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Research Article

Psychological Problems and Quality of Life among Transfusion-Dependent Thalassemic Children: Sharing Experience from a Thalassemia Care Center in West Bengal, India

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ABSTRACT

Introduction: Thalassemia children are highly vulnerable to emotional and behavioral problems. Those born with this congenital deficiency are unable to cope with the illness. Although current treatment strategies aim cure of the disease, a little emphasis is being given at improving the quality of life (QoL) of these patients. **Aim:** The present study aimed to analyze and explore the common psychological problems and QoL among transfusion-dependent thalassemia children. **Materials and Methods:** Parents and/or caregivers of 100 children aged between 6 and 12 years with transfusion-dependent thalassemia attending day care services for blood transfusion were interviewed for the assessment of psychological problems using the Childhood Psychopathology Measurement Schedule and QoL was assessed using the EURO-QoL 5 dimension (EQ-5D) tool, an EQ standardized scale. Data were analyzed using standard statistical methods and total scores were expressed as mean, median, and standard deviation. **Results:** All children had psychological problems with 91% having mild problem and 9% moderate problem; none of the patients had either severe or very severe type of illness. Anxiety and depression (100%), conduct problems (94%), low intelligent quotient and behavioral problems (95%), and somatization (77%) were the main findings. The children were most likely to report impaired QoL due to anxiety and depression (94%), pain/discomfort (91%) followed by difficulty with usual activities (83%), and mobility (67%). Psychological problems were a significant predictor of impaired QOL. **Conclusion:** Treatment strategies for thalassemia must also aim at recognizing psychological problems and their appropriate and timely management along with emphasis on improvement of QoL.

Keywords: Children aged 6–12 years, Psychological problems, Quality of life, Transfusion-dependent thalassemia

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Introduction

Children with chronic illnesses like thalassemia are highly vulnerable to emotional and behavioral problems.[1] Each year, approximately 70,000 children are born with various forms of thalassemia worldwide.[2] Except for a minority of thalassemia patients who are cured by hematopoietic stem cell transplantation, all patients with severe forms of β-thalassemia require regular blood transfusions and iron chelation therapy for life.[3,4] Their life expectancy is short and has poor quality of life (QoL).[5]

Thalassemia is a challenge for medical professionals and a life-threatening experience for the patients. Those born with this congenital deficiency are unable to cope with the illness. Thalassemia as a chronic illness by itself is debilitating for the patient and subsequent iron overload makes them prone to complications such as heart failure, hypogonadism, hypothyroidism, and diabetes mellitus. Simultaneously, it severely affects the child's physical competence and scholastic performance. The bone deformities and typical facial appearance negatively impact their self-esteem, giving them always the feeling of being different, affecting their social relationships and psychological well-being.[6] This impacts not only the patient's QoL but also has a great impact on overall QoL of whole family. Patients with thalassemia are nevertheless at risk of developing increased emotional and psychological stress. Although the current treatment guidelines mostly aim at improving medical management of these patients and devising a cure, very little efforts are being made to uplift their psychological health.[7] In fact, the burden of psychological morbidity among patients with thalassemia has not been well documented, especially from this part of the country. There are very limited studies where QoL of thalassemia patients has been addressed. In the present study, we have analyzed and explored the common psychological problems and QoL among transfusion-dependent thalassemia (TDT) children aged between 6 and 12 years by interviewing their parents and caregivers.

