PSM Journals

PSM
Biological Research

Data Analysis 2026 | Volume 11 | Issue 1 | 84-89

Open Access

Article Information

Received: August 15, 2026

Accepted: September 3, 2026

Published: September 21, 2026

Authors' Contribution

SM conceived and designed the study; AS and II conducted experiments; RH did statistical analysis; MH and RH wrote and revised the paper.

How to cite

Hasan, M., Malik, S., Sajid, A., Imaan, I., Hasan, R., 2026. Knowledge, Awareness, and Attitudes toward Thalassemia and Premarital Screening among Young Adults. PSM Biol. Res., 11(1): 84-89.

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Knowledge, Awareness, and Attitudes toward Thalassemia and Premarital Screening among Young Adults

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Abstract:
Thalassemia is among the most common genetic hemoglobin disorders and remains a major public health concern in Pakistan. Premarital screening is an effective preventive measure; however, its success depends on adequate public knowledge and awareness. This study assessed the knowledge, awareness, and attitudes toward thalassemia and premarital screening among young adults. A cross-sectional survey was conducted among 165 young adults using a structured self-administered questionnaire. Data on demographic characteristics, knowledge, awareness, attitudes, and sources of information were collected. Descriptive statistics and the Chi-square test were used for data analysis. Overall, 86.1% of participants had heard of thalassemia, 78.8% identified it as a genetic disorder, and 65.5% correctly recognized it as hereditary, whereas only 49.7% were aware that the disease is preventable. Positive attitudes toward premarital screening were observed, with 69.1% considering screening important before marriage and 65.5% favoring mandatory screening. Educational institutions (41.8%) and social media (37.6%) were the reported primary information sources. More than half (56.9%) of participants exhibited good knowledge, and no significant statistical relationship was observed between gender and knowledge level ($p = 0.120$). Young adults demonstrated generally good knowledge and positive perceptions toward thalassemia and premarital screening. However, important gaps in knowledge regarding disease prevention persist, highlighting the need for comprehensive educational and community-based awareness programs.
Keywords: Thalassemia, β-thalassemia, Premarital screening, Inherited disorders, Genetic counseling, Awareness of thalassemia.

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INTRODUCTION

Thalassemia is one of the most prevalent hemoglobinopathies, characterized by defective biosynthesis of globin chains, resulting in impaired erythropoiesis, chronic hemolytic anemia, and varying degrees of disease severity (Cousens *et al.,* 2010; WHO, 2021). β - Thalassemia is the most prevalent form and poses a major public health challenge in South Asia, the Middle East, and the Mediterranean region (Weatherall, 2010). Globally, approximately 270 million individuals are carriers of hemoglobin disorders, and nearly 60,000 children are born annually with severe thalassemia requiring lifelong treatment (Cao and Kan, 2013). In Pakistan, the carrier frequency of β-thalassemia is estimated to be 5–7%, with approximately 90,000–100,000 affected individuals, making prevention a national health priority (Ahmed *et al.,* 2002; Durrani *et al.,* 2023; Haq *et al.,* 2025).

As thalassemia is transmitted through an autosomal recessive pattern of inheritance, carrier couples with each pregnancy have a 25% probability of producing an affected offspring (Cousens *et al.,* 2010). Thalassemia major patients depend on lifelong repeated blood transfusions and iron chelation therapy, resulting in substantial psychological, social, and economic burdens on families and healthcare systems (Taher *et al.,* 2018). Therefore, strategies, including carrier detection, genetic counseling, and premarital screening, are considered the most effective preventive measures for reducing the incidence of thalassemia (Old, 2003; Weatherall, 2010).

Premarital screening performs a critical role in the identification of carrier couples before marriage to promote informed reproductive decision-making. Countries that have implemented premarital screening and counseling programs have reported significant reductions in the number of children born with thalassemia (Old, 2003; Alhamdan *et al.,* 2007). Despite the awareness of the genetic inheritance of thalassemia, carrier status, and the importance of premarital screening remains insufficient in many developing countries, including Pakistan (Ahmed *et al.,* 2002; Mirza *et al.,* 2013; Bakar and Khan, 2024). The marriages within the family increase the chances of hereditary hematological disorders, thus emphasizing the importance of public awareness programs (Bittles, 2001).

