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A Study of Knowledge, Attitude, and Practice about Thalassemia among the People of Gilgit and Azad Kashmir, Pakistan

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Abstract: *Thalassemia, an inherited blood ailment with a 5 to 8% frequency in the beta-thalassemia gene, is a significant health issue in Pakistan, regardless of ethnicity. A study was conducted in Gilgat, Azad Jammu Kashmir, Pakistan, to assess the general public's awareness of the disease. A systematic questionnaire was created, asking 24 questions on awareness. Only 178 participants answered the questionnaire, indicating low knowledge. Those who correctly answered 13-18 questions had average knowledge, while those who answered more than 18 questions had strong knowledge. Of the 178 participants who had heard the term, 5.4% had a "good" level of awareness, 20.6% had average understanding, and 74% had poor understanding. The study revealed that the general population of Gilgit and Azad Jammu Kashmir, Pakistan, had little understanding of Thalassemia.*

Key Words: Thalassemia, Gilgat, Azad Kashmir, Anemia, Pakistan, Blood Born Disease, Family Marriages

Introduction

Greek words thalassa, meaning "sea," and haima, meaning "blood," are the basis of the word "thalassemia." A broad category of hereditary blood disorders known as thalassemias are defined by low or nonexistent production of normal hemoglobin, which leads to variable degrees of microcytic anemia (Unissa et al., 2018). This condition is characterized by a marked decrease in the synthesis of one or more globin chains (Fazal et al., 2021). Worldwide, the number of newborns with clinically significant Thalassemia condition is predicted to reach 9,000,00 during the next 20 years, making it an increasing public health concern (Tang et al., 2021). Depending on the kind of reduced globin chain, this illness is categorized into the alpha and beta groups and is inherited in an autosomal recessive manner (Shang and Xu, 2017). There is a 25% probability of having a major case of Thalassemia in every pregnancy when two carriers of the Thalassemia gene are married, a 25% chance of having a normal, healthy kid, and a 50% chance of having a career affected by Thalassemia. Globally, some 240 million individuals are heterozygous for beta-thalassemia, meaning they are carriers of the disease, and every year, about 200,000 new homozygotes, or those with transfusion-dependent Thalassemia, are born (Noori et al., 2019). Nine million β-thalassemia carriers live in Pakistan, where a lack of knowledge about the disease causes 5,000 transfusion-dependent Thalassemia (TBD) babies annually. Approximately one million instances of Thalassemia, or 5% of all cases worldwide, have been documented in Pakistan so far. With a carrier percentage ranging from 5 to 8%, β-thalassemia poses a significant threat in Pakistan (Akhtar et al., 2020). Hereditary and chronic hemolytic anemia resulting in excess medullary hematopoiesis and anemia is known as beta-thalassemia. The bulk of adult hemoglobin is made up of -globin chains, which can be partially or completely defectively synthesized (Zaheer et al., 2020). Those who are impacted, therefore, require iron chelation as they become permanently dependent on blood transfusions. Pakistan is among the countries with the highest prevalence of this worldwide illness, with Thalassemia being the most frequent genetic hemoglobinopathy. It is believed that there are over 100,000 transfusion-dependent thalassemia major patients in the nation, with a yearly growth of 5000–9000 cases, despite the lack of a

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good registry (Kiani et al., 2016). The whole population consists of about 10 million carriers, which translates to an approximate carrier rate of 5-8%. One-fourth of all donated blood is used by thalassemia kids in Pakistan, and the optimal course of treatment usually costs "US$4500" for each child year. The average life expectancy of these patients is ten years. As a result, the illness severely affects the limited health and transfusion services in our country (Ahmed et al., 2021). Premarital screening for carrier identification and prenatal diagnosis, followed by the early pregnancy termination of the afflicted fetus, can be used to prevent the disease from spreading (Ansari et al., 2018).