Materials and Methods

A quantitative non-experimental descriptive survey approach was adopted to assess the psychological problems and QoL among TDT children by interviewing the parents or caregivers. One hundred parents/caregivers of TDT patients aged 6–12 years of age who attended "Thalassemia Day Care Centre" of a tertiary hospital of West Bengal, India, from December 1, 2018, to December 31, 2018, were interviewed. Descriptive survey design was adopted for collection of necessary data. Non-probability purposive sampling techniques were employed [Table 1]. Sociodemographic variables were studied and the demographic data were analyzed. Childhood Psychopathology Measurement Schedule (C.P.M.S.) scoring was done.[8] The total score of all subjects was summarized and expressed as mean, median, and standard deviation. The children were categorized according to their presence of problem in mild, moderate, severe, or very severe category. The domains were differentiated in D1 – low intelligence with behavioral problem, D2 – conduct problems, D3 – anxiety, D4 – depression, D5 – psychotic symptoms, D6 – special symptoms, D7 – physical illness, and D8 – somatization. The QoL was estimated from the information provided by the parent or caregiver in five aspects of life through EURO-QoL 5 dimension (EQ-5D), an EQ standardized scale. The assessment was done on the basis of five components of daily life, for example, mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The score was made according to observation value by the direct caregiver (mostly parents) of the children suffering from TDT. The scores of QoL were explained as: No problem (0), slight/mild pain (1), moderate difficulty (2), severe problem (3), and unable to do (4).[9,10] Analysis was done using standard statistical methods.

Table 1: Data collection tools and techniques

S. No.	Variables	Data collection tool	Techniques
Part-I	Sociodemographic variables	Semi-structured interview schedule	Interviewing
Part-II	Psychological problems	Structured interview schedule-CPMS	Interviewing
Part-III	QoL	Structured interview schedule EQ-5D	Interviewing

QoL: Quality of Life; CPMS: Child Psychopathology Measurement Schedule; EQ-5D: Euro quality of life 5 dimension

Results

Among a total of 100 respondents, 80% were mothers, 14% were fathers, and other caregivers constituted rest 6%. The frequency (percentage) distribution of samples in terms of different sociodemographic variables is enlisted in Table 2. C.P.M.S score obtained by the children showed that among 100 TDT children, 91% had mild type of psychological problem while 9% had moderate type of illness; none of the patients had either severe or very severe type of illness [Figure 1]. Domain-wise interpretation of C.P.M.S score [Figure 2] showed that most of the children (94%) were suffering from low intelligence with behavioral problem (D-1), 95% had conduct disorder (D-2), and all the patients (100%) had anxiety disorder (D3) and depression (D-4). Psychotic symptoms were seen in 95% of children (D-5) and special symptoms associated with psychological illness were seen in 58% (D-6), whereas 59% had different type of physical illness (D-7) and 77% of children suffered with

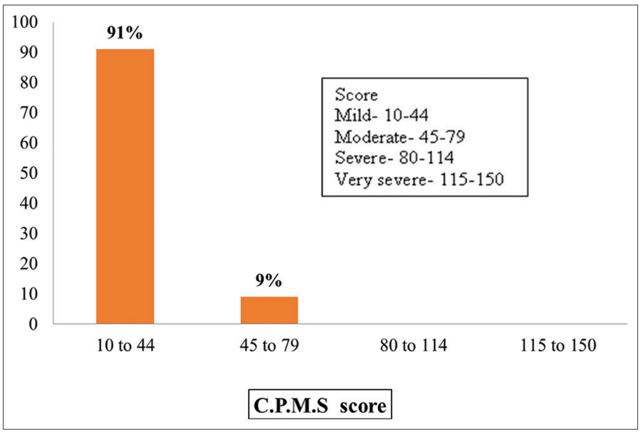

Figure 1: Bar diagram showing frequency (percentage) distribution of Child Psychopathology Measurement Schedule score of the children (*n*=100)

Table 2: Distribution of samples in terms of different sociodemographic variables (n=100)

