview schedule of the participants were translated into Bengali and retranslated into English by Language experts to rectify the discrepancies. The schedule was pilot tested on 10 parents of thalassaemic children in Bishnupur District Hospital, West Bengal fulfilling the inclusion criteria. Modification of question wordings were done to make them lucid, intelligible and in logical sequence.

Data were collected and analysed by the 1st author and sanctity of data collection, analysis and preservation were supervised by the corresponding author. All the other authors contributed to interpreting the data and critically revising the manuscript and provided approval of the final manuscript. Data were checked for consistency, completeness and entered into MS excel spread-sheet. Data analysis was done with the help of MS excel and statistical software SPSS 22.0 version.

Descriptive statistics were expressed by mean, SD and proportion of baseline characteristics. Normality of the data set was tested by Shapiro-Wilk's normality test as well as P-P plot. Score of overall QOL and other

continuous data followed normal distribution. Relationship between the QOL and other variables was calculated by Pearson correlation coefficient, unpaired t-test and one-way ANOVA with post hoc analysis (Tukey) (Bivariate analysis). Multiple linear regressions technique was used to find out the strength of association of different variables with QOL of the participants. p value ≤ 0.05 was considered as significant with 95 % Confidence Interval.

Results

Table-1: Distribution of participants according to baseline characteristics: (N=96)

Age group (Years)	Gender		Total No. (%)
	Male No. (%)	Female No. (%)	
≤ 20	0	5 (7.8)	5 (5.2)
21-30	11 (34.4)	42 (65.6)	53 (55.2)
31-40	13 (40.6)	14 (21.9)	27 (28.1)
>40	8(25.0)	3 (4.7)	11 (11.4)
Total	32(100.0)	64(100.0)	96(100.0)
Occupation			
Home maker	0	58 (90.6)	58 (60.4)
Laborer	11 (34.4)	6 (9.4)	17 (17.7)
Business & Govt. service	10 (31.3)	0	10 (10.4)
Others*	11 (34.4)	0	11 (11.5)
Total	32(100.0)	64(100.0)	96(100.0)
Religion		No. (%)	
Hindu		81 (84.4)	
Muslim		15 (15.6)	
Caste			
General		38 (39.6)	
Scheduled caste		29 (30.2)	
Scheduled tribe		2 (2.1)	
Other Backward Classes		27 (28.1)	
Residence			
Rural		93 (96.9)	
Urban		3 (3.1)	
Educational level			
Illiterate		16 (16.7)	
Primary		7 (7.3)	
Middle		37 (38.5)	
Secondary and above		36 (37.5)	

Type of family		No. (%)
Joint		70 (72.9)
Nuclear		26 (27.1)
Socio-economic status **		
Class I,II,III		5 (5.2)
Class IV		38 (39.6)
Class V		53 (55.2)
Type of substance abuse ***		
Absent	70 (73.0)	
Present	Smoking tobacco	3 (11.5)
	Chewing Tobacco	24 (92.3)
	Alcohol	1 (3.8)

*Others included- farmer, private job and private car driver. **modified and updated BG Prasad scale 2016, *** Multiple responses present

This study revealed that the overall age of mother of thalassemic children was 27.4±6.7 years (mean ± SD) and overall age of father was 36.8±9.3 years (mean ± SD). Most of the participants (55.2%) belonged to 21-30 years age group in which female were predominant (65.6%). Majority of the participants were Hindu (84.4%), belonged to General caste (39.6%) and from rural area (96.9%). Nearly 17% participants were illiterate. Most of the mothers of thalassemic children (90.6%) were homemaker and most of the fathers of thalassemic children were laborer or doing other type of job i.e. farmer, private job and private car driver (34.4%). More than half (55.2%) of participants belonged to lower Socio-economic class (class V). Nearly one third of the participants had history of addiction and chewing tobacco (92.3%) was the most common type of substance abuse among them [Table.1].