High gene frequency, consanguineous marriages, high birth rate, population expansion, and low literacy rates are among the risk factors contributing to the high prevalence of β-Thalassemia, which affects the largest number of children with Thalassemia-dependent transfusion globally (Inam et al., 2021). Thalassemia major has a substantial economic and societal impact since a patient needs iron chelation therapy and blood transfusions either once or twice a month. Hereditary illnesses known as Thalassemia are caused by partial or complete mutations in one or more globin gene chains. Beta thalassemia is the most common genetic disorder in the world, and it is also widespread in Pakistan. It was noted that infants with Thalassemia major were born to the majority of moms who possessed the trait but were unaware of their carrier status (Qayyum et al., 2022). Many nations, such as Iran, Greece, Italy, and Cyprus, have effectively managed Thalassemia by introducing education campaigns, raising public knowledge of the disease, and emphasizing its preventative measures (Haq et al., 2017). As such, it is imperative that individuals are made aware of these challenges. In order to improve awareness of Thalassemia and enable modifications to programs promoting it, the current study evaluated the general public's knowledge of the disease in Gilgit and Azad Kashmir, Pakistan. The goal is to rid Pakistan of Thalassemia (Ahmed et al., 2017).

Review of Literature

A study evaluating parents of children with beta-thalassemia in Pakistan found that 98.4% had good views and 83.5% had sufficient understanding. The study also found a positive correlation between attitude and knowledge. 91% chose to terminate the afflicted fetus, while 93% chose to diagnose the condition during pregnancy. However, 12 percent encountered resistance from family members during diagnostic testing, increasing to 20 percent when forced to choose termination. Local religious clergy rejected prenatal diagnosis in 3% of cases and opposed abortion in 7%. The study population's knowledge, attitudes, and practices were superior to earlier research, suggesting that population screening programs can improve the knowledge, attitudes, and practices of parents of thalassemia patients (Tariq et al., 2021).

Pakistan's population is around 225 million, with a complex healthcare system involving national and local governments. Over 10 million people have a β-thal trait frequency of 5.0-7.0%, with 5000 children diagnosed annually. Blood transfusions are the main treatment, but there are no established guidelines. Many lower socioeconomic strata cannot afford treatment due to large families. There is no national thalassemia preventive program in place, and premarital screening laws have been enacted in Sindh, KPK, and Baluchistan, but implementation is still challenging at the provincial level (Khaliq, 2022).

A study was conducted at the Children's Hospital & Institute of Child Health in Multan, Pakistan, to assess parents' understanding of Thalassemia. The study involved 120 registered patients with Thalassemia major, with a sample of 120 parents used for data collection. Two senior physicians with over eight years of experience from public health institutions and thalassemia centers were consulted for the structured interview schedule. The study asked questions about disease, blood screening awareness, disease transmission mechanisms, and practices and knowledge about disease prevention and treatment. The majority of parents were mothers, with 75.0% being sent to the thalassemia center for their children's treatment. Parents comprised around 73.3% of the Seraiki ethnic group, and 63% of parents made less than 10,000 rupees a month. Only half of parents were aware that Thalassemia is a hereditary condition. The study concluded that very little was known about Thalassemia by parents. A broad public thalassemia awareness program and district-level thalassemia preventive programs should be implemented. The research was conducted from January 1st, 2015, to July 30th, 2015 (Ishfaq et al., 2016).

Methods

Study Design

The study was cross-sectional. Adults of both genders who are at least 18 years old and in their residences while the data is being collected, meet the inclusion criteria. Data was collected from different women, men, and old age people. This was a survey-based study, and people were involved in this way. Different questions were asked, and we gave them different options, and then they chose one option according to their knowledge. A few questions have only yes and no options, while the others have four options. We basically targeted 500 population-based samples, and they asked if they had heard or knew about Thalassemia, and only 178 responded that they knew or heard about this. Then we selected these seventy-eight persons and asked them different questions, and they answered according to their knowledge. Exclusion Standards Exclusions from the research were those who were not aware of the term Thalassemia, people in any medical profession, as we only consider local persons who are not involved in any medical profession, such as Doctors, Lady health visitors, nurses, and all those persons who were linked to any medical field, and parents of children known to have Thalassemia such as those parents who have one or more Thalassemia child.

Sample Size

The study comprised 500 randomly selected persons of both genders from families in Gilgit and Azad Kashmir, including urban and rural regions. Then, from these 500, we asked them whether they knew about the term Thalassemia or not, and 178 responded that they knew about Thalassemia, so we selected these 178 persons for our study. The respondents' degree of knowledge was only evaluated if they were aware of the existence of Thalassemia.

Study Period

Twelve months, from January 2022 until December 2022. After 24 questions, the Level of Awareness was determined and classified as low, average, or good. People who properly answered less than 12 questions were deemed to have inadequate knowledge. Those who properly answered 13–18 questions were considered to have ordinary knowledge. Those who properly answered more than 18 questions were deemed to have strong knowledge. The Institutional Review Board was consulted on ethical matters. The results were analyzed by SPSS version 20.

