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ASSESS AWARENESS AND KNOWLEDGE AMONG PARENTS OF CHILDREN WITH BETA THALASSEMIA MAJOR IN KARACHI, PAKISTAN.

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Abstract

Thalassemia is a genetic disorder characterized by impaired hemoglobin production and is the second most prevalent disorder worldwide.

Methodology: *An analytical cross-sectional study was conducted amongst 250 participants from both the Fatima foundation and Kashif Iqbal Thalassemia Care Private centers from June 2024 to January 2025, and convenient sampling techniques was used in this study.*

Results: *The majority of the children were cared for by their mothers (61.6%), who had no formal education (58.0%), who reported consanguineous marriages (73.6%) after childbirth, mainly (84.8%) one child was affected by thalassemia. However, to assess the knowledge and awareness, over half of the respondents (52.8%) correctly identified thalassemia as a hereditary disease, (88.8%) of participants reported No knowledge about thalassemia prior to their child being, (43.2%) did not know about spreading through blood transfusion, while according to the awareness about complication (62.4%) did not aware, well in term of prevention (38.0%), and (52.4) were unaware about the screening during antenatal period. Besides, Chi X^2 was also used to identify the association between independent and dependent variables in which there is an association between the both parents need to have thalassemia minor for a child to be born with thalassemia major 56 (30.4%) with ($p = 0.027$), similarly related to the antenatal screening parents were not aware 79 (42.93%) as ($p = 0.015$). Pertaining, to the Parents Based on Number of thalassemia children; where statistically significant difference was observed in awareness of the types of thalassemia, with (22.4%) of respondents with one child and (27.5%) with more than two children indicating "Yes" ($p = 0.039$), likewise Awareness of antenatal screening for thalassemia children was also significantly higher in those with more than two children, with (53.8%) of those with one child and (34.1%) of those with more than two children indicating "Yes" ($p = 0.009$) respectively.*

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Conclusion: *We conclude that parents of thalassemia-affected children do not know enough about the condition. There is no screening to rule out the etiology of the condition, and parents know very little about hereditary disorders.*

INTRODUCTION

Thalassemia is a genetic disorder characterized by impaired hemoglobin production due to defects in the synthesis of alpha and beta globin chains, leading to excessive destruction of red blood cells. This autosomal recessive condition is classified into two primary types: alpha thalassemia, involving defective alpha-globin chains, and beta thalassemia, involving defective beta-globin chains, resulting in varying degrees of anemia and other complications [1]

Beta thalassemia impairs hemoglobin's beta globin chain synthesis, leading to premature red blood cell destruction. The disorder's severity varies depending on genetic involvement: Thalassemia minor occurs when one gene is normal and one abnormal, Thalassemia intermedia when both genes are involved with symptoms appearing later in life, and Thalassemia major, the most aggressive form, when both genes are involved with symptoms manifesting early in infancy. This results in abnormal red blood cells being rapidly destroyed, primarily by the spleen, causing microcytic hypochromic anemia and iron overload due to excessive red blood cell turnover.[2]

Thalassemia ranks as the second most prevalent hemoglobin disorder worldwide, surpassed only by sickle cell disease in terms of global frequency. [3], according to the World Health Organization [WHO] (2020), thalassemia is the most prevalent genetic blood disorder globally. A recent study reveals alarming statistics: approximately 9 million thalassemia carriers become pregnant annually, putting 1.33 million children at risk of developing thalassemia major each year. [4] Approximately 56,000 pregnancies worldwide are affected by thalassemia each year, with around 30,000 cases being beta thalassemia, according to global estimates.[5]

Beta thalassemia is predominantly found in tropical and subtropical regions, particularly in Mediterranean countries, South East Asia, the Middle East, and the Indian subcontinent. The disorder has notably high carrier frequencies in Cyprus (14%), Sardinia (10.3%), and Southeast Asia (1-9%), indicating a significant genetic presence in these populations, making targeted screening and prevention strategies crucial in these areas.[6]

