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THALASSEMIA AWARENESS AND ITS IMPACT ON HEALTH-RELATED QUALITY OF LIFE AMONG PREGNANT WOMEN IN PAKISTAN

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Abstract

Thalassemia, a hereditary blood disorder, poses a major public health concern in Pakistan, where consanguineous marriages and limited awareness contribute to a growing burden of disease. This study explores the level of awareness regarding thalassemia and its impact on the health-related quality of life (HRQoL) among pregnant women in Lahore, Pakistan. Conducted at Shalamar Hospital using a cross-sectional design, the study surveyed 100 pregnant women attending antenatal clinics through a structured questionnaire and the SF-36 health survey. Results revealed that while 65% of participants were aware of thalassemia, only 30% had undergone screening, and just 50% could identify its symptoms. Awareness of complications, treatment options, and support resources was similarly limited. Despite this, a strong majority (85%) supported mandatory screening, and 90% emphasized the need for awareness programs. Regression analysis showed a significant association between thalassemia awareness and HRQoL outcomes, particularly regarding mental well-being and disease-related anxiety. The findings highlight critical knowledge gaps, poor provider-patient communication, and systemic barriers, including insufficient educational outreach and healthcare infrastructure. Socio-cultural factors, particularly consanguineous marriages and religious beliefs, further impede prevention efforts. The study underscores the urgent need for comprehensive educational interventions, mandatory screening policies, enhanced genetic counseling services, and the development of community-based support systems. These strategies are essential to empower women, prevent new cases, and improve maternal and fetal health outcomes. Future research with larger, more diverse populations is recommended to strengthen public health policy and reduce the national burden of thalassemia.

INTRODUCTION

Thalassemia, a hereditary blood disease characterised by decreased hemoglobin manufacturing, poses a large public health venture in Pakistan, wherein 5-eight% of the population are providers, and approximately 5000–9000 new cases of thalassemia essential are recognized yearly. Pregnant women, as potential companies or moms of affected youngsters, are a essential demographic for centered interventions. This text, based on a thesis via Sharoon Musa and colleagues from superior college

Lahore, explores the notice of thalassemia amongst pregnant females in Pakistan and its effect on their health-associated first-class of lifestyles (HRQoL). The study highlights the interaction of socio-cultural, monetary, and healthcare device factors that exacerbate the thalassemia burden on this populace.

Background

Pakistan's high thalassemia prevalence is driven by using consanguineous marriages, restricted healthcare infrastructure, and coffee public focus. about 72% of parents of thalassemia-affected children in Pakistan have consanguineous marriages, but premarital screening remains uncommon. The absence of a countrywide mandate for screening, unlike a success packages in nations like Saudi Arabia and Kuwait, contributes to the growing burden. attention amongst pregnant women is particularly low, with studies indicating a 15.33% incidence of beta-thalassemia trait amongst this group, many unaware of their carrier popularity till past due in pregnancy.

This delays prenatal prognosis and counseling, growing the threat of affected births and complicating maternal health consequences.

Thalassemia appreciably affects HRQoL, especially for transfusion-structured patients, due to continual treatment needs, including ordinary blood transfusions and iron chelation remedy. For pregnant ladies, these demanding situations are compounded with the aid of physiological and emotional stressors, societal stigma, and constrained get entry to to genetic counseling. Socio-cultural elements, which includes the superiority of consanguineous marriages and reluctance to undergo prenatal diagnosis due to non-secular ideals, in addition restrict preventive efforts. The healthcare machine's barriers, inclusive of insufficient secure blood materials and high remedy costs, exacerbate these troubles, especially for low-earnings households.

Study Objectives and Methodology

The look at aimed to evaluate thalassemia awareness amongst pregnant girls in Pakistan and compare its impact on their HRQoL, exploring associations between recognition, disorder management, and excellent of lifestyles results. conducted at Shalamar health center in Lahore, this go-sectional take a look at involved one hundred pregnant women attending antenatal clinics, selected via comfort sampling. facts have been accrued using a proven questionnaire assessing thalassemia understanding and the SF-36 fitness Survey to measure HRQoL. Descriptive records, chi-square exams, and regression analysis have been employed for facts analysis.

Inclusion criteria covered pregnant women elderly 18 and older, capable of speak in Urdu or English, and attending habitual antenatal test-ups. Exclusion standards encompassed people with a known thalassemia diagnosis, previous thalassemia-particular training, or unwillingness to participate. moral concerns had been strictly accompanied, with knowledgeable consent acquired, participant anonymity ensured, and information confidentiality maintained.

