

Original Research Article

Psychopathology of the Children Suffering from Chronic Illnesses due to Thalassemia Major and Nephrotic Syndrome

**Dr Pradiprava Paria¹, Dr Ramesh Chandra Halder², Dr Kaustav Nayek³, Dr Divyagopal Mukhopadhyay⁴, Prof
(Dr) Sibarjun Ghosh⁵**

¹RMO-cum-Clinical tutor, Dept of Pediatrics,

²Asst professor, Dept of Pediatrics,

³Professor, Dept of Pediatrics,

⁴Professor & HOD, Dept of Psychiatry,

⁵Professor & HOD, Dept of Pediatrics

R. G. Kar Medical College and Hospital, Kolkata, West Bengal, India

***Corresponding author**

Dr Pradiprava Paria

Email: drpradip83@gmail.com

Abstract: A descriptive observational study of cross sectional design was undertaken for children suffering from thalassemia major and nephrotic syndrome to evaluate the psychopathology amongst them. Each group comprising 30 randomly selected cases within the age range of 5-14 years. Children with illnesses of less than 12 months duration and having mental retardation or any other associated medical or surgical illness were excluded. CPMS (Childhood Psychopathology Measurement Schedule) were used to measure the behavioral profile of the children. There after each case is evaluated thoroughly to supplement the diagnosis according to ICD – 10 Classification. Data were entered into Microsoft Excel datasheet and analysed with SPSS-17.0. Life-style changes were seen in 73% of thalassemia cases and 36% of nephrotic syndrome patients. Parents of thalassemia patients felt more stress (83%) than those of nephrotic syndrome (53%). The study also revealed, 60% of thalasseemics were poor academic achiever compared to 30% amongst nephrotics. Behavioral changes were seen in 73.3% of thalasseemics compared to 43.3% of nephrotic syndrome patients. The common observed behavioral changes were conduct disorder, mixed disorder of conduct and emotion (like depression), anxiety disorder and other childhood emotional disorder. No association was found between socio-demographic variables and psychiatric morbidities except males were affected more frequently in both the study population. At the end, this study emphasizes the importance of integrating a multidimensional psychosocial battery in the regular follow up and clinical assessment of children with chronic illness like thalassaemia major and nephrotic syndrome.

Keywords: Chronic illness, Behavioral changes, Psychopathology, Thalassemia, Nephrotic syndrome

INTRODUCTION

Any major physical illness usually has an impact on the psychological wellbeing of an individual [1]. Chronic illness of early onset, with necessity of repeated diagnostic and therapeutic interventions or frequent relapses can adversely affect the emotional balance and behavioral adaptation of children as they are confronted with a variety of issues, like separation from parents, restriction in activities, multiple and frequent absences from school, dependency, pain and deformity and even threat of death

Thalassemia, an autosomal recessive disorder, caused by the defect in globin chain synthesis of

haemoglobin, affects about 7% of the world population and is a very common chronic hemoglobin disorder [2]. There are about 65,000- 67,000 thalassemia patients in our country [3]. Diagnosis of thalassemia spells physical and psychological trauma due to repeated blood transfusions, innumerable needle pricks and sometimes even surgery (splenectomy). These repeated blood transfusions and their complications make the experiences even more harrowing for the child than acute serious illness [4]. Thus, organic and psychosocial aspects are interwoven for a chronic disease problem.

Another chronic physical illness is childhood nephrotic syndrome. More than 90% of childhood nephrotic syndrome is primary or idiopathic and caused by minimal change glomerulonephritis which is steroid responsive but characterized by relapses. Nephrotic syndrome can also be due to many other types of glomerulonephritis where the cases are steroid resistant and have poor outcome [5]. Its long term remitting and relapsing course & prolonged corticosteroid treatment contribute to behavioural disturbances [6].