Similarly, in Pakistan, beta thalassemia is the most common inherited disorder where prevalence rates range from 5-9%, with approximately 9 million carriers nationwide and 4,000 to 9,000 newborns being diagnosed with transfusion-dependent thalassemia annually and their average life expectancy for these patients is only around 10 years, but due to scarcity in national registry for many villages dwelling children remain unregistered therefore only22,000 registered patients receiving care of the significant genetic disorder.[7]

Most of this figure consists of children residing in villages that are not registered with any Centre. Due to lack of research at national level, accurate data is nonexistent at the population level. The available data is mostly from hospital based and selective small-scale studies conducted at the local level [8]

Data from these studies suggest that the prevalence rate of beta thalassemia is around 5-9%, and approximately 9 million carriers of beta thalassemia produce around 4,000 to 9,000 newborns every year who are transfusion-dependent for thalassemia, with the patient's average life expectancy being 10 years.[9]

In addition, Beta-thalassemia's high frequency in Pakistan is exacerbated by socio-cultural factors, including low income, lack of awareness, and marriages within the same ethnic groups, besides consanguineous marriages, a common practice, increase the disease's risk due to inherited genetic mutations, Limited education, patriarchal structures restricting women's decision-making, and cultural norms prioritizing family ties over health considerations further contribute to the issue(World Health Organization, 1997, Rafique,& Moinuddin,1991.[10,11]

The WHO also initiated the thalassemia control program, focusing on public awareness, screening, and genetic counseling, which has successfully prevented affected births. Implemented in various countries, this program has yielded remarkable results, with Cyprus reporting no thalassemia births

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since 2001 and Sardinia reducing the birth rate of thalassemia major from 1:250 to 1:4000, demonstrating the effectiveness of preventive measures in mitigating the impact of this genetic disorder.[12,13]

Thalassemia Major imposes significant economic and social burdens due to the necessity of frequent medical interventions, including monthly or bi-monthly blood transfusions, ongoing iron chelation treatment, blood analysis, and electrophoresis testing, resulting in substantial healthcare expenditures and impacting patients' quality of life.[14,15,9]

A significant majority of mothers carrying the Thalassemia trait lacked awareness of their status, resulting in the birth of children afflicted with Thalassemia Major as Pre-marital screening can benefit couples at risk of genetic issues or marital problems.[9] Likewise, in traditional Asian cultures, marriage is a complex, family-driven institution. Even if screening reveals high risks, committed couples may proceed with the wedding to avoid social stigma, shame, and family disapproval from the breaking of the relationship between the two families.[16]

Moreover, the Regions with high concentrations of thalassemia include Africa, the Mediterranean, the Middle East, the Indian subcontinent, Southeast Asia, Melanesia, and Pacific islands, where carrier frequencies range from 1% to 20%. Notably, while prevalence range can be between (10-20%) in Sub-Saharan Africa, in the Middle East and India (up to 40%), and in Northern Papua New Guinea and North-East India (up to 80%). Globally, approximately 3% of the population carries β-thalassemia.[17]

Additionally, a 2023 study at Muhammad Abdur Rahim Medical College in Bangladesh surveyed 320 caregivers of children with thalassemia, revealing significant awareness and healthcare access gaps. The caregivers, comprising 46.9% fathers and 53.1% mothers, mostly (80%) of them had one affected child, while 17.2% had two or more. Notably, 90.9% were unaware of thalassemia before their children were diagnosis, and none underwent pre-marital thalassemia screening due to unequal access to quality healthcare, high out-of-pocket expenses, and cultural norms, highlighting the need for improved education and healthcare access to effectively address thalassemia in Bangladesh [18]

