Socio-Emotional Issues Encountered by Thalassemia Patient in Islamabad, Pakistan

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DEDICATION

It is with great affection that I dedicate this research to my devoted father, Ishtiaq Hussain, as well as to my beloved siblings, Nouman Ishtiaq, and Dr. Zainab Ishtiaq, and my late mother, Attiya Ishtiaq. In addition, I would like to express my gratitude to Dr. Majid Hussain, who serves as my esteemed supervisor, for the essential assistance and guidance he has provided during this research.

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ABSTRACT

The purpose of this study is to investigate the social and emotional difficulties that are experienced by families of thalassemia patients in Islamabad, Pakistan. The qualitative research that was conducted, served as the source of inspiration. Participant observation, unstructured talks, interviews with key informants, a life history approach, and in-depth interviews were some of the qualitative methods that were utilized throughout the research process. To shed light on the effects of socioeconomic situations, cultural beliefs, and the dynamics of the healthcare system, the study investigates the healing procedures that are utilized in Islamabad.

In thalassemia, families battle with particular socio-emotional challenges. The practices of religious belief play a role in creating views, reflecting the larger landscape of healthcare more generally. When it comes to embracing contemporary health practices for thalassemia, there are substantial challenges that include poverty, political economy, and a positive belief in religious rituals. The insufficiency of the health services provided by the government, in conjunction with the obstacles posed by organizations and cultures, makes the difficulties that families who are looking for help for thalassemia patients confront even more difficult.

Furthermore, the findings in Islamabad are validated by the study since it highlights the stressed relationship that exists between the local population and the health services provided by the government authorities. The provision of necessary services to patients who are afflicted with thalassemia is hampered by allegations of corruption, power-based relationships, and the actions of healthcare professionals working in public institutions. The findings of the study on traditional therapy approaches are consistent with the notion that religious prejudices have a role in reinforcing a reluctance to adopt modern treatment.

The socio-emotional obstacles that families dealing with thalassemia face are numerous and include issues such as poverty, cultural values, belief systems, and a lack of trust in the healthcare system. Recommendations for targeted treatments and enhanced healthcare delivery are presented, with an emphasis placed on the significance of community engagement and cultural sensitivity in the process of supporting the well-being of thalassemia patients and their families.

LIST OF ABBREVIATIONS/ACRONYMS

TH	Thalassemia
FTEI	Family Thalassemia Emotional Issues
SIE	Socio0Emotional Encounters
FQoL	Family Quality Life
TFSC	Thalassemia Family Support Challenges
PFC	Patients Family Communication
WHO	World Health Organization
NGO	Non-Governmental Organization
DR	Doctors
MBBS	Bachelor of Medicine and bachelor of surgery
PIMS	Pakistan Institute of Medical Science
PRCS	Pakistan Red Crescent Society
EHR	Emotional Health Risks
THC	Thalassemia Health Concerns
SS	Social Stigma
OPD	Outpatient Department
SRE	Social Support Resource
TEI	Thalassemia Emotional Impact
FAC	Family Adjustment Challenges
CFT	Coping Family Techniques
ETC	Islamabad Thalassemia Center
TRE	Thalassemia Related Experiences
EIP	Emotional Impact Perception
FCC	Family Caregiver Challenges
HAP	Health Access Problems
PSR	Parents Siblings Relationship
TCI	Thalassemia Caregiver Impact
RA	Research Advancement
TRC	Turkish Red Crescent

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CHAPTER NO. 1

INTRODUCTION

Thalassemia, a hereditary blood disorder prevalent in Islamabad, Pakistan, stems from genetic mutations that cause inadequate hemoglobin production. Scientifically it has been proven during the first six months, a child contains genes that are inherited from its parents but after that child must produce its genes called adult hemoglobin. This proclaim according to (Zaheer, 2000) contains two alpha and two beta globin chains. In thalassemia patients, a mutation occurs in beta globin chains. It may be a major mutation if it occurs in both the beta globin chains or it may be minor if it occurs in a single beta globin chain this condition not only affects the individuals diagnosed with it but also intricately weaves challenges into the fabric of their families' lives. Families of thalassemia parents in Islamabad grapple with a multitude of socio-emotional and economic issues that significantly impact their daily existence. On a social level, the stigma attached to chronic illnesses can lead to feelings of isolation and marginalization within communities. Furthermore, the emotional toll on family members is profound as they navigate the complexities of caring for a child with a chronic condition, managing their emotional well-being, and addressing the inherent uncertainties associated with thalassemia. Economically, the financial burden of managing thalassemia is formidable. According to (Widyanti et.al, 2011) the costs associated with regular blood transfusions, specialized medical care, and ongoing monitoring can strain family resources, particularly in a setting where access to comprehensive healthcare may be limited. Understanding the intricate interplay of these social and economic factors is crucial for developing targeted interventions and support systems that can alleviate the burden faced by families of thalassemia parents in Islamabad.

According to (Chong, 2019) the management of thalassemia poses a substantial financial burden on countries, including Pakistan, as they grapple with the associated healthcare costs. According to the World Health Organization (WHO), thalassemia is recognized as a major global health issue, with an estimated 1.5% of the world's population carrying the genetic trait for this blood disorder. In Pakistan, the prevalence of thalassemia is noteworthy, further contributing to its economic impact. The annual cost of managing thalassemia, including medical treatments, blood transfusions, and associated healthcare expenses, places a strain on healthcare systems and national economies. In Pakistan β-thalassemia (β-thal) trait frequency ranges between 5.0-7.0%, thus, there are more than

10 million carriers in the country; and every year, around 5000 children are diagnosed carry β-thal major (β-TM) in Pakistan. Statistics reveal that, on average, the lifetime cost of treating an individual with thalassemia can surpass tens of thousands of dollars, a considerable financial burden for families and the healthcare infrastructure alike. Notably, the economic challenges associated with thalassemia are not distributed evenly across all socioeconomic classes. The work of Socio- religious Prognosticators of the Psychosocial Burden of Beta Thalassemia Major (Rashid, 2020) has discussed that Families belonging to lower-income brackets often bear a disproportionate share of the economic burden, as they face barriers to accessing quality healthcare and specialized treatments. The prevalence of thalassemia in these communities is higher, further exacerbating existing disparities.

According to (Desai, 20019) Thalassemia patient and their families face many challenges due to the inadequacy of knowledge, consanguineous marriage among first cousins has a significant role in the continuation of the disease process and superstitious cultural beliefs, ignorance of the disease, and lack of premarital screening practices play a major role in the propagation of this disease that causes immense psychosocial, physical, and financial burdens to patients and their families.

Despite the attention to the biological factors in literature citation, the research in Pakistan is mainly focused on its social impacts. To explore the different dimensions of this disease or to uncover the realm of its social factors as our focus is on that thalassemia is not a biological disease but a social so we will a qualitative method for researching to gain a deeper understanding of thalassemia disease and what kind of problems faced by the families of thalassemia's patients in the society. This research will contribute to Anthropological knowledge as well as in the applied field for health policy makers or the public domain.

1.2 Rationale of Locale and Study

A significant number of people who are affected by the disease reside in Islamabad and the areas surrounding it. Islamabad is a significant and representative place to gain an understanding of the socio-emotional effects that thalassemia has on families. This is due to the high occurrence of the disease in the city. In this context, it is essential to have a thorough understanding of the cultural shades and potential stigma that are connected with thalassemia to design strategies for targeted medicines and support mechanisms.

There are specialized treatment centers for thalassemia in the city, which makes it a center for healthcare services. To identify gaps and provide recommendations to improve the quality of care and emotional support that is provided to families impacted by thalassemia, it is essential to investigate the experiences that families have had with healthcare and support services.