Children with both of these chronic diseases suffer from emotional distress and behavioral changes. But in our busy clinical practice the psychosocial aspect of care is usually overlooked. There have been a few studies in India and abroad documenting the behavioral difficulties in children suffering from chronic illnesses [7, 8]. Thalassemia and nephrotic syndrome are two such chronic illnesses commonly available in pediatric ward. Our study aimed to measure the psychopathology of children with these two common chronic illnesses. It also aimed at finding out the relationship of the psychopathologic changes with various socio-demographic and treatment related variables.

MATERIAL AND METHODS

This observational, cross-sectional study was undertaken in the department of Paediatric Medicine of R G Kar Medical College, Kolkata over the period from January, 2011 to April, 2012. Approval was taken from the institutional ethics committee before starting the study. Study population was indoor admitted children suffering from thalassemia major or nephrotic syndrome. Informed consent was taken from the parent for each study case. Exclusion criteria were illnesses of less than 12 months duration, presence of mental retardation or any other associated medical or surgical illness. The cases were divided in 2 groups comprising of 30 children each within the age range 5-14 years, - i) group A includes children of thalassemia major and ii) group B includes children of nephrotic syndrome. Clinical and socio-demographic parameters for the study subjects were recorded on a predesigned proforma.

Psychopathological study tool:

The behavioural profile of the children was assessed by using the CPMS (Childhood Psychopathology Measurement Schedule), a reliable and valid instrument for assessing psychopathology in Indian children in clinical settings. This tool was developed by Malhotra *et al* [9] in 1998. The CPMS is based on a dimensional rather than categorical approach. The scale consists of 75 items and identifies the following clusters of developmental problems/disorders: low intelligence with behavioural problem, conduct problems, anxiety, depression, psychotic symptom, physical illness and summarization.

This instrument has been used in various studies in India [10, 11] and has good validity and reliability. Based on a cut off score of 10, children scoring above that value were considered to have a significant level of maladjustment.

Assessment by CPMS was followed by independent clinical examination to supplement the diagnosis. The ICD – 10 Classification [12] of Mental and Behavioural disorders was followed in this context. A semi-structured proforma was used for clinical and mental status examination, along with physical examination. These were documented in standard case record forms and follow-up data sheets. To assess the socioeconomic status the Kuppaswamy's scale [13, 14] was used.

Data were entered into Microsoft Excel datasheet and analysed with SPSS-17.0. Number and proportion were calculated for categorical variables. Chi-square test was applied for comparison of these categorical variables. P-value <0.05 was considered statistically significant.

RESULTS

Total sixty cases were divided into two groups of 30 each for thalassemia and nephrotic syndrome. Mean age was 8.1 yrs for thalassemia and 7.9 yrs for nephrotic syndrome. Male children predominated in both thalassemia (56.7%) and nephrotic syndrome (66.7%) groups. Distribution of religion and family type were almost similar in both the groups. No association was found between these two variables and psychiatric morbidities. (Table-1).

Regarding affection of sibling, 26.7% of thalassemia patients had sibling history of the same disease; whereas only 7% of nephrotic syndrome cases had such history. Majority of the patients came from rural area (thalassemia and nephrotic syndrome; 56.7% and 60% respectively) both the groups were subdivided according to the duration (< 5 yrs and ≥ 5 yrs) of the disease. We found 83.3% of thalassemia and 46.7% of nephrotic syndrome cases suffered for more than 5 years. Data of socio-economic status evaluation showed 76.7% of thalassemia is from lower and 23.3% from lower middle class but none from upper class. Similar finding was noticed with nephrotic syndrome cases where 80% came from lower and 20% from middle class (Table-1). By administering direct interview technique, the following factors were assessed regarding life-style changes which include (i) changed daily routine, (ii) restricted play and other activities and (iii) changed peer relationship. According to the parents, 76.6% of thalassemia children showed lifestyle changes which, however, were present in 36% of nephrotic syndrome patients. Parents of thalassemia patients felt stress (83%) more commonly than those of

nephrotic syndrome (53%). Amongst the cases of thalassemia, 60% were poor academic achiever whereas

the same amongst nephrotic children it was 30% (Table-2).

