



Incidence of β -thalassaemia in Peshawar

Qamruz Zaman¹, Muhammad Azam², Muhammad Iqbal¹ and Shah Khusro³

¹Department of Statistics, University of Peshawar, Pakistan

²Department of Statistics, Forman Christian College, Lahore

³Department of Computer Science, University of Peshawar, Pakistan.

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ABSTRACT

A questionnaire, interview survey of 320 patients was made in Peshawar, Pakistan to study the severity of beta thalassaemia on different aspects. The study revealed that it was common in male than female. The other things were that inter family marriages played an important part. The average family income was very less as compared to the family members and the expenditure of the treatment. The analysis showed that the father income is associated with the knowledge about thalassaemia and education. It was also revealed that the disease was more common in positive blood groups.

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Introduction

Thalassaemia is inherited gene disorder and varies in different population groups [1]. Like many other countries, thalassaemia also pose an important public health problem in Pakistan. At present, more than 150,000 thalassaemia major patients exist in the country, and this number is on an increase every year. Death from the thalassaemia major can be delayed but not averted. Thalassaemia is an inherited disorder in which there is an abnormality in one or more of the globin genes. In general thalassaemia can be divided into two groups, α -thalassaemia and β -thalassaemia. Thalassaemia Major is also called Cooley's Anemia, Homozygous β -thalassaemia, Homozygous thalassaemia or Mediterranean anaemia [2]. This is the most severe form of β -thalassaemia in which the complete lack of beta protein in the hemoglobin causes a life-threatening anemia that requires regular blood transfusions and extensive ongoing medical care.

β -thalassaemia major is more severe in Pakistan and this research is also based on it. The question of premarital screening or counseling of individuals with a family history of the disease is still answerable. Thalassaemia has been initiated its web all over Pakistan since 1947 and out of every 100 Pakistanis, six are carriers of the thalassaemia gene [3]. Thalassaemia is the commonest inherited disorder in Pakistan. The homozygously affected children have a life long transfusion dependent anaemia. The disorder can now be diagnosed during very early pregnancy. Ahmed S et. al. 1994 have started the country first regular prenatal diagnostic service for thalassaemia [4]. The only way to prevent the disease is by educating the general population. For this reason in this present study, a question about the awareness among parents of thalassaemic patients regarding the disease was also evaluated.

Very few studies in Pakistan have dealt with the thalassaemia. The present study is an attempt to quantify the degree of the problem of β -thalassaemia in Pakistan

- To find out the basic characteristics of the respondents

- To give some suggestions for the improvement of patients

Data Source

The data of 320 patients were collected from the Fatimid Foundation, Peshawar. The objective of the study was to analyze the prevalence of Thalassaemia in the patient population registered with the organization. Fatimid Foundation, a non-profit charitable organization is the pioneer of voluntary blood transfusion services in Pakistan. It is a symbol of hope for millions of blood disease carriers in Pakistan. Starting with a small center at Karachi in 1981 by Barrister Nazim Jeeva and a handful of volunteers, Fatimid has grown into the largest organization of its kind, now it have four centers at Peshawar, Karachi, Lahore and Multan staffed by a Professional team of physicians and trained workers[5]. Even in terms of quantitative output of blood and blood products, it is the leader of the fraternity of blood transfusion services in Pakistan. The country first regular prenatal diagnostic service for thalassaemia has been started in 1994[4]. Convenient sampling procedure used for the selection of units. The questionnaire and interview were designed to collect information on different aspects. Since the majority of patients and their parents were illiterate, so the two methods combined to get the information. The questionnaire and interview were mainly consisted of nine questions, namely

1. Age of Transfusion
2. Sex of the patient
3. Relation of the patient parents
4. Education of the patient
5. Father income
6. Blood group of patient
7. Family members
8. Parents Education
9. Parents knowledge about thalassaemia.

Responses to structured questions were entered and analysed using SPSS, version 11.5[6]. Results have been presented in the form of frequencies and percentages where applicable. Values of $P \leq 0.05$ were considered significant. The chi-square test was used to test the association between different factors.

Results

The data of 320 patients consisted of 60% male patients and 40% female patients were observed.

Table 1 summarizes the response of the questions. 70% of the patients spent less than 10 years in the foundation and 30% were under treatment for more than 10 years. The majority of patient parents were first cousins, but it was also revealed in the unknown parents. 67% of the patients belonged to the families whose family sizes were greater than 4. Further, 95% of the patients belonged to the positive blood groups and 5% to negative.

From education question, it summarized that 39% of patients had no interest in education. 60% had less interest. While only 1% of 320 patients were matriculate. Tables 2 and 3 showed the associations between the father income with parents knowledge about thalassaemia and parents education. Tables revealed the significant associations between income and the other factors.

Discussion

It has been found that thalassaemia is a blood disease and is more common in male than female, which may be due to the fact that in this part of the world, parent's pay more attention to male than female. The majority of the patient parents were relatives, while it was revealed that 23.7% of the patient parent's before marriage were unknown to each other. Disease is more common in positive blood group as compared to negative group. Patients were not in position of receiving education, which may be due to lifelong treatment procedure. Large family size and less income is one of the main hurdles in the treatment of disease. Family income is highly associated with with parents knowledge about thalassaemia and parents education.

β - thalassaemia occurs worldwide, with a higher prevalence in the Middle East, Pakistan, South East Asia etc. Thalassaemia

is a major problem in the country. Lack of awareness and education make the problem more severe. No custom of pre marriage counseling is also one of the reasons for the spread of disease.

Suggestions

The present study concluded that the awareness of parents regarding this disease was not up to the mark and need proper attention.

There is need to create general awareness among the people regarding the features and complications of Thalassaemia. There is need to aware the people about the adverse effects of interfamily marriage which are very common in our society. This is not only the duty of foundation and government to control the disease. But it is also the duty of every carrier and especially, it is the duty of carrier marriage women to visit the doctors regularly during pregnancy.

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Table 1: Response of the questionnaire and interview

Variable	Percentage
Age of Transfusion	
<= 10 years	70%
>10 years	30%
Sex	
Male	60%
Female	40%
Parents Blood Relation	
Relatives	76%
No Relation	24%
Family Size	
≤4	33%
>4	67%
Blood Group	
Positive	95%
Negative	5%
Education Tendency	
No Interest	39%
Less Interest	60%
More Interest	1%

Table 2: Parents Knowledge about Thalassaemia and Father Income

Father Income	Parents Knowledge about Thalassaemia		Total
	Yes	No	
≤ 2000	106	35	141
>2000	103	76	179
Total	209	111	320

Table 3: Parents Education and Father Income

Father Income	Parents Educated		Total
	Yes	No	
≤ 2000	17	124	141
>2000	52	127	179
Total	69	251	320