Several programs have been initiated by the government of Pakistan to combat thalassemia; it is of the utmost importance to evaluate the impact that these programs have had on the psychological and social well-being of families. To guide ideas for improvements and better integration of socio-emotional support into the overall thalassemia care system, analyzing the effectiveness of existing policies can be of great use. The mission of the proposed research project in Islamabad is to provide substantial insights into the socio-emotional issues that families of thalassemia patients confront, while also taking into account the unique socio-cultural, healthcare, and community dynamics that are present in the capital city. The findings have the potential to inform targeted interventions, policies, and support systems that can improve the overall well-being of families afflicted by thalassemia not just in Islamabad, but also in other locations that are facing difficulties that are analogous to those in Islamabad.

1.2.1 Theoretical Framework

The theoretical framework that I have incorporated into my research is **Socio-Psychological Theory.** This theory was introduced by Lewin who was a German-American psychologist and is often regarded as the "father" of social psychology. He is also well-known for the enormous contributions he made to the study of group dynamics and social behaviors. He established the groundwork for a wide range of socio-psychological ideas and studies through his work (Lewin, 1951).

Psychological anthropology and medical anthropology have long been intertwined in their exploration of human behavior, health, and culture. This interdisciplinary approach has evolved over time, drawing from various theoretical frameworks and perspectives to understand the complex interplay between psychological factors and medical practices within diverse cultural contexts.

This research aims to understand the problem of the thalassemia patients and their families faced by the society and **Socio-psychological theory** fits to understand the thoughts of the society behind this disease. The purpose of this chapter is to present an outline of the theory, as well as a history of the theory. Within the second chapter, which is titled "Literature review," a full discussion of the application of the theory's primary components is provided in a brief method.

1.2.2 Conceptual Gap

Thalassemia is a hereditary blood illness that not only can hurt a person's physical health but also on their social and emotional well-being. It presents substantial hurdles to both the individual and their family. In literature mostly research conducted on its biological and economic factors but there is a clear research gap in understanding the nuanced socio-emotional challenges that are confronted by families of thalassemia patients, particularly in the context of Islamabad, Pakistan. This is even though various research has concentrated on the medical aspects of thalassemia. The purpose of this study is to fill this illegal by investigating the numerous difficulties that these families are confronted with, to shine light on the emotional, psychological, and social aspects of their experiences.

To fill this vacuum, the purpose of this study is to investigate the complexities of the socio-emotional issues that families of thalassemia patients in the capital city of Pakistan encounter. It is the medical elements of thalassemia that are the primary emphasis of the existing body of literature, with particular attention paid to treatment protocols, genetic counseling, and technological breakthroughs in the medical field. On the other hand, there is a relatively small body of research that investigates the psychological aspects of thalassemia, particularly in the framework of Islamabad's distinctive sociocultural environment.

The purpose of this study is to give useful insights into the socio-emotional issues that families of thalassemia patients in Islamabad face by addressing the conceptual gap that exists in the existing body of research. It is anticipated that the findings will provide healthcare professionals, policymakers, and support groups with information that will facilitate the creation of focused interventions to improve the overall well-being of individuals and families in the region who are suffering from thalassemia.

1.2.3 Methodological Gap

A greater methodological gap is revealed while doing an investigation into the socio-emotional challenges that families of thalassemia patients face using a variety of research approaches. To research a substantial number of the relevant issues, qualitative approaches are used. Several studies have been conducted on the associated subjects, and these studies have utilized only qualitative research methods such as participant observation, unstructured interviews, and life history methods, I am making an effort to address this gap by utilizing these techniques.

1.3 Problem:

Thalassemia is increasingly prevalent in Pakistan, driven by factors such as poverty, endogamy (marriage within families), limited health awareness, and substandard treatment in government healthcare facilities. Despite hospitals offering free blood and blood transfusion services, low-income families, deeply embedded in tradition and culture, often resort to homemade remedies rather than seeking proper medical treatment.

This situation highlights a complex interplay of socio-economic factors influencing healthcare choices. While hospitals may provide essential services at no cost, cultural beliefs and financial constraints often steer individuals towards alternative remedies, posing challenges for effective thalassemia management and prevention within these communities.

As society perceives individuals affected by thalassemia as burdensome, they become especially vulnerable to the challenges associated with the disease. This study seeks to explore the specific difficulties encountered by families of thalassemia patients, particularly in the context of Islamabad, shedding light on the intersection of societal attitudes and the realities of managing this condition within the community.

1.4 Problem Statement:

Thalassemia, a growing global health concern, disproportionately affects impoverished individuals who lack access to expensive treatments. The disparity in healthcare accessibility is evident as middle-class patients endure lengthy queues at government hospitals, where overcrowded conditions and inadequate monitoring by doctors exacerbate frustrations and diminish trust in these institutions. Consequently, reluctance

to seek medical care increases susceptibility to the disease, perpetuating a cycle of vulnerability among socioeconomically disadvantaged populations.

Medical professionals are urged to uphold ethical standards by treating all patients with dignity, irrespective of social status, ethnicity, or religion. Adhering to the principle of "first come, first served" is essential in ensuring equitable healthcare delivery. To address overcrowding and prolonged wait times in outpatient departments (OPDs), hospital must implement strategies such as augmenting staff and streamlining appointment systems. Accurate diagnosis and prompt treatment are imperative in mitigating the impact of thalassemia, necessitating the integration of telemedicine services for timely intervention and comprehensive care.

The emotional and social burdens faced by thalassemia patients and their families compound the challenges associated with the disease. From the psychological toll of diagnosis to the financial strain of treatment and the pervasive stigma, inadequate access to specialized support exacerbates mental health disorders. Understanding and addressing these multifaceted issues are paramount in crafting effective interventions that empower and uplift affected families in Islamabad. By prioritizing holistic care and fostering a supportive healthcare ecosystem, strides can be made towards enhancing the well-being of thalassemia patients and their families. Management must implement strategies such as augmenting staff and streamlining appointment systems. Accurate diagnosis and prompt treatment are imperative in mitigating the impact of thalassemia, necessitating the integration of telemedicine services for timely intervention and comprehensive care.

1.5 Objectives:

1) To study the emotional phase of the patient family during the disease treatment.
2) To explore the discrimination, stigma & and mental health issues in Thalassemia patient.
3) To discuss the social problem faced by the patient family in the treatment of thalassemia patients.

1.6 Research Questions:

1) How do thalassemia families face emotional crises during the disease?
2) What is the impact of discrimination and stigma on the mental health of thalassemia patients and how can these issues be addressed to improve their

overall well-being?"

3) What are the social challenges faced by families and how can healthcare providers and policy makers better support them?

1.7 Significance of the Study

The significance of this study on Socio-Emotional Issues Encountered by Families of Thalassemia Patients in Islamabad, Pakistan, resonates across multiple dimensions of human development and societal progress. Firstly, as a prerequisite for the M.S. in Applied Anthropology, this research serves as a foundational exploration into the intricacies of traditional treatments and regional medical practices, particularly within the context of Islamabad's healthcare system. By shedding light on the challenges faced by families dealing with thalassemia, it not only deepens our understanding of healthcare dynamics in Pakistan but also offers insights into broader socio-emotional phenomena surrounding illness perception and management in the region.

Moreover, this study holds immense potential to advance both theoretical discourse and practical interventions in Pakistani Applied Anthropology and healthcare. By elucidating the cultural nuances influencing behaviors and healthcare-seeking patterns, it provides a critical lens through which to examine the intersection of culture, health, and societal norms. Furthermore, the findings of this research can inform the development of tailored interventions and policies aimed at improving healthcare delivery and support systems for thalassemia patients not just in Islamabad but across Pakistan. Thus, beyond academic enrichment, this study stands to make tangible contributions to public health policies and interventions, thereby benefiting both the public and commercial sectors by fostering a more holistic approach to healthcare provision in the country.

