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THE POWER OF THALASSEMIA: A JOURNEY THROUGH THE LIVE EXPERIENCES OF PATIENTS AND THEIR FAMILIES, SHOWCASING RESILIENCE AND HOPE

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Thalassemia a genetic blood disorder, psychosocial sufferings, treatment barriers, medical support and nongovernmental organizations (NGOs).

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Abstract

Thalassemia is a genetic blood disorder characterized by impaired hemoglobin production. This study aims to provide an in-depth qualitative analysis of the experiences of thalassemia patients and their families in Pakistan, showcasing their resilience and hope amidst adversity. A qualitative research design is employed to investigate the lived experiences of patients and families. A purposive sampling technique was employed to select participants who were most knowledgeable and experienced with management. The qualitative research method employs an exploratory qualitative method to explore the psychosocial dynamics of the disease. The results of this study show that there are significant treatment access barriers for patients and parents that indicate the need for better medical support roles of support groups and nongovernmental organizations (NGOs). Moreover, the study reveals critical gaps in healthcare accessibility, particularly in rural areas, and stresses the role of NGOs in alleviating these challenges. Moving forward, nationwide premarital and prenatal screening programs should be implemented to control the prevalence of Thalassemia.

1.INTRODUCTION

Inherited hemoglobin disorders, especially Thalassemia, contribute to 17% of hemoglobinopathies globally, with over an estimated 3,30,000 infants born annually, modeling B.darleston M.2008.Thalassemia is an inherited genetic disorder characterized by defective or missing alpha and beta globulin genes. It can be classified as minor, intermediate, or major to describe the severity of conditions and symptoms. The symptoms experienced will depend on the type of Thalassemia one has and to what extent severe it is.

The symptoms might include growth problems, comma, delayed puberty, bone abnormalities (such as osteoporosis), poor appetite, and pale or yellow skin (jaundice).

Major Thalassemia is often diagnosed in early childhood due to prevalent symptoms. It can be diagnosed by complete blood count (CBC), reticulocyte count, iron deficiency, and hemoglobin electrophoresis. The standard treatment procedures for Thalassemia are blood transfusions and iron chelation therapy. Developed countries do offer treatments to cure Thalassemia, including bone marrow transplant and stem cell transplant, or Luspatercept enhances late-stage red blood cell maturation) The severity of this disease leads this

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condition to a chronic stage. Therefore, mothers have a critical role in caring for these children.

Many studies emphasize that mothers are more active in caring for their children during chronic illness. Caring for a child with Thalassemia exposes mothers to many challenges (Nabavian et al., 2022). In the study conducted by Perin et al., 49% of mothers of children with Thalassemia had moderate to severe levels of care stress. In addition, it has been revealed that the mothers of children with thalassemia major face many problems, such as a history of psychosocial distress, bearing an extra-economic burden, and lack of knowledge and its sources, worries, and fears of the worsening of the disease and concerns over the future of the child are critical Psychological Problems and Conflicts of These Mothers.

Although the impact of Thalassemia on families has been studied extensively using quantitative approaches, there is limited evidence to evaluate the experience of Psychosocial Challenges Faced by Mothers with Thalassemia Children (Nabavian et al., 2022). In describing their experiences of uncertainty, almost all Thalassemia major patients expressed fears and worries. This theme included two categories: fear of complications and unknown future. According to this category, fears and concerns about the complications of the disease and the complications of repeated blood transfusions are important factors in uncertainty in patients with Thalassemia major (Ahmadi et al., 2020).

Fear and concern over the possibility of multiple complications caused by the disease or the possibility of the progress of the complications had made the future of the disease uncertain and unpredictable for the patients. The patients participating in the study expressed concern about the future of their lives and their families and, eventually, described their lives as ambiguous and wrapped in a halo of uncertainty. This category consists of three subcategories that obscure the future of marriage and parenting, present new roles, think about death, and influence family structure (Ahmadi et al., 2020).

The suffering of children due to this chronic disease imposes a great social, psychological, and financial burden on the parents and families. The family feels the burden owing to the long-standing character of the sickness, the treatment modalities, the complications and mortalities caused by the disease, and the need for frequent visits to healthcare centers for blood transfusions and other necessary blood investigations.

