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ORIGINAL RESEARCH ARTICLE

FEATURES AND AWARENESS OF THALASSEMIA IN GENERAL POPULATION AND ANALYSIS UNDER CERTAIN MEDICAL APPROACHES IN DISTRICT SIALKOT.

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ABSTRACT

The present study was conducted to determine the medicinal approach in population of Sialkot, Pakistan, against thalassemia. The purpose of this study was to understand the financial and social problems faced by the parents and to analyze the general awareness of thalassemia. This study was carried out from November-2017 to August-2018 through two Thalassemia centers, Sundas Foundation Sialkot and DHQ (District health quarter) Sialkot. The survey was also conducted at Government College Women University Sialkot. Total of 50 patients were considered as a population of thalassemia patients, registered by two thalassemia centers of Sialkot, Pakistan. Total 150 respondents were drained from the students in GCWUS from natural and social sciences in present study. Data was collected by standardized questioner, interview and discussed in detail with a senior doctor, dealing with thalassemia patients for almost ten years. The study has two major sections. 1st section was conducted in Sundas Foundation and DHQ Sialkot and found that 66.7% of patients were males and among them, 78.4% belonged to rural areas. In those areas, intermarriages are a common practice (72%). It was found that most of the patients (52.9%) had a family history of the disease. The second section of a study conducted was in GCWU Sialkot to find the awareness regarding the disease in the general population. The study concluded that misconceptions regarding the disease were common, such as 51.7% of participants have the misconception that thalassemia is caused by malnutrition. In comparison, no dietary restrictions exist during the treatment was the concept of 58.6% of participants. It was concluded that different awareness programs should be established regarding the disease to control the increasing number of thalassemic births in the country.

INTRODUCTION

The term thalassemia is derived from the Greek word "thalas" which means the sea, and "emia" translated as blood (Nosheen *et al.,* 2015). It is estimated that 15 million people worldwide, and 4.4 of every 10,000 births are thalassemic patients (Mahmoud 2015). A major complication in chronically transfused patients is developing irregular antibodies (Sharma *et al.,* 2017). Beta thalassemia is one of the most common autosomal recessive genetic disorder; annually about 3% inhabitants and 5000 children all over the world are diagnosed with beta thalassemia each year. Around 25000 children are registered with the thalassemia federation of Pakistan. However, the original figure is still unknown as many patients that live in rural areas are not listed with any thalassemic center (Asif and Hassan, 2016). It is estimated that a total of 18% population of Maldives is the thalassemia carrier. There is 3-8% prevalence in people from Asia, including India, Pakistan, China, Bangladesh, and Malaysia, documenting the highest prevalence rate is in Cyprus, that is 16%.(Sharma *et al.*, 2017).

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Among different strategies to prevent thalassemia, the most successful strategy adopted by Cyprus and Turkey is to stop the birth of thalassemic children's. Whereas Iran has made premarital tests compulsory to avoid the birth of thalassemic children. (Ishfaq *et al.,* 2016). The least expensive and best effective preventive strategy against thalassemia is to check the genetic status of the parents or carriers of the disease at the pre-marital stage and to provide the proper counselling and guidance about the consequences. Proper screening programs to detect the carries are hence helpful in reducing the probability of new thalassemia births. (Nosheen *et al.,* 2015). The majority of thalassemic patients, around 1,00,000 in Pakistan, do not get proper treatment or blood transfusion due to the financial burdens, as it costs around Rs. 8,000 pk monthly, which for most families is a huge deal. To provide an international level of equipment and treatments to such patients, above Rs.900 million monthly and Rs 7.2 billion annually must be provided, which Pakistan's health budget fails to provide. Keeping in mind the incapability to provide such facilities, the only substitute is to stop the birth of a thalassemic child which is only possible if people are aware of the causes and consequences of the disease. (Ishfaq *et al.,* 2016)

Beta Thalassemia leads to anemia, involving chromosome 11. It upsets the production of the B globin chain of hemoglobin. So, it is either reduced or lost, leading to an early production of abnormal Red Blood

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Cells (RBC) destroyed immediately by the mononuclear phagocytic system (MPS), mainly by the spleen resulting in anemia. The major requirement in thalassemia is regular blood transfusion to survive. But due to repeated blood transfusion, patients experience many life-threatening complications such as cardiomyopathy, liver diseases and endocrine dysfunction. Only 50-65% of patients reach beyond the age of 35 years in high-income countries (Ishfaq *et al.*, 2013). The present study aims to create awareness among people about the chronic disease, thalassemia by highlighting the social and economic problems faced by the parents of diseased child and to analyze the treatments being given to thalassemia patients in Pakistan.