Overall age of the thalassemic children was 80.47 ± 42.49 months (mean± SD) and most of them were male (53.1%). More than half of the participants (62.5%) had thalassemic children with 1st birth order. In most of the thalassemic children (70.8%) thalassemia was diagnosed before attaining the first year of life. Most of participants (65.0%) had thalassemic children with educational status at primary level. Nearly 73% participants had history of monthly blood transfusions of their children. Nearly 15% of participants had to spend more than Rs 2000/- per month for the treatment of thalassemia [Table.2].

Table-2: Distribution of participants according to baseline characteristics of their thalassemic children (N=96)

Age group (Months)	Gender		Total No. (%)
	Male No. (%)	Female No. (%)	
12-35	10 (19.6)	12 (26.7)	22 (22.9)
36-59	6 (11.8)	5 (11.1)	11 (11.5)
60-83	7 (13.7)	10 (22.2)	17 (17.7)
84-107	7 (13.7)	6 (13.3)	13 (13.5)
≥108	21 (41.2)	12 (26.7)	33 (34.4)
Total	51(100.0)	45(100.0)	96(100.0)
Birth order		No. (%)	
1 st		60(62.5)	
2 nd		25(26.0)	
3 rd		9(9.4)	
≥4 th		2(2.1)	
Age at diagnosis of thalassemia (months)			
≤12		68 (70.8)	
13-24		7 (7.3)	
25-36		8 (8.3)	
37-48		7 (7.3)	
> 48		6 (6.3)	
Level of education			
Primary		39 (65.0)	
Middle school		21 (35.0)	
Time interval of two consecutive blood transfusions (days)			
≤15		10 (10.4)	
16-30		70 (73.0)	
31- 45		7 (7.4)	
>45		9 (9.4)	
Monthly treatment cost for Thalassemia (Rs.)			
≤500		31 (32.3)	
501-1000		19 (19.8)	
1001-1500		20 (20.8)	
1501-2000		11 (11.5)	
>2000		15 (15.6)	

Cronbach's Alpha of the quality of life scale (WHOQOL-BREF) was 0.860 showing good reliability. Four domains of QOL were measured: Physical, Psychological, Social and Environmental among them the mean score of quality of life was found to be highest in overall QOL (78.57±9.8) (Mean ±SD) ranging from 57 to105 and lowest in Psychological domain (42.50±13.4) ranging from 13 to 75. The mean score of QOL in physical domain was 58.35 with a standard deviation of 15.6 ranging from 19 to

88, in social domain was 61.34with a standard deviation of12.6, ranging from 19 to 94 and in environmental domain was (50.42±9.4) ranging from 25 to 75 [Table-3].

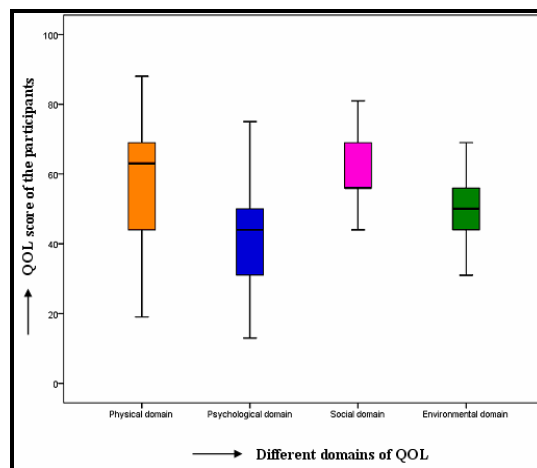
Table-3: Quality of life of the participants in respect of physical, psychological, social and environmental domains (N=96)

Quality of life	Transformed Score, Mean ±SD	Range
Physical domain	58.35±15.6	19-88
Psychological domain	42.50±13.4	13-75
Social domain	61.34±12.6	19-94
Environmental domain	50.42±9.4	25-75
Overall QOL*	78.57±9.8	57-105

*Overall QOL included Physical, Psychological, Social, Environmental domains including Q.25 & Q.26

The mean score of overall QOL was 78.57±9.8 (Mean ±SD) with a median of 77.50, ranging from 57 to 105. Median score (63) and IQR (25) of QOL in Physical domain was highest and median sore (44) in psychological domain was lowest among other domains (Fig. 1).