Also, a study at the Children's Hospital in PIMS, Islamabad, 2022-2023, surveyed 250 parents of thalassemia-affected children, revealing varied awareness levels. The participants, mostly mothers (77.6%), with 68% having consanguineous marriages, showed knowledge gaps: only 38.8% recognized thalassemia's inherited nature, and 71.6% were unaware of pre-marital screening's importance. However, 97.2% supported pre-marital screening. The study found significant correlations between residence (rural/urban) and emphasized the need for education and awareness of disease, particularly in rural areas, to improve thalassemia understanding and prevention.[19]

In addition to a 2019 cross-sectional study involving 272 parents of thalassemia patients in Rawalpindi revealed concerning gaps in awareness and prevention. Notably, 72% of parents had consanguineous marriages, yet none had undergone pre-marital thalassemia screening. Furthermore, a staggering 98.5% reported that no thalassemia awareness campaigns had ever been conducted in their area, underscoring the urgent need for targeted education and preventive measures to address this genetic disorder, particularly in regions with high consanguinity rates.[20]

RESEARCH METHODOLOGY:

An analytical cross-sectional study was conducted from both Private centers, Fatima Foundation and Kashif Iqbal Thalassemia Care Center, from June 2024 to January 2025, and convenient sampling techniques were used in this study**.** Though, sample size was calculated based on the affected child with an assumed incidence in Bangladesh 80% (Islam, Kamruzzaman, Sarker, Riaaz, & Ilhan, 2024), at 5% Level of significance and 80% power. The minimum sample size was 250. Openepi.com/SampleSize/SSPropor.htm was used to calculate the sample size.

Inclusion and Exclusion Criteria: Parents of children with beta thalassemia major and those who were given consent were included, whereas parents of thalassemia minor, patients of thalassemia major,

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patients of thalassemia minor, and those who were not given consent were excluded from this study.

Ethical Consideration: Ethical approval was obtained from the Ethical Review Committee (ERC) of the College of Nursing, Female Dr. Ruth K.M PFAU, Civil Hospital Karachi, and anonymity and confidentiality were assured throughout the study.

Data Collection: Data was collected through self-structured questionnaire by visiting the selected hospitals and formal permission were granted through official correspondence.

Data Analysis: The collected data was coded, tabulated and analyzed using Statistical Package –of Social Science (SPSS) V-16 software. Percentages and Frequencies were used to describe socio-demographic characteristics while the Chi-Square test was used to identify the association between independent variables. The pilot testing was also conducted to assess the reliability and the Cronbach's alpha was 0.87 were identified respectively.

Results:

Table 1: Socio-Demographic Data:

S.NO	QUESTION	RESPONSE	FREQUENCY	PERCENTAGE
1.	Caregiver	Father	96	38.4%
		Mother	154	61.6%
2.	Consanguineous marriage	Yes	184	73.6%
		No	66	26.4%
3.	Father's education	No formal education	113	45.2%
		Primary	64	25.6%
		Secondary	60	24.0%
		Graduate	13	5.2%
4.	Mother's education	No formal education	145	58.0%
		Primary	68	27.2%
		Secondary	29	11.6%
		Graduate	08	3.2%
5.	Monthly family income	Middle	67	26.8%
		Lower	183	73.2%
6.	No. of children	1 child	13	5.2%
		>2 child	237	94.8%
7.	No. of thalassemia children	1 child	212	84.8%
		>2 child	38	15.2%

The sociodemographic data in table # 1 reveals that, a majority of the children were cared for by their mothers, accounting for (61.6%) of the cases, while fathers served as caregivers in (38.4%) of the cases. A significant proportion of the families, (73.6%), reported consanguineous marriages, indicating a possible genetic risk factor for inherited conditions such as thalassemia. The educational background of the parents was generally low, with (45.2%) of fathers and (58.0%) of mothers having no formal education. Only a small percentage of fathers (5.2%) and mothers (3.2%) were graduates. Economic conditions were also a concern, as (73.2%) of families fell into the lower income category, and only (26.8%) reported a middle income. Most families (94.8%) had more than two children, and in (84.8%) of cases, only one child was affected by thalassemia, while (15.2%) had more than one affected child. This data highlights a population facing multiple socio-economic and educational challenges, which may influence health outcomes and access to care for children with thalassemia.

