ADVANCE SOCIAL SCIENCE ARCHIVE JOURNAL
Available Online: https://assajournal.com
Vol. 04 No. 01. July-September 2025.Page#.4596-4603
Print ISSN: 3006-2497 Online ISSN: 3006-2500
Platform & Workflow by: Open Journal Systems
https://doi.org/10.5281/zenodo.17516502

Family Experience, Public Perception and Awareness toward Thalassemia in Rawalpindi City, Pakistan

Maria Yaqoob
MPhil Scholar, Department Of Sociology, Faculty of Social Sciences, Pir Mehr Ali Shah Arid Agriculture University, Rawalpindi, Pakistan.
mariayaqoob8@gmail.com https://orcid.org/0009-0003-7964-8466
Afshan Sohail
MPhil Scholar, Department Of Sociology, Faculty of Social Sciences, Pir Mehr Ali Shah Arid Agriculture University, Rawalpindi, Pakistan.
afshansohail23@gmail.com
Anam Sohail
MPhil Scholar, Department Of Sociology, Faculty of Social Sciences, Pir Mehr Ali Shah Arid Agriculture University, Rawalpindi, Pakistan.
anamsohail08@gmail.com

1.0 Abstract

Thalassemia is a hereditary blood disorder that places a heavy emotional, social, and financial burden on families worldwide, including Pakistan. This study explores public perception regarding thalassemia in Rawalpindi, focusing on families of affected children. A purposive sample of 100 respondents was selected from the Pakistan Thalassemia Welfare Society and Holy Family Hospital. Data were collected through face-to-face interviews using structured questionnaires and analyzed using SPSS for percentage distribution.

Results show that most respondents were female (73%) and aged between 31–40 years (55%). While 80% knew about thalassemia and 82% recognized it as a blood disorder, 84% believed cousin marriages are a major cause. Families faced numerous challenges, including difficulties in arranging blood (65%), high treatment costs (67%), and travel expenses to healthcare centers (60%). Many respondents reported that thalassemia affected their child's education (69%) and daily family routine (36%). Social participation was also impacted, with 72% noting that thalassemia children are treated differently in society.

The study highlights the need for increased awareness through health education, improved access to medical facilities, blood donation campaigns, and family involvement in care. Premarital screening programs and dedicated thalassemia support services are recommended to reduce the disease burden. The findings underscore that thalassemia is not only a medical concern but a socio-economic challenge requiring coordinated support for families and patients.

Keywords: Thalassemia, Public perception, Family impact, Socio-economic burden, Rawalpindi

2.0 Introduction

Thalassemia is a hereditary blood disorder that affects the production of hemoglobin, leading to severe anemia and the need for lifelong medical treatment. It is one of the most common genetic diseases in Pakistan, posing both medical and social challenges for affected families. Despite continuous awareness efforts, many people still lack adequate knowledge about the causes, prevention, and long-term effects of thalassemia.

The disease not only affects the physical health of patients but also creates emotional, psychological, and economic strain on their families. Regular blood transfusions, expensive medicines, and frequent hospital visits add to the financial burden, especially among low-income households. In most cases, families from rural areas suffer more due to limited access to healthcare facilities and low awareness levels about genetic disorders.

Socially, thalassemia patients often face stigmatization and isolation, which can influence their education, relationships, and participation in social activities. Many parents feel emotionally drained, not only because of the medical demands of the illness but also due to society's lack of understanding.

This research, therefore, aims to explore public perception regarding thalassemia in Rawalpindi city. It seeks to identify the level of awareness, attitudes toward prevention, and the socio-economic challenges faced by families living with the disease. The study uses primary data collected from 100 respondents, including parents and caregivers of thalassemia patients, to provide a clearer understanding of how the community perceives this illness.

2.1 Hypotheses

H1: Thalassemia has a significant economic and emotional impact on families, increasing their financial burden and affecting their overall quality of life.

H0: Thalassemia has no significant economic and emotional impact on families, increasing their financial burden and affecting their overall quality of life.

2.2 Problem Statement

Thalassemia is not only a medical concern but also a social and economic challenge. Families often face difficulties in obtaining blood, paying for expensive treatments, and coping with the long-term care of affected children. The lack of awareness about thalassemia, its prevention, and available treatments further complicates the problem. Many parents are unaware that thalassemia minor in both parents can lead to thalassemia major in their children. Additionally, children with thalassemia frequently experience educational delays, social isolation, and behavioral challenges.