Results and Discussion

Have you ever heard of Thalassemia?

Yes	No	Total
178	322	500

From where did you know about Thalassemia?

Newspaper	Tv	Lecture	None	Total
22 (12%)	36 (20%)	45 (25%)	75(43%)	178 (100%)

Do you have ever seen any thalassemic child?

Yes	No	I don’t know	Total
36 (20%)	112 (63%)	30 (17%)	178 (100%)

Do you think Thalassemia is a genetic disease?

Yes	No	I don’t know	Total
52 (29%)	20 (11%)	106 (60%)	178 (100%)

Do you think it is a blood-borne disease?

Yes	No	I don't know	Total
96 (54%)	14 (8%)	68 (38%)	178 (100%)

How many types of Thalassemia are?

One	Two	I don't know	Total
9 (5%)	14 (8%)	155 (87%)	178 (100%)

Can a normal person have Thalassemia minor gene?

Yes	No	I don't know	Total
34 (19%)	52 (29%)	92 (52%)	178 (100%)

Do you have a Thalassemia minor gene?

Yes	No	I don't know	Total
27 (15%)	78 (44%)	73 (51%)	178 (100%)

Could a child be thalassemic if one of the Does a parent have a Thalassemia minor gene?

Yes	No	I don't know	Total
140 (79%)	9 (5%)	28 (16%)	178 (100%)

Should a normal person marry with a Thalassemia carrier?

Yes	No	I don't know	Total
71 (40%)	36 (20%)	71 (40%)	178 (100%)

Do you think Thalassemia spreads through food/eatables?

Yes	No	I don't know	Total
52 (29%)	64 (36%)	62 (35%)	178 (100%)

Do you think repeated blood transfusion is the only way of survival for a thalassemic child?

Yes	No	I Don't Know	Total
62 (35%)	34 (19%)	80 (45%)	178 (100%)

Does Thalassemia carrier need any kind of treatment?

Yes	No	I don't know	Total
41 (23%)	25 (14%)	112 (63%)	178 (100%)

Do you think the presence of Thalassemia can be detected during pregnancy?

Yes	No	I don't know	Total
41 (23%)	14 (8%)	123 (69%)	178 (100%)

If the fetus is diagnosed with Thalassemia, one should carry the pregnancy or abort it?

Yes	No	I don't know	Total
38 (21%)	96 (54%)	44 (26%)	178 (100%)

Is there any prevention for Thalassemia?

Yes	No	I don't know	Total
109 (61%)	18 (10%)	51 (29%)	178 (100%)

Do you think Govt. should use electronic or print media for Thalassemia awareness?

Yes	No	I don't know	Total
142 (80%)	7 (4%)	29 (16%)	178 (100%)

Do you think a screening test of Thalassemia should be performed on both male and female before marriage?

Yes	No	I don't know	Total
102 (57%)	14 (8%)	64 (35%)	178 (100%)

Is there any permanent solution for Thalassemia?

Yes	No	I don't know	Total
52 (29%)	22 (12%)	104 (59%)	178 (100%)

If it is, then what it should be?

Bone marrow transplant	Gene Therapy	I don't know	Total
13 (7%)	22 (12%)	143 (81%)	178 (100%)

Is there any risk of repeated blood transfusion?

Yes	No	I don't know	Total
27 (15%)	45 (25%)	106 (60%)	178 (100%)

Should iron chelating therapy be advised for a thalassemic child?

Yes	No	I don't know	Total
30 (17%)	69 (39%)	79 (44%)	178 (100%)

Is there any precaution/avoidance for some specific eatables? (iron-containing food)

Yes	No	I don't know	Total
30 (17%)	69 (39%)	79 (44%)	178 (100%)

Do you have ever donated blood to a thalassemic child?