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Table 2: Assess Knowledge and awareness regarding thalassemia children amongst parents.

S.NO	QUESTIONS	RESPONSE	FREQUENCY	PERCENTAGE
1.	Is thalassemia a hereditary disease?	Yes	132	52.8%
		No	65	26.0%
		Don't Know	53	21.2%
2.	Did you had knowledge about thalassemia before your child was affected?	Yes	22	8.8%
		No	222	88.8%
		Don't Know	6	2.4%
3.	Thalassemia could be transmitted through blood transfusion from a person with thalassemia?	Yes	50	20.0%
		No	92	36.8%
		Don't Know	108	43.2%
4.	Can marriage between two carriers can lead to a child with thalassemia major ?	Yes	151	60.4%
		No	33	13.2%
		Don't Know	66	26.4%
5.	Are you aware of the types of thalassemia?	Yes	60	24.0%
		No	127	50.8%
		Don't Know	63	25.2%
6.	Do you know the symptoms of thalassemia major?	Yes	115	46.0%
		No	88	35.2%
		Don't Know	47	18.8%
7.	Can thalassemia be diagnosed by blood test?	Yes	188	75.2%
		No	28	11.2%
		Don't Know	34	13.6%
8.	What is the most important complication of thalassemia?	Yes	45	18.0%
		No	156	62.4%
		Don't Know	49	19.6%
9.	Is thalassemia curable?	Yes	39	15.6%
		No	169	67.6%
		Don't Know	42	16.8%
10.	Do you know how thalassemia can be prevented?	Yes	102	40.8%
		No	95	38.0%
		Don't Know	53	21.2%
11.	Do you know about the permanent treatment of thalassemia?	Yes	51	20.4%
		No	124	49.6%
		Don't Know	75	30.0%
12.	Is blood transfusion required throughout life?	Yes	204	81.6%
		No	22	8.8%
		Don't Know	24	9.6%
13.	Do you know about the antenatal screening for thalassemia children?	Yes	119	47.6%
		No	89	35.6%
		Don't Know	42	16.8%
14.	Do you know about premarital screening for thalassemia is going?	Yes	156	62.4%
		No	45	18.0%
		Don't Know	49	19.6%

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The table # 2 the data provides insights into the level of awareness and knowledge regarding thalassemia among the respondents. Just over half (52.8%) correctly identified thalassemia as a hereditary disease, while 26.0% believed it is not hereditary, and 21.2% were unsure. A striking 88.8% of participants reported having no knowledge about thalassemia prior to their child being diagnosed, reflecting a significant gap in public health education. When asked whether thalassemia could be transmitted through blood transfusion, only 20.0% answered correctly, while 36.8% said no, and a large proportion (43.2%) did not know, showing confusion about transmission routes. Understanding of genetic inheritance was somewhat better, with 60.4% recognizing that marriage between two carriers can result in a child with thalassemia major, though 26.4% remained unaware. Knowledge about the types of thalassemia was low, as only 24.0% were aware of them, and 50.8% admitted they were not. Regarding symptoms of thalassemia major, 46.0% claimed awareness, while 35.2% were not familiar with them. The majority (75.2%) correctly identified that thalassemia can be diagnosed through a blood test, which is encouraging. However, when asked about complications of thalassemia, only 18.0% provided an accurate response, and 62.4% did not know. Belief in the curability of thalassemia was limited, with only 15.6% considering it curable, while 67.6% believed it was not, and 16.8% were uncertain. In terms of prevention, 40.8% knew how thalassemia could be prevented, while 38.0% did not, and 21.2% lacked knowledge on the subject. Awareness of permanent treatment was also low, with only 20.4% aware, 49.6% unaware, and 30.0% uncertain. Most respondents (81.6%) correctly recognized that lifelong blood transfusions are required for thalassemia patients. On the topic of screening, 47.6% were aware of antenatal screening, and 62.4% knew about premarital screening, suggesting a moderate level of awareness in this area, though significant gaps remain. Overall, the data highlights limited and inconsistent awareness about thalassemia, emphasizing the need for targeted education and awareness programs to improve public understanding of this genetic condition.

