

## BEHAVIORAL PROFILE AND SCHOOL PERFORMANCE OF THALASSAEMIC CHILDREN IN EASTERN INDIA

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### ABSTRACT

India contributes to 10% of the annual world incidence of thalassemia. The early onset of symptoms, multiple somatic complaints, frequent transfusions and uncertain prognosis drain the emotional resources of thalassaemic children and their families. We aim to assess the prevalence of behavioral disturbance in children with transfusion dependant thalassaemics and the relative contribution of sociodemographic and clinical factors to the development of psychopathology and the factors that influence school going behaviour. 49 randomly selected cases and 51 age, sex and socioeconomic status matched controls were assessed using DPCL, ICD 10 based clinical examination and Malin's Intelligence Scale for Children. Behavioral abnormalities were present in 67.3% of cases, compared to 21.6% of controls (p=0.01). There was an overall effect with the presence of psychopathology in thalassaemic children. Presence of psychopathology significantly predicted school dropout - an outcome not affected by IQ, socioeconomic status, residence, or parental education.

**Keywords:** Thalassemia, behavior, children, school performance, India

### INTRODUCTION

Thalassaemia syndromes are inherited disorders of alpha or beta globin biosynthesis. The diagnoses of transfusion dependant thalassaemias are readily made during childhood. They are associated with significant mortality and morbidity. Chronic transfusion with RBCs improves oxygen delivery and prolongs life for patients with beta thalassaemia major, but inevitable side effects, notably iron overload, usually prove fatal by age 30.

Each year 8000 children are born with thalassaemia in India, which contributes around 10% of the annual world incidence.<sup>1</sup> The early onset of symptoms, multiple somatic complaints, frequent transfusions and subsequent absence from school, not to mention the overall uncertainty of prognosis make large demands on the emotional and interpersonal resources of the child and the family. It is therefore, not surprising that various authors have reported high rates of psychopathology in children with thalassaemia syndromes.<sup>2,3,4,5</sup>

In India, medical management of thalassaemia takes precedence over integrated biopsychosocial management. A low doctor-patient ratio, increasing prevalence and low awareness on part of the patients' families and treating physicians ensure that the psychosocial aspects of care are overlooked in the pressures to treat the disease process. This leads to a poorer quality of life for the patients, poor adherence to treatment which remains the commonest cause of death<sup>6</sup>, and a huge drain on the medical resources of the country. Our study aims to assess the prevalence of psychological and behavioral disturbance in children with transfusion dependant thalassaemias and the relative contribution of various sociodemographic and clinical factors to the development of psychopathology in this group. We have also compared the school attendance of thalassaemic children with matched controls and sought to evaluate the factors that influence their school going behaviour.

### METHOD

#### Sample selection

The study was conducted at the Calcutta Medical College and Hospital, Kolkata. An institutional ethical committee clearance was obtained. The sample consisted of children with transfusion dependant thalassaemias (aged 5 to 15 years) attending the day care facility (thalassaemia clinic) of the department of pediatrics. Those with mental retardation and other chronic medical conditions

including HIV/AIDS were excluded. The inclusion criteria were: a) Children with a diagnosis of transfusion dependant thalassaemia b) Those aged between 6 to 15 years c) Both children and guardians capable of understanding instructions in the local dialect. The exclusion criteria included - a) Presence of mental retardation b) Presence of any other medical or surgical illness including HIV/AIDS.

From the clinic register, 70 children were found to fulfill the above criteria. From this 50 patients were randomly selected by draw of lots. These children, along with their parents were interviewed during their respective follow up times. A standard Indian Council for Medical Research form was used to obtain informed consent from the children's parents or legal guardians.<sup>7</sup>

One patient's family refused consent to be interviewed. The remaining 49 (29 males and 20 females) were assessed. Data for the control group (51 children: 31 male, 20 female) was collected by one of the investigators from age and sex matched healthy children belonging to two suburban schools.

#### Study design

The behavioral profile of the children were assessed using the DPCL (Developmental Psychopathology Check list), a reliable and valid instrument for assessing psychopathology in Indian children in clinical settings. This tool was developed at the National Institute of Mental Health and Neurosciences, Bangalore by Kapur and colleagues in 1994.<sup>8</sup> The checklist identifies the following clusters of developmental problems/ disorders: emotional disorders, hyperkinesis, childhood psychosis, learning disorder, hysterical syndrome, conduct disorder, autism, and obsessive compulsive neurosis. Assessment using DPCL was done by a psychiatrist, blind to the children's clinical and sociodemographic status, in a single sitting.

