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Research Paper

Assessing Knowledge, Attitudes and Practices Related to Thalassemia: A Cross-Sectional Study Among University Students in Swat, Pakistan

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Abstract

Thalassemia is one of the most common single-gene hereditary disorders affecting hemoglobin synthesis, with significant prevalence in Pakistan. This study evaluates the knowledge, attitudes, and practices related to thalassemia among university students in Swat, Pakistan. A cross-sectional survey using a structured 37-item questionnaire was conducted with 200 students across multiple departments. The key findings indicated that 44% of the participants demonstrated sufficient knowledge of thalassemia, highlighting significant gaps in understanding, particularly regarding prenatal diagnosis (38%) and prevention measures (61%). Despite this, the majority (88.5%) exhibited positive attitudes, including support for premarital screening (84%) and public awareness campaigns (84%). However, practices such as prenatal testing (47%) and fetal termination for thalassemia major (24%) were less commonly reported. These findings highlight gaps in knowledge and practices despite favorable attitudes, underscoring the need for targeted educational and awareness programs to mitigate the burden of thalassemia in resource-limited settings like Pakistan.

Introduction

Thalassemia is a single gene disorder characterized by failure of hemoglobin synthesis (Lee et al., 2021). The ß-globin gene on chromosome 11 contains over 200 different mutations that

lead to thalassemia. Beta-thalassemia and alpha-thalassemia are the two main types of thalassemia caused by defects in the β-globin gene. These types are based on defective or absent alpha and beta chains in the hemoglobin molecule, leading to anemia and extramedullary hematopoiesis (Mitsuhara et al., 2008). If both parents are the carriers of the disease, there is a 25% chance that the baby will inherit thalassemia major as it is an autosomal recessive trait. Children with the condition present with hepatosplenomegaly and severe pallor usually in the first year of their life (Hussein et al., 2021).

Beta-thalassemia is caused by the absence or defective two beta-globin chains (Shafique et al., 2021). It is divided into thalassemia minor, intermediate thalassemia and thalassemia major. Thalassemia minor is caused by the deficiency or defect of single globin chain. patients with thalassemia minor are asymptomatic but have simple anemia (Zhou et al., 2022). Thalassemia intermediate is the intermediate condition between minor and major thalassemia. Patients with this condition require blood transfusions in times of pregnancy and illness (Baqer & Al-Humairi, 2022). Patients affected with thalassemia major have severe anemia and need repeated blood transfusion for survival. The average life expectancy of thalassemia major patients is 10 years (Tariq et al., 2021). The symptoms of the conditions appear in children in first two years of their life and not at the time of birth (Pinto et al., 2019).

Thalassemia is prevalent globally in the Mediterranean, Middle east, South Asia, North Africa, and Southern China (Baqer & Al-Humairi, 2022). According to WHO (world health organization), worldwide thalassemia is prevalent in 50 million populations across 60 countries. In south Asia, Pakistan is one the leading country with significant number of thalassemia patients, predominantly beta thalassemia. The estimated number of thalassemia major patients is 100,000 with the addition of 5000-9000 new cases every year (Kiani et al., 2016). The milder form, thalassemia minor carriers present in the population are 5% - 7% (Patel et al., 2020). Thus, the disease has a socioeconomic burden on a resource-limited country like Pakistan. One of the major causes associated with high prevalence of thalassemia is consanguineous marriages and marriages between the carrier individuals (Sohail et al., 2020).

Thalassemia is diagnosed on complete blood film suggesting microcytic and hypochromic red blood cells. It can be confirmed by PCR (polymerase chain reaction or hemoglobin electrophoresis (Sohail et al., 2020). Regular blood transfusion and bone marrow transplantations are the option for the treatment of thalassemia. Blood transfusion has its own complication although it is a convenient option. On the other hand, bone marrow transplant is not affordable for majority of the patients in the developing countries (Sidra et al., 2019).

The only way out is the prevention of the disease and that can be achieved through carriers screening, genetic counseling, prenatal detection, and creating awareness among the general population (Kalra et al., 2019). Premarital testing and counseling is not common in our society and prenatal diagnosis can be used as tool for prevention by analyzing fetus DNA via chorionic villi biopsy (CVS) in 9-10 week of pregnancy and termination of the effected fetus (Sohail et al., 2020).