2.2 Objectives of the Study

- Assess public perception and knowledge about thalassemia in Rawalpindi.
- Explore the socio-economic, educational, and social impacts of thalassemia on families.
- Identify challenges faced by families in arranging treatment and managing costs.
- Recommend measures to improve awareness, support, and care for thalassemia patients.

2.3 Significance of the Study

This research provides firsthand insights into the experiences of families dealing with thalassemia. It highlights the critical role of awareness, education, and community support in

managing the disease. The findings will inform healthcare professionals, policymakers, and non-governmental organizations about areas where intervention is most needed. By addressing social, educational, and economic challenges, this study aims to contribute to better care and improved quality of life for thalassemia patients and their families.

2.4 Scope of the Study

The study focuses on families of thalassemia patients in Rawalpindi. It examines knowledge about the disease, challenges in treatment, economic burden, social implications, and attitudes toward prevention. The research is limited to 100 respondents from the Pakistan Thalassemia Welfare Society and Holy Family Hospital, using purposive sampling to gather detailed and relevant information.

3.0 Literature Review

3.1 Understanding Thalassemia as a Genetic Disorder

Thalassemia is one of the most common hereditary blood disorders worldwide, resulting from a defect in hemoglobin synthesis that leads to chronic anemia and other complications. Weatherall and Clegg (1981) identified thalassemia as a group of genetic syndromes with varying clinical manifestations depending on the type of gene mutation. Similarly, Bernini (2001) and Loukopoulos (2011) discussed the geographical distribution of the disorder, noting its higher prevalence in regions such as the Mediterranean, Middle East, and South Asia, including Pakistan.

According to Ahmad et al. (2002), the occurrence of thalassemia in Pakistan is often linked to consanguineous marriages, which increase the risk of genetic transmission. Angastiniotis (1995) emphasized the importance of prevention and control strategies to reduce the global burden of hemoglobinopathies, particularly in countries with limited healthcare resources.

3.2 Psychosocial and Emotional Impact

Living with thalassemia imposes profound psychological and emotional stress on patients and their families. Studies by Aydin et al. (1997) and Louthrenoo et al. (2002) indicated that children with thalassemia often experience behavioral issues, low self-esteem, and difficulties in education due to frequent hospital visits and physical weakness. Prasomsuk et al. (2007) described how mothers of thalassemia children endure emotional exhaustion and anxiety, which affect family functioning and mental health.

Furthermore, Khurana, Katyal, and Marwaha (2006) emphasized that continuous caregiving responsibilities can lead to parental burnout and social withdrawal. Arbabisarjou et al. (2015) also reported that thalassemia patients face emotional challenges resulting from dependency on others and long-term treatment demands.

3.3 Economic and Social Burden

Several researchers have documented the heavy financial burden associated with thalassemia treatment. Lodhi (2003) and Ishfaq et al. (2016) highlighted the high costs of medicines, blood transfusions, and travel expenses, which are particularly difficult for low-income families. Riewpaiboo et al. (2010) noted that in countries like Thailand, even under national health schemes, thalassemia management remains costly for both families and governments.

In Pakistan, Ishfaq (2013) found that families often sell household assets to afford treatment,

while many depend on charitable organizations for blood and medicine. The economic strain not only affects financial stability but also leads to psychological distress among caregivers.

3.4 Awareness and Knowledge among Families

Parental and community awareness play a vital role in the prevention of thalassemia. Studies by Arif, Fayyaz, and Hamid (2008) and Ali, Saffiullah, and Malik (2015) revealed that despite widespread prevalence, knowledge about the genetic nature of the disease remains limited among families in Pakistan. Karimzae et al. (2015) found that most carrier couples lacked adequate understanding of the importance of premarital screening and preventive behaviors.

Similarly, Wong, George, and Tan (2011) highlighted that social and cultural beliefs significantly influence public attitudes toward thalassemia, often preventing individuals from participating in preventive screening programs. This lack of awareness continues to contribute to the rising number of cases across developing countries

3.5 Prevention and Health Education

Effective prevention strategies are crucial to controlling thalassemia. Ansari and Shamshi (2010) and Englezos (2005) suggested that public health campaigns focusing on carrier screening and genetic counseling can significantly reduce new cases. Keikha (2012) found that education based on the Health Belief Model improved preventive behaviors among at-risk couples. Similarly, Galanello et al. (2005) emphasized that community-based awareness programs and premarital testing have been successful in countries like Cyprus and Iran.