Yes	No	Total
16 (9%)	162(91%)	178 (100%)

First of all, we took a journal survey, and in this survey, we chose 500 people, mainly from the different areas of Kashmir and Gilgit. Basically, Gilgit and Azad Kashmir are the two states of Pakistan and are called the northern areas of Pakistan, which are full of beauty and cold regions as well. People have less access to schools and other job-related areas, so also check their education level. Then, all of the five hundred respondents were asked whether they knew about Thalassemia or not. Then, only one hundred and seventy-eight responded that they had heard about the word Thalassemia. Then, for those persons who said they had heard about these diseases, we collected data, asked them different questions, and gave different options, and they responded to us according to their knowledge. We asked these 178 people where they knew or heard of this disease, and 12% told us they heard about Thalassemia from the Newspapers, 20% responded that they heard this from TV, 25% told us that they listened to this through the awareness lectures and other community-based activity lectures while 43% told different things like they heard this from any clinic base doctor, Lady health visitor, other females, mobile, internet and many other ways from where they heard about Thalassemia. Only 178 (35.6%) of the 500 survey participants had ever heard of Thalassemia; therefore, data from just these participants was used for further knowledge analysis. The individuals ranged in age from 18 to 75 years old. Of the 500 research participants, 62 people (12.4%) were under 25, 364 people (72.8%) were between the ages of 25 and 45, 72 people (14.4%) were between the ages of 46 and 65, and only two people (0.4%) were above 65. 312 (62.4%) of the 500 were male, and 188 (376.6%) were female. 310 (62%) of the 500 research participants in this study were from metropolitan areas. Out of 500 randomly selected subjects, 39 (7.8%) were illiterate (i.e., could not even write or read their own name), 87 (17.4%) had completed primary to middle school, 230 (46%) had completed their matriculation, and 144 (28.8%) had completed higher education. Of the 500 participants in the research, 124 (24.8%) were housewives, 115 (23%) workers for the government, 150 (30%) were students, 53 (10.6%)

were businessmen, 32 (6.4%) were farmers, and 10 (2.0%) were jobless. 322 out of 500 persons, or 64.4%, were not even aware of the existence of the Thalassemia disorder. Merely 178 (35.6%) research participants were informed about Thalassemia illness and underwent further testing. Many individuals were unaware that 96 out of 178 (54%), or 52 out of 178 (29%) cases of Thalassemia are blood-borne diseases. 52 out of 178 people, or 29%, believed that the sickness was spread via food and was environmental in nature. 39 out of 178 (21%) who did not wish to terminate their pregnancy even after receiving a diagnosis of Thalassemia did not realize that it may be identified during pregnancy (123 out of 178, or 69%). Additionally, they were unaware that 106 out of 178 (60%) children may suffer injury from repeated transfusions or iron. After many blood transfusions, chelation treatment is required to reduce iron excess 79 (44%).

The degree of disease awareness in a community is closely correlated with the prevalence of the illness. The goal of the current study was to determine the general public's awareness of Thalassemia in Gilgit and Azad Kashmir, Pakistan. Of those who had heard about Thalassemia, only 36% had an average to good degree of awareness. Out of 178 people, only 7 (5.4%) had an excellent understanding of Thalassemia, and 27 (20.6%) out of 500 had moderate knowledge. Out of 178 blood donors, only 9% had ever given blood to thalassemic patients. We asked them if a normal person should marry a Thalassemic carrier, and 40% persons said they didn't know whether they should marry a thalassemic person or not, and 20% said no, a person should not marry a thalassemic person. 79% of persons from the areas of Gilgit and Azad Kashmir think that a child could be thalassemic if their parents have thalassemic minor genes. Another question that is very important is whether they had a thalassemic minor gene or not. 51% didn't know about this, and 44% didn't have the minor gene, but 15% of these persons had the thalassemic minor gene. Then we asked them if a child was carrying Thalassemia. that child or about and the majority of these 178 persons thought that they should not carry that child and the percentage is 54 while 26% didn't know whether they should carry or abort, and only 21% responded yes they should abort that child. Of these 178 persons, 57% thought that before marriage, they have to do a blood test for Thalassemia. Furthermore, thirty percent of people believed that illness could be prevented by avoiding food or consumables from thalassemic individuals. Out of 178 respondents, 59% were unaware of the condition's treatment and cure, and 57% said that tests should be conducted on both sexes before marriage. Additionally, they believed that the government should inform people through electronic devices, a view that is supported by 80% of the 178 respondents.

Conclusion

It was determined that the general public in Gilgit and Azad Kashmir, Pakistan, did not know enough about Thalassemia. Public education initiatives and programs raising awareness of Thalassemia have to be planned and implemented in places of worship, education, and culture. To dispel myths, public health messages should be disseminated via print and electronic media. It is important to prioritize prenatal diagnosis and screening for Thalassemia carriers. The incidence of this deadly illness will eventually decline if all of these precautions are followed.

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