Detailed and independent clinical examination by two psychiatrists were carried out to supplement the diagnosis made by DPCL. The ICD - 10 diagnosis corresponding to each cluster of DPCL were as follows - Emotional disorders (emotional disorders with onset specific to childhood), hyperkinesis (hyperkinetic disorders), childhood psychosis (schizophrenia, acute and transient psychotic disorders, other non organic psychotic disorders), learning disorders (specific developmental disorders of scholastic skills), hysterical syndrome (dissociative/ somatoform disorders), conduct disorder (conduct disorder), autism (pervasive developmental disorders), and obsessive compulsive neurosis (obsessive compulsive disorder). The subjects were also administered the

Malin's Intelligence Scale for Children (MISIC)<sup>9</sup> by a clinical psychologist for assessment of IQ.

The treating paediatricians, who were blind to the patients' psychiatric status, recorded all necessary clinical and sociodemographic details. These were documented in standard case record forms and follow up data sheets. Sociodemographic details were collected using a semistructured proforma developed especially for this purpose.

To assess the socioeconomic status, the Kuppuswamy scale was used. This instrument has been used in various studies in India and has good reliability and validity.<sup>10</sup> Normative data was collected by one of the investigators from age and sex matched controls belonging to two suburban schools. Those suffering from any acute or chronic physical illness were excluded. Informed consent was obtained. The DPCL was used to record data after interview with the parents and children. Sociodemographic data were collected using the same proforma as in patients with thalassaemia.

#### Data analysis

The data was analyzed using the SPSS 14.00 for windows (SPSS Inc., Chicago, USA). Descriptive statistics like frequency, mean, standard deviation were used to describe the data. The Fisher's exact test was done to compare the prevalence of behavioral abnormalities in thalassaemic children and control group. Logistic regression analysis was performed to measure the correlation between sociodemographic and clinical variables and behavioral abnormality. We also tried to detect variables that predict school going behavior of children, an important indicator of their overall situational adjustment.

#### RESULTS

The behavioral profile of 49 patients of thalassaemia was compared with that of 51 age and sex matched controls. Of the 49 patients, 59% were male (N=29) and 41% female (N=20). Their mean age was 8.16 years (6- 12 years). 30% belonged to the lower, 54% upper lower, and 16% lower middle socioeconomic status. Mean age of maternal education was 4.5 years. The mean age for diagnosis of thalassaemia was 17.55 months (2 - 94 months). 28 patients had a diagnosis of beta thalassaemia major (57%), and rest (43%) had been diagnosed as having other forms of transfusion dependant thalassaemia.

In the control group, 60% were male, with a mean age of 8.19 years (5- 15 years). 22% hailed from the lower, 58% from upper lower, and 20% from a lower middle socioeconomic status. The mean years of maternal education was 4.66 years (0-15 years -Table 1).

**TABLE 1: SOCIODEMOGRAPHIC VARIABLES OF THALASSAEMIC CHILDREN AND CONTROLS**

SOCIAL VARIABLES	THALASSAEMIA	CONTROL
Male (%)	59	60
Mean age (years)	8.16	8.19
SES (lower to upper lower)	84%	80%
Mean maternal education (yrs)	4.5	4.7

In the thalassaemia group, presence of behavioral disturbance in any of the subscales of DPCL was recorded in 67.3% (33/49) of children. Similar disturbances were documented in 21.6% of the control group. Applying Fisher's exact test, this difference was statistically significant (p=0.01). In the thalassaemia group, 7 patients suffered from emotional disorder (22%), 6 had hyperkinesis (18%), 4 experienced conduct problems (12%), and 6 scored positive in the obsessive compulsive neurosis subscale (18%). 6 suffered from both conduct disorder and hyperkinesis (18%), two from a combination of conduct disorder and emotional disorder (6%) and two had both emotional disorder and obsessive compulsive neurosis (6%). In comparison, six children in the control group scored positive in the hyperkinesis subscale (55%), one in the emotional disorders subgroup (9%), and four suffered from symptoms of obsessive compulsive neurosis (36% -Table 2). As per MISIC scores, IQ was average in 55.1%, bright normal in 24.5%, and dull normal in 20.4% of the thalassaemic children.