Fig-1: Whisker chart (boxplot) showing IQR of QOL of the participants in respect of different domains of QOL



In this study it was found that mean scores of overall QOL of the participants was higher among Hindu (79.48±9.8) and belonged to joint family (80.09±9.7). The mean scores of overall QOL was higher among the participants who belonged to General caste (82.34 ±9.4), with educational status secondary & above (82.33±11.1), SES class I to II (92.40±10.6) and the participants who

were businessman and service holder statistically significant [Table-4] (Multiple Comparisons -Post Hoc, Tukey). (92.20±7.5). All these differences were

Table-4: Distribution of participants according to various attributes and QOL				
Variables	No. (%)	Mean scores of overall QOL ± SD	Unpaired t, df	p value
Religion				
Hindu	81 (84.4)	79.48±9.8	2.150, 94	0.034
Muslim	15 (15.6)	73.67±8.1		
Type of family				
Joint	70 (72.9)	80.09±9.7	2.551, 94	0.012
Nuclear	26 (27.1)	74.50±8.9		
Caste				
	No. (%)	Mean scores of overall QOL ± SD	F, df *	p value
General	38 (39.6)	82.34 ±9.4	5.180, 2, 93	0.007
OBC**	27 (28.1)	75.44±9.1		
SC & STΦ	31 (32.3)	76.68±9.6		
Level of education				
Illiterate	16 (16.7)	73.38±8.4	3.932, 3,92	0.011
Primary	7 (7.3)	79.43±3.4		
Middle school	37 (38.5)	77.00±8.6		
Secondary & above	36 (37.5)	82.33±11.1		
Occupation				
Home maker	58 (60.4)	77.86±9.8	9.814, 3, 92	0.000
Laborer	17 (17.7)	75.53±5.6		
Business & Govt. service	10 (10.4)	92.20±7.5		
Others†	11 (11.5)	74.64±5.9		
Socio-economic status (Modified and Updated BG Prasad Scale 2016)				
Class I to III	53(55.5)	92.40±10.6	5.878, 95	0.004
Class IV	38 (39.6)	78.32±10.2		
Class V	5 (5.2)	77.45±8.5		
*One way ANOVA, **Other Backward Classes, Φ Scheduled caste & Scheduled tribe, †farmer, private job and private car driver				

Table-5: Multiple linear regressions between overall quality of life of the participants and its correlates (N=96)							
Variables*		Unstandardized coefficient		Standardized coefficient	t	P value	95% Confidence Interval for B
		B	Std. Error	Beta			
(Constant)		69.092	3.723	-	18.557	0.000	(61.686 to 76.497)
Educational level (Ref. Illiterate)	Primary	4.043	2.822	0.158	1.433	0.156	(-1.570 to 9.655)
	Middle school	10.727	2.518	0.547	4.260	0.000	(5.718 to 15.736)
	Secondary & above	13.539	2.744	0.624	4.935	0.000	(8.082 to 18.996)
Occupation (Ref. Home maker)	Laborer	-1.505	1.913	-0.059	-0.787	0.434	(-5.311 to 2.300)
	Business & service	7.716	2.560	0.242	3.014	0.003	(2.624 to 12.808)
	Others†	-1.289	2.295	-0.042	-0.562	0.576	(-5.853 to 3.274)
SES (Ref. Class V)	Class I to III	10.463	3.290	0.279	3.180	0.002	(3.919 to 17.006)
	Class IV	2.844	1.525	0.143	1.865	0.066	(-0.190 to 5.877)
*Dependent variable= Overall Quality of life †farmer, private job and private car driver							

In multiple linear regressions analysis revealed that overall QOL score was increased by 10.727 unit & 13.539 unit on every unit increase of educational level from illiterate to middle school and secondary & above level respectively and 7.716 unit & 10.463 unit on every unit change in occupation from homemaker to business & service and SES from Class V to Class I to III respectively and these findings were statistically significant [Table-5].