Variable (s)	Category	Results (%)	
Respondent	Father	14	
	Mother	80	
	Others	6	
Age of patient		Male (63)	Female (37)
	6–9 years	36.5 (n=23)	29 (n=11)
	10–12 years	63.5 (n=40)	71 (n=26)
Religion	Hinduism	54	
	Muslim	46	
	Christian/other	0	
Habitat	Urban	6	
	Semi-urban	14	
	Rural	80	
Education level	Secondary	53	
	Primary	21	
	I.C.D.S	12	
	Less than primary	5	
	Never gone to school	9	
Education of parent (s)		Father	Mother
	Secondary education	54	67
	High school	15	6
	Primary education	5	7
	Just literate	6	9
	Non literate	20	11
Marriage between spouses	Interfaith	87	
	Consanguineous	13	
Occupation of parents		Father	Mother
	Private job/homemaker	20	84
	Self-employed	69	10
	Daily worker	10	4
	Government job	1	2
Monthly family income (INR)	<5000	6	
	5000–7000	44	
	8000–10,000	33	
	>10,000	17	
Total number of children in the family	1 child	27	
	2 children	45	
	3 children	17	
	More than 3 children	11	
Birth order of the patient under study	First	48	
	Second	32	
	3rd or more	20	
Age at first diagnosis (years)	Within 1 year afterbirth	49	
	After 1 year of birth	20	
	Between 2 and 3 years	13	
	Between 4 and 5 years	5	
	After 5 years	13	
Medical expense per month for affected child (INR)	<500	41	
	500–1000	45	
	1000–2000	6	
	2000–3000	5	
	3000–4000	2	
	>4000	1	

ICDS: Integrated Child Development Services

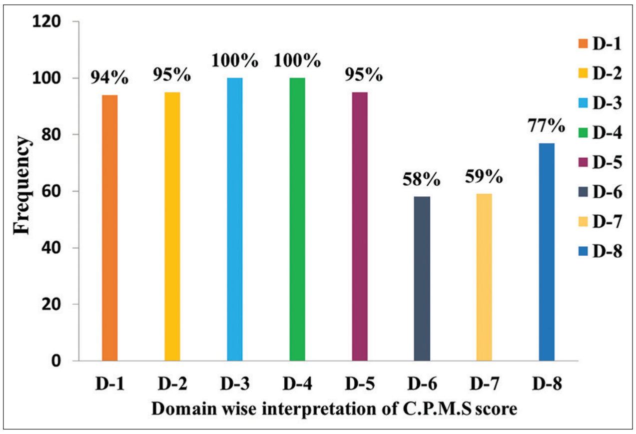

Figure 2: Bar diagram showing distribution of domain-wise interpretation of Child Psychopathology Measurement Schedule score

psychosomatic disorder (D-8). Domain-wise interpretation of C.P.M.S score is shown in Table 3.

The QoL among the children as stated by parents/caregivers during interview showed mild (47%) and moderate (11%) problem in mobility aspect. In self-care activities, severe and very severe problem was seen in 4% and 1% of patients, respectively. Pain and discomfort due to iron chelation therapy, incomplete bone growth, and other factors revealed moderate and severe problem in 20% and 4%, respectively. In psychological aspect, 76% had mild type of illness; 4% and 1% had suffered from severe and very severe problems, respectively [Table 4]. As shown in Table 5, higher education and occupation level of mother/caregivers showed less psychological problems (as per the C.P.M.S score) among the children suffering from TDT ($P < 0.05$). However, there was no association with the income status of the family and C.P.M.S score. Multiple linear regressions with C.P.M.S and QoL showed a positive correlation between the children suffering from low intelligent quotient and behavioral problems and mobility self-care and usual activities ($P < 0.05$), between anxiety score by C.P.M.S. and self-care, and anxiety score in QoL ($P < 0.05$). Depression, that is, low mood aspects of C.P.M.S. scale highly affects the self-care, pain, and discomfort and anxiety score in EQ-5D ($P < 0.05$). A correlation was also seen between somatization of C.P.M.S score and mobility, self-care, usual activities, and pain discomfort in QoL ($P < 0.05$).