Parents feel that they become socially victimized and stigmatized as they feel that they lack a support system and experience constant stress, which requires coping strategies. All these issues ultimately cause immense suffering to the parents and caregivers. The parents and the family become socially isolated and communicate poorly.

The other reason parents become socially isolated and contribute to the impairment of social relations is that they need to spend more time constantly with their children. In Thalassemia major patients, the financial burden is prominent, like any chronic disease, due to follow-up visits, treatment, and frequent admissions, besides the transportation cost and high living costs. This is more problematic for parents in low socioeconomic countries with families having poor financial conditions and limited income (Yousuf et al., 2022).

The psychological resilience of thalassemia patients and their families is shaped by a range of interrelated factors. Strong social and family support provides emotional strength and reduces feelings of isolation, while hope, future aspirations, and inner psychological strength foster
motivation and a sense of purpose.

Effective management of physical symptoms like fatigue and pain contributes to better daily functioning, whereas poorly managed health issues can hinder resilience. Educational and career aspirations play a crucial role in sustaining optimism and self-worth, though interruptions in schooling or work due to illness can negatively impact mental health. Trust in healthcare services, satisfaction with medical support, and the presence of supportive groups or NGOs further enhance coping, while gaps in these systems can lead to anxiety and distress. Additionally, positive coping strategies strengthen resilience, whereas maladaptive behaviors may exacerbate emotional challenges.

Altogether, these factors collectively influence the ability of patients and their families to adapt, cope, and maintain hope through the journey of living with Thalassemia. Limited research on the psychosocial challenges faced by thalassemia patients and caregivers. Inadequate exploration of resilience

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factors, especially in adolescents.Lack of cross-cultural studies and regionally inclusive perspectives. Poorly addressed issues of delayed diagnosis and irregular access to transfusions. Scarce attention to the unavailability of iron chelation therapy in low-resource settings. Insufficient integration of psychosocial and medical care in healthcare models. Limited evaluation of policy measures to improve quality of life. In this study, we observe the experience of families living with thalassemia patients. We cover the Qs about how their lifestyle changes. We explore their way of survival with this pandemic disease. We notice the difference in their relations with their relatives after Thalassemia. We observe what they're facing emotionally, psychologically, and financially in their daily lives.

1.1 Problem Statement

Despite advances in clinical treatments for Thalassemia, there remains a significant lack of research on how families manage the disease's psychosocial burden (Low et al., 2018). The absence of comprehensive qualitative research on these individuals' lived experiences hinders the development of holistic, patient-centered care strategies.

1.2 Research Gap

This study aims to fill this gap by examining the personal narratives of thalassemia patients and their families in Pakistan. It will identify key challenges, coping mechanisms, and sources of resilience. The findings will help promote a more inclusive approach to healthcare, emphasizing emotional support, social integration, and policy reforms to enhance the quality of life for those affected by the condition.

1.3 Research Question

1. How do thalassemia patients and their families cope with the difficulties of the disease?
2. Why do families of thalassemia patients find their experience physically, emotionally, and socially challenging?
3. How does the accessibility and availability of healthcare services in Pakistan influence the treatment and health of thalassemia patients?

1.4 Research Objectives

1. To discover the lived experiences of thalassemia patients and their families.
2. To understand Thalassemia's emotional, social, and psychological effects on affected families.
3. To examine the role of healthcare services, such as public and private sector hospitals, in managing Thalassemia in Pakistan.

2.LITERATURE REVIEW

Inherited haemoglobin disorders, especially Thalassemia, contribute to 17% of hemoglobinopathies globally, with over an estimated 3,30,000 infants born annually, modelling B.darleston M.2008.Thalassemia is an inherited genetic disorder characterized by defective or missing alpha and beta globulin genes. It can be classified as minor, intermediate, or major to describe the severity of conditions and symptoms. The symptoms experienced will depend on the type of Thalassemia one has and to what extent severe it is.

The symptoms might include growth problems, comma, delayed puberty, bone abnormalities (such as osteoporosis), poor appetite, and pale or yellow skin (jaundice).

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The other reason parents become socially isolated and contribute to the impairment of social relations is that they need to spend more time constantly with their children. In Thalassemia major patients, the financial burden is prominent, like any chronic disease, due to follow-up visits, treatment, and frequent admissions, besides the transportation cost and high living costs. This is more problematic for parents in low socioeconomic countries with families having poor financial conditions and limited income (Yousuf et al., 2022).