Table-1: Showing the relationship between psychiatric morbidities and socio- demographic variables

Demographic variables		Psychiatric morbidities in Thalassemia major group (n=30)					Psychiatric morbidities in Nephrotic syndrome group (n =30)				
		Present		Absent		p-value	Present		Absent		p-value
		No.	%	No.	%		No.	%	No.	%	
Sex	Male	15	40.00	02	16.67	0.034	12	40.00	08	26.67	0.009
	Female	07	33.33	06	10.00		01	03.33	09	30.00	
	Total	22	73.33	08	26.67		13	43.33	17	56.67	
Religion	Hindu	10	33.33	04	13.33	0.825	08	26.67	10	33.33	0.880
	Muslim	12	40.00	04	13.33		05	16.67	07	23.33	
	Total	22	73.33	08	26.66		13	43.34	17	56.66	
Family	Nuclear	10	33.33	05	16.67	0.408	07	23.33	11	36.67	0.547
	Joint	12	40.00	03	10.00		06	20.00	06	20.00	
	Total	22	73.33	08	26.67		13	43.33	17	56.67	
Socio-economic status	Lower	17	56.67	06	20.00	0.896	10	33.33	14	46.67	0.712
	Middle	05	16.67	02	06.66		03	10.00	03	10.00	
	Total	22	73.34	08	26.66		13	43.33	17	56.67	
Habitat	Rural	14	46.67	03	10.00	0.201	08	26.67	10	33.33	0.880
	Urban	08	26.66	05	16.67		05	16.67	07	23.33	
	Total	22	73.33	08	26.67		13	43.34	17	56.66	

Amongst the thalassemics children, 73.3% showed behavioural changes or psychiatric morbidities whereas 43.3% of nephrotic children were found to have such changes. Psychiatric morbidities of the thalassemia patients comprised of conduct disorder (6.7%), depressive conduct disorder (13.3%), mixed disorder of conduct and emotion (20%), separation

anxiety disorder (3.3%), social anxiety disorder (6.7%) and childhood emotional disorder. In cases of nephrotic syndrome, the psychiatric morbidities were hyperkinetic disorder (3.3%), conduct disorder (10%), depressive conduct disorder (10%), mixed disorder of conduct and emotion (13.3%), separation anxiety disorder (3.3%) and phobic anxiety disorder (3.3%) (Table-3)

Table-2: Showing the relationship between psychiatric morbidities and the disease along with disease related variables

Disease and disease related variables		Psychiatric morbidities in Thalassemia major group (n=30)					Psychiatric morbidities in Nephrotic syndrome group (n=30)				
		Present		Absent		p-value	Present		Absent		p-value
		No.	%	No.	%		No.	%	No.	%	
Duration of Disease	< 5yrs	03	10.00	02	06.67	0.460	08	26.66	08	26.66	0.430
	≥ 5yrs	19	63.33	06	20.00		05	16.66	09	30.00	
	Total	22	73.33	08	26.67		13	43.32	17	56.66	
Relapse	Infrequent	-	-	-	-	0.0005	05	16.66	15	50.00	0.0005
	Frequent	-	-	-	-		07	23.33	00	-	
	Total	-	-	-	-		12	39.99	15	50.00	
Parental stress	Present	18	60.00	07	23.33	0.711	06	20.00	10	33.33	0.490
	Absent	04	13.33	01	03.33		07	23.33	07	23.33	
	Total	22	73.33	08	26.66		13	43.33	17	56.66	
Poor scholastic performance	Present	16	53.33	02	06.67	0.018	07	23.33	02	06.67	0.0126
	Absent	06	20.00	06	20.00		06	20.00	15	50.00	
	Total	22	73.33	08	26.67		13	43.33	17	56.67	
Life-style Change	Present	20	66.66	03	10.00	0.0003	07	23.33	04	13.33	0.087
	Absent	02	06.67	05	16.66		06	20.00	13	43.33	
	Total	22	73.33	08	26.66		13	43.33	17	56.66	
Restricted activity	Present	19	63.33	04	13.33	0.037	-	-	-	-	-
	Absent	03	10.00	04	13.33		-	-	-	-	
	Total	22	73.33	08	26.66		-	-	-	-	

