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Original Research Article

Knowledge, attitude, and practices of thalassemia amongst urban community members: a cross-sectional study

Besher Shami[1]*, Rameen Khalid[2], Abdullah Bin Kamran[2], Muhammad Ahmad Khalid[2], Farhan Shahzad[2], Muhammad Ebad ur Rehman[2], Omaima Asif[2], Faizan Shahzad[2], Hamza Khan[2]

[1]Department of Medicine, Berkshire Medical Center, Pittsfield, MA, USA
[2]Department of Medicine, Rawalpindi Medical University, Rawalpindi, Pakistan

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***Correspondence:**
Dr. Besher Shami,
E-mail: Besher_shami@outlook.com

ABSTRACT

Background: Thalassemia is a global health concern due to its high prevalence and the absence of a cure. Around the world, there are approximately 100 million carriers of beta-thalassemia, with roughly 100,000 of them being children. A KAP study on thalassemia can provide valuable insights into the perceptions, and behaviors of Pakistani individuals, communities, or healthcare professionals related to the disease.
Methods: We conducted a descriptive cross-sectional study in Rawalpindi, Pakistan. After taking consent, data was collected from 368 individuals, through a mixed-mode questionnaire that was administered both online and in person, from July 2nd, 2023 to August 30th, 2023. Data was collected and cleaned in excel and then imported into IBM® SPSS v27 statistical package.
Results: Data was gathered from 368 individuals with 168 (43.8%) males and 206 (55.7%) females. The mean age of the participants was 34.57±13.19. Independent Samples T-test showed no significant difference in KAP Scores between both genders (p= 0.448). One-way ANOVA showed significant differences among different education level (F-statistic= 40.45, p=0.02). Lastly, bivariate correlation analysis between Age and KAP Scores showed a negative weak correlation (Coeff. = -0.25, p= 0.01).
Conclusions: The population mean scores for knowledge were 5.95±3.200 out of 12, for attitude, 6.40±2.032 out of 10, and for 3.49±1.526 out of 6. Higher Education led to higher KAP scores. Lastly, age was seen to negatively affect KAP scores, with higher KAP scores pertaining to thalassemia seen in younger individuals.

Keywords: Attitude, Knowledge, Thalassemia

INTRODUCTION

Thalassemia is a genetic blood disorder affecting the production of globin chains, essential for making hemoglobin. It is the most widespread single-gene disorder in the world. Thalassemia can be caused by different mutations in the genes that code for globin chains, resulting in two primary forms: alpha- and beta-thalassemia.[1] Hemoglobin carries the oxygen inside RBCs. A normal hemoglobin molecule (HbA) has four chains: two alphas and two betas. In normal adult blood, there are also small amounts of other types of hemoglobin: hemoglobin A2 (HbA2), which has delta chains instead of beta chains, and hemoglobin F (HbF), which is the fetal hemoglobin which has gamma chains instead of beta chains.[2] The child's body does not make hemoglobin chains enough or at all. However, the other chains that form globin keep being made. This leads to the creation of harmful protein parts that damage the blood cells.[3] Thalassemia is a condition that occurs when

the body does not make enough of one or more globin polypeptide chains (beta, alpha, gamma, delta), which are the parts of hemoglobin. This causes the red blood cells to be small, often misshaped, and easily broken down. This leads to low blood count and often too much iron in the body.[4]

Thalassemia is a global health concern due to its high prevalence and the absence of a cure. Around the world, there are approximately 100 million carriers of beta-thalassemia, with roughly 100,000 of them being children.[1] Thalassemia is a condition that is commonly found in regions such as Southeast Asia, the Indian subcontinent, the Mediterranean, Middle Asia, Central Asia, and West Africa.[5] Hemoglobinopathy is a condition that is highly prevalent in South Asia, including countries such as India, Pakistan, Bangladesh, and Sri Lanka. This region represents approximately 23% of the world's population, or around 1.56 billion people.[6]