A range of interrelated factors shapes the psychological resilience of thalassemia patients and their families. Strong social and family support provides emotional strength and reduces feelings of isolation, while hope, future aspirations, and inner psychological strength foster
motivation and a sense of purpose.

Effective management of physical symptoms like fatigue and pain contributes to better daily functioning, whereas poorly managed health issues can hinder resilience. Educational and career aspirations play a crucial role in sustaining optimism and self-worth, though interruptions in schooling or work due to illness can negatively impact mental health. Trust in healthcare services, satisfaction with medical support, and the presence of supportive groups or NGOs further enhance coping, while gaps in these systems can lead to anxiety and distress. Additionally, positive coping strategies strengthen resilience, whereas maladaptive behaviours may exacerbate emotional challenges.

Altogether, these factors collectively influence the ability of patients and their families to adapt, cope, and maintain hope through the journey of living with Thalassemia. Limited research on the psychosocial challenges faced by thalassemia patients and caregivers. Inadequate exploration of resilience factors, especially in adolescents.Lack of cross-cultural studies and regionally inclusive perspectives.

Poorly addressed issues of delayed diagnosis and irregular access to transfusions. Scarce attention to the unavailability of iron chelation therapy in low-resource settings. Insufficient integration of psychosocial and medical care in healthcare models.

Limited evaluation of policy measures to improve quality of life. In this study, we observe the experience of families living with thalassemia patients. We cover the questions about how their lifestyle changes. We explore their way of survival

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with this pandemic disease. We notice the difference in their relations with their relatives after Thalassemia. We observe what they're facing emotionally, psychologically, and financially in their daily lives.

3. Research Methodology:

Thalassemia patients and their caregivers face multifaceted challenges beyond the disease's medical aspects. Despite advancements in treatment, the emotional, psychological, and social impacts remain underexplored in the context of Pakistan. There is a critical need to understand how families cope with the psychosocial burdens and how gaps in healthcare infrastructure influence their experience. This study adopts an exploratory qualitative research design to investigate the lived experiences of thalassemia patients and their families. Since the aim is to gain deep, contextual insights into emotional and social experiences rather than test a hypothesis, an exploratory approach is most appropriate. It allows for uncovering subjective realities, coping mechanisms, and resilience narratives. A qualitative research method was employed to facilitate an in-depth understanding of the psychosocial dynamics of Thalassemia. This method focuses on meanings, experiences, and the social contexts of participants through non-numeric data, which is suitable for analyzing sensitive issues such as chronic illness and mental wellbeing.

3.1 Research Population

- Thalassemia patients (both children and adults)
- Caregivers (primarily parents)
- Medical professionals (doctors treating Thalassemia in public and private hospitals).

3.2 Sampling Techniques

A purposive sampling technique was used to select participants who were most knowledgeable and experienced with thalassemia management. This non-probability sampling is appropriate for qualitative studies where insights, rather than generalizability, are prioritized.

3.3 Sample Size

- 21 Thalassemia patients and their caregivers
- 13 Doctors and medical professionals

This sample size ensures data saturation while balancing the depth of individual stories with diversity in participant demographics and roles.

3.4 Research Tools

a. **Observation Checklist:**

A structured observation procedure was document caregiver behavior, patient-doctor interactions, and clinical setting quality (e.g., waiting times, transfusion protocols, and child engagement).

b. **Interview Guide**:

An interview guide was developed with open-ended questions focusing on:

Emotional and psychological effects of Thalassemia. Daily caregiving challenges. Social support and stigma. Experience with healthcare facilities. Perceptions of resilience and hope

c. **Questionnaire:**

A short demographic and open-ended questionnaires were administered to collect socioeconomic background. Treatment history. Role of government & NGOs

Ethical Considerations: Informed consent was obtained from all participants, including parental consent for minors. The study-maintained confidentiality and anonymity.

3.5 Data Collection Procedure

Primary Data Collection: In-depth semi-structured interviews were conducted with patients, caregivers, and doctors. This allows flexibility in exploring participant experiences while maintaining consistency across interviews. Participant observations was occurred in thalassemia treatment centers, noting non-verbal cues, hospital environment, and family interactions during visits or transfusions. Questionnaires were distributed to healthcare professionals where interviews were not feasible, especially to collect demographic and contextual data.