There is no association between socio-demographic variables and psychiatric morbidities in both the groups. However, psychiatric morbidities were significantly higher amongst males. Psychiatric morbidities were found to be significantly associated with lifestyle changes (p-value 0.0003) and poor scholastic performance (p-value 0.018) amongst the

cases of thalassemia major. Of the life style changes, only restricted play and other activities showed significant association (p-value 0.037). In cases of nephrotic syndrome, psychiatric morbidity changes were noticeable significantly with poor scholastic performance (p-value 0.0126) and frequent relapse (p-value: 0.037) (Table-2)

Table-3: showing distribution of population of Thalassemia (3.1.) and Nephrotic syndrome case (3.2.) according to behavioural problems

3.1. Behavioural & emotional disorders amongst Thalassemia cases (According to ICD-10 classification)		Total	%
	Not affected	08	26.67
F91 Conduct disorder	F91.9(conduct disorder, unspecified)	02	06.67
F92 Mixed disorder of conduct and emotions	F92.0(depressive conduct disorder)	04	13.33
	F92.8(other mixed disorders of conduct & emotions)	02	06.67
	F92.9(mixed disorder of conduct &emotion, unspecified)	04	13.33
F93 Emotional disorders with onset specific to childhood	F93.0(separation anxiety disorder)	01	03.33
	F93.2(social anxiety disorder)	02	06.67
	F93.8(other childhood emotional disorders)	02	06.67
	F93.9(childhood emotional disorder, unspecified)	05	16.67
3.2. Behavioural & emotional disorders amongst cases of Nephrotic syndrome (According to ICD-10 classification)		Total	%
	Not affected	17	56.67
F90 Hyperkinetic disorder	F90.0(disturbances in activity and attention)	1	03.33
F91 Conduct disorder	F91.0(conduct disorder confined to the family context)	1	03.33
	F91.9(conduct disorder, unspecified)	2	06.67
F92 Mixed disorder of conduct and emotions	F92.0(depressive conduct disorder)	3	10.00
	F92.8(other mixed disorder of conduct and emotions)	4	13.33
F93 Emotional disorders with onset specific to childhood	F93.0(separation anxiety disorder)	1	03.33
	F93.1(phobic anxiety disorder)	1	03.33

DISCUSSION

Children with chronic physical illnesses suffer from biological, social, behavioral and psychological impacts that affect the psychosocial development of the patient and family members [8]. Epidemiological surveys suggest that at any given point of time, 6–12% of children are afflicted with serious chronic physical illnesses. Studies addressing this issue have confirmed that behavioural problems such as neurosis, attention deficit, hyperactivity, misconduct in school, and adjustment problems are twice as common in children with chronic disease as in healthy children of the same age [15].

Present study with children of nephrotic syndrome revealed that a higher proportion of children (43.3%) suffer from behavioural problems in contrast to the 10% affection in the study by Bagga *et al.*; [16]. The discrepancy of results may be due to the difference in culture and socioeconomic status of the sample population [about 80% cases belonging to upper and middle upper socioeconomic class compared to nearly 80% of lower socioeconomic status in our study].

The behavior abnormalities noticed was hyperkinesia; conduct disorder, mixed disorder of conduct and emotion (like depression) and anxiety disorder. This finding is in keeping with other studies of children with nephrotic syndrome [17, 18]. None of the patients with nephrotic syndrome showed features of schizoid, obsessive compulsive, uncommunicative and delinquent behavior. Boys with nephrotic syndrome were significantly (p= 0.009) more frequently suffering from psychiatric co-morbidities than girls contrary to the study of Nagla *et al.*; [19]. An Indian study by Bagga *et al.*; [16] revealed that nephrotic boys have hyperactive disorder more commonly than girls. Howe *et al.*; 1996 reported that girls adjust better than boys showing less hostility and withdrawal. On the other hand, Ann Marie McKenna *et al.*; [20] found no significant correlation between gender and development of psychiatric problems in children with chronic kidney disease.