Thalassemia is a genetic disorder that results in an imbalance in the ratio of alpha and beta chains, leading to ineffective production of red blood cells and chronic hemolytic anemia. The condition is divided into two groups based on the severity of the symptoms: transfusion-dependent thalassemia (TDT) and non-transfusion-dependent thalassemia (NTDT). Both conditions are characterized by chronic anemia, ineffective production of red blood cells, and an overload of iron, but their clinical courses and complications can differ.[7] In Vietnam, screening for thalassemia is primarily based on two indicators, mean corpuscular volume (MCV) and mean corpuscular hemoglobin (MCH), and is performed manually. There is currently no clinical decision support system (CDSS) in place for thalassemia screening. This can create challenges in preventing disease at primary healthcare facilities and in ethnic minority areas, where there may be limited understanding of thalassemia among both the general population and medical staff at the grassroots level.[3]

In Indonesia, definitive treatments for thalassemia, such as bone marrow transplant and hematopoietic stem cell therapy, are not widely available, particularly for those with low socioeconomic status. As a result, the recommended approach for preventing thalassemia in Indonesia is through population screening.[8] Many countries have reported success in reducing the number of new cases of thalassemia through preventive measures. For example, Cyprus, Greece, and Italy have all implemented successful thalassemia prevention programs.[9] It is not clear whether couples who have undergone screening for thalassemia would be willing to cancel their marriage based on the test results. A study conducted in Iran found that half of all couples who were carriers of β-thalassemia still chose to proceed with their marriage. In other countries, couples who are carriers of thalassemia can undergo antenatal diagnosis to prevent their baby from being born with the disease, but this may not be a feasible option for everyone.[10]

A Knowledge, Attitude, and Practice (KAP) study on thalassemia can provide valuable insights into the understanding, perceptions, and behaviors of Pakistani individuals, communities, or healthcare professionals related to this genetic disorder. The rationale for conducting such a study includes awareness and education, early diagnosis and treatment, prevention and management, and policy development, and the KAP study can also reveal the social and physiological impact of thalassemia on individuals and families.

METHODS

Study design

We conducted a descriptive cross-sectional study in Rawalpindi, Pakistan. The study lasted from July 2nd, 2023, to August 30th, 2023. Participants who were: (1) age 18 and above; (2) willing to provide informed consent after understanding the research aims and objectives; (3) residents of Pakistan, were included in the study. STROBE guidelines were followed for reporting the data.

Questionnaire

A questionnaire was used to assess Knowledge, Attitudes, and Practices concerning Thalassemia among the participants. This questionnaire was adapted from the works of Wahidiyat et al.[10] Data was collected through a mixed-mode questionnaire that was administered both online and in person.

Data collection

Convenience sampling (non-probability) was used. Data was collected from 368 participants after taking informed consent. Male and Female participants ranging from 18 years of age onwards, took part in the study. The sample size was calculated to be 200, by keeping the value of significance as less than 0.05 and using the prevalence of thalassemia in Pakistan as 7% and a design effect of 2.[11]

Outcomes

KAP scores were calculated. For each component, correct knowledge answers, good attitudes, and good practices were awarded 1 point, while incorrect knowledge answers, bad attitudes, and bad practices were awarded 0 points. The maximum points for knowledge component, attitude component, and practice component were 12, 10, and 6, respectively. The points for individual questions were summed and reported as KAP score totals.

Data Analysis

Data was collected and cleaned in Excel and then imported into IBM® SPSS v27 statistical package. Descriptive Statistics were explored. Normality was analyzed for Age and categories of KAP scores using the Shapiro-Wilk test. Independent Samples T-test was used

to compare KAP score means for males and females. ANOVA was performed to evaluate the association between Education Level and KAP scores. Bivariate correlation analysis was employed to assess the relation between Age and KAP scores. The p values of <0.05 were considered significant. All personal data was kept confidential and anonymity was maintained. The study was approved by the Institutional Review Board of Rawalpindi Medical University, Pakistan.