CHAPTER NO. 2

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

This chapter has two distinct sections. A theoretical framework is presented in the first section, and through the lens of the theory we'll understand the phenomena of disease in a natural setting by using the Interpretivism approach which is then followed by a survey of the relevant literature. To give a full evaluation of the topic, this chapter does a literature survey and analyzes the theoretical framework. The theoretical framework is responsible for establishing the fundamental concepts and theory social psychological theory of health that were generated from the study. On the other hand, the literature review is responsible for conducting an in-depth analysis of existing research to find gaps and improve upon previous knowledge. Within the part titled "Theoretical Framework," the cornerstone for the research study is laid by providing the essential concepts, theories, and models that will serve as the driving force behind the investigation. It emphasized the value of theoretical perspectives in the process of designing, collecting, and interpreting research data. The part on the literature review provides a critical analysis and synthesis of the most recent academic publications and research findings that are pertinent to the topic being investigated about the study. It is capable of performing several duties, including determining the research gaps, establishing the relevance of the current work, and elaborating on information that has been previously presented. The part starts with a brief overview of the research problem, emphasizing how significant it is in the context of the academic setting. After that, it investigates the historical development of the study area, focusing on significant landmarks and noteworthy accomplishments among them. In conclusion, the section concludes by providing a summary of the research gaps and calling attention to the significance of the study.

2.1 Theoretical Framework

The aim of this research is to delve into the intricate interplay of social and psychological factors influencing the healthcare behaviors of individuals grappling with thalassemia. Chronic thalassemia patients have a hard time staying healthy because of the widespread effects of poverty, especially on disadvantaged groups, and the complicated interactions between government health policies, people's cultural backgrounds, and how they see their right to health. Because the public health system is

so complicated and there aren't many experts to choose from, especially in capitalist pharmaceutical companies, thalassemia patients often have to use home treatments. Medicine is an important way to deal with these health problems because it deals with things like the political economy of health and sheds light on assumptions that have an unfair effect on the health outcomes of people with thalassemia, especially those who are poor and socially excluded.

2.1.1 Socio-Psychological Theory

Psychological anthropology and medical anthropology have long been intertwined in their exploration of human behavior, health, and culture. This interdisciplinary approach has evolved, drawing from various theoretical frameworks and perspectives to understand the complex interplay between psychological factors and medical practices within diverse cultural contexts.

One prominent psychological theory that has influenced the field is Freudian psychoanalysis, which emphasizes the unconscious mind and its influence on behavior and mental health. Freud's work has been instrumental in shaping psychological anthropology's understanding of cultural norms, taboos, and how individuals negotiate their desires and anxieties within societal structures (Good 1994). From a medical perspective, the biopsychosocial model proposed by Engel (1977) has been influential in integrating psychological, biological, and social factors in understanding health and illness.

This holistic approach acknowledges the interconnectedness of mind, body, and environment, emphasizing the importance of considering cultural beliefs and practices in medical diagnosis and treatment (Kleinman 1980). In the realm of psychological anthropology, cultural psychology has emerged as a key framework for studying how cultural context shapes cognitive processes, emotions, and behavior. This perspective highlights the role of culture in shaping individual and collective psychological phenomena, challenging universalistic assumptions about human nature and cognition (Shweder 1991).

On the other hand, medical anthropology has drawn extensively from social constructionist theories to examine how medical knowledge, illness narratives, and healing practices are socially constructed within specific cultural contexts. This approach emphasizes the importance of understanding health and illness as dynamic

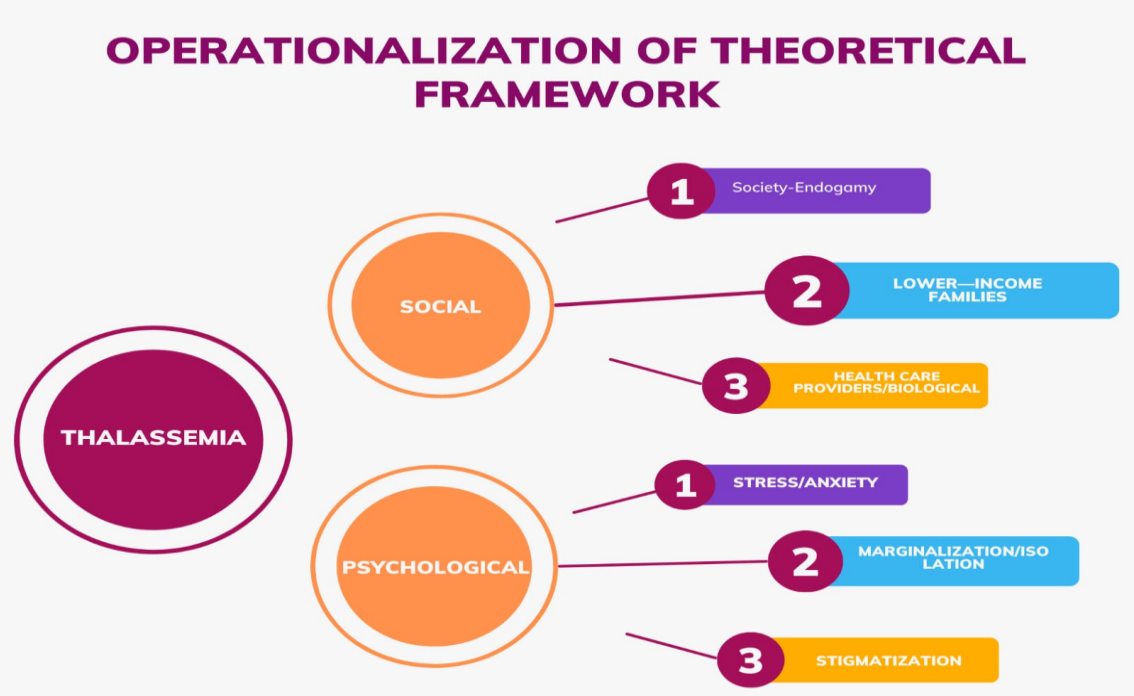
processes shaped by cultural beliefs, power dynamics, and historical contingencies (Lock and Scheper-Hughes 1996).

In conclusion, psychological anthropology and medical anthropology offer complementary perspectives for understanding the intricate relationship between culture, psychology, and health. While psychological theories provide insights into individual cognition and behavior, medical perspectives emphasize the sociocultural dimensions of health and illness. By integrating insights from both fields, scholars can develop more holistic approaches to addressing the complexities of human experience within diverse cultural landscapes.

2.1.2 Operationalization of Theoretical Framework

The operationalization of the theoretical framework is given below:

Figure No.2.1: Theoretical Framework



Source: Literature & Field Data

The theory Socio-Psychological can take it as according to my objectives that we live in a collectivist society and the interaction is based on groups so our behaviors and personality are shaped by our society. Like Thalassemia patients-, mostly lower-class families are affected by Thalassemia due to malnutrition and due to endogamy_ (medical perspective) in this way.

