ORIGINAL ARTICLE

PSYCHOSOCIAL PROBLEMS ASSOCIATED WITH TRANSFUSION DEPENDENT THALASSEMIA IN A TRIBAL POPULATION

Kumaravel KS, Jagannathan S, Balaji J, Karthick NR, Pugalendhiraja KV

Abstract

Aim: Children with chronic physical illnesses like thalassemia are vulnerable to psycho-social problems. In the Dharmapuri district of Tamilnadu, increased prevalence of thalassemia is noted in the tribal population at Sitheri. This study is aimed to evaluate the psycho-social problems in the tribal children with thalassemia.

Methods: This is a cross sectional case control study done in the tribal village Sitheri. All the transfusion dependent children in 5 to 15 years age group who were present in the village on the day of visit were included and age and sex matched controls were derived from the tribal school in the same village. The tool used was Developmental Psychopathological Check List (DPCL).

Results: In the study, there were 32 thalassemic children and 32 age and sex matched controls. In the thalassaemia children group, presence of the behavioural disturbance in any of the subscales of DPCL was seen in 26 (81.2%) children. In the control group similar disturbances were documented in 9 (28.1%) children ($p < 0.001$). Learning disorder (53.1% in cases and 15.6% in controls, $p < 0.001$), somatization (46.9% in cases and 0% in controls, $p < 0.001$) and emotional disorders (31.3% in cases and 9.4% in controls, $p = 0.039$) were more common in the cases than in controls.

Conclusion: The high frequency of psycho-social disturbances warrants routine psycho-social screening and therapy for the thalassemic children and it should form a part of standard management protocol.

Keywords: thalassemia, psychosocial disturbances, tribal population

Introduction

Beta-thalassemia is the most common form of hemolytic anemia (1) and every year approximately 60,000 thalassemic babies are born worldwide. (2) Children with chron¬ic physical illnesses like thalassemia are vulnerable to emotional and behavioral problems. (3) The chronicity and complications of thalassemia affect the quality of life of victims and cause physical, psychological, and economic problems to the patient and their parents. (2) As there is no definitive cure for this disease, the majority exclusively depend on blood transfusions as a treatment option that creates a burden not only on health system but also on the affected families, who are vulnerable to social and psychological problems. (4) It is expected that these children are at high risk of developing behavioral and psychosocial problems like opposition, passiveness, anxiety, phobias and depression, which affect their self-confidence and give rise to emotions and thoughts which negatively affect their quality of life and compliance to therapy. (5)

Children with thalassemia in the pre-school and latency age groups are usually anxious and excessively dependent on their parents. (6) They display psychosomatic symptoms and are frequently absent from school. Thalassemic children have more of negative self-concept when compared to their normal counterparts. (7) Various authors have reported that up to 80% of children with thalassemia are likely to have psychological problems e.g. oppositional defi¬ant disorder, anxiety disorders and depression. (8) Although children with all types of blood disorders are exposed to similar stressors, those with thalassemia are unique in that they have to attend hospital regularly for blood transfusions. (9)

The disease is commonly seen in the Mediterranean basin and parts of Africa, Middle East, Indian Sub-continent, South-East Asia and Pacific Islands. In the Dharmapuri district of Tamilnadu, there is increased prevalence of thalassemia in the tribal population at Sitheri and its surrounding hamlets. Sitheri is a conglomerate of hilly tribal hamlets situated at an altitude of 3600 feet above mean sea level. The practice of consanguineous marriages in tribal population propagated the disease among the generations. Many studies are available which describe the psychosocial disturbances in thalassemic children. All these studies were done in urban centers. (3,4) However there are no studies available to describe the psychosocial problems in thalassemic children in tribal population. The presence of psychosocial problems in a tribal setting will be difficult to analyze as their environmental, educational, social and cultural influences are different.

The objective of this study was to assess the prevalence and pattern of psycho-social disturbances in tribal thalassemic children and to compare them with normal children.

Methods & Materials

This is a case-control study done at the tribal village of Sitheri, Dharmapuri District. A team of investigators including all the authors and a psychiatrist visited the village and conducted the study. Prior information about the visit and the study were given to the children and parents. Informed consent was obtained from the parents for the study. All the thalassemic children who were present in the village on the day of visit were included in the study. The inclusion criteria were: presence of transfusion dependent thalassemia major and thalassemia intermedia and age group of 5 to 15 years. The thalassemic children with illness like HIV and Hepatitis B were excluded. The age and sex matched controls were drawn from healthy children in the tribal school in the same village. Institutional ethical committee approval was obtained.

The basic demographic data including age, gender, socio-economic class and age at diagnosis were recorded. The behavioural profile of the thalassemic children were assessed using the DPCL (Developmental Psychopathology Check list), which is a reliable and validated instrument for assessing psychopathology in Indian children. (10) This tool was developed at the National Institute of Mental Health and Neurosciences, Bangalore by Kapur and

colleagues in 1994. The DPCL contains 124 easy to administer questions. 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. The psychiatrist present in the team carried out an independent examination to supplement the diagnosis made by DPCL.