**TABLE 2: PATTERN OF BEHAVIORAL DISORDERS OF THALASSAEMIC CHILDREN AND CONTROLS**

CLINICAL STATUS	ED	HK	OCN	CD	CD+ HK	CD+ ED	ED+ OCN
Thalassaemia	22%	18%	18%	12%	18%	6%	6%
Control	9%	55%	36%	---	---	---	---

**ED: emotional disorders, HK: hyperkinesis, OCN: obsessive compulsive neurosis, CD: conduct disorders.**

The effects of various sociodemographic and clinical variables on the psychological profile was looked into. In children with thalassaemia, no independent clinical or sociodemographic factor correlated significantly with the presence of psychopathology. It was an overall effect. (Table 3)

**TABLE 3: FACTORS ASSOCIATED WITH PSYCHOPATHOLOGY AMONG THALASSAEMIC CHILDREN**

Variables in the Equation		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1	SEX	-.039	.793	.002	1	.961	.962
	AGEYEARS	.141	.167	.711	1	.399	1.152
	THALSTYP	-1.647	1.067	2.382	1	.123	.193
	AGEDIAGN	.074	.052	2.023	1	.155	1.077
	FRQTRNSF	-2.213	1.806	1.502	1	.220	.109
	IQ	-.229	.623	.135	1	.713	.795
	Constant	3.210	2.631	1.489	1	.222	24.789

a. Variable(s) entered on step 1: SEX, AGEYEARS, THALSTYP, AGEDIAGN, FRQTRNSF, IQ.

**Ageyears: age in years, thalstyp: type of thalassaemia, agediaagn: age at diagnosis of thalassaemia, frqtrnsf: frequency of transfusion.**

While all children in the matched group were school students, nearly 53.1% of thalassaemic children were not going to school. Interestingly, the presence of psychopathology significantly predicted this behavior (not going to school) (p<0.01), an outcome not affected by intelligence quotient, socioeconomic status, rural urban divide, or maternal/ paternal education. (Table 4)

**TABLE 4: FACTORS INFLUENCING SCHOOL GOING BEHAVIOR OF CHILDREN WITH THALASSAEMIA**

Variables in the Equation		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1	IQ	-.621	.567	1.200	1	.273	.537
	PSYCHOP	2.589	.817	10.043	1	.002	13.313
	THALSTYP	.553	.809	.468	1	.494	1.739
	AGEYEARS	.047	.151	.098	1	.754	1.048
	SEX	-.469	.830	.319	1	.572	.626
	Constant	-.811	1.829	.197	1	.657	.444

a. Variable(s) entered on step 1: IQ, PSYCHOP, THALSTYP, AGEYEARS, SEX

**Psychop: presence of psychopathology, thalstyp: type of thalassaemia, ageyears: age in years.**

#### DISCUSSION

In this study a cross sectional rather than longitudinal design was used due to logistic constraints, because most of the children who attended the hospital came from far flung areas of the state and stayed in the inpatient ward only for the duration of blood transfusion. Assessment was performed prior to the transfusion in order to avoid pain and other related side effects. The high percentage (67.3%) of psychopathology is not surprising in an Indian setting. European studies usually report 43% to 47% prevalence of psychological problems in thalassaemic children.<sup>5</sup> However, a study with children of beta thalassaemia major in Turkey reported that 80% of the patients had at least one psychiatric disorder according to DSM IV.<sup>11</sup>

An Indian study conducted in 2005 reported 54% of transfusion dependant thalassaemia major children (5 - 15 years) suffered from

significant psychopathological disorder (Childhood Psychopathology Measurement Schedule score  $\geq 10$ ).<sup>12</sup> In another Indian study with 8-16 year old thalassaemic children, 44% had psychological problems measured by the Childhood Psychopathology Measurement Scale (CPMS).<sup>1</sup> While most of the children in our sample suffered from emotional disorders (ED) (21%), a significant number suffered from obsessive compulsive neurosis (OCN) (18%) and hyperkinesia (18%). A similar Indian study, however, reported a much higher incidence of anxiety and related problems (67%) in children with beta thalassaemia major. A unusual finding is the relative absence of somatization in our sample, which is common in other studies (upto 56%).<sup>1,12</sup> A significant number in our study sample suffer from a combination of psychopathologies, viz., CD (conduct disorder) and hyperkinesia, CD with ED, and ED with OCN. Overlapping psychopathology is fairly common in children and it is surprising that other studies did not report the latter.