Table 3: Domain-wise interpretation of C.P.M.S score (*n*=100)

Parameter	Grading (scores)	Percentage of patients
Low intelligence and behavioral problem (D-1)	No problem (0)	6
	Mild problem (1–4)	85
	Moderate problem (5–8)	9
	Severe problem (≥9)	0
Conduct disorder (D-2)	No problem (0)	5
	Mild problem (1–11)	80
	Moderate problem (12–22)	14
	Severe problem (23–33)	1
	Very severe problem (34–44)	0
Anxiety disorder (D-3)	No problem	13
	Mild problem	63
	Moderate problem	23
	Severe problem	1
Depression (D-4)	No problem (0)	0
	Mild problem (1–7)	70
	Moderate problem (8–14)	30
	Severe problem (15–21)	0
	Very severe problem (22–28)	0
Psychotic symptoms (D-5)	No problem (0)	5
	Mild problem (1–8)	91
	Moderate problem (9–16)	4
	Severe problem (≥17)	0
Special symptoms associated with psychological illness (D-6)	No problem (0)	42
	Mild problem (1–4)	56
	Moderate problem (5–8)	2
	Severe problem (9–12)	0
	Very severe problem (≥13)	0
Physical illness with emotional problems (D-7)	No problem (0)	41
	Mild problem (1)	57
	Moderate problem (2)	2
	Severe problem (3)	0
Somatization (D-8)	No problem (0)	23
	Mild problem (1)	44
	Moderate problem (2)	28
	Severe problem (3)	4
	Very severe (4)	1

CPMS: Child Psychopathology Measurement Schedule

Table 4: Frequency distribution of the patients based on EQ-5D (rated for the child by the parent/caregiver)

Parameter	Mobility (E1)	Self-care (E2)	Usual activities (E3)	Pain/discomfort (E4)	Anxiety depression (E5)
No problem	42	33	17	9	6
Mild	47	55	67	67	76
Moderate	11	9	11	20	13
Severe	0	3	4	4	4
Unable to do	0	0	1	0	1

Score – No Problem – 0, mild problem – 1, moderate problem – 2, severe problem – 3, unable to do – 4. Mean: 9.97; SD – 2.63; median – 9; EQ-5D: Euro quality of life 5 dimension

Discussion

The present study revealed that mothers constituted the majority (80%) of the respondents. In our study, all ($n = 100$) the children had some psychological problem or the other; 91% had mild problem and 9% had moderate problem. These results were quite high compared to other previous studies. A study by Shaligram *et al.*[11] showed that the prevalence of psychological problems was 44% and a similar Greek study[12] reported psychological problems in 42.9% of patients. In our study, the prevalence of low intelligence and behavioral problems was 94%, whereas the prevalence of conduct disorder was 95%. In keeping with other studies, anxiety and related problems (100%), emotional problems,

Table 5: Association between CPMS and selected demographic variables

Parameter	Sample characteristics	Below median	Above median	Chi-square test (*P*-value)	Significance
Gender				1.27	N.S
	Male (6–12 years)	24	39		
	Female (6–12 years)	10	27		
Religion				0.136	N.S
	Hindu	25	29		
	Muslim	23	23		
Father's education				2.7	N.S
	Primary	06	09		
	Secondary and above	36	29		
	Illiterate	09	11		
Father's occupation				0.64	N.S
	Self-employed	35	43		
Mother's education				<0.001	Significant
	Primary	8	16		
	Secondary and above	38	29		
	Illiterate	4	5		
Mother's occupation				<0.001	Significant
	Homemaker	43	40		
	Self-employed	02	08		
	Others	05	02		
Family income				0.08	N.S
	a) Low income	2	5		
	b) High income	30	63		

CPMS: Child Psychopathology Measurement Schedule; N.S: Not significant

particularly depression (100%), and somatization (77%) were the other main findings. Shaligram *et al.*[11] showed anxiety and related problems (67%), emotional problems particularly depression (62%), somatization (56%), and conduct problems (49%) were the main problems in thalassemia patients. However, our study found higher rates of anxiety, depression, conduct problems, and somatization than the previous studies.[11,13] Differences in sociocultural factors may account for these findings. Furthermore, the current study unlike previous studies included young and old children where young children may express psychological distress in the form of conduct problems and somatization while older children have a growing insight into the nature of the illness which might account for the increase in depressive symptoms with increase in age. Psychological distress might form a common base which evolves into depression, anxiety, and somatization in vulnerable individuals. All children in the present study had some form of anxiety disorder and depression. Unfulfilled expectations from life with a dream to lead a normal healthy life like other peers of their age may lead to increased depression in these patients. In the present study, psychotic symptoms (95%) and special symptoms (58%) were higher compared to the study results by Shaligram *et al.*[11] However, physical symptoms (59%) were comparable. These symptoms could have been the result of emotional stress experienced by these children.