To assess the socioeconomic status of the parents, the Modified Kuppuswamy scale was used. (11) Normative data was obtained from age and sex matched controls belonging to a school in the same village. Those children suffering from physical illness were excluded. Informed consent was obtained from parents.

The data was analyzed using the Statistical Package for Social Studies (SPSS) version 17 for windows. Descriptive statistics like frequency, mean and standard deviation were used to describe the data obtained. The McNemer's chi-square test was done to compare the behavioural abnormalities in thalassemic children and control group. To measure the correlation between sociodemographic and clinical variables and behavioural abnormality conditional logistic regression method was performed.

Results

In the study there were 32 thalassemic children and 32 age and sex matched controls. Their socio-demographic and clinical profile is depicted in table 1.

Table I: Socio-demographic Profile of the children in the study

Character	Cases (N=32) Frequency (%)	Controls (n=32) Frequency (%)
Age group		
5-7 years	14 (43.8%)	14 (43.8%)
8-10 years	11(34.3%)	11 (34.3%)
11-15 years	7(21.9%)	7 (21.9%)
Sex		
Female	12(37.5%)	12 (37.5%)
Male	20(62.5%)	20 (62.5%)
Socio Economic Status		
Lower middle	2(6.3%)	2 (6.3%)
Upper lower	19(59.4%)	20 (62.5%)
Lower	11(34.4%)	10 (31.25%)
Age at diagnosis		
1 to 1½ years	10(31.3%)	NA
1½ to 2 years	11(34.3%)	NA
2 to 2 ½ years	6(18.8%)	NA
2 ½ to 3 ½ years	5(15.6%)	NA
Transfusion frequency		
Monthly twice	3(9.4%)	NA
Monthly once	28(87.5%)	NA
Once in two months	1(3.1%)	NA
Oral Iron chelation		
No	7(21.9%)	NA
Yes	25(78.1%)	NA
Siblings with Thalassemia		
No	30(93.8%)	NA
Yes	2(6.3%)	NA

NA = Not Applicable

Table 2: Comparison of Psychopathological Problems among Cases and Controls

Psychopathological problems as per DPCL Scales	Cases (n=32)	Controls (n=32)	P value
	No	No	
Developmental History	3(9.4%)	0	0.250
Developmental problems	0	0	
Hyperkinesis	5(15.6%)	0	0.063
Conduct disorder	3(9.4%)	2(6.3%)	1.000
Obsessive Compulsive Disorder	0	0	
Psychoses	0	0	
Learning disorder	17(53.1%)	5(15.6%)	<0.001
Emotional disorder	10(31.3%)	3(9.4%)	0.039
Somatisation	15(46.9%)	0	<0.001
Family history	2(6.3%)	0	0.500
Temperament	4(12.5%)	2(6.3%)	0.625
Stressors	0	0	

In the thalassemia children group, presence of the behavioural disturbance in any of the subscales of DPCL was seen in 26 (81.2%) children. In the control group similar disturbances were documented in 9 (28.1%) ($p<0.001$) (Odd's ratio = 65.2). Table: 2 shows the prevalence of the psychopathological problems among cases and controls.

Discussion

In a developing country like India, the medical management of a chronic disease takes the centre stage of treatment. The psychosocial aspects of chronic diseases like thalassemia are often neglected. The higher prevalence (81.2%) of psychopathology in a tribal population is a new observation in the medical literature. Sadowsky et al reported 43% to 47% prevalence of psychological disturbances in thalassemic children. (12) A study by Aydin et al in Turkey reported 80% of the patients had at least one psychiatric disorder. (5) A study by Saini et al in India reported about 54% of psychological abnormalities using Childhood Psychopathological Measurement Schedule (CPMS). (13) Shaligram et al reported the presence of psychological disturbances in 44% of thalassemic children using CPMS. (4) The high prevalence of psychopathology in thalassemic children can be explained by their chronic illness, frequent hospitalizations for regular blood transfusion, fear of injection or discomfort in hospital.

We observed that the commonest psychopathological problems were learning disorders, somatization and emotional disorder in the thalassemic children. In a study from Indore, school problems were seen in all (100%) the thalassemic children. (12) Similar prevalence of somatisation (56%) was observed in a study in Bengaluru. (14)

The interesting finding in this study is the complete absence of obsessive compulsive disorder and psychosis. Many studies have reported the presence of both these conditions. (15,16) Ghanizadeh et al in 2006 studied the prevalence of psychiatric disorders, depression, and suicidal behaviour in thalassemic children using Kiddie-Schedule for Affective Disorders and Schizophrenia (K-SADS). They observed depressive disorder and separation anxiety disorder as the most common disorders. (17) A significant number of thalassemic children in our study sample suffered from combination of psychopathologies. Multiple psychopathologies are common in thalassemic children and it was also reported in many other studies. (15,16)

There are only a few studies available which have evaluated the benefits of therapy for psycho-social disorders in thalassemic children. One such study is by Mazzone et al, who carried out a Cognitive Behavioural Family Therapy (CBFT) among twenty-eight β-thalassemic major children for one year, and the results were encouraging. (18)

Because of logistical and time constraints the study was conducted as a cross sectional one rather than a longitudinal one which is one of the limitations of this study.

