Research Article

A study on the demographic and morbidity patterns of thalassemia patients registered at a tertiary-care center of central India

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Received September 10, 2014. Accepted September 29, 2014

Abstract

Background: Thalassemia is an autosomal recessive disease. According to the WHO data, there are 269 million carriers of thalassemia worldwide, out of which 40 million are in South East Asia.

Objectives: This study was conducted with the primary objective to assess demographic profile of patients with thalassemia at a tertiary care hospital of Bhopal along with morbidity pattern in them and economic burden on the patient's family.

Materials and Methods: A cross-sectional, hospital-based study was carried out in the pediatric ward of Kamla Nehru Hospital of Gandhi Medical College, Bhopal. Information regarding the patient's sociodemographic profile, morbidity pattern, economic burden, and other relevant aspects was collected on a predesigned and pretested proforma from the parents or attendant of all the patients who visited the clinic or were admitted in Kamla Nehru Hospital during July 2014 to December 2014.

Results: During the study period, 180 children with thalassemia were identified. Of them, 61.7% were males and 38.3% were females, and 56.7% were diagnosed for thalassemia within first 6 months of age. Religion-wise distribution shows maximum cases 134 (74.4%) were Hindus followed by 37 (20.5%) Muslims, and 9 (5.0%) others. Children with thalassemia showed a higher frequency of illness as compared to their sibling with negative thalassemia history.

Conclusion: This study is the first of its kind in the setting of central India, and the results of this study will lead to increased awareness about the different aspects of thalassemia.

KEY WORDS: Thalassemia, illness, hospital

Introduction

Thalassemia is an autosomal recessive disorder. The genetic defect results in reduced rate of synthesis of one of the globin chains that produce hemoglobin. Thalassemia is classified as α, β, γ, δ, and E thalassemia, depending on the chain whose synthesis is impaired. According to the WHO data, there are 269 million carriers of thalassemia worldwide alone, of which 40 million are in South East Asia. In India, thalassemia is the most common single-gene disorder with approximately 30 million carrying the defective gene, with carrier frequency ranging from 3% to 17 %.[1–4] Higher frequency has been reported in northern, western, and eastern parts of India. The highest frequency of β-thalassemia is reported in Gujarat (10.0%–15.0%) followed by Calcutta (10.2%), Punjab (6.5%), Delhi (5.5%), Tamil Nadu (4.0%), Bengal (3.5%), Mumbai (2.6%), Maharashtra (1.9%), and Kerala (0.6%).[5] This study was conducted with the primary objective to assess demographic profile of the patients with thalassemia at-tertiary care hospital of Bhopal along with morbidity pattern in them and economic burden on their family. The ultimate aim was to get insight into this major genetic problem for further research through effective prevention programs and to attract more attention toward the various aspects of thalassemia.

In this scenario, prevention and control of thalassemia deserve top priority. Experiences in Cyprus, Greece, and Italy show that this genetic disease can be efficiently controlled by public education, population screening, genetic counseling, and antenatal diagnosis. The incidence of thalassemia major by these simple measures has been reduced by 96% in Cyprus, 62% in Italy, and 52% in Greece.[7–9]

Access this article online

Website: http://www.ijmsph.com

DOI: 10.5455/ijmsph.2015.1009201417

Quick Response Code:

Prevention is possible by public awareness, carrier screening, genetic counseling, prenatal diagnosis, and selective termination of affected fetuses. Though there is a definite need for carrier screening in the population, it is hard to draw a consensus regarding time of screening because of lack of education and public awareness about the disease.

Every year, approximately 100,000 children are borne worldwide with thalassemia major, of which 10,000 are born in India.[10]

It is estimated that there are about 65,000–67,000 patients with β-thalassemia in India and approximately 30 million carriers of β-thalassemia with a mean prevalence of 3.3%.[1] The average life of patients with untreated β-thalassemia major was less than 4 years, with <80% dying in the first 5 years. The main modality of treatment is regular blood transfusions every 2–4 weekly coupled with iron chelation. With this treatment, a few lucky ones have reached third or fourthÂ decade of life. The only curative treatment currently available, which is in the form of bone marrow transplantation, is beyond the reach of all but a lucky few.[11] The cost of ideal treatment for one child with thalassemia is substantial. It is observed that 70% of the families had to spend up to 20% of their yearly income on treatment of thalassemia. This staggering cost is beyond the reach of most of the people of our country; moreover, this cost is expected to increase due to additional children being born. Transfusions alone cost 20%–30% of the income for most families. The chronic nature of the disease and demanding treatment place significant financial, emotional, and social stress on the family.[12,13]

Material and Methods

This study was a cross-sectional study conducted at the Department of Pediatrics, Kamla Nehru Hospital of Gandhi Medical College, Bhopal, on the registered cases of patients who visited clinic or admitted in the hospital during July 2014–December 2014.

Before the conduction of the interviews, informed consent was obtained from the parents or attendants of all participants.

Overall, 180 thalassemia children were assessed and information was recorded on the predesigned and pretested proforma consisting of four basic sections, the first section included the questions about the sociodemographic profile of the patient; the second section included questions regarding morbidity pattern; the third section included questions regarding economic burden on the family, if any, due to the disease as compared to their normal children; and the fourth section included any other relevant information from the parents or attendant of all the patients. Collected data were compiled in an MS Excel worksheet and analyzed by Epi Info, version 7.