METHODOLOGY

Study Area

The current study was conducted in District Sialkot, Pakistan. It is Pakistan's 12th most populated and one of the most important industrialized area of Pakistan.

Study Design

A survey on Thalassemia was conducted by distributing the self-administered questionnaire among patients at DHQ Sialkot and Sundas Foundation Sialkot. Consent was taken from patients, doctors and parents in case of patient was child, for their participation in the study. The questionnaire developed was divided in two sections. The first section included data on Socio-demographic and economic aspects of patients, including the area of residence (urban/rural), current age, sex and weight, family history of the disease, dietary restrictions and treatment being given. The second section of the study was carried out to estimate the awareness level regarding thalassemia among the bachelor students of GCWUS which belongs to general population of District Sialkot.

Table 1: Showing the Patient's Data

Factors to be studied	**Analysis**	**%ages**
Does patient have any family history of Thalassemia?	Yes	54%
	No	46%
Are the patient's parents' cousins/intermarriages a common practice in family?	Yes	74%
	No	26%
Gender	Male	66.7%
	Female	31.4%
Area	Urban	80%
	Rural	20%

Statistical Analysis

The data were analyzed statistically using SPSS.

RESULTS

Out of total 50 patients, 72.5% (n=37) were reported that intermarriages are common practice in their family and 52.9% (n=27) patients have a family history of thalassemia. Most patients belonged to rural areas, and the rate of thalassemia was significantly (P<0.001) high in males i.e., 66.7% and 31.4% in females (Table 1).

In the second part of study, 145 students participated. Most of them were between 18 to 23 years of age. 41.4% of were 18-19 years old, 35.2% of students were 20-21 years old, and 23.4% of students were 22-23 years old.

Table 1: Relative knowledge of students about thalassemia.

Factors	Categorization	Frequencies
Age	18-19 years	41%
	20-21 years	35%
	22-23 years	23%
Education Level	BS 2nd semester	24%
	BS 4th semester	21%
	BS 6th semester	26%
	BS 8th semester	27%
Knowledge about thalassemia	Yes	87%
	No	13%
Genetic disorder	Yes	76%
	No	24%
Cousin marriage	Yes	79%
	No	21%
Malnutrition	Yes	52%
	No	48%
Dietary restriction	Yes	41%
	No	59%
Environmental factor	Yes	32%
	No	68%
By birth	Yes	72%
	No	28%
Curable	Yes	62%
	No	38%
Genetic counseling	Yes	87%
	No	13%
Medicine	Yes	51%
	No	49%

From the sample size of 145, 86.9% (n=126) have knowledge about thalassemia, and 13% (n=19) didn't know anything. From the former group, 75.9% (n=110) students consider that it's a genetic disorder and 79.5% (n=115) consider that the high rate of thalassemia disorder is in those families in which cousin marriages are common. Additionally, 41.4% (n=60) population believe that dietary restriction while treating thalassemia and 58.6% (n=85) think that there is no dietary restriction in thalassemia. 62.1% (n=90) population consider that thalassemia is completely curable, and 31.7% (n=46) population said that an environmental factor causes it. Furthermore, its thought of 51.7% (n=75) population that

malnutrition causes thalassemia while 72.4% (n=105) population consider thalassemia is a by the birth disorder. On the other hand 59.3% (n=86) population said that there are medications used to treat thalassemia and 86.9% (n=126) population reported that genetic counseling is necessary for a genetic disorder (Table 2).

DISCUSSION

Thalassemia is one of the biggest problems faced by the world today. Studies have shown that nearly 60000 thalassemic children are born every year in the world (Ishaq *et. al.,* 2012). To date, no treatment has been known to cure thalassemia or of its root; hence the only effective methodology adopted by many countries is to prevent the birth of thalassemic children. In the currently designed first study the numbers of effective males (66.7%) were more than that of females (31.4%). A study conducted by Kiani *et al.,* (2016) and Ishfaq *et al.,* (2013) also showed that the probability of males having thalassemia was much higher than females in their respective research areas.