Young adults are the suitable audience to educate about thalassemia prevention as they are at the stage of life where decisions about marriage and to start the family are made. Assessment of their knowledge, awareness, and attitudes about thalassemia and premarital screening enables to identify misconceptions and Knowledge deficits while also provides the foundation for developing effective educational programs. Therefore, the objective of this study is to evaluate the knowledge, awareness, and attitudes toward thalassemia and premarital screening among young adults.

MATERIALS AND METHODS

A cross-sectional survey was conducted among young adults. A total of 165 participants were selected via convenience sampling during a university awareness campaign and through an online survey. Subjects who provided consent to participate and completed the study questionnaire were included in the study. Ethical approval was obtained from the Departmental Ethical Review Committee (Approval # DRC-16/2025).

Data were obtained using a structured questionnaire, containing four sections: demographic characteristics (age, gender, and educational level), knowledge and awareness of thalassemia, attitudes toward premarital screening, and sources of information regarding thalassemia. During the awareness campaign, participants were given a brief information on thalassemia and the importance of premarital screening.

Participants voluntarily enrolled in the study, and the confidentiality and anonymity of participants' responses were ensured. Data were analyzed using descriptive statistics, while relationship between categorical variables were assessed

using the Chi-square test. A p value < 0.05 was considered statistically significant.

RESULTS

In the present study the total number participants were 165 young adults. Females constituted 69.1% of the sample (n = 114), whereas males comprised 30.9% (n = 51). Most of the participants were undergraduates (72.7%), followed by graduates (23.0%) and postgraduates (4.2%) (Table 1).

Table 1. Characteristics of the participants (N = 165).

Variable	n	%
Gender		
Female	114	69.09
Male	51	30.91
Education		
Undergraduate	120	72.73
Graduate	38	23.03
Postgraduate	7	4.24

Awareness and Knowledge of Thalassemia

A total of 86.1% of participants had heard of thalassemia. Approximately 78.8% of the respondents correctly identified thalassemia as a genetic disorder, while 65.5% recognized its hereditary nature. However, only 49.7% were aware that thalassemia can be prevented through appropriate preventive measures. Overall, 65.5% of participants supported premarital screening (Table 2).

Table 2. Overall awareness of thalassemia.

Variable	Correct response	n	%
Heard about thalassemia	Yes	142	86.06
Knows thalassemia is a genetic disease	Yes	130	78.79
Knows thalassemia is hereditary	Yes	108	65.45
Knows thalassemia can be prevented	Yes	82	49.7
Supports premarital screening	Yes	108	65.45

Attitudes toward Premarital Screening

Table 3 represented the attitudes toward premarital screening were common. A majority of participants (69.1%) believed that screening before marriage is important. Similarly, 65.5% supported mandatory premarital screening, while 45.5% reported that they would encourage others to undergo premarital screening.

Table 3. Attitude toward premarital screening.

Attitude statement	Response	n	%
Screening before marriage	Yes	114	69.09
Mandatory premarital screening	Yes	108	65.45
Encourage others for premarital screening	Yes	75	45.45

Sources of Information

Educational institutes were the most frequently reported source of information about thalassemia (41.8%), followed by social media (37.6%). Family and friends accounted for 17.0% of responses, whereas healthcare professionals were reported by only 3.6% of participants (Table 4).

Table 4. Sources of information about thalassemia.

Source of information	n	%
Social media	62	37.58
Educational institutes	69	41.82
Healthcare professionals	6	3.64
Family/Friends	28	16.97

Overall Knowledge Level

Based on the combined knowledge score (Table 5), 56.9% of participants demonstrated a good level of knowledge regarding thalassemia, while 26.1% had moderate knowledge and 17.0% had poor knowledge.

Association between Gender and Knowledge Level

Chi-square analysis revealed a non-significant relationship between gender and knowledge level regarding thalassemia ($\chi^2 = 4.24$, $p = 0.120$), indicating that knowledge levels were

comparable between male and female participants (Table 6).