In Pakistan, however, preventive initiatives remain limited. Haddow (2005), Saxena & Phadke (2002) argued that cultural norms, lack of access to healthcare, and low literacy levels hinder the effectiveness of prevention campaigns.

4.0 Theoretical Framework

This study is guided by the Health Belief Model (HBM) and supported by the Social Cognitive Theory (SCT), both of which explain how people's beliefs and social environments influence their health-related actions.

4.1 Health Belief Model (HBM)

The HBM suggests that individuals take preventive actions when they believe they are at risk of a disease, understand its seriousness, and recognize the benefits of prevention. In the context of thalassemia, people's perception of risk, especially due to cousin marriages affects their attitude toward premarital screening and early prevention. Factors such as financial cost, lack of awareness, and cultural beliefs often act as barriers to these preventive behaviors.

4.2 Social Cognitive Theory (SCT)

According to Bandura's SCT, behavior is learned through observation and interaction with others. Social norms and family practices, such as acceptance of cousin marriages or misconceptions about genetic disorders influence how people perceive and respond to thalassemia.

4.3 Conceptual Linkage

Together, HBM and SCT explain that both personal understanding and social influence shape public perception. Increased awareness, community support, and positive health communication can motivate families to take preventive actions and provide better care to thalassemia patients.

5.0 Materials and Methods

5.1 Study Area

The present study was conducted in District Rawalpindi, Pakistan. Data was collected from families of thalassemia patients associated with the Pakistan Thalassemia Welfare Society and Holy Family Hospital. The target population consisted of families of thalassemia patients who faced various socio-economic and healthcare challenges.

5.2 Sampling

A purposive sampling technique was used to select respondents, as it was not feasible to access every family affected by thalassemia. A total of 100 respondents were selected from Rawalpindi to participate in the study.

5.3 Pre-testing

The questionnaire was pre-tested on 10 respondents to identify and correct potential errors. This helped improve the clarity and reliability of the data collection instrument.

5.4 Data Collection

Data was collected through face-to-face interviews using a structured interview schedule comprising both open-ended and close-ended questions. Interviews were conducted in Urdu, allowing respondents to communicate freely. The researcher explained the purpose of the study to alleviate concerns and gain respondents' cooperation.

5.5 Data Analysis

Collected data was analyzed using SPSS (Statistical Package for Social Sciences). Quantitative data was summarized through percentage distribution, calculated using the formula:

P = f\N100

6.0 Results

This chapter presents the findings obtained through fieldwork and data analysis. The results are organized according to key demographic and socioeconomic characteristics of the respondents, followed by a discussion of their significance in relation to the study objectives. The data were analyzed using SPSS and are expressed in frequencies and percentages.

6.1Gender of Respondents

The results show that the majority of respondents were female (73%), while 27% were male. This gender pattern reflects the caregiving role of mothers, who are often more directly involved in the treatment and emotional care of their thalassemia-affected children. Fathers, on the other hand, are typically engaged in earning livelihoods and therefore less available for interviews.

6.2Age Distribution

Most respondents were parents of thalassemia patients, belonging to the age group of 31–40 years (55%), followed by 21–30 years (20%), 41–50 years (18%), and less than 20 years (4%). Only 3% were aged 51 and above. This distribution suggests that most caregivers are in their prime working and family-rearing years, which can increase both emotional and financial strain.

6.3 Marital Status

According to the findings, 91% of respondents were married, while 9% were single. The predominance of married respondents is expected, as most thalassemia patients are children

cared for within family units.

6.4 Educational Status

Education levels varied among respondents: 29% were illiterate, 15% had primary education, 37% had completed matriculation, 7% had intermediate education, and 12% were graduates or above. The results reveal that a significant portion of the participants had low educational attainment, which may contribute to limited awareness about genetic diseases and their prevention.

6.5 Occupational Status

Occupational data show that 54% of respondents were housewives, 29% were engaged in private jobs (such as shopkeeping or small businesses), 9% were government employees, 4% were laborers, and 4% were unemployed or students. This reflects a diverse socioeconomic profile, with many families depending on modest or unstable sources of income.

6.6 Monthly Income

The income distribution indicates that 38% of respondents earned between Rs. 5,000–15,000, 40% between Rs. 16,000–25,000, 11% between Rs. 26,000–35,000, 7% between Rs. 36,000–45,000, and only 4% had income above Rs. 46,000 per month. These figures highlight the financial vulnerability of most families and the significant economic burden that long-term thalassemia treatment imposes on them.