Discussion

Baseline characteristics of participants and their thalassaemic children: In the present study it was revealed that 66.67% were mothers and 33.33% were fathers. Similar result was found by Ismail M et al in 2013 at Malayasia where 63% of the participants were mothers, by Khairkar P et al in 2010 at Chandigarh, India (76%), by Ali S et al in 2012 (57.5%) and by Saldanha S J et al in 2015 at Bangalore (58%) [9-12].

The reason for participation of higher proportion of mother may be because male participants have daily work to do for earning money for livelihood. Hence, sometimes it might not have been possible for them to accompany their thalassaemic children. But there was another study conducted by Yengil E et al in 2014 at Turkey where 44.4% were female participants [13].

In the current study majority of the participants were Hindu (84.4%). Similar results was found in the study by Khairkar P et al in 2010 at Chandigarh (72%), by Saldanha S J et al in 2015 at Bangalore (75%) and by Shanmugam V et al in 2015 at Bangalore (66.67%) [10, 12, 14].

In this study majority of the participants were from rural areas (96.9%). Similar finding were seen in the study conducted by Yengil E et al in Turkey in 2014 where most of the participants came from rural area (58.7%) as also by Khairkar P et al in 2010 at Chandigarh (54%) [10, 13]. However, in two other studies by Ismail M et al in 2013 at Malayasia and by Saldanha S J at Bangalore in 2015 where most of the participants came from urban areas [9, 12]. Nearly 17% participants were found to be illiterate in the present study. Similar trends in illiteracy were found in the studies done by Khairkar P et al in 2010 at Chandigarh (8%), by

Saldanha S J at Bangalore in 2015 (9%) and by Shanmugam V et al in 2015 at Bangalore (5%) [10,12, 14].

In this study almost 40% were observed to be employed among whom 17.7% were labourer. Majority (60%) of the participants were homemaker. This is because among the study participants most of them were accompanying mothers. In a study by Khairkar P et al in 2010 conducted at Chandigarh revealed that 44% were employed [10]. A study conducted by Shanmugam V et al in 2015 at Bangalore showed 18.30% were labourer and 41.70% of the participants were homemaker [14]. In this study mean age of the thalassaemic children was 80.47 ± 42.49 months (mean \pm SD) but a study done in Sri Lanka by Mettananda S in 2018 revealed that the mean ages were 10.9 ± 3.6 years [15].

In this study more than half of the participants (62.5%) had thalassaemic children with first birth order. Similar trends in birth order were reflected in studies conducted by Ismail M, et al at Malayasia in 2013 (69%), by Ishfaq et. al. in the year 2015 in Pakistan (69.6%) and by Saldanha S J (56%) at Bangalore in 2015 [9, 12,16]. In the present study nearly 73% participants had history of 30 days interval between two consecutive blood transfusions of their thalassaemic children. Similarly Ismail M, et al found that majority (88%) of the thalassaemic children received blood transfusion once per month at Malayasia in 2013 as also by Yengil E, et al (94%) at Turkey in 2014 [9,13].

Social and psychological domains: In this study the mean score of quality of life of the participants in social domain was the highest (62.83 ± 9.2) and lowest in psychological domain (42.50 ± 13.4). Similar result was found in the study conducted by Yengil E et al at Turkey in 2014 where mean score of social domain (80.95 ± 17.22) was highest and mean score of psychological domain (57.39 ± 12.71) was lowest [13]. In a study done by Mazzone L et al in Catania, Italy in 2009 Social relationship got the highest score (74.01 ± 14.25) [17]. But in a study done by Thiyagarajan A et al at Chennai in 2017 where mean psychological well-being score

for the parent was 83.99 with a standard deviation of 11.41 [18]. In developing countries like India, the main cause of death from thalassemia is non-compliance with the treatment due to psychosocial factors [19].

Physical domain: In the present study mean score of QOL of the participants in physical domain was 58.35 ± 15.6 (Mean \pm SD). Similar finding was shown in the study done by Mazzone L et al in Catania, Italy in 2009 where mean score in physical health was 57.29 ± 11.47 [3].

Environmental domain: In the present study mean score of QOL of the participants in Environmental domain was 50.42 with a standard deviation of 9.4. In a study done by Mazzone L et al in Catania, Italy in 2009 where the mean score of QOL in Environmental domain was (48.54 ± 14.41) [17].