Due to societal needs, the lower families cannot meet their needs and society does not

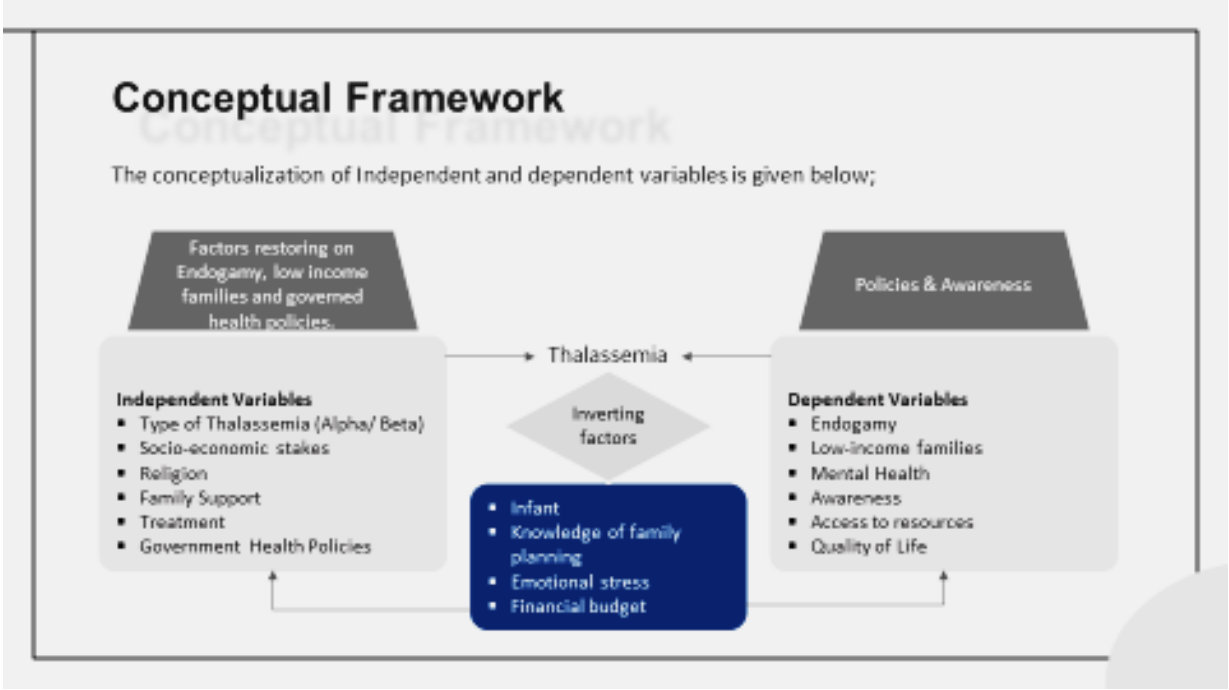
support them in a positive way, which causes social and mental pressure on them.

Due to Thalassemia, families were neglected socially, psychologically, or emotionally and became isolated from society which caused stress and anxiety to them.
So, my theory is going to test how families were neglected by society and how itcauses mental pressure on them, how endogamy plays a role in society because it is an important factor in causing Thalassemia. In addition, endogamy is prevailing due to the Patriarchal culture of the society.

2.2. Conceptual Framework

The conceptualization of Independent and dependent variables is given below:

Figure No.2.2 Independent and Dependent Variables



Source: Literature

The basic idea behind the conceptual framework is the presence of dependent and Independent Variables, which was used in this research. The independent variables are a type of thalassemia, socio-economic stakes, religion, poverty, family support, treatment, and government health policies, whereas the dependent variables are endogamy, low-income families, mental health, awareness, access to resources, and quality of life. The above framework shows the relationship of interdependency between these variables and how these two are affected. Field data proved the same that these factors are evident and

are directly dependent upon each other. (Safdar, 2018) quoted that the frequency of thalassemia has historically been high in the Middle East, in part because of a high carrier rate and a propensity for Endogamy in the region. With regards to the cousin marriages, one of the respondents, Ms. Tanzela, had an opinion, that is similar to the results of the research, she stated: “I believe that the thalassemia condition was caused by cousin marriage in the relative known as consanguineous marriage or endogamy”.

2.2 Literature Review

A review of the relevant published material begins with the assumption that new information can be gained through analyzing the previous research carried out by other people. Establishing one's credibility and demonstrating one's expertise with a body of material are often the primary goals of a literature review. Regarding the link that exists between the recently completed project and the research course that came before it. Compiling and synthesizing information pertinent to a specific subject area. Acquiring new information from other people and coming up with original ideas.

This chapter's objective is to have a deeper comprehension of how the relevant literature affected the daily lives of thosewho are related to thalassemia patients. I organized the material that was examined by fundamental presumptions, such as how the outcomes of thalassemia patients affect the conduct of families all over the world, particularly in Pakistan.

2.3.1 Thalassemia:

Thalassemia, a hereditary blood disorder prevalent in Islamabad, Pakistan, stems from genetic mutations that cause inadequate hemoglobin production. According to (Zaheer, 2000) scientifically it has been proven during the first six months, a child contains genes that are inherited from its parents but after that child must produce genes called adult hemoglobin. It contains two alpha and two beta globin chains. In thalassemia patients, a mutation occurs in beta globin chains. It may be a major mutation if it occurs in both the beta globin chains or it may be minor if it occurs in a single beta globin chain.

Individuals who are diagnosed with β-thalassemia must have the ability to have regular blood transfusions every two to four weeks throughout their entire lives. An excess of iron is caused by persistent transfusion therapy, which results in iron overload. Specifically, as stated in the article Transfusions in Patients of B-Thalassemia Major (Naz, 2023) argued that this extra iron deposits in various organs of the body, which

ultimately leads to harm to those organs. Throughout their lives, patients who have β-thalassemia are required to have regular blood transfusions, in addition to the frequent utilization of chelating therapy, which involves the administration of chelating drugs such as deferoxamine and deferiprone.

According to World Health Organization (Aydinok, 2012) many people throughout the world are afflicted with a blood disorder known as anemia. According to reports WHO prepared, around sixty thousand infants are born each year with a significant form of thalassemia. The WorldHealth Organization (WHO) created a worldwide database of population-based cross-sectional surveys and intervention trials to determine the prevalence of anemia across the world. According to (Petry et al., 2016) statistics gathered between 1993 and 2005, anemia was predicted to affect 1.6 billion people, or roughly 25% of the world's population, with thehighest prevalence rates seen in South East Asia and Africa among women and preschoolers(PSC) and PSC, respectively. PSC and WRA continue to have the largest burden of anemia,according to a more recent study of survey data from 185 different nations (257 surveys in all) gathered between 1990 and 2011. Over 60% of PSCs in Africa and 800 million PSCs andWRA are anemic (Inamdar et al. 2015). According to a World Bank report, Thalassemia has 25,000 registered patients in Iran, and the health ministry classifies it as a unique disease. Individuals who are diagnosed with β-thalassemia intermedia will, at some point in their lives, develop mild anemia. Even though they may be sentient in the same way that normal people are, they will need to be monitored consistently, and they may occasionally require blood transfusions. This information was found by the (Shaukat Ali, 2021) administration of iron supplements is not indicated; however, the administration of folic acid supplements is frequently suggested.

2.3.2 Blood Disorder

There are approximately 1.24 billion people around the world who are affected by iron deficiency anemia (IDA). According to (Demir, 2002) it has a disproportionate impact on women, low-middle socioeconomic groups, and communities in Asia and sub-Saharan Africa, and it is one of the leading causes of years spent with a disability for people all over the world. The prevalence of maternal anemia is estimated to be one million women across the globe. A sizeable cohort study conducted in the United Kingdom found that 46 percent of pregnant women experienced anemia at some stage throughout their pregnancy.