Table # 3 Comparison of Thalassemia Awareness among Parents Based on Consanguineous Marriage.

Question		Consanguineous Marriage (Yes)	Consanguineous Marriage (No)	p value
Do both parents need to have thalassemia minor further baby to be born with thalassemia major?	Yes	56 (30.4%)	9 (13.6%)	0.027
	No	108 (58.7%)	49 (74.2%)	
	Don't Know	20 (10.9%)	8 (12.1%)	
Do you know about the antenatal screening for thalassemia children?	Yes	82 (44.57%)	19 (28.79%)	0.015
	No	79 (42.93%)	42 (63.64%)	
	Don't Know	23 (12.5%)	5(7.58%)	

The study assessed knowledge in table # 3 about thalassemia among participants with and without consanguineous marriages. A significant difference was observed in the understanding that both parents need to have thalassemia minor for a child to be born with thalassemia major. Here, 56 (30.4%) of the consanguineous group answered "Yes," compared to 9 (13.6%) ($p = 0.027$). Similarly, Awareness of antenatal screening for thalassemia children was significantly different, with 79 (42.93%) of the consanguineous group reporting no knowledge as compared to 19 (28.79%) ($p = 0.015$) respectively.

Table # 4 Comparison of Thalassemia Awareness among Parents Based on Number of thalassemia children.

Question	Response	1 child	>2 child	p value
Are you aware of the types of thalassemia?	Yes	38 (22.4%)	22 (27.5%)	0.039
	No	81 (47.6%)	46 (57.5%)	
	Don't Know	51 (30%)	12 (15%)	
What is the most important complication of	Yes	24 (14.1%)	21 (26.3%)	<0.001

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thalassemia?	No	102 (60%)	54 (67.5%)	
	Don't Know	44(25.9%)	5 (6.3%)	
Do you know how thalassemia can be prevented?	Yes	46 (27.1%)	32 (40%)	0.01
	No	84 (49.4%)	41 (51.3%)	
	Don't Know	40 (23.5%)	7 (8.8%)	
Do you know about the antenatal screening for thalassemia children?	Yes	58 (34.1%)	43 (53.8%)	0.009
	No	89 (52.4%)	32 (40%)	
	Don't Know	23 (13.5%)	5 (6.3%)	
Do you know about premarital screening for thalassemia?	Yes	51 (30%)	29 (36.3%)	0.032
	No	87 (51.2%)	46 (57.5%)	
	Don't Know	32 (18.8%)	5 (6.3%)	

The study investigated in table # 4, the awareness and knowledge regarding thalassemia among parents with one child versus those with more than two children. A statistically significant difference was observed in awareness of the types of thalassemia, with (22.4%) of respondents with one child and (27.5%) with more than two children indicating "Yes" ($p = 0.039$). A significant difference was noted in awareness of the most important complications of thalassemia, where (14.1%) of those with one child and (26.3%) of those with more than two children responded "Yes" ($p < 0.001$) Knowledge about preventing thalassemia was significantly different, with (27.1%) of those with one child and (40%) with more than two children indicating "Yes" ($p = 0.01$). Awareness of antenatal screening for thalassemia children was significantly higher in those with more than two children, with (53.8%) of those with one child and (34.1%) of those with more than two children indicating "Yes" ($p = 0.009$). Lastly, knowledge of premarital screening for thalassemia showed a significant difference, with (30%) of those with one child and (36.3%) with more than two children answering "Yes" ($p = 0.032$).