RESULTS

Data was gathered from 368 individuals with 168 (43.8%) males and 206 (55.7%) females. The mean age of the participants was 34.57±13.19. Education status was divided into 5 categories: 42 (11.4%) participants never went to school, 52 (14.1%) were in primary school, and 68 (18.4%) participants were in secondary school. 70 (18.9%) participants were in high school, whereas 136 (36.8%) were in a bachelor's program. 286 (77.3%) of the participants knew that thalassemia is a problem with RBCs. However, only half were knowledgeable of the inheritance (64.1%), carrier state (35.3%), and relation with consanguinity (53.3%), detection (64.1%), and treatment (69%) of thalassemia. However, the participants had a piece of low knowledge regarding screening (49.3%), prevention (37%), and curative treatments such as bone marrow transplant (32.1%)

KAP scores were divided into knowledge, attitude, and practice scores. They were summated to calculate total KAP scores.

Age, knowledge scores, attitude scores, practice scores as well and KAP scores in total were all normally distributed. Independent Samples T-test showed no significant difference between male and female participants (p=0.448), as shown in Table 2.

Table 1: Description of participant data.

		Value
Age (years)[a]		34.57±13.199
Gender	Male	162
	Female	206
Education level	Never went to school	42
	Primary school	52
	Secondary school	68
	High school	70
	Bachelor's program	136
Knowledge scores[a]		5.95±3.200
Attitude scores[a]		6.40±2.032
Practice scores[a]		3.49±1.516
KAP scores[a]		15.84±5.319

[a]Values are mean±SD

One-way ANOVA was run to evaluate the association between the education level of the participants and KAP scores. The results showed significant differences among the groups in education level (F-statistic= 40.45, p=0.02). KAP score means for each education level are shown in Table 1. These indicate an increasing trend for KAP scores with higher education levels as shown in Figure 1.

Table 2: Independent Samples T-test for gender and KAP scores.

		Sig. (2-tailed)	Mean difference	Std. error difference
KAP scores	Equal variances assumed	0.448	-0.424	0.559
	Equal variances not assumed	0.450	-0.424	0.561

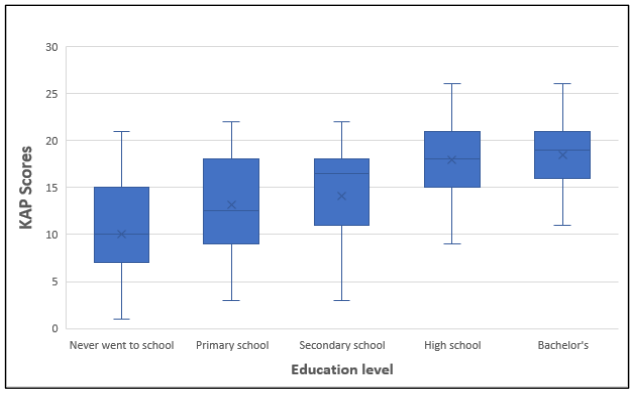

Figure 1: Distribution of KAP scores across education levels.

Lastly, bivariate correlation analysis between age and KAP scores showed a negative weak correlation (Coeff. = -0.25, p=0.01).

DISCUSSION

This research uncovered the level of awareness and behavior patterns among people of Rawalpindi about thalassemia. There were 368 responses gathered from Holy Family and Benazir Bhutto Hospital, Rawalpindi. Out of these there were 168 (43.8%) males and 206 (55.7%) females. 77.3% of respondents knew that thalassemia is a blood cell (RBC) related disorder, however 22.3% did not know thalassemia. This is a positively fair response as compared to other countries which include Bangladesh at 33%, Saudi Arabia at 48%, Turkey at 58%, Bahrain at 65%, Malaysia at 76.4%, Italy at 85%, and Greece at 95%.[12]

According to our survey, the majority of participants were already familiar with the basic concept of thalassemia. They understood it as a blood disorder characterized by abnormalities in red blood cells and inherited in an

autosomal recessive manner (64.1%). According to demographics, there were more females than males who filled out the questionnaire and had knowledge about thalassemia, but this is not true in many areas of Pakistan especially rural areas as most women are housewives there and have no such knowledge about thalassemia and other diseases. The majority of people knew that thalassemia is a red blood-related disorder, but more than half of respondents did not know the difference between leukemia and thalassemia