Anyhow, in the research that was related to the economic burden to patients' families (Knoth, 2023) the noteworthy part of the way of life of the tribal community is the health state of its members, which is also a reflection of the activities and routines that they engage in daily. Patients who have β-thalassemia have low hemoglobin levels, which leads to decreased oxygen levels in various parts of the body. To treat the chronic anemia that arises as a consequence of this condition, regular red blood cell transfusions are administered. Additionally, iron chelation therapy (ICT) is also administered concurrently to manage iron overload. Patients with β-thalassemia and their careers experience a significant negative impact on their physical and mental health, as well as their overall health-related quality of life (HRQoL), which is a result of their continual dependency on red blood cell transfusions (RBCs) this dependence is aggravated by difficulties connected to therapy.

2.3.3 Family, (Endogamy) the cause of Thalassemia

People in Pakistan traditionally show a preference for weddings to take place within their extended families, which is a form of endogamy that goes beyond the concept of caste to encompass clan or radar. It is commonly believed that the ideal relationship would be between cousins, particularly individuals who are first cousins. According to (Safdar, 2018) these kinds of weddings validate and strengthen the links that are already there within the clan or family, as well as the conceptions of kinship that are already present. One more key point that lends credence to this kind of marriage is the fact that it is reasonable to anticipate that the cousins will already be acquainted with one another before entering into a lifelong partnership.

The explanation was provided by (Sandhu, 2020) caste system existed in India in the past, and it was based on social position as well as jobs that were inherited. However, this is no longer the case at this time. It is common for people to change occupations and move away from their hometowns to make ends meet. On the other hand, endogamy is still readily apparent among the numerous caste classifications. Because of the genetic inheritance that occurs within blood groups, the characteristic hereditary pattern of these caste groups is continuously preserved. The complex caste structure that exists in India, along with certain discoveries.

This research that was related to the marriage to the same person was provided by (Shah, 2015) as a result of the fact that thalassemia is extremely uncommon and the

majority of people in Pakistan are married to the same person for life, it should not come as a surprise that more than 50,000 people in Pakistan In most cases, thalassemia manifests itself as a severe form of anemia the only option to assist those who have this condition is to administer blood transfusions to them over an extended period.

Families with hereditary illnesses are stigmatized in this region of the world and have access to subpar medical treatment. In the study that was about psychological burden (Zaheer, 2015) that the total psychological strain on the family might rise because of this. This study sought to examine the psychological toll that thalassemia imposes on families and the impact that cultural norms and family structure have on it. The statistics revealed that a high percentage of parents 96percentage were concerned about their kids' health. When asked what their largest concern is for their children, the majority of parents mention the lack of blood, the child's life and health, and the cost of the necessary therapy. Parents also expressed fear over the marriage of their children. Some parents disclosed that they are primarily concerned about their child's health and whether or not it would ever be cured.

The findings (Zaheer, 2015) indicate that insufficient knowledge of the disease, insufficient or misdirected social support, stigmatization, and marriage breakups caused by the disease, superstitions, and misinterpretations of religion and the subsequent practices accordingly as significant predictors of the psychosocial burden of beta thalassemia major among couples who are not cousins and couples who are cousins for the first time. Apart from that, it also discovers that patriarchy is the sole significant predictor of outcome variables among cousin couples.

2.3.4 Religious Beliefs Regarding Thalassemia

Religion is the most frequently reported coping method utilized by parents who are facing emotional difficulties, according to studies conducted on people from Asia, India, and Pakistan. These parents believe and conviction that God provides them with the mental and emotional fortitude to deal with tough situations or feelings. This research was conducted in Malaysia (Chong, 2019) asserts that people frequently turn to religion to assist them in coping with or adapting to stressful conditions. For instance, when people are in high-stress situations, they may pray to God for assistance or undertake religious rituals during these times. Religious practice has the potential to alleviate the

psychological discomfort experienced by parents. Nurses and other professionals in the health care industry can offer support to parents to assist them in coping with their distress.

One of the five fundamental foundations of Islam is the practice of fasting throughout the month of Ramadan. According to (Ibraheem, 2023) As part of their customary fast, Muslims consume a meal before dawn and another meal after dusk to break their fast. The impact of Ramadan intermittent fasting (RIF) on a variety of medical issues has been investigated in a wide range of published works. However, it is worth noting that there are no specific criteria that can assist medical professionals in determining whether or not they should recommend fasting to patients who have β-TM during the month of Ramadan.

2.3.5 Economic Burden of Treatment

Concisely examined by (Udeze, 2023) majority of families are unable to afford the expenses associated with treating serious thalassemia disease, which are estimated to be $3,200 per child per year in the United States. As a result of the fact that the treatment of thalassemia is not only upsetting for the family but also has a substantial socioeconomic impact on the nation, the prevention and control of this condition should be a top priority. The prevention of the birth of any fetuses that are affected by the disease is therefore the initial step towards reducing the burden of the disease.

During the course of the research on red blood cell transfusion (Knoth, 2023) argued that the patient may experience treatment tiredness as a result of the problem of treatment burden, which has been linked to unfavorable treatment behavior in other chronic diseases. This includes a lack of commitment to therapy or the use of complementary and alternative medicine as a substitute for controlling their difficulties, which frequently leads to treatment failure and an increased risk of consequences resulting from adverse interactions.

The financial strain of treating Thalassemia pushes families to extreme measures, necessitating government health safety nets for assistance. According to (Qamar & Shaikh, 2022) the expense of treating Thalassemia out of pocket is quite significant, families are forced to take out loans, sell or mortgage their houses, and put a great deal of financial burden on themselves given their current financial status. One of how these

individuals could be assisted would be through the health safety net that the government provides.

One of the most important aspects of thalassemia management is the utilization of blood transfusion therapy and iron chelation. According to (Ragab, 2013) early and consistent blood transfusions reduce the risk of complications associated with severe anemia and extend the patient's lifespan. Nevertheless, there is a possibility of problems with transfusion. Therefore, it is extremely important to be aware of the various harmful consequences that can occur as a result of receiving a blood transfusion when managing thalassemia patients. It is usual practice to refer to adverse events that take place in conjunction with the transfusion of blood products as transfusion reactions.

Sevinc had discussed that the Turkish Red Crescent Society (TRC) is the institution that supplies the patients with the blood that they require. The International Red Cross and Red Crescent Movement includes the Turkish Red Crescent, which is the largest humanitarian organization in Turkey. The Turkish Red Crescent is also a member of the movement. Considering the difficulties associated with thalassemia treatment and care, it is not uncommon for the families of children who have this condition, particularly the primary careers, to be affected as well. Depending on whether or not the family member is also a carrier or whether or not there is more than one patient in the household, this effect may be more pronounced; overall life satisfaction may be impacted. The factors that determine whether or not a person is happy with their life are their bodily, social, emotional, and mental health, as well as their psychological well-being, their capacity to communicate in a way that is both functional and successful, their ability to initiate and maintain social relationships, and their social connections (Sevinc, 2023).

Thalassemia causes enormous expenses for the public health system in addition to being a health issue for patients and their families. Regular bloodtransfusions, excessive bodily iron excretion, and repeated hospital stays are some of these expenses. Thalassemia major in children necessitates long-term care and frequent blood transfusions, putting social issues and financial burdens on patients, families, and the healthcare system. Children's lives are significantly impacted by thalassemia. These individuals have anemia, which makes exercise monotonous and unbearable for them. Additionally, excessive bone marrow stimulation results in altered facial features, delayed development, osteoporosis, ascites, an enlarged liver, and ultimately arrhythmias that cause death (Alizadah, 2019).

The impact of economic sanctions on public health and Iranian patients has never been quantified before, and this study is the first clinical study to evaluate that impact. The availability of iron chelators and coagulation factor concentrates is very limited, which means that patients who suffer from thalassemia and hemophilia are facing a significant challenge. The quantity of pharmaceuticals that are produced within Iran has been significantly less impacted. Patients with lower incomes and fewer resources may be experiencing the effects of the situation more acutely (Mehran Karimi, 2015).