Being a common genetic blood disorder, thalassemia has a considerable negative impact on both health and the economy, especially in areas like Pakistan. The frequency of new cases is still high despite advancements in prevention and treatment, frequently as a result of low awareness and ineffective preventive measures. University students represent a critical demographic as future parents and active members of society, capable of influencing public health consequences. Assessing their knowledge, attitudes, and practices (KAP) regarding thalassemia is crucial to guide educational interventions, premarital screening and genetic counseling. The objective of this cross-sectional study was to assess the knowledge, attitude, and practices among young university students regarding thalassemia in Swat. This study provides data for designing targeted strategies to reduce the prevalence of thalassemia in the study area.

Methods

A cross-sectional descriptive KAP study was conducted with students from the University of Swat from December 2021 to March 2022. Ethical approval was obtained from the vice chancellor and head of department of the University of Swat. Informed consent was obtained from all the participants in the study. Both the genders of university students were interviewed. Total 200 students were included who provided the complete data and exclusion criteria was only the refusal to participate in the study. The interviews for this pre-designed research were conducted by two interviewers fluent in Pashto (the native language) and Urdu (the national language) to avoid any possible miscommunication. A standard pre-tested structured questionnaire was designed comprising 37 questions, divided into six sections: demographics, knowledge, treatment, attitudes, households, and practices. The knowledge section evaluated participants' understanding of thalassemia’s nature, genetics, and prevention, with a scoring system defining adequate knowledge as answering at least 60% of the questions correctly (9 out of 15). Attitude and practice scores were similarly structured to classify participants' responses. The demographic and knowledge section included 7 questions, 12 questions in the

treatment section, 5 in the practice, and 2 questions in the household section respectively. The questionnaire was distributed to different departments and centers of the university.

Data analysis

Data analysis was conducted using the Statistical Package for Social Sciences (IBM SPSS, version 23). Descriptive statistics, including frequencies, percentages, means, medians, and standard deviations, were used to summarize the dataset.

Results

This study enrolled a total of 200 university students for data collection using a questionnaire. Among the participants, 54% were female and 46% were male students. The median age of the students was 21-25 years. The findings of the study presented below:

Knowledge

The questionnaire's knowledge part assessed the students' understanding of thalassemia's nature, genetics, and potential treatments (Table 1). Most of the students were informed about thalassemia as a blood disorder (89.5%).

Table 1: Distribution of study participants' (n=200) knowledge about thalassemia.

KNOWLEDGE SECTION	Responses	Percentage
Knowledge About Thalassemia		
Is thalassemia a blood disorder?	YES	89.5%
Are there different types of thalassemia?	YES	67.5%
Do parents of children with thalassemia show disease related symptoms?	NO	25.5%
Is it possible to identify thalassemia in a developing fetus in early stages of pregnancy?	YES	38%
Is there fatwa available for termination of thalassemia major fetus before 16 weeks of pregnancy?	YES	29%
Is it possible to prevent thalassemia?	YES	61%
Do pre-marital screening and pre-natal testing for thalassemia help in its prevention?	YES	49%
Knowledge About Genetics of Thalassemia		
Is thalassemia a genetic disease inherited from parents to offspring?	YES	74%
Is it required for both parents to have thalassemia major for a child to be born with it?	YES	57%
What is the percentage of having thalassemia major child in each pregnancy if both parents are thalassemia carrier?	25%	8%
Is the chances of thalassemia are higher among children born in cousin marriages?	YES	71%
Knowledge About Treatment of Thalassemia		
Do children with thalassemia require lifetime treatment?	YES	62.5%

Do regular medications for iron excess necessary for thalassemia major patients?	YES	46.5%
Is thalassemia can only be permanently cured by bone marrow transplant?	YES	55%
Can an iron overload be achieved through frequent blood transfusions?	YES	49%

About 61% of the participants knew that thalassemia is a preventable disease. The majority of students (74%) knew that thalassemia is a hereditary condition and the risk of affected children born in consanguineous marriages is high (71%). Less than a half (38%) of participants had knowledge that thalassemia can be detected in fetus in early pregnancy through pre-natal diagnosis. Only 16.8% students were aware of the fact that a Fatwa (Islamic ruling by recognized authorities) is available for terminating pregnancies affected by thalassemia major is available for the termination of pregnancy in the first trimester.

Attitude

Upon assessing the attitudes of the students regarding the prevention of thalassemia, 67% of the participants agreed to avoid consanguineous marriages and 68% agreed that two thalassemia carriers in a family should not get married. Half of the participants (51%) agreed to have prenatal testing in case of future pregnancy and only 48% were willing to abort the fetus as a result of positive results for thalassemia major. Majority (84%) advised in favor of pre-marital screening for the couple and 86% agreed to prefer both the genders for the screening. Majority of the respondents (84%) agreed on the importance of the awareness of the public for the prevention of the disease (Table 2).