4. RESEARCH INTERPRETATION AND ANALYSIS:

The research was designed to be qualitative and exploratory; thus, thematic analysis was employed to analyze the data.

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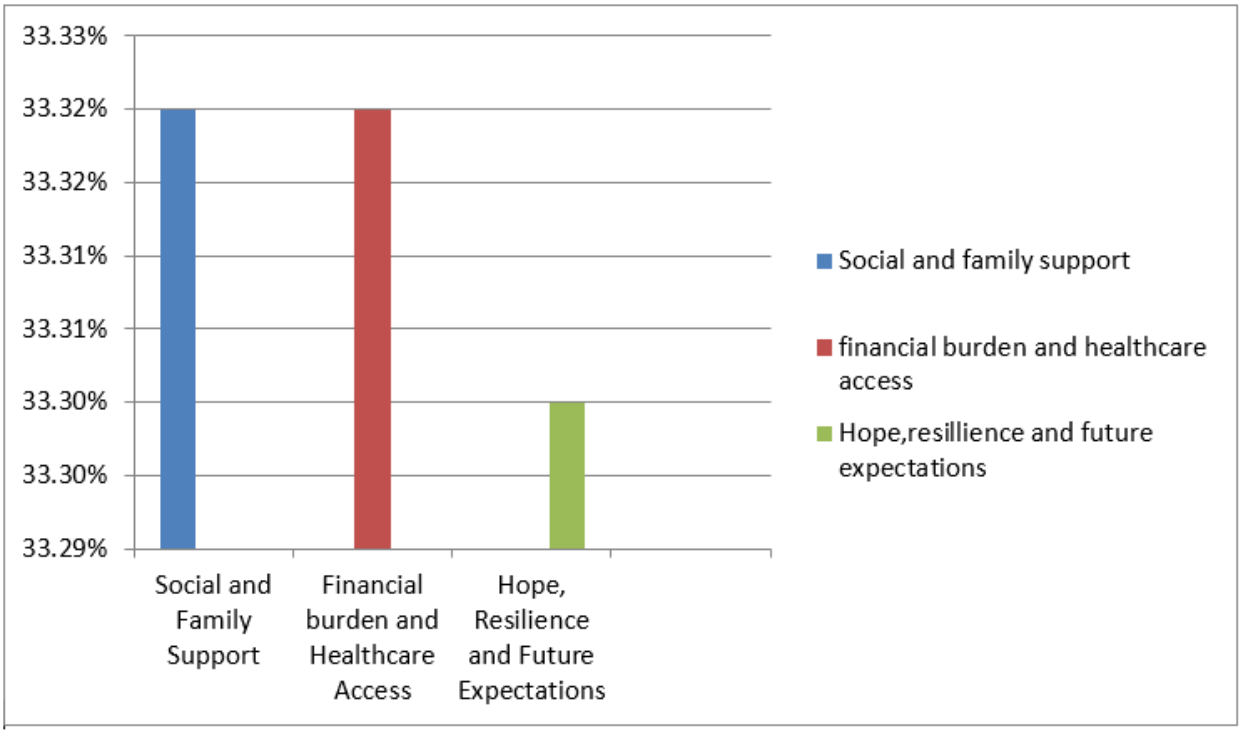
Table 4.1: The perspectives of parents of children with thalassemia on disease management and its financial and psychological impacts.

Theme	Social and Family Support			Financial burden and Healthcare Access			Hope, Resilience and Future Expectations		
Codes	Family Support and Involvement	Community and Peer Support	Coping strategies	Healthcare Accessibility	Economic Challenges	Government and NGO Support	Sources of Strength	Child's Psychological Well-being	Future Aspirations
Frequency	14	8	13	13	13	6	27	12	13
Percentage	40%	22.85%	37.1%	40.6%	40.6%	18.75%	51.92%	23.08%	25%
Overall Percentage	33.32%			33.32%			33.3%		

Table 4.1 shows thalassemia patients' overall response percentages regarding their experiences: Challenges in managing physical health and disease are significant issues faced by patients (33.32%). Barriers to accessing education and career opportunities are notable concerns (32.32%). Perceptions of healthcare and support systems highlight the need for improved services and resources (33.3%).