To summarize there was a high frequency of psycho-social disturbances in thalassemic children belonging to tribal population when compared to normal children. The common psychopathological problems noted in the study were learning disorders, somatisation and emotional disorder. The treating physicians should screen and manage the psycho-social disturbances in

thalassemic children and it should be part of standard management protocol of thalassemia. The study place was a tribal hamlet, where the access to health care is limited. Thalassemia support groups should be formed to educate patients and their families.

Acknowledgement

We sincerely thank the social workers and school teachers in Sitheri, Department of Psychiatry, Government Dharmapuri Medical College, Dharmapuri and thalassemic children and their parents who helped in conducting this study.

Funding: None

Conflict of Interest: None

References :

1. Dubey AP, Parakh A, Dublish S. Current trends in the management of beta thalassemia. Indian J Pediatr. 2008;75(7):739–43.
2. Weatherall DJ, Clegg JB. Inherited haemoglobin disorders: an increasing global health problem. Bull World Health Organ. 2001;79(8):704–12.
3. Eiser C. Psychological effects of chronic disease. J Child Psychol Psychiatry. 1990 Jan;31(1):85–98.
4. Shaligram D, Girimaji SC, Chaturvedi SK. Psychological problems and quality of life in children with thalassemia. Indian J Pediatr. 2007 Aug;74(8):727–30.
5. Aydin B, Yaprak I, Akarsu D, Okten N, Ulgen M. Psychosocial aspects and psychiatric disorders in children with thalassemia major. Acta Paediatr Jpn. 1997;39(3):354–7.
6. Khurana A, Katyal S, Marwaha RK. Psychosocial burden in thalassemia. Indian J Pediatr. 2006 Oct;73(10):877–80.
7. Moorjani JD, Issac C. Neurotic manifestations in adolescents with thalassemia major. Indian J Pediatr. 2006 Jul;73(7):603–7.
8. Clemente C, Tsiantis J, Sadowski H, Lee C, Baharaki S, Ba G, et al. Psychopathology in children from families with blood disorders: a cross-national study. Eur Child Adolesc Psychiatry. 2002 Aug;11(4):151–61.
9. Sharghi A, Karbakhsh M, Nabaei B, Meysamie A, Farrokhi A. Depression in mothers of children with thalassemia or blood malignancies: a study from Iran. Clin Pract Epidemiol Ment Health CP EMH. 2006;2:27.
10. Kapur M, Barnabas I, Reddy MV. Development of a checklist for assessment of childhood psychopathology in the Indian setting. Indian J Clin Psychol. 1994;21:40–2.
11. Mishra D, Singh HP. Kuppuswamy's socioeconomic status scale- A revision. Indian J Pediatr 2003; 70: 273-274
12. Sadowsky H, Kolvin I, Clemente C, Tsiantis J, Baharaki S, Ba G. Psychopathology in children from families with blood disorders: a cross national study. Eur Child Adolsc Psychiatry 2002;11:151- 161.
13. Saini A, Chandra J, Goswami U, Singh V, Dutta AK. Case Control Study of Psychosocial Morbidity in β Thalassemia Major. J Pediatr. May 2007; 150(5):516-520.
14. Beratis S. Psychosocial status of preadolescent children with beta-thalassaemia. J Psychosom Res 1993;37(3):271-279.
15. Arunansu Talukdar, Arun De, Raja Bhattacharya, Sumita Pal, Gargi Dasgupta, Malay K Ghosal et al, Behavioral profile and school performance of thalassaemic children in eastern india. Asian J Pharm Clin Res. 2013; 6,: 49-52
16. Shah HD, Vaishnav JG, Javdekar B. Psychological assessment in children with thalassemia major using DPCL tool at medical college - Vadodara, Gujarat. Int J Int Med Res. 2015; 2(3):28-31.
17. Ghanizadeh A, Khajavian S, Ashkani H. Prevalence of psychiatric disorders, depression, and suicidal behavior in child and adolescent with thalassemia major. J Pediatr Hematol Oncol. 2006; 28(12): 781-4.
18. Mazzone L, Battaglia L, Andreozzi F, Antonietta M, Mazzone D. Emotional impact in β-thalassaemia major children following cognitive-behavioural family therapy and quality of life of caregiving mothers. Clinical Practice and Epidemiology in Mental Health 2009; 5:5

From: Department of Pediatrics, Government Dharmapuri Medical College Hospital, Dharmapuri Tamilnadu, India.

Address for Correspondence: Dr. K S Kumaravel, M.D (Pediatrics), 191A, Shankar Nagar, Salem, Tamil Nadu 636007, India.

Email : kumaravelks@rediffmail.com

DOI : 10.7199/ped.oncall.2016.45