Table 2: Distribution of study participants' (n=200) attitude towards thalassemia

ATTITUDE QUESTIONS	RESPONSE	Percentage
Will you prefer cousin marriages for your children between families and other members in extended family?	NO	67%
Will you encourage a person knowingly who has thalassemia to marry someone else who has the disease in your family?	NO	68%
Would you want to know if your unborn child has thalassemia if you are expecting one?	YES	51%
Will you choose abortion of your fetus if a pre-natal testing discovers thalassemia major?	YES	48%
Should a thalassemia have children if both are the carriers?	YES	53%
Which family members would you want to screen for thalassemia carriers?	BOTH	86%
Do you believe it's important to get a pre-marital screening for thalassemia?	YES	84%

Do you believe it is critical to raise public awareness of thalassemia in general population?	YES	84%

Practices

Regarding the practices of thalassemia, 70% encouraged the members of their family and relative to go for thalassemia carrier testing. Among respondents, 33% had the opportunity to advise against the marriage of two family members who are known to be thalassemia carriers. Of the respondents, 47% had the opportunity of pre-natal testing in the future pregnancy and 24% agreed on the termination of the pregnancy (Table 3). Religious, social and family opposition are the reasons for those (19%) not willing to opt for carrier screening, prenatal diagnosis and abortion of the affected fetus.

Table 3: Distribution of study participants' (n=200) practices of thalassemia

INFORMATION SOUGHT	YES	NO	DID NOT HAVE THE OPPORTUNITY
Would you advise your close relatives to have themselves and their children tested for thalassemia after seeing a family member with the disease suffering?	70%	12%	18%
Would you advise against the marriage of two family members that are known to be thalassemia carriers?	33%	31%	36%
Would you choose prenatal screening if you know your family have thalassemia as a hereditary disorder?	47%	18%	34%
Would you choose to abort the fetus with known thalassemia major after knowing thalassemia is an inherited disorder in your family?	24%	31	44%
with regard to prenatal testing, will you experience resistance from other members of your family and social circle?	19%	25%	56%

The key findings indicate that only 44% (score achieved was ≥ 60%) of participants demonstrated sufficient knowledge of thalassemia, highlighting significant gaps in understanding, particularly regarding prenatal diagnosis (38%) and prevention measures (61%). Despite this, the majority (88.5%) exhibited positive attitudes, including support for premarital screening (84%) and public awareness campaigns (84%). However, practices such as prenatal testing (47%) and fetal termination for thalassemia major (24%) were less commonly reported.

Discussion

The cross-sectional design of this study included 200 subjects. The majority of the study participants were females (54%) which was more than those included 53 (28.19%) in the study

by Basu et al. (2016). In our survey, only 44% of the study respondents having adequate knowledge of the disease. In comparison with previous studies, where 54.7% and 54.5% had adequate knowledge about thalassemia (Mirza et al., 2013; Sohail et al., 2020). Another study by Pujani et al. (2017) on first- and second-year Indian medical MBBS students found that 36.2% of students had outstanding scores of 13 (out of 15), and 52.1% of students received good scores of 10 to 12 (out of 15) (Pujani et al., 2017). Indonesian medical first-year students' median knowledge score ranked as having moderate understanding, giving them a score of 9 (out of 18) (Dewanto et al., 2015). Furthermore, a study of young Indian doctors revealed that 78.72% of the participants had enough knowledge, which was significantly higher than that of medical students (Basu et al., 2016).

In our study, we found that 74% of students accurately understood the inheritance pattern of thalassemia, compared to 66.3% of medical students in Pakistan and 85.11% of junior doctors in India (Basu et al., 2016; Sohail et al., 2020). The understanding of disease inheritance among Malaysian students was poor (Haque et al., 2015). Majority of the participants (57%) correctly identified the likelihood of a child with thalassemia having both parents as carriers, whereas 39.5% of junior doctors in Iraq gave the correct response (Baqer & Al-Humairi, 2022). In our survey, 71% of the students were aware of the role of consanguineous marriages in thalassemia transmission, which was higher than recorded by Sidra et al. (2019) and Ishaq et al. (2012). Similarly, in another research by Basu and Health (2015) only 60% of participants were aware of the hereditary nature (Basu, 2015). In this study students' knowledge of the disease's prognosis and treatment was good than many other studies. (Haque et al., 2015; Sohail et al., 2020). The most of study participants were aware of thalassemia preventive techniques, which was also in line with many previous studies (Basu et al., 2016; Mirza et al., 2013; Sohail et al., 2020).