Graph 4.1: The perspectives of parents of children with thalassemia on disease management and its financial and psychological impacts

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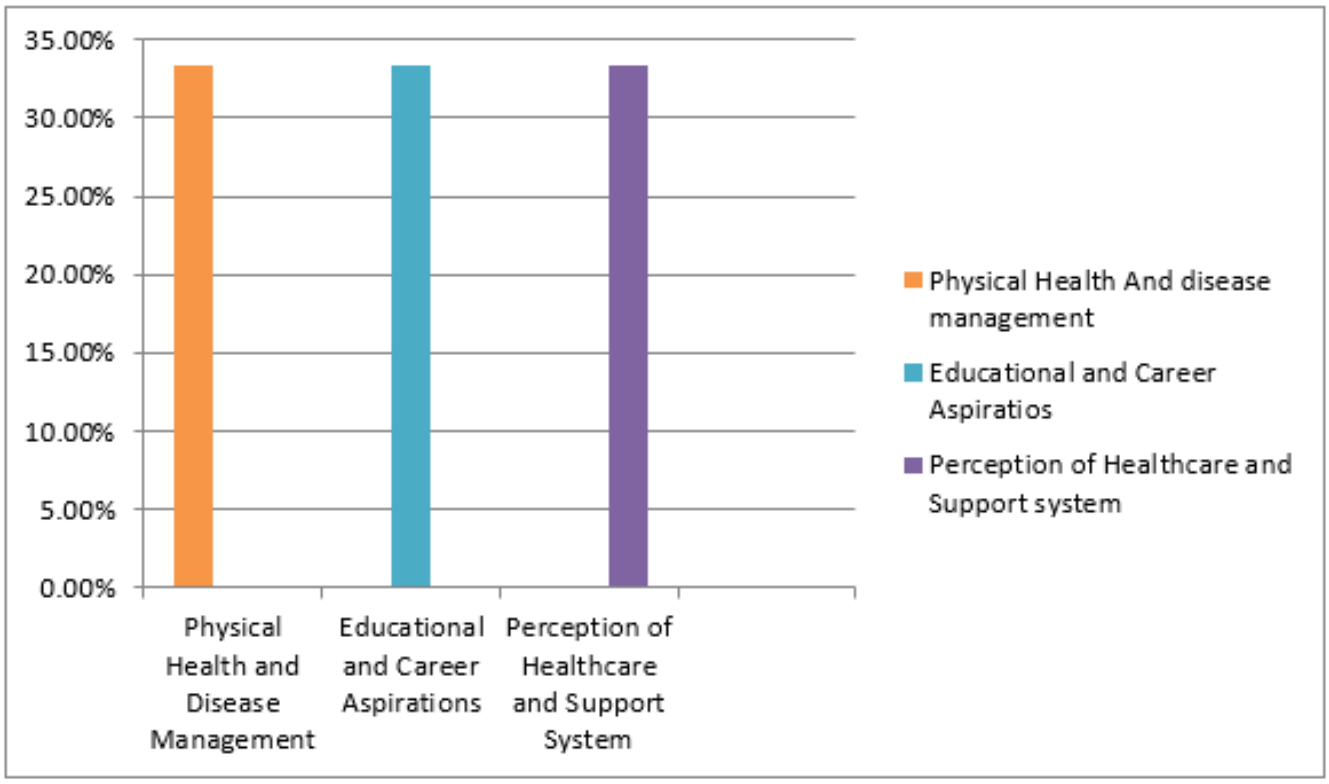
Table 4.2: The perspectives of children with thalassemia on disease management and their future perspective

Theme	Physical Health and Disease Management		Educational and Career Aspirations			Perception of Healthcare and Support System		
Codes	Fatigue and Energy Levels	Pain and Discomfort	Impact on School/Uni Life	Employment and Workplace Challenges	Career Aspirations and Future plans	Satisfaction with Healthcare Services	Need for Better Medical Support	Role of Support Groups and NGOs
Frequency	15	16	14	10	16	10	26	18
Percentage	48.38%	51.61%	35%	25%	40%	18.52%	48.15%	33.3%
Overall Percentage	33.3%		33.3%			33.3%		

Table 4.2 shows that the responses of thalassemia patients, with all themes—physical health and disease management, educational and career aspirations, and perception of healthcare and support systems equally reported at 33.3%. This indicates a balanced distribution of concerns across these critical areas in the lives of thalassemia patients.