Discussion:

The present study identifies limited knowledge of the hereditary nature of thalassemia among parents, highlighting the need for improved genetic education. With regards to the present study findings, a study postulates that for the hereditary nature of thalassemia, both parents must be carriers (thalassemia minor) for a child to have thalassemia major, suggesting that genetic risks might be more commonly discussed in consanguineous families[15]. In terms of Knowledge of thalassemia symptoms, complications, and curability was similar across groups, while the majority of parents correctly recognized blood tests as a diagnostic tool, awareness of antenatal screening was significantly higher among non-consanguineous parents compared to the consanguineous group, indicating possible gaps in prenatal health education within consanguineous families. Similarly, a study exhibits that genetic inheritance knowledge was slightly better among consanguineous parents, their awareness of antenatal screening was lower, suggesting the need for targeted educational programs emphasizing genetic risks and preventive measures[18]. This idea was consistent with the present study on Thalassemia awareness among different family groups.

Additionally, the present study investigates the awareness and knowledge regarding thalassemia among parents with one child versus those with more than two children. A similar study had taken place by Fazzal and colleagues in Pakistan, results that (72%) of the parents had consanguineous marriages, none of them had a thalassemia screening test before their marriage. (98.5%) of the parents said we're not aware, and (50%) of families had affected thalassemia-affected children[19]. Furthermore, the current study shows that, the knowledge was statistically significant in both groups, suggesting that both groups had similar awareness of the disease's inheritance. In addition, a large majority in both groups (88.2% and 90%) reported having no prior knowledge of thalassemia before their child was affected. Similarly, a study shows that when it came to the transmission of thalassemia via blood transfusion, awareness was low among affected

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children's parents [21]. In addition, the present study shows a statistically significant difference in awareness of the types of thalassemia, with (22.4%) of parents with one child and (27.5%) of parents with more than two children recognizing the different types, suggesting that parents with more children might have better knowledge in this regard, this is consistent with the finding of [22]. In terms of symptoms of thalassemia major, the two groups had similar levels of understanding, with 36.5% of parents with one child and 43.8% of those with more than two children answering correctly, but this difference was not statistically significant. However, awareness of the most important complications of thalassemia showed a significant difference, with (14.1%) of parents with one child and (26.3%) of those with more than two children, indicating that parents with more than two children were more aware of the potential complications. In contrast, a study shows that parents with more than one child with thalassemia affected have a better understanding of the cause, they are better aware of the disease, its implications and curability [23]. Overall, the study highlights both a general lack of awareness about thalassemia as well as significant differences in knowledge among and between parents with one child and those with more than two children, particularly regarding complications, prevention, and screening options. There should be a proper health care sessions and a briefing on Thalassemia awareness in order to prevent and mitigate it in society.

Conclusion:

We conclude that awareness regarding thalassemia is inadequate in parents of children with thalassemia. Parents have limited knowledge of hereditary education and no screening to rule out the nature of the disease.

Limitations of the study:

The study's cross-sectional design limits the ability to establish causality and track changes over time. The sample may not be representative of all parents of children with beta thalassemia major in Karachi, which may limit generalizability. Data collection was hindered by the government thalassemia centers denying permission.

Recommendations:

Low level of knowledge and the trend of consanguineous marriage highlight the importance of urgency of implementing effective public health interventions. These findings strongly necessitate the importance of prevention programs, including premarital genetic counselling, mass screening for carrier detection should be implemented by the government to tackle this public health issue.

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The authors declared no conflict of interest.

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The approval was taken from both the Hospital for data collection.

Authorship Contribution:

SP conceptualized the project, MM, BH, AC, MN, AN, SS worked in data Collection and literature search by MM. SP performed the statistical analysis. While Writing, revision, and writing of manuscript done by MM, SP, SM, KK.

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