46.7% of the respondents did not know about consanguinity and thalassemia. There is a need to enhance public understanding of the risks associated with marriages between close relatives, as such unions can increase the likelihood of having a child with thalassemia. Marriages between relatives can lead to a higher occurrence of recessive alleles, resulting in a concentration of mutations within a specific community. It has been observed that the frequency of marriages between relatives is high in rural areas and among communities that are economically disadvantaged and have low levels of education.[13] According to another study, in 36% of the families surveyed, marriages between relatives were common, given that they did not perceive any associated risk. Only a small number of individuals considered it crucial to undergo thalassemia screening before marriage, with the actual practice of such testing being as low as 2%. The fear of social stigma in the event of a positive outcome, along with religious beliefs, are thought to influence decisions about screening.[14]

A significant number (64.7%) of the survey participants still lacked detailed knowledge about thalassemia carriers and the distinction between carriers and patients with thalassemia major. This could be attributed to a lack of understanding of the different forms of thalassemia, which are primarily categorized into alpha and beta-thalassemia. Individuals who are carriers of the thalassemia trait typically do not show any symptoms, and as a result, they may never seek medical care.

The study participants' educational status was categorized into five groups, each demonstrating a distinct level of knowledge about thalassemia, as measured by the KAP score. Those who never attended school, representing 11.4% of the participants, had a basic understanding of thalassemia, with a KAP score of 10.10. Participants with primary education, comprising 14.1% of the group, showed a slightly improved understanding, reflected in their KAP score of 13.15. As the level of education increased to secondary school and high school, 18.4% and 18.9% of the participants respectively, a noticeable improvement in thalassemia knowledge was observed. Their KAP scores were 14.09 and 17.91 respectively. The group with the highest level of education, those in the bachelor's program, made up the largest portion of the participants at 36.8%. They also had the highest KAP score of 18.46, indicating a strong understanding of thalassemia. This pattern suggests a positive correlation between the level of education and knowledge about thalassemia. As participants' education level increased, so did their understanding of the disease, highlighting the role of education in enhancing disease awareness.

Most respondents had a positive attitude towards the treatment of thalassemia but only 37% had knowledge about prenatal screening, around half of respondents had knowledge of prevention and one-third had knowledge about treatment options (including gene therapy and bone marrow transplant) of thalassemia. Given that a mother's attitude towards carrier testing significantly influences her future reproductive decisions, it's crucial to educate young people about the importance of carrier testing, as they are the future parents.[15] Research conducted in Malaysia revealed that while a significant majority of participants had a positive view toward screening for thalassemia, only 13.6% of those who were married underwent the test.[16]

Respondents had a positive attitude towards treatment and prevention but many of them did not know the treatment options and methods of prevention of thalassemia. It's heartening to see that a majority of the respondents were already aware of thalassemia. However, there's a subtle but significant difference between simply knowing about the disease and truly understanding it. This distinction becomes particularly important considering many respondents who were aware of thalassemia reported getting their information from social media. Over the years, there has been a substantial increase in the number of young people using the Internet to seek health information. However, it's suggested that only a small percentage consider social media as a reliable and useful source of information.[17]

This study is not representative of the Pakistani youth population; the results of this study cannot be generalized to the overall population of Pakistan. The study duration is from July 2nd, 2023, to August 30th, 2023, which is a very small frame of time. Cross-sectional studies cannot establish a cause-effect relationship. The sample size of this study is also very small and only represents a part of the population of Rawalpindi. We cannot analyze behavior over time with a cross-sectional study as it is limited to a specific moment, for analysis of behavior over time it's optimal to conduct longitudinal or experimental study.

CONCLUSION

The study showed the population mean scores for knowledge to be 5.95±3.200 out of 12, for attitude to be 6.40±2.032 out of 10, and for 3.49±1.526 out of 6. There was no significant difference among genders, in KAP scores. Although, education proved to be a strong influence on KAP scores, with an increase in KAP scores seen with increasing education levels. Lastly, age was seen to negatively affect KAP scores, with higher KAP

scores pertaining to thalassemia seen in younger individuals.

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