Graph 4.2: The perspectives of children with thalassemia on disease management and their future perspective.

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Extract (1) from the patient's Interview
A. Gender: Female
Age:27
Thalassemia type: Major
Social Life OF patients
1. How has living with thalassemia affected your relationships with friends and peers?
Answer: "There was no change in their behavior; they supported and motivated me.But some relatives may not fully understand or relate to living with thalassemia".
2. Have you ever felt excluded or treated differently because of thalassemia?
Answer: "No, my friends and family have always been supportive and inclusive. They make sure I never feel like an outsider."
3. Do you receive government, NGO, or community-based financial assistance?
Answer: "There is no such assistance from the government but Sundas Foundation has supported me a lot financially."
4. Have you ever experienced feelings of anxiety, depression, or low self-esteem because of your condition?
Answer: I never felt depression or Low self-esteem because I have accepted thalassemia as part of who I am.
B. Gender: Female
Age:20 years
Thalesimia type: Major
Social Life patients
1. How has living with thalassemia affected your relationships with friends and peers?
Answer: "There was no change in the behavior of my family but I felt insecure around my friends and classmates."
2. Have you ever felt excluded or treated differently because of thalassemia?
Answer: "Yes,my relatives did not understand my condition and treated me as an outsider."
3. Do you receive government, NGO, or community-based financial assistance?
Answer: No, I did not receive any support from the government; only the Sundas Foundation helped and supported me financially.
4. Have you ever experienced feelings of anxiety, depression, or low self-esteem because of your condition?
Answer: "Yes I felt anxiety and depression many times when my condition made me feel really down and I struggled with feeling like I wasn't good enough because of my limitations."
C. Gender: Female
Age:17
Thalassemia type: Major
Social Life patients
1. How has living with thalassemia affected your relationships with friends and peers?
Answer: My family and friends are really supportive, so living with thalassemia hasn't really affected my relationship with them. We have learned to adopt plans to fit my needs.
2. Have you ever felt excluded or treated differently because of thalassemia?
Answer: I haven't felt excluded or treated differently because of thalassemia. My family and friends are really supportive and accommodate me at every step.
3. Do you receive government, NGO, or community-based financial assistance?
Answer: Only Sundas Foundation supported me, and it's been four years since I connected with this foundation. They helped me A lot.
4. Have you ever experienced feelings of anxiety, depression, or low self-esteem because of your condition?
Answer: "No, I didn't feel depression or anxiety because my family is really understanding, and they encouraged me on every step. They know when I need to take breaks or skip certain activities."

Figure 4.1: Extract from Patients

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Extract (2: from the Family Members

Social Life:

1. How has your family's social life changed since the diagnosis of thalassemia in your child/family member?

Answer: It has not changed drastically because friends and family are really supportive and inclusive. My life has become more organized because of their support

2. Are there people or groups who offer emotional or practical help?

Answer. "My family has been really supportive but my relatives did not provide any financial support "

Psychiatric Issues 1.

How do you emotionally support your child/family member with thalassemia?

Answer:We have dealt with her patiently by motivating her that this too shall pass as it is a test from Allah.

2. How do you stay hopeful and resilient during difficult times?

Answer:As it's a test from Him, and we have tawakkul on Him, we can stay hopeful and resilient during difficult times. We believe that Allah's wisdom and plan are beyond our understanding, and He will guide us through challenges.

Figure 4.2: Extract from Family Members

4.1 Discussion:

The lived experiences of thalassemia patients and their families in Pakistan provide a window into the complex interplay of medical, social, and economic challenges that accompany this chronic condition. Thalassemia, a genetic blood disorder characterized by impaired hemoglobin production, is a significant public health concern in Pakistan, which ranks among the countries with the highest prevalence rates globally. Approximately 5-8% of the population, or nearly 10 million individuals, are carriers of the beta-thalassemia gene mutation, and an estimated 5,000-6,000 children are born annually with beta-thalassemia major, the most severe form of the disease (Ahmed et al., 2022).