Table 5. Overall Knowledge Score Regarding Thalassemia among Participants.

Knowledge Level	n	%
Poor	28	16.96
Moderate	43	26.06
Good	94	56.97
Total	165	100

Table 6. Genderwise Knowledge Score Regarding Thalassemia among Participants.

Knowledge Level	Females	Males
Poor	17	11
Moderate	26	17
Good	71	23
Total	114	51

DISCUSSION

The present study about the assessment of knowledge, awareness, and attitudes toward premarital thalassemia screening among young adults demonstrated satisfactory awareness of thalassemia and generally positive attitudes toward premarital genetic screening. Most participants had heard about thalassemia and correctly identified it as a genetic disorder. However, important knowledge gaps remained regarding its hereditary nature and prevention, as only about half of the participants were aware that thalassemia can be prevented through effective preventive interventions. These observations are consistent with previous studies conducted in Pakistan and other countries, which indicated moderate-to-good awareness of thalassemia but limited knowledge about carrier status, inheritance patterns, and early detection screening among young adults and the general population (Ebrahim *et al.,* 2019; Noor *et al.,* 2020; Durrani *et al.,* 2023; Musa *et al.,* 2025; Mehndrani *et al.,* 2025).

More than 50 % of the participants had a good overall knowledge score, while approximately 25% had moderate knowledge and a smaller proportion had poor knowledge. A statistically non-significant association was found between gender and knowledge level, suggesting comparable thalassemia awareness among male and female participants. These results are in agreement with some previous studies, although other studies have reported higher awareness among females, potentially due to greater interest in reproductive and preventive health issues (Ebrahim *et al.,* 2019; Qayyum *et al.,* 2022).

In the present study a positive attitude toward premarital screening was observed. More than 66 % of the participants considered premarital screening as important and favored its implementation mandatory before marriage. These findings indicated an increasing adoption of preventive measures among young adults. Consistent to the present observations, the studies from Pakistan and neighboring countries reported the positive attitudes towards the premarital screening as an effective measure for reducing the prevalence of thalassemia (Mirza *et al.,* 2013; Durrani *et al.,* 2023).

Successful national screening initiatives launched in countries particularly in Iran and Cyprus have shown that premarital screening, in conjunction with genetic counseling, can significantly reduce the incidence of thalassemia major among newborns (Samavat and Modell, 2004).

Educational institutions were the most frequently reported source of information, followed by social media, whereas healthcare professionals contributed only a small proportion of participants' knowledge. Similar findings have been reported previously, highlighting universities and digital media as major sources of health information for young adults (Alhowiti and Shaqran, 2019; Ebrahim *et al.,* 2019; Maqsood *et al.,* 2026). The relatively limited role of healthcare professionals in providing thalassemia-related information in the present study highlights the need for greater involvement of physicians, laboratory professionals, and genetic counselors in thalassemia awareness initiatives. In addition educational initiatives through universities, seminars, and social media campaigns, may improve awareness and

encourage the participation in premarital thalassemia screening.

Overall, the findings highlight the importance of comprehensive educational strategies to improve awareness of thalassemia, its genetic transmission, and preventive premarital screening. Introducing thalassemia education in university curricula, together with community-based awareness and genetic counseling services, may contribute to reducing the burden of β-thalassemia in Pakistan through informed reproductive decision-making (Samavat and Modell, 2004; Maheen *et al.,* 2015; Taher *et al.,* 2018).

CONCLUSION

The present study demonstrated adequate awareness and generally positive attitudes toward thalassemia and premarital screening among young adults. Despite this many subjects were unaware of the genetically inherited nature of thalassemia and how it can be prevented. Implementing educational programs through universities, healthcare professionals, and community-based awareness programs may improve public knowledge and facilitate informed reproductive decision-making, thereby contributing to thalassemia prevention in Pakistan.

CONFLICT OF INTEREST

The authors hereby declare that they have no conflict of interest.

ACKNOWLEDGEMENT

The authors are sincerely grateful to the Chairperson, Department of Physiology, University of Karachi, for providing the facilities required for the successful completion of this research.

Generative AI statement

The author(s) declare that no Generative AI was used in the creation of this manuscript.

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