2.3.6 High rate in Lower-Income families

The study was conducted by Siddique in the four Thalassemia Centers in Lahore, Northern Punjab, Pakistan. The sickness has had a devastating impact on parents'financial situation; the majority of the families of the affected children were low-income andunable to pay for expensive therapies. In addition to blood purchases, the average monthly cost of treating a patient with thalassemia is roughly 10,000 Pakistani rupees (US$100), which is too expensive for a household with limited resources. However, the government offers freeand discounted drugs in public teaching hospitals, which are only found in major cities, as well as blood transfusion services. Similarly, many donors and NGOs are collaborating to cure the condition; however, this is insufficient because the suffering of impoverished people exceeds the efforts done thus far. Children with thalassemia who are nottreated promptly risk dying between the ages of 1 and 8 years (Siddiqui, 2015).

According to Shahraki-Vahid stated that the thalassemia trait presents in their offspring, such patients' parents consider themselves accountable for their children's illness in addition to other issues, carry a heavy load of shame and despondency, and worry about their children's health and future. The purpose of this study was to investigate the actual experiences of parents of children who have thalassemia. The findings showed that parents of thalassemia-affected children have a wide variety of challenges in several spheres,including the physical, emotional, mental, social, and familial dimensions. Their experiencesare valuable and may aid in better comprehending their issues, allowing the treatment team members to take on more responsibility and the public to have a better grasp of this illness (Vahed, 2017).

2.3.7 Psychological Distress

Psychological pressure may harm the well-being of families. Children who have thalassemia and their families have fewer obstacles in today's world because of advancements in medical care; however, the psychological impact on the development

of sick children and their families is and will continue to be a factor. (Batool, 2017) argued that both patients and careers often have to deal with many stresses at once. As there are now more thalassemia patients than ever before, the disease has emerged as a significant source of psychological distress. Mental health issues such as increased anxiety, sadness, social disengagement, violence, bad relationships, and subpar academic performance are frequent among thalassemia patients. Physical, emotional,and mental difficulties all contribute to a decrease in life satisfaction for the patient and theirloved ones. Both parents and patients experience the psychological strain of worrying about potential problems and a short life span. The patient's deteriorating health, or the inability of the parents to pay for therapy, medication, blood transfusion, or hospitalization, are all reasonable reasons for this burden. Around 9.8 million people in Pakistan are carriers of thalassemia, making it one of the country's most pressing health issues.

Around 5,000 infantsare born with severe thalassemia in Pakistan every year. The high rate of this illness in Pakistan may be directly attributed to the country's high rate of endogamous marriages. About25,000 children in Pakistan have been diagnosed with thalassemia, according to the Thalassemia Federation of Pakistan. The illness is preventable, but there is currently no national screening program in Pakistan; instead, only a small number of NGOs are doing so in their own time. In several surveys, patients with thalassemia have been found to experience a significant rate of psychological discomfort. In research carried out by (Hajibeigi, 2009) in Italy, children with thalassemia major were shown to have depressive moods and anxiety.

A comparable study out in Singapore produced the same results. Additionally, it hasbeen found that those who have everyday limitations due to a chronic illness tend to be depressed more than people who do not. According to (Shaligram, 2007) among adult thalassemia patients, worse perceptionand sleep quality are linked to higher anxiety and depressive symptom levels. Therefore, a standard medical evaluation of this condition should include screening for anxiety and depression. As children with thalassemia live longer, psychosocial issues have become more prominent.

In research carried out by (Anwar, 2022) the majority of mothers whose children were diagnosed with thalassemia were affected by mental health issues, as indicated by our research. As a consequence of this, these mothers are more likely to have negative health outcomes, and they ought to be provided with diagnostic procedures and therapies that are geared at enhancing their health and well-being.

The religious practices in Malaysia (Chong, 2019) argued that the findings of the study indicated that the parents themselves were experiencing mental health issues. They utilized positive means of coping with their religious beliefs more frequently than they utilized negative ways of coping. According to the findings, there was a significant correlation between psychological distress and both organized and unorganized religious practices, as well as good and bad ways of coping with religious beliefs.

2.3.8 Health providers and policy makers

In any group of medical professionals that are involved in the treatment of patients who have chronic diseases, including hemoglobin (Hb) abnormalities like sickle cell disease and thalassemia, the nurse is an essential member of the team. There is, nevertheless, the possibility of efficiently managing these illnesses through the dissemination of expert knowledge regarding their prevention and treatment. According to (Elewa, 2017) a nurse's education is comprised of both theoretical and practical training that is delivered to nurses to prepare them for the responsibilities that they will have as nursing care providers.

The health condition of tribal people (Behrera, 2022) believed that policy-level intervention at both the state and federal levels is necessary to improve tribal health. It is conceivable to see good changes if it is made possible to carry out a systematic intervention at every level of governance and operation. To ensure the continuation of traditional medical practices, particularly those that involve the utilization of medicinal plants, it is necessary to provide support and documentation for these practices.

The study was conducted in Iran (Esmaeilzadeh, 2016) and discussed that due to the high expenses of treatment for patients with thalassemia major, it appears important to adopt new policies in the short term. These policies should include providing patients with full insurance coverage and providing subsidies to patients to lower the prices that patients are required to pay. In addition, several studies have reported that bone marrow transplantation is a very cost-effective procedure, which can be taken into consideration in the long run to bring down the expenses associated with this industry. As a result of the low costs associated with thalassemia screening 24 and the high costs associated with treatments, new decisions need to be taken with respect to the practice of thalassemia screening, even if the prices are higher than the ones that are typically utilized. Active

screening, in addition to making it free, appears to be useful in regions where there is a high frequency of mild thalassemia and where the population has a low income.

The average score of individuals who spoke Urdu was greater than the average score of those of other ethnicities when it came to the amount of knowledge they held regarding Thalassemia. Education programs should be made available to the extended families of persons who already have Thalassemia at every hospital that specializes in the disease. The Siraiki and the Pathan are two ethnic groups that are considered to be in a high danger and require severe interventions. In addition to this, a national Thalassemia worker program must be established (Maheen, 2015).

The study was conducted by (Hafeez, 2023) thalassemia care workers suffer from mild to severe states of depression. Researchers discovered that higher levels of sorrow were associated with a variety of factors, including being a mother, not attending school, and having a large number of children who suffered from thalassemia illnesses. In light of the surprisingly high rates of depression that have been discovered among thalassemia care workers, immediate action must be taken to treat their mental health.

2.3.9 Donors' contribution to blood

The research is concisely described (Jonahs, 2023) that Hemovigilance on the part of donors is an essential component in ensuring the safety of blood donation. To ensure that the donor would return for additional donations in the future, it is essential to provide pre-donation information and an understanding on how to handle post-donation issues.

2.3.10 Treatment of Thalassemia

Children who have thalassemia need to be treated for the rest of their lives to prevent anything negative from occurring. According to (Palanisamy, 2024) although bone marrow transplantation is the only treatment that can permanently cure the disease, it is also the only treatment that involves a complex treatment plan that includes imaging, blood transfusions, drugs, regular doctor appointments, and laboratory monitoring. However, indigenous families are required to spend a significant amount of money for transportation and tests, even though government health institutions provide free blood and drugs. A multidisciplinary approach is required for the effective care of thalassemia. This includes the identification of carriers, the provision of treatment while being aware

of the molecular heterogeneity of thalassemia and its clinical correlations, and the transfusion of only red blood cells rather than whole blood, among other things.