Results

During the study period, 180 thalassemia children from 148 families were identified. Among these children, 111 (61.7%) were males and 69 (38.3%) were females [Figure 1]. Table 1 shows the distribution of study subject according to their age at the time of interview and at the time of diagnosis of thalassemia. Of the total 180 patients, 102 (56.7%) were diagnosed with thalassemia were between 0 and 6 months, 48 (26.7%) between 6 and 12 months, 24 (13.3%) between 13 and 24 months, and 6 (3.3%) between 25 and 36 months of age. Of the total 180 children, 42 (23.3) had a positive sibling history.

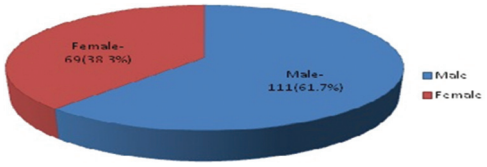

Figure 1: Percentage of male and female patients in this study

Table 2 shows characteristics of subjects regarding their demographic and clinical profile and economic burden. According to religion-wise distribution, maximum cases were Hindus (134, 74.4%) followed by Muslims (37, 20.5%), and others (9, 5.0%). Of the total, 39 (21.6%) children were born to consanguineous parents and remaining 141 (78.3%) to non-consanguineous parents.

Thalassemia children showed a higher frequency of illness as compared to their sibling with negative thalassemia history; the highest being ARI (acute respiratory infection, 72%), followed by diarrhea (58%), and anemia/jaundice (19%) during past 6 months. On comparison of these children with their non-thalassemia siblings, it was found that maximum (72, 48%) parents faced an extra economic burden of Rs. 500–1000 per month, followed by 57 (31.7%) of more than Rs. 1000 per month, and 51 (28.3%) below Rs. 500 per month. This mainly contributed to increased frequency of morbidity pattern and other incidental charges (transport, food) during their hospital visit for blood transfusion.

Discussion

In this study we assessed the patients diagnosed with thalassemia according to their demographic profile, morbidity pattern, and economic burden on their family. In this study, 180 patients [111 (61.7%) males and 69 (38.3%) females] were enrolled. Similar results were also reported earlier by Wasi *et al*.[19] Yagnik,[20] and Balgir[21], which showed the prevalence of 65.5%, 56%, and 62.1%, respectively. This might indicate that thalassemias are more common in males than in females because the parents give more attention to their male child and ready to spend more money on a male child compared to a female one. We found that most of the patients (56.7%) were diagnosed for β-thalassemia within 6 months of age [Table 1]. Similar result was reported by Modell and Berdoukas[14] and Agarwal[15].

Table 1: Age of patients at the time of interview and age at which initial symptom presented

Patient characteristics	N = 180	%
Age at the time of interview		
0–1 year	15	8.3
>1–2 years	27	15.0
>2–5 years	48	26.6
>5–10 years	48	26.6
>10 years	42	23.3
Age at the time of diagnosis of thalassemia		
0–6 months	102	56.7
>6–12 months	48	26.7
>12–24 months	24	13.3
>24 months	6	3.3

The thalassemia children showed a higher frequency of illness as compared to their sibling without thalassemia, the highest being ARI (72%), followed by d
iarrhoea (58%) and anemia/jaundice (19%). Similar clinical features for thalassemia were observed by Weatherall and Clegg[16,17] and Deyde *et al*.[18]

On comparison of thalassemia children with their non-thalassemia siblings, it was found that maximum parents (48%) faced an extra economic burden of Rs 500–1000 per month followed by 31.7% who faced more than Rs 1000 per month, and 28.3% who faced below Rs 500 per month. This mainly contributed to the increased frequency of morbidity pattern and other incidental charges (transport, food) during their hospital visit for blood transfusion. This finding shows that there is higher economic burden on the parents of a child with thalassemia, which is also supported by an earlier study conducted by Riewpaiboon *et al.* 2010[22].

Table 2: Certain characteristics of patients with thalassemia

Patient characteristics	N =180	%
Sex		
Male	111	61.7
Female	69	38.3
Sibling history		
Present	42	23.3
Absent	138	76.7
Religion		
Hindu	134	74.4
Muslim	37	20.5
Others	9	5.0
Economic burden (rupees)		
<100	0	0
100–499	51	28.3
500–1000	72	48.0
>1000	57	31.7
Frequency of blood requirement		
<1 month	112	62.2
>1 month	68	37.8

Conclusion

The study finding shows higher number of thalassemia patients come to tertiary-care centers for regular blood transfusion and for treatment of other medical condition, and it is necessary to take it as a public health problem because thalassemia causes a huge psychological and financial drain on patients and their families. Thalassemia patients and their parents require life-long psychological support for prevention of mental health issues. Several effective psychological strategies are available. Cognitive-behavioral family therapy, which is capable of increasing compliance to treatment, lessening the emotional burden of disease, and improving the quality of life of caregivers, can be an effective psychological approach for children with β-thalassemia major.[23]

To improve the situation, public education about thalassemia is of a great importance and should be imparted through periodic meetings addressed to health professionals including doctors and nurses working in the community and family members. This fatal disease can be prevented by taking measures such as premarital screening, genetic counseling, and prenatal diagnosis; identifying silent carriers; and counseling them so as to avoid marriages between them. This study is first of its kind in the setting of central India, and the results of this study will lead to increased awareness about different aspects of thalassemia.

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How to cite this article: Bhatia P, Nagar V, Meena JS, Singh D, Pal DK. A study on the demographic and morbidity patterns of thalassemia patients registered at a tertiary-care center of central India. Int J Med Sci Public Health 2015;4:85-88

Source of Support: Nil, **Conflict of Interest:** None declared.