Unawareness regarding the disease and high illiteracy rate people are unaware about the increased risk of thalassemia and so most thalassemic patients belonged to rural areas (78.4%). Since the literacy rate is much higher in urban areas as compared to rural areas, it was observed that cousin marriages were less common there than in rural areas and so more thalassemic babies were born to rural parents. Similar results were obtained by a study conducted by Ishfaq *et al.,* (2013). The families of most of the patients were poor and were extremely worried due to financial burden they were facing. Most patients need blood transfusions once or twice a month, for most parents, frequent blood arrangements are quite difficult. Because of low family income and high treatment charges, they fail to provide sufficient treatment facilities to their children. Financial burdens eventually increase the stress level of parents. A study conducted by Ishfaq *et al.,* (2016) also showed similar results.

In the second section of designed study, awareness in general population of students belonging to different age groups was observed. It was observed that students had inadequate information regarding the disease. Most students (86.9%) claimed that they have just minor introduction of thalassemia, while a small size of population (13.1%) claimed that they have no idea about thalassemia. Many misconceptions were commonly observed among population. As, some participants about (51.7%) among population believed that the root cause behind thalassemia is malnutrition and (48.3%) believed against this idea. Some students (31.1%) believed that thalassemia was caused by some environmental factor whereas most population knew it wasn't (68.3%) thaught it's not because of these considerations. Most of respondents (62.1%) believed that thalassemia is a curable disease. These misconceptions are due to a lack of awareness programs, and because of such misconceptions, the idea of pre-marital screening is further becoming nonexistent. Keeping in view the increasing density of the disease, proper awareness sessions should be scheduled in educational and non-educational institutes. Although government and some NGOs are helping thalassemic patients by providing blood transfusion facilities and free medicines but these practices are restricted to the major urban areas and no serious effects have seen till now. The tension or superstitions seen usually in the illiterate people regarding the disease can be eradicated by proper counselling of the families suffering through it. Proper screening programs should be run in schools, colleges, and universities. Awareness must be created through seminars and social media. The only possible way to control or eradicate thalassemia from the country is to stop producing thalassemic child must be emphasized **(**Ishfaq *et al.,* 2015).

CONCLUSION

Study concluded that most of the people are unaware about the causes and consequences of thalassemia. Highly expensive treatment and medication process causes death of many children die all over the world. The awareness programs like seminars and educational lectures must be formulated about genetic counselling of people to control the thalassemia in the country.

Declaration of interest: The authors report no declarations of interest.

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REFERENCES

Asif N and Hassan K. (2016). Management of Thalassemia in Pakistan. J. Islamabad Med. Dent. Coll., 5(4):152-153.

Ishaq FH, Abid F, Kokab A, Akhtar and S. Mahmood. (2012). Awareness Among Parents of bb-Thalassemia Major Patients, Regarding Prenatal Diagnosis and Premarital Screening. J. Coll. Physicians Surg. Pak. 22 (4): 218-221.

Ishfaq K., Shabbir M., Naeem S. B., Hussain S. (2015). Impact of thalassemia major on patients; families in south Punjab, Pakistan. Prof. Med. J., 22(5):582-589.

Ishfaq, K., S.B. Naeem and J. Ali. (2013). Socio-Economic Factors of Thalassemia Major On Patients' Families: A Case Study of the Children's Hospital and the Institute of Child Health Multan, Pakistan. Int. J. Med. Appl. Health., 1(1):1-5.

Ishfaq, K., S.B. Naeem, T. Ahmad and S. Zainab. (2016). Psycho-Social and Economic Impact of Thalassemia Major On Patients' Families. Isra Med. J., 8(1): 24-28.

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Kiani, A., R., M. Anwar, U. Waheed, M. J. Asad, S. Abbasi and H. A. Zaheer. (2016). Epidemiology of Transfusion Transmitted Infection among Patients with β-Thalassaemia Major in Pakistan. J. Blood Transfus. 1-5. doi: 10.1155/2016/8135649.

Mahmoud, M.A.M. (2015). Better Understanding of Health-Related Quality of Life In Thalassemia Patients Treated By Iron Chelation Therapy In The United Arab Emirates. University of Oslo. M.Phil Thesis (Published).

Nosheen, A., Inamullah, H. Ahmad, I. Qayum, N. Siddiqui, F. Abbasi, Aziz ud Din and M. Iqbal. (2015). Premarital Genetic Screening for Beta Thalassemia Carrier Status of Indexed Families Using HbA2 Electrophoresis. J. Pak. Med. Assoc., 65(10):1047-1049.

Sharma, D.C., A. Arya, P. Kishor, P. Woike, J. Bindal. (2017). Overview on Thalassemias: A Review Article. Med. Res. Chronicles, 4 (3): 325-329.