On assessment of QoL, it was found that 58% suffered from mobility issues, 67% had self-care problems, 83% with usual activities, 91% suffered from pain/discomfort, and 94% had mild anxiety and depression. QoL was affected for all the children in one dimension or another; majority having mild problems and a few having severe problems. In contrast, a study by Shaligram *et al.*[11] showed that QoL was affected in 74% of children. The impairments in the pain/discomfort, anxiety/depression, and mobility dimensions of QOL may be explained on the basis of complications of thalassemia and side effects of treatment. Some iron chelators are known to produce arthritis, abdominal pain, diarrhea, and vomiting which may have a bearing on the high scores on the pain, mobility, and anxiety/depression dimensions.[11] On C.P.M.S. scoring, 100% of children had anxiety and depression while on EQ-5D, 94% had anxiety/depression. These results were different from the study by Shaligram *et al.*,[11] where 67% of children had anxiety and 62% had depression on C.P.M.S while on EQ-5D 66% had neither anxiety/depression. The difference in results of the two studies could have been due to the difference in sample size and difference in age groups and sociodemographic variability among the two studies. The current study found a positive correlation between psychological problems and poorer QoL similar to a study in Greece[14] and the study by Shaligram *et al.*[11] Anxiety, depression, and somatization symptoms may have similarly contributed to poorer QOL.

A previous study by Alzahrani *et al.*[15] showed a significant difference in QoL in TDT patients between male and female patients. Thyagarajan *et al.*[16] found that factors such as family income and parent's and children's education status have a direct association with health-related QoL of children with thalassemia. From our study, we have seen that these patients suffered from psychological problems irrespective of differences in gender, age, religion, income of the family, or father's educational or occupational status. However, mother's education and occupation had a significant impact on care of the child and development of psychological problems ($P < 0.05$). These could have been because almost all the patients in our study population had almost similar family income and majority of the caretakers of these patients were mothers.

Studies all over the world have tried to evaluate QoL of thalassemia patients; some[5,17,18] had compared it with healthy controls and concluded that there is an urgent need to ensure better QoL of the thalassemic children and counseling of parents is an important part to improve it.[5,19,20] A study by Roy *et al*.[6] from West Bengal explored the experiences of adolescent thalassemic patient respondents and concluded that the consequence of thalassemia is extremely stressful and patients face a variety of physical, psychological, and social problems. A study by El-Alameey *et al*.[21] showed that IQ was significantly affected by duration of illness, serum ferritin, and serum iron levels. Furthermore, Chordiya *et al*.[22] concluded that low QoL was associated with higher age, increased transfusion frequency, and injectable mode of chelation. In a review, the authors had concluded that delayed initiation of chelation therapy or inadequate chelation therapy was one of the various factors which contributed to poor QoL in thalassemic children.[23] However, no such correlation was studied in the present study. These emotional issues must be addressed and taken care of while devising a treatment plan of thalassemia patients. Only regular transfusion and regular iron chelation are not enough. Emphasis should also be given on improving the QoL and reducing the emotional and mental stress these patients suffer from. Counseling of caregivers/parents for the need of improvement of QoL can be of help.[5]

Conclusion

Thalassemia patients suffer from psychological problems which, in turn, impair their QoL. Hence, treatment must also aim at recognizing these psychological problems; their appropriate and timely management may, in turn, would improve their QoL. Need of counseling of parents/caregivers must also be emphasized.

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