Correlates of QOL: In the present study mean scores of overall QOL was significantly higher among the participants belonged to joint family (80.09 ± 9.7) than those in nuclear family (74.50 ± 8.9). The most plausible reason behind this differential is that joint families act as shock absorbent providing a cushioning effect on the parents' stress. But in the study by Shaligram D et al in 2006 at Bangalore revealed that nuclear family acted as a protective factor [1]. It has been revealed that the mean scores of overall QOL was higher among the participants with educational status secondary & above than those who were illiterate ($p=0.011$). This finding was concordant with the study done by Ismail M et al at Malaysia in 2013 where participants with lower educational levels had poorer quality of life than participants with higher educational status [9]. The reason may be attributed that lower educational status leads to inadequate understanding of the sequelae and consequences of the disease.

In the present study mean scores of overall QOL was highest among the participants who were businessman & service holder (92.20 ± 7.5) and there was a significant difference among businessman and service holder with Home maker, labourer and those who were doing other types of job ($p=0.000$). Similarly the study by Miskam HM et al in Malaysia in 2017 showed that mean value for the quality of life among

participants who are working was higher compared with those who were not working ($p=0.021$) [20]. This may be due to the fact that participants, who are homemaker, by staying at home, are constantly exposed to different stressors which put them under great strain or more psychological breakdown. Besides higher level of occupation leads to better earning and higher socio-economic status which help in access of better treatment modalities and making out of pocket expenditure which further leads to better treatment outcome; thus entailing better quality of life.

In the current study mean scores of overall QOL was highest among the participants who belonged to SES class I to II (92.40 ± 10.6) and there was a significant difference with the participants who belonged to class IV ($p=0.006$) and class V ($p=0.003$). This is because the parents with higher earnings have less financial problems related to provision of treatment, transport and social problems leading to better living status, better quality of life. However, in the study in Malaysia in 2013, Ismail M et al did not find any significant relationship between family income and quality of life [9].

Multiple linear regressions analysis revealed that QOL was statistically associated with level of education, occupation and socio-economic status while adjusting the effect of other variables in the regression model. So, with increase of the level of education, occupation and socio-economic status the quality of life of the participants can be increased. The strides in medical management have increased longevity without commensurate attention to the quality of life (QOL) [1]. Parents of thalassaemic patients not only have concerns regarding their children's goal and expectation and standard of life but also the impact of diagnosis and treatment on family stability and dynamics [17].

They undergo a significant psychological impact, causing emotional burden, hopelessness and difficulty with social integration. They experience negative thoughts about their life, guilt, increased anxiety and low self-esteem as well as remain

worried about the health and future of the affected children [11, 21]. Significant advances in the diagnosis and management have not been matched by progress in psychosocial rehabilitation of Thalassemia patients and their parents [22-24]. The ability to measure the QOL of parents of children with chronic conditions gives insight to the challenges of the parents' everyday lives as they care for their children [25].

Strengths of the study: In this study the quality of life scale (WHOQOL-BREF) had a good internal consistency (Cronbach's Alpha 0.860). Most of the findings in this study had the similarities with other studies from various region of Eastern India.

Limitations of the study: Equal participation of both parents of thalassemic children and random sampling could have increased internal validity. Absence of a control group of parents of healthy children is one of the limitation of the study. During the study period, the participants had to

recall to answer few questions. So the recall bias might have happened.

Future directions of the study: More such studies with larger sample size from various Thalassemic clinics may be helpful in formulating strategies on this issue.

Conclusion

Besides the medical management of thalassemic children, the psychological well-being of parents should also be an area of clinical attention. Their QOL can be improved by ameliorating the educational status, proper execution of social security measures for amendment of socio-economic status and adopting coping strategies.

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*All correspondences to: Dr. Aditya Prasad Sarkar, Professor, Department of Community Medicine, Bankura Sammilani Medical College, Kenduadihi, Bankura-722102, West Bengal, India E-mail: dradityaprasadsarkar@gmail.com