In terms of attitude, 85.5% of participants had a positive attitude regarding thalassemia, which was higher (83.3%) than the Indonesian students (Wahidiyat et al., 2021). Basu et al. (2016) indicated 83.88 positive, however the score was only 32.5% among the junior doctors (Baqer & Al-Humairi, 2022). The preferences for consanguineous marriages were in case of thalassemia carrier were 68% while it was reported 77.5% by Baqer and Al-Humairi (2022). In our study positive attitude toward blood test before marriage was 86% for the family members. Testing blood for thalassemia for oneself was 70.5%, while testing blood for spouse and children for thalassemia was 71.5%. The majority (70%) of participants supported screening tests by family members. However, 33% of the students opposed to the marriage of two known

thalassemia carriers. Prenatal testing was endorsed by 47% of students. In a study by Baqer and Al-Humairi (2022) the percentage of attitude of blood testing for thalassemia themselves was 70.5% and for spouse and children was 71.5%. Though, preference for obligatory pre-marital carrier screening responses was 80.5% in junior doctors (Baqer & Al-Humairi, 2022), which was somewhat higher than this study. In this survey 84% of participants agreed that larger-scale awareness campaigns were required throughout Pakistan. The percentage was slightly higher 96.5% in the study conducted by Ahmed et al. (2020).

Despite having a good attitude toward thalassemia, many respondents had inadequate practice with the condition. Although 70% of the students are determined to encourage their family members to get themselves and their children screened for thalassemia mutations. But only 33% would oppose the marriage of the two family members that are known to be carriers for thalassemia carriers while 47% would opt for prenatal testing after knowing about the disease in the family. In the case of fetus diagnosis with thalassemia major, 24% of the participants were in favor to practice termination of the pregnancy, however, only 19% agreed to face opposition from family members and social circle regarding prenatal diagnosis. Premarital screening and prenatal diagnosis were strongly supported by a study by Sohail et al. (2020) with 92% recommending obligatory premarital counselling and screening. While among young Indian doctors, 93% suggested prenatal testing for the couple known to be carriers (Basu et al., 2016). However, only 5.3% of the participants in the survey among the medical students had strong thalassemia practices, compared to 33.5% of the young Indian doctors (Basu et al., 2016; Sohail et al., 2020). Only 19.3% of trainees in survey had taken a thalassemia test, relative 55.35% of Malaysian medical students (Murthy et al., 2015).

We acknowledge some limitations in our survey. This study did not analyze the results based on demographic factors such as gender, education, marital status, or socioeconomic level, which might have affected the findings. Future research could include stratified analyses to explore how these factors influence knowledge, attitudes, and practices. This would help identify specific groups that need focused interventions. Additionally, since the data was self-reported, there is a risk of response bias. Future studies could reduce this by using anonymous surveys or combining surveys with interviews to gather more detailed and reliable information.

Our findings revealed significant knowledge gaps among university students, with only 44% demonstrating adequate knowledge about thalassemia. This is particularly concerning given that university students are future community leaders and potential change agents. Addressing these gaps through targeted educational campaigns is crucial. Tailored interventions could

include integrating thalassemia awareness into university health programs, utilizing peer educators, and leveraging digital platforms for wider reach. Emphasizing the hereditary nature of thalassemia, the role of consanguineous marriages, and the importance of premarital screening could help mitigate the disease's prevalence in Pakistan.

Conclusion

The results of this study highlight significant knowledge gaps about thalassemia, particularly regarding its prevention and early detection. In Pakistan, where healthcare resources are limited, these gaps contribute to the increasing burden of thalassemia. To address this, targeted educational interventions are essential. Universities could implement awareness programs, such as workshops and informational campaigns, focused on thalassemia prevention, genetic counseling, and the importance of premarital screening. Public health initiatives should also promote the integration of thalassemia education into school curriculums and community health programs to foster early awareness and prevent further cases. These steps can significantly reduce the prevalence and socioeconomic burden of thalassemia.

Ethical approval and consent to participate

Ethical approval was obtained from ethical approval committee, Department of Zoology University of Swat (UOS/FS/2021/70). An informed consent was obtained from all participants of the study.

Authors' Contribution

All authors equally contributed to the study design, creation of the study protocol, and development of the questionnaire.

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