2.3.11 Lack of Awareness and knowledge caused the rise of Thalassemia

The study indicated that there was a poor level of awareness when it came to the treatment and prevention of thalassemia sickness. Because their child has thalassemia, the majority of parents are dealing with the social and financial struggles that come along with their child's illness. To prevent the spread of thalassemia illness in Pakistan, it is appropriate to have an understanding of the magnitude of the problem and to raise awareness among parents who are carriers of the disease (Ishfaq, 2013).

Continued difficulties with hemoglobin are experienced by several different populations in Pakistan. According to (Bibi, 2023) that it is necessary to implement preventive measures, such as determining the carrier status of a pair before marriage and conducting screenings for beta thalassemia minor, to reduce the number of cases of beta thalassemia major. This can be accomplished by compelling couples who have beta thalassemia minor to terminate their pregnancies. His research (Mia, 2023) revealed that Bangladesh, like other nations in South Asia, does not have any national programs that are aimed at increasing awareness, screening carriers, or gathering information about people who have thalassemia.

2.4 Conventional Methods and Their Repercussion

This study was conducted by Payen Beta-thalassemia this disease's establishment in several different regions around the world. All of the patients have abnormalities in the formation of the beta-chain of hemoglobin (Hb), but the phenotypes that are produced as a result are quite diverse. These phenotypes can range from severe anemia to the absence of clinical signs. Even though the underlying genotype is not taken into consideration, classification and severity grading are mostly determined on spontaneous hemoglobin levels and clinical tolerance. Patients with beta-thalassemia intermedia don't need to get regular transfusions because their blood hemoglobin concentrations range from 7 to 10 g/dL. The severity of the imbalance between alpha and non-alpha globin chains, as well as several hereditary and environmental factors, might cause them to exhibit a wide range of clinical symptoms. They are at risk of experiencing a wide range of consequences, such as pulmonary hypertension, thrombotic events, infection, endocrine dysfunction, and leg ulcers (Dreuzy, 2016).

2.4.1 Home Remedies:

Home remedies are an important component for people who suffer from Thalassemia. According to (Chauhan, 2014) Wheatgrass juice is consumed twice daily, and they also consume foods that are high in folic acid, such as beans, bananas, soy products, beets, and sweet potatoes. In addition to that, they incorporate four basil leaves into their routine. To support the health of their blood, grass juice is regarded to be of particular significance for patients suffering from Thalassemia.

2.4.2 Medication for Thalassemia:

The study was conducted by (Cappellini, 2014) the blood disorder known as thalassemia is a hereditary condition that alters the production of hemoglobin, which ultimately results in anemia. Because standard medical therapies, including blood transfusions and iron chelation therapy, are frequently required for the management of thalassemia, it is possible that traditional medicine alone will not be sufficient to control the condition. Nevertheless, there are some traditional practices and nutritional choices that might be supplemented by conventional therapy. It is essential to have a conversation with a healthcare provider about any alternate courses of action.

2.4.3 Cultural Beliefs:

There is a significant amount of variation in the cultural notions that are connected to thalassemia from one society and area to another. According to (Modell, 2008)families that are afflicted with thalassemia may view the ailment as a one-of-a-kind obstacle that serves to strengthen the relationships that bind them together. A confirmation of the unwavering love and togetherness that exists throughout the family is the fact that they have been through the experience of controlling thalassemia together.

2.4.4 Spiritual Beliefs:

Spirituality is examined in this article as a potential source of support and resilience for individuals who are afflicted with thalassemia treatment (Poon, 2004) quoted that many people find comfort and strength in their spiritual beliefs, in addition to the medical therapies and support networks that are available to them. Understanding and embracing one's spiritual beliefs can be a significant source of strength, resilience, and inner peace when confronted with the hardships that are associated with thalassemia. Individuals who are living with thalassemia can improve their overall well-being and build a positive view on their journey by adopting spiritual activities such as prayer, as well as mindfulness,

acceptance, community support, and optimism. It is of the utmost importance that healthcare providers and support networks recognize and respect the various spiritual requirements of thalassemia patients and that they incorporate these beliefs into a holistic approach to treatments.

2.4.5 Poverty Preferences and Awareness:

This research was conducted by (Weatherall, 2010) important factor in both the prevalence of thalassemia and its impact is the presence of poverty. In economically disadvantaged communities, the availability of healthcare services, such as genetic counseling and prenatal screening, is restricted, which makes the transmission of thalassemia even more difficult. Individuals and families who are living in poverty confront additional obstacles that are compounded by the financial burden of managing thalassemia. This burden includes the cost of specialist drugs as well as the necessity of receiving regular blood transfusions.

It is vital to increase awareness of the condition to make it easier to discover thalassemia at an earlier stage, to prevent it from occurring, and to provide effective treatment for it. Both the general public and medical professionals should be the target audience for educational efforts that aim to raise awareness about the importance of genetic counseling, prenatal screening, and the necessity of sticking to treatment procedures. In his article Beta –Thalassemia (Origa, 2012) had revealed that an increase in awareness can lead to the development of greater support systems for individuals who are afflicted with thalassemia, which in turn serves to reduce the burden that the disease places on society because of its prevalence.

2.4.6 Modern Treatments for Thalassemia:

There is a wide range of severity associated with thalassemia, and the treatment methods employed are contingent upon the particular type and degree of the disorder. Those who suffer from thalassemia typically receive the following medical treatments.

a) Blood Transfusion:

This study was conducted by (Keun, 2023) to restore the minimal quantities of hemoglobin and red blood cells that are present in the body, the objective of this treatment is to restore your blood. In a cycle with ongoing scientific and clinical advancements, the field of transfusion medicine is continuously undergoing development. As a result of the use of more sophisticated serological and molecular techniques for microbiological

testing, as well as more stringent criteria for the selection of donors, the risks of infection that is transmitted through blood transfusions have been significantly reduced. When it comes to clinical transfusion practice, the most important considerations include avoiding unnecessary transfusions, adhering to the principles of Patient Blood Management (PBM), and minimizing avoidable transfusion errors whenever it is practicable to do so. To perform critical actions to ensure safe transfusion practice and appropriate use of blood, a hospital needs to have a solid clinical governance infrastructure. This infrastructure should include an active hospital transfusion team as well as a hospital transfusion committee.

b) Iron Chelation Therapy

The purpose of chelation therapy is to ensure that a "safe" iron status is maintained at all times. According to (Saliba, 2015) that Chelation therapy with deferoxamine has generally been started only after two to three years of transfusion or when ferritin increases to a level that is greater than one thousand nomograms per milliliter. The treatment of iron overload and the reduction of the negative effects that are linked with iron burden can be accomplished through the utilization of iron chelation therapy.

Bone Marrow Transplant (BRT)

Bone marrow transplantation, often known as BMT, (Ghavamzadeh, 2008) is the only treatment that allows patients with beta-thalassemia major to experience a successful cure. Within the field of thalassemia transplantation, bone marrow stem cells are utilized by the vast majority of centers rather than peripheral blood stem cells.

Gene Therapy

The objective of gene therapy for the treatment of beta-thalassemia is to achieve a stable introduction of functional globin genes into the patient's hematopoietic stem cells (HSCs). According to (Naldini, 2015) to cure inefficient erythropoiesis and hemolytic anemia, hence eliminating the requirement for transfusions. In light of this, it is imperative that the framework of treatment, which encompasses the creation of fresh directions in gene therapy and the provision of equitable public access, be made available to a substantial number of β-thalassemia patients. This is necessary to achieve a more favorable outcome that is also effective

c) Folic Acid Supplements

Folic acid (vitamin B9) supplements will be good for people who have thalassemia conditions. However, it is not a cure for the underlying genetic problem that causes the illness. Blood transfusions, iron chelation therapy, and various other supportive measures are often included in the multidisciplinary approach that is typically utilized in the management of thalassemia disorders. According to (Musallam, 2024) Patients who have thalassemia should always make sure to follow the recommendations of their healthcare experts regarding the correct dosage of folic acid and any other supplements they may be following. Individuals can have different requirements, and a healthcare professional can modify the treatment plan to the specific requests of the patient.