The prevailing rise in thalassemia observed in various regions of Pakistan, including Southern Punjab, Kashmir, Swabi, and FATA, is largely attributed to cousin marriages, lack of awareness, and a lower rate of blood screening, with only 30% of blood donations adequately screened (Sundas Foundation, Islamabad). Without timely treatment, the probability of death in untreated patients is between one to three years, underscoring the urgency of comprehensive medical care. One primary contributing factor to this condition is inadequate hemoglobin levels in parents, with the standard levels being 13.5 g/dL for males and 13 g/dL for females.

Figure.4.3 Thalassemia ward Sundas Foundation, Islamabad

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The patriarchal nature of Pakistani society exacerbates the challenges faced by families, with diagnoses of thalassemia often leading to increased divorce rates, further straining the affected households emotionally and financially.

The financial burden of managing thalassemia is staggering; the cost of treatment for a single patient ranges from PKR 500,000 to PKR 1,000,000 per year, encompassing blood transfusions, medications, and diagnostic tests. This is far beyond the reach of most families, particularly those in rural areas, where healthcare infrastructure is inadequate and access to specialized treatment centers is limited. A recent study highlighted that only 30% of patients in Pakistan receive adequate chelation therapy due to high costs and limited availability, leading to poor disease outcomes and reduced life expectancy (Ansari et al., 2021). Private NGOs, such as the Pakistan Thalassemia Welfare Society (PATWOS) and the Fatimid Foundation, have emerged as critical lifelines, providing free or subsidized treatments, with some organizations supporting over 25,000 registered patients annually.

The psychosocial impact of thalassemia on patients and families is equally profound. Caregivers, often parents or close relatives, face significant emotional and financial stress, with 70% of families in a recent survey reporting symptoms of anxiety and depression directly linked to the challenges of caregiving (Khan et al., 2020).

Patients, particularly adolescents, frequently experience social stigma, isolation, and disrupted education due to the demanding nature of their medical regimen. Awareness about the disease remains alarmingly low; only 10% of the population undergoes premarital genetic screening, despite evidence suggesting that mandatory screening programs could reduce the incidence of beta-thalassemia major by up to 90% in high-risk populations (Fatima et al., 2021).

Countries such as Iran and Cyprus, which have implemented robust genetic screening and counseling programs, have demonstrated the efficacy of these measures in significantly reducing disease prevalence, highlighting the urgent need for Pakistan to adopt similar strategies.

Medical advancements, including bone marrow transplantation and gene therapy, offer a glimmer of hope for thalassemia patients.

Bone marrow transplants, considered a potential cure, have a success rate of over 85% in carefully selected cases, but the procedure's cost—ranging between USD 25,000 and USD 50,000—is prohibitive for most families, and only a few specialized centers in urban areas like Karachi and Lahore perform these transplants. Similarly, while gene therapy represents a groundbreaking development in the global fight against thalassemia, its accessibility in Pakistan remains limited due to high costs, lack of infrastructure, and insufficient expertise. The disparity in access to these treatments highlights broader inequalities within the healthcare system, where urban-rural divides and socioeconomic disparities significantly influence patient outcomes.

Despite these overwhelming challenges, the resilience of thalassemia patients and their families is remarkable. Many find strength in community support networks and NGOs that provide medical assistance, psychosocial support, educational programs, and advocacy initiatives.

Religious faith often serves as an additional source of solace and hope for families, helping them navigate the emotional toll of the condition. This study emphasizes the pressing need for a multifaceted approach to thalassemia management in Pakistan, which includes national-level preventive programs such as premarital genetic screening, increased funding for public healthcare systems, and enhanced accessibility to advanced treatments.

This study aims to spread awareness and promote prevention, providing a framework for future strategies to mitigate the prevalence of thalassemia in Pakistan (Sundas Foundation, Islamabad).

At the same time, it celebrates the strength and determination of affected individuals and their families, whose unwavering hope and resilience continue to inspire and advocate for change in the face of immense adversity. The burden of thalassemia in Pakistan is further compounded by the lack of a national registry system to track affected individuals and carriers. Without comprehensive data, policymakers face significant challenges in designing targeted interventions and allocating resources effectively (Iqbal et al., 2022).