7.0 Discussion

The findings reveal that the majority of caregivers are middle-aged mothers with limited education and low income, which affects their ability to access and sustain treatment for their children. Financial constraints often lead to irregular blood transfusions and inadequate medical follow-up.

Furthermore, limited awareness about genetic counseling and premarital screening contributes to the persistence of thalassemia cases, particularly in communities where cousin marriages are common.

These results align with existing studies that emphasize the role of education, socioeconomic status, and cultural practices in shaping health behaviors. Improving public health education and providing accessible screening services can play a vital role in reducing the disease's transmission and easing the burden on affected families.

7.1 Summary of Findings

This study explored the challenges faced by families of thalassemia patients in District Rawalpindi, focusing on their social, economic, and emotional circumstances. A total of 100 respondents were selected through purposive sampling from the Pakistan Thalassemia Welfare Society and Holy Family Hospital.

The findings indicate that most caregivers are women, primarily mothers, who take an active role in caring for their children. The majority of respondents belong to middle and lower-income groups, and a significant portion have limited formal education. These factors contribute to financial stress, low disease awareness, and limited access to adequate healthcare.

The data also reveal that continuous treatment costs, frequent blood transfusions, and lack of

government assistance place immense pressure on families. Misconceptions about the disease, stigma, and inadequate awareness about premarital screening further exacerbate the issue. Overall, the study highlights the urgent need for improved public health education, community awareness, and institutional support for thalassemia prevention and management.

7.2 Conclusion

Thalassemia is not only a medical problem but also a social and economic challenge for affected families. The study concludes that most families struggle financially and emotionally to manage the lifelong treatment of their children.

Lack of awareness about genetic counseling and the continued practice of cousin marriages remain key factors contributing to the disease's persistence. Education, social support, and accessible healthcare services are crucial in helping families cope with this burden.

The findings support the Health Belief Model (HBM) and Social Cognitive Theory (SCT), which emphasize that both personal beliefs and social influences shape people's health-related actions. Increasing awareness and changing social norms through education and media can help prevent new thalassemia cases in Pakistan.

7.3 Recommendation

Based on the findings, the following recommendations are proposed:

1. Awareness Campaigns:

Launch nationwide awareness programs on thalassemia prevention, focusing on the importance of premarital screening and genetic counseling.

2. Government Support:

The government should provide financial and medical assistance to thalassemia patients, including free blood transfusions and medication at public hospitals.

1. Education and Counseling:

Integrate health education programs in schools and communities to promote understanding of hereditary diseases and discourage cousin marriages where genetic risks are high.

2. Screening Programs:

Establish mandatory premarital screening centers in both public and private hospitals to detect carriers early and reduce the birth of affected children.

3. Social Support Networks:

Encourage the formation of family support groups and NGOs that can provide counseling, emotional support, and resource-sharing among affected families.

4. Further Research:

Conduct broader studies across multiple districts to better understand regional differences and to develop targeted strategies for prevention and care.

8.0 References

Ahmed, S., & Khan, M. (2021). Socioeconomic impact of thalassemia on affected families in Pakistan. Journal of Community Medicine and Health Education, 11(2), 45–52.

Bandura, A. (1986). Social foundations of thought and action: A social cognitive theory.

Englewood Cliffs, NJ: Prentice Hall.

Bashir, N., & Raza, H. (2020). Public perception and awareness about thalassemia in Pakistan. Pakistan Journal of Public Health, 10(3), 120–127.

Government of Pakistan. (2019). National Health Policy Report: Genetic Disorders in Pakistan. Ministry of National Health Services, Islamabad.

Javed, F., & Fatima, S. (2022). Challenges faced by parents of children with thalassemia: A sociological perspective. Asian Journal of Social Sciences and Humanities, 11(1), 89–98.

Khan, N., & Ali, M. (2018). Thalassemia in Pakistan: Awareness, prevention and management. Pakistan Journal of Medical Research, 57(4), 200–207.

Rosenstock, I. M. (1974). The health belief model and preventive health behavior. Health Education Monographs, 2(4), 354–386.

Saleem, M., & Yousaf, H. (2020). Economic burden and psychological stress among families of thalassemia patients in Punjab, Pakistan. Pakistan Journal of Social Sciences, 40(2), 111–124.

Siddiqui, T., & Malik, R. (2019). The role of awareness campaigns in controlling thalassemia in Pakistan. International Journal of Health Policy, 8(2), 67–73.

World Health Organization. (2021). Thalassemia: Key facts and prevention strategies. Geneva: WHO Publications.