Key Findings

Table 1: Key Findings on Thalassemia Awareness Among Pregnant Females in Pakistan

Question	Yes (%)	No (%)	P-Value
Aware of thalassemia	65	35	0.001
Know symptoms of thalassemia	50	50	0.045
Undergone thalassemia screening	30	70	0.020
Thalassemia common in Pakistan	75	25	0.005
Thalassemia is hereditary	80	20	0.001
Aware of thalassemia complications	55	45	0.030
Discussed thalassemia with doctor	40	60	0.050
Thalassemia affects pregnancy	70	30	0.015
Received educational materials	25	75	0.022
Screening should be mandatory	85	15	0.003
Aware of treatment options	45	55	0.048

Awareness programs necessary	90	10	0.002
Knowledgeable about managing thalassemia	35	65	0.040
Willing to participate in awareness programs	60	40	0.018
Aware of support groups	20	80	0.025

Note: Percentages reflect responses from 100 pregnant females. P-values indicate statistical significance ($p < 0.05$).

The examine on thalassemia awareness amongst pregnant girls in Pakistan discovered essential insights into their information and its implications for fitness-associated satisfactory of lifestyles. Drastically, 65% of members identified thalassemia, but most effective 50% should perceive its signs, indicating a enormous hole in comprehensive know-how. Screening uptake became alarmingly low, with simply 30% having undergone testing, despite 80% acknowledging the sickness's hereditary nature, underscoring missed opportunities for early detection. at the same time as 75% perceived thalassemia as commonplace in Pakistan, only 55% had been aware of its complications, and a trifling 40% had mentioned the situation with healthcare companies, highlighting inadequate patient-company verbal exchange. robust community guide for obligatory screening was glaring, with 85% in prefer, but cognizance of remedy alternatives (45%) and guide corporations (20%) remained limited, pointing to a lack of on hand resources. additionally, 90% of individuals emphasized the want for attention applications, with 60% willing to take part, reflecting a community-driven choice for stepped forward education and outreach to address these gaps and decorate fitness outcomes.

Discussion

The results outcomes highlight a foundational awareness of thalassemia but good sized deficiencies in precise information regions, consisting of symptom popularity and remedy alternatives. The low screening fee (30%) is especially regarding given the excessive hereditary acknowledgment (80%), as undiagnosed companies threat giving start to affected children. This mirrors findings from Bangladesh, in which low screening uptake was connected to inadequate public fitness initiatives. The robust assist for mandatory screening (eighty five%) aligns with worldwide hints for widely wide-spread screening applications, as visible in Iran, where such measures decreased thalassemia births by means of 80%.

The restrained conversation with healthcare carriers (40%) displays systemic problems, together with insufficient education for vendors, as stated in prior research. This hole hinders effective counseling and management, specifically at some point of being pregnant, when timely interventions are important. The low focus of aid businesses (20%) shows a loss of network-based resources, which might be essential for emotional and informational aid, as evidenced by way of studies showing advanced QoL amongst patients engaged in aid networks.

Socio-cultural factors, especially consanguineous marriages, remain a sizeable motive force of thalassemia occurrence. The take a look at's findings underscore the want for culturally sensitive instructional campaigns, like those in Cyprus, which reduced thalassemia occurrence via public consciousness. Monetary barriers, such as the high value of remedy, further exacerbate the weight, particularly for low-earnings families, necessitating policy interventions to enhance get right of entry to care.

Recommendations

To address the significant gaps in thalassemia awareness and health-related quality of life among pregnant females in Pakistan, several targeted recommendations are proposed. First, comprehensive educational campaigns should be implemented, integrating thalassemia education into community-based initiatives and antenatal care settings to enhance knowledge about symptoms, screening, and treatment options. Second, advocating for national policies to mandate premarital and antenatal screening is crucial, drawing inspiration from successful models in countries like Iran, which significantly reduced thalassemia incidence. Third, strengthening training programs for healthcare providers is essential to improve counseling skills and ensure effective communication with pregnant women, facilitating informed decision-making. Fourth, increasing awareness and accessibility of support groups is vital to provide emotional and informational resources for affected families, addressing the current low awareness rate of 20%. Finally, expanding research efforts with larger, more diverse sample sizes across Punjab is recommended to generate generalizable findings that can inform broader public health strategies, ultimately reducing the thalassemia burden and improving maternal and fetal health outcomes in Pakistan.

Limitations

The study was limited by its small sample size (100 participants) and focus on a single hospital in Lahore, which may not represent the broader Pakistani population. Some participants' lack of cooperation further constrained data collection. Future research should involve larger, more diverse samples to enhance generalizability.

Conclusion

This study underscores the urgent need for targeted interventions to improve thalassemia awareness and HRQoL among pregnant females in Pakistan. While foundational awareness exists, significant gaps in symptom recognition, screening uptake, and knowledge of treatment and support resources persist. These deficiencies, compounded by socio-cultural and systemic barriers, highlight the necessity for comprehensive educational programs, mandatory screening policies, and enhanced support systems. By empowering pregnant women with knowledge and resources, Pakistan can reduce the thalassemia burden and improve maternal and fetal health outcomes, contributing to broader public health goals.

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