We found no significant association between independent clinical (age of diagnosis, frequency of transfusion, type of thalassaemia) and sociodemographic (age, gender, socioeconomic status etc) variables and presence of behavioral disturbance. It seemed more like a combined effect of all factors taken together. Literature search revealed similar findings in other Indian studies. In a study by Shaligram et al conducted at the National Institute of Mental Health & Neurosciences (NIMHANS) no correlation was found between clinical and sociodemographic variables (except sex of child, more girls than boys) and psychopathology.<sup>1</sup>

The high prevalence of psychopathology in thalassaemic children clearly calls for systematic assessment and intervention methods to reduce distress in this population. Leads in this direction have been provided by some investigators like Mazzone et al, who carried out a cognitive behavioral family therapy (CBFT) among twenty-eight  $\beta$ -thalassaemic major children for one year, focusing particularly on behavioural, mood, and temperamental characteristics as well as compliance with chelation. Preliminary findings show CBFT can be a valid tool to increase the compliance with chelation therapy in  $\beta$ -thalassaemic children, though treated children continued to show ongoing emotional burden.<sup>13</sup>

The most striking finding of the present study, according to us, is that 53.1% of thalassaemic children were not going to school. The presence of psychopathology alone significantly predicted this behavior (not going to school) ( $p < 0.01$ ). School going behavior was not affected by intelligence quotient, socioeconomic status, rural urban divide, or maternal/ paternal education. A study by Khurana et al, enquiring into the psychosocial burden in thalassaemia, found that in the domain of education, 70% adolescents felt thalassaemia had an adverse impact on their scholastic performance. They had to take 1-3 days off from school every month to get their regular red cell transfusions. The affected adolescents complained that their academic performance was average or less because of their disease and its related problems. 38% of the adolescents reported that they had faced deprecatory remarks from their peers or teachers.<sup>6</sup> In a study by Ratip and colleagues<sup>14</sup> in United Kingdom with 27 thalassaemic subjects, it was observed that 90% of these subjects had to take time off from school because of their medical condition. These findings are in consonance with the observations made by us.

It is known that school presents particular challenges to the chronically ill children, both physically and socially. A school environment that includes verbal abuse and less peer support for ill children may be a problem. Teachers' insufficient knowledge about the illness and inability to spend adequate time with chronically ill children present barriers to the integration of the chronically ill child into the classroom situation.<sup>15,16</sup> In the absence of adequate psychosocial intervention, many chronically ill children remain outside the scope of formal education, something that in turn increases their isolation and misery.

The psychological and behavioral reactions of a person afflicted with a chronic disease depend on his/her developmental age. An adolescent is most affected by issues related to body image and peer acceptance. For a child in the 5 -15 year age group the most important determinant of quality of life may be whether he/she is going to school or not. It is time for our educational and health

systems to wake up to this problem and introduce appropriate awareness and intervention programmes.

## CONCLUSION

Thalassaemia, at present, is one of the most challenging hematological disorders with no permanent cure. Patients with  $\beta$ - thalassaemia major and some other variants need regular blood transfusions in order to live. The resulting iron overload also requires chelation therapy. Although optimal medical management has reduced the difficulties faced by thalassaemics, the psychosocial problems faced by them are now of primary importance. In developing countries like India, the main cause of death from thalassaemia is non-compliance with the treatment due to psychosocial factors.<sup>6</sup>

Thalassaemia support groups are very important as they not only educate patients and their families about the disease but also provide patients with an opportunity to meet their peers and participate in social activities. Psychosocial support may, in addition, include liaison with teachers or school authorities who should be informed about the disease. The adolescents must be allowed to get involved in normal activities with healthy peers to allow the development of adequate self-image.

The need for psychosocial support is even higher in a developing country like India where the regular and expensive treatment can pose a financial burden for the families of the thalassaemic patients. It is imperative to focus our attention on psychosocial aspects of the life of thalassaemic children and initiate intervention programs with a view to help those lead healthy, creative and fulfilling lives.

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