The age, socioeconomic status, religion and type of family are not significantly related to behavioral

problems. The disease or its related factor that showed a significant association with behaviour problems in the nephrotic syndrome children is the frequency of relapse and poor scholastic performance. Increased frequency of relapse in nephrotic syndrome leads to more frequent follow up visits at the clinic resulting in more absenteeism from school, inactivity, isolation from peer groups and inability to catch up with academic sessions. A similar study in India [16] also mentions about lower school performance of nephrotic children compared to a control group. Further, frequent visits to the health care facilities result in more work days lost for the caregivers, adding to the financial burden of the already economically compromised households.

Beta-thalassemia major is another chronic illness whose clinical manifestations usually develops early in life and wherein invasive procedures cause considerable suffering [21], pose excessive psychological burden to the children. In our sample of children with thalassemia, 73% cases were found to suffer from behavioural abnormality in comparison with the reported incidence of 54% and 67% by Sainy *et al.*; [22] and D.Shaligram *et al.*; [23] respectively. Our observation about behaviour abnormality revealed conduct disorder, mixed disorder of conduct and emotion (like depression), anxiety disorder and other childhood emotional disorder. Major depression was the commonest psychiatric morbidity in the study by Ahmed *et al.*; [24] as the study population comprised predominantly older children and adolescents. Scholastic performances are poorly affected amongst the thalassemic children of the present study. In a UK based study [25] with 27 thalassemic subjects, 90% had to take time off from school because of their medical condition. In one Indian study [26] 70% thalassemic adolescents showed scholastic performance affected. This is because of various factors, such as school absenteeism, behavior or conduct disorders, over-protective nature of parents, poor self esteem, disturbed peer relationship and also economic factors.

Sainy A *et al.*; [22] showed that concerns for the future of a thalassemic child (within the family) contribute to worsening of relationships among members, increased marginalization and isolation, but our study couldn't support it.

Literature search revealed two observational studies presenting comparison of behavioral changes, one [23] between cases of thalassemia and epilepsy, and another [27] between those of thalassemia and bronchial asthma. No previous study compared the behavioral effect of two common chronic childhood illnesses namely thalassemia major and nephrotic syndrome. Amongst two populations, parental stress is much more common with thalassemia. This stress is augmented by inability of the parents to follow the

advices of chelation therapy due to economic constraint. On the other hand, parents of nephrotic syndrome were often anxious regarding the nature of disease (bad or very bad). In the present study, thalassemic children were more commonly affected by behavioral changes (73%) than nephrotic children (44%). Psychiatric morbidities are expected to be higher amongst the children suffering longer. Difference was statistically significant with thalassemic children (3/22 vs 19/22; $p=0.004$), but not with nephrotic cases (8/13 vs 5/13; $p=0.495$). Though school performance was affected in both the groups, it was significantly (18/12 vs 9/21; $p=0.019$) more with thalassemia group. This might be due to more absenteeism and associated low I.Q in chronic anemia [28].

CONCLUSION:

The results of this study emphasize the need for considering the psycho-social aspects of the chronic illnesses like thalassemia and nephrotic syndrome in their management protocol. The pediatrician should deal with these issues more empathetically while communicating with the parents and the suffering children. In our institute, we referred the children with behavior problem to child guidance clinic, run under the supervision of Dept. of Psychiatry. They had gone through some cognitive behavior therapy or drug treatment there, according to their corresponding diagnosis.

LIMITATION:

1. In nephrotic syndrome group, we did not exclude whether corticosteroids use have any influences on behavioural changes or not.
2. Longitudinal follow-up studies might be valuable in the assessment of the course and prognosis of behavioral problems diagnosed in our study.

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