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Moreover, the absence of uniform protocols for managing thalassemia across healthcare facilities has led to inconsistent treatment standards, particularly in rural areas, where trained hematologists are scarce, and healthcare facilities lack essential resources, such as blood banks and chelation medications (Ali et al., 2021).

One of the critical gaps in thalassemia management in Pakistan is the limited focus on psychosocial rehabilitation programs. While NGOs provide critical medical support, only a few address the psychological needs of patients, such as counseling services for dealing with depression, anxiety, and social stigma.

Studies have shown that comprehensive care models, which integrate mental health support, significantly improve patient outcomes and quality of life (Raza et al., 2020). Public health education remains a significant challenge in combating thalassemia. Despite the availability of awareness campaigns, their reach and impact are limited due to cultural barriers, low literacy rates (estimated at 59% nationwide), and insufficient funding.

For instance, many communities still resist premarital genetic counseling due to societal taboos and misconceptions about its implications for family honor and marriage prospects (Naseer et al., 2019). Implementing culturally sensitive education programs could help address these barriers and encourage greater acceptance of preventive measures.

Another neglected aspect is the role of technology in improving thalassemia care. Digital health tools like telemedicine could bridge the gap between rural patients and urban healthcare providers, enabling remote consultations and better disease monitoring. However, the adoption of such technologies is hindered by limited internet penetration and digital literacy, particularly in remote regions (Saeed et al., 2021).

Lastly, environmental factors influencing the management of thalassemia need to be addressed. For example, power outages in rural blood banks disrupt the storage of blood supplies, leading to wastage and shortages during emergencies. Sustainable solutions, such as solar-powered storage systems, could mitigate this issue and ensure the availability of safe blood for transfusions (Habib et al., 2021).

5. CONCLUSION

The purpose of this study was to understand the psychosocial experiences of thalassemia patients and their families to comprehend how they cope with chronic illness while balancing these concepts with hope and mental fortitude. In addition to exhibiting emotional, psychological, and financial stress themes, our results also demonstrate remarkable strength derived from family, community, and personal resilience. Significant treatment access barriers for thalassemia caregivers and parents indicate the need for more integrated healthcare systems such as hub-and-spoke thalassemia care centers. This also emphasizes the need to increase levels of public awareness promoting premarital and antenatal carrier screening as necessary components of public health agendas. These conclusions offer valuable insights into thalassemia care in resource-limited settings and will aid the development of clinical policies geared toward public health prevention and supportive interventions. There are limitations, however. The study was conducted within specific geographic and sociocultural boundaries, which may not be experienced by all patients and families impacted by thalassemia.

Furthermore, time limitations may have impacted how narratives could be fully developed. Further research should focus on looking at more remote regions of the country for cross-province comparative studies on how varying social, economic, and healthcare system factors affect lived experience. Longitudinal studies of patience will also help deepen the understanding of patience over time. To sum it up, the road traveled by these people encompasses mostly not infirmity but courage, love, and unending hope for a brighter tomorrow. The proof of resilience really shows what humanity is capable of when summoned through adversity. It is a power to survive against strength."

5.1 Implications of research

This research sheds light on the need to broaden the scope of thalassemia care by addressing its medical aspects and the profound emotional and social struggles faced by patients and their families. It underscores the importance of understanding how these challenges impact caregivers and their ability to cope with the burden of the disease. The findings

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highlight the significant role of psychosocial support, emphasizing the necessity of integrating emotional and financial assistance into the care model. Furthermore, the study reveals critical gaps in healthcare accessibility, particularly in rural areas, and stresses the role of NGOs in alleviating these challenges. The research calls for a more inclusive approach to thalassemia care by addressing these aspects.

5.2 Future Recommendations

To control the prevalence of thalassemia, nationwide premarital and prenatal screening programs should be implemented. These programs must be accompanied by culturally sensitive awareness campaigns to address societal stigmas and misconceptions.

Healthcare systems should work towards improving access to advanced treatments, particularly in rural and underserved areas, ensuring equitable care for all patients. Additionally, establishing robust emotional and financial support systems, including counseling services and community-based initiatives, is critical to easing the burden on families.

NGOs and innovative technologies such as telemedicine should be leveraged to bridge gaps in healthcare delivery, providing comprehensive care regardless of location. A compassionate, inclusive approach can enhance the quality of life and support for those affected by this chronic condition.

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