2.4.7 Pharmaceutical Companies:

There are many aspects to the role that pharmaceutical companies play in meeting the requirements of thalassemia patients. Pharmaceutical companies (Prathyusha, 2019) have revealed that these aspects include research and development, the production of drugs, patient support programs, and advocacy. Pharmaceutical corporations can provide financial support to external research projects, academic institutions, and non-profit organizations that are engaged in thalassemia-related research. Educational initiatives offered by pharmaceutical corporations are a significant contributor to the process of increasing awareness of thalassemia. To guarantee that individuals suffering from thalassemia receive the right care, businesses work together with medical professionals, hospitals, and clinics respectively. Training for healthcare providers, the provision of essential medical equipment, and the facilitation of access to specialized care are all potential components of this project.

2.5 Approaches of Medical Anthropology

Medical anthropology is a multidisciplinary field that examines the intersection of culture, society, and health. When studying a specific medical condition like thalassemia, various approaches within medical anthropology can be employed. Here are two commonly used approaches.

2.5.1 Critical Medical Anthropology:

Critical medical anthropology is an interdisciplinary field that examines the relationship between health, illness, and society from a critical perspective. It combines insights from medical anthropology, sociology, cultural studies, and critical theory to explore how social, cultural, economic, and political factors shape health and healthcare practices.

This approach focuses on the social, political, and economic factors that influence health and healthcare. In medical anthropology (Singer, 2019) critically examines the power dynamics, inequalities, and structural factors that shape the experiences of individuals living with thalassemia. Critical medical anthropology investigates issues such as access to healthcare, social stigma, discrimination, and the impact of globalization on the disease. It emphasizes the need for social justice and equity in addressing thalassemia.

2.5.2 Bio-cultural Anthropology:

Bio-cultural anthropology, also known as biological anthropology, is a subfield of anthropology that focuses on the interplay between biology and culture in human populations. It seeks to understand how biological and cultural factors interact and shape human behavior, health, and adaptation. Bio-cultural anthropology (Niewohner, 2018) argues that by explores the interaction between biological and cultural factors in shaping health and disease. In the context of thalassemia, it examines how cultural beliefs, practices, and social norms influence the experience, management, and treatment of the disease. It investigates how thalassemia is perceived by individuals, families, and communities, and how cultural factors influence decisions regarding treatment, reproductive choices, and stigma associated with the condition.

This research on thalassemia is primarily associated with bio-cultural anthropology. Thalassemia, a genetic blood disorder characterized by abnormal hemoglobin production, presents a complex interplay of biological, cultural, and social factors. Bio-cultural anthropology seeks to understand how biological and cultural factors interact to shape health outcomes within populations. In the case of thalassemia, researchers investigate not only the genetic basis of the disorder but also how cultural practices, such as consanguineous marriage patterns prevalent in certain communities, influence its prevalence and impact on affected individuals and families. By integrating biological and cultural perspectives, bio-cultural anthropology offers a holistic understanding of thalassemia and informs strategies for prevention, management, and support within affected communities.

CHAPTER NO. 3

RESEARCH METHODOLOGY AND AREA PROFILE

In this chapter, there are two distinct sections. The first section provides an introduction to the many techniques and methodologies that are typically used in applied anthropology. Within the second part of this chapter, a comprehensive discussion is held regarding the Pakistan Red Crescent Society as well as the PIMS Hospital's region profile. A justification and explanation of the procedures and instruments that were utilized to collect data for this qualitative study is provided in the first part. In the second section, the qualitative perspectives of the families of thalassemia patients who live in the Islamabad region are offered.

3.1 Research Methods

The goal of the study is to provide an objective analysis of the various factors that affect the quality of health care. Through qualitative methods, such as interviews, key informants, life history methods, and rapportbuilding, I collected data that was helpful in my analysis. With qualitative methods, I collected reliable data and gained a deeper understanding of the subject.

3.1.1 Key Informant

A key informant is a person who helps the researcher develop a rapport with the community by introducing them to its members. Three individuals were chosen for the study. Oneof them was a senior citizen from the area who helped the researcher with the residents of Islamabad. One of the key informants was from the PIMS healthcare system, and he was one ofthe individuals who was interviewed. A midwife is also a likely candidate. The researcher's main concern when choosing key informants is their availability.

3.1.2 Participant observation

Anthropological research is carried out through participant observation, which involves embedding oneself in the community's social fabric. This method allows researchers to collect information about the people's collective and individual behaviors, as well as other personal perceptions and thoughts. Although it provides an opportunity for the researcher to become part of the community, taking part in daily routines helps the participants feel more comfortable with their surroundings. The researcher was able to observe the daily activities of the respondents. Apart from being involved in various games and activities, such as cricket, the researcher also met the village's elderly residents to gather information

and establish a connection. Throughthis study, the researcher tried to understand what kinds of traditional methods work when it comesto treating various conditions. As a participant, she or he was able to assess the results of the treatment and learn more about the factors that affect it.

Within this study, attention was specifically directed toward observing the symptoms of Thalassemia patients, which may include fatigue, weakness, pale skin, and jaundice, among others. Through this immersive approach, the researcher aimed to elucidate the efficacy of traditional treatment methods for managing such conditions. By actively participating in treatment processes and closely assessing outcomes, the researcher gained valuable insights into the factors influencing treatment efficacy and patient outcomes.

3.1.3 Rapport Building

The process of building a research base is very important for a researcher to be able to carry out effective ethnographic studies. This was the case for the study that was conducted in Islamabad. Through the key informant, the researcher was able to introduce herself to the community. Through games and other activities, the researcher was able to establish a connection with the residents. In addition, informal conversations can also help develop this connection. The researcher then builds rapport with the key informants to determine the scope and sample size ofthe study.

3.1.4 Sampling

The study comprised 22 participants, selected through various sampling methods based on participant demographics and roles. Six male respondents aged 30 to 60 were chosen, along with six females aged 40 to 60, utilizing **convenience sampling**. Additionally, five healthcare professionals and five administrative staff aged 30 to 50 were **purposively sampling** to meet the study's requirements.

Convenience sampling involves selecting participants who are readily available and accessible, often chosen due to their convenience rather than representing the entire population accurately. It can lead to biased results as certain groups may be over or underrepresented.

Purposive sampling, on the other hand, involves selecting participants based on specific criteria relevant to the research objectives. This method allows researchers to target individuals who possess the desired characteristics or experiences necessary for the study, enhancing the relevance and depth of the findings. However, it may also introduce bias

if the selection criteria are not appropriately defined or applied. In this study, purposive sampling was employed to ensure that participants with relevant expertise and experience were included, thereby enriching the study's data and insights.

The one below the table describes the Patients' families in Islamabad. In this table their name, age, gender, Occupation, and Income.

Table No. 3.1: Demographic of Patients Families in Islamabad

No.	Name	Age	Gender	Type of Thalassemia	Occupation	Location	Income
1	Saba Zaiafat	35	Female	Beta	House Wife	PIMS Hospital	25,000
2	Iqra Shaheen	28	Female	Beta	Teacher	PRCS Blood Bank	No source of income
3	Adnan Khan	36	Male	Beta	Driver	PIMS Hospital	1000 daily
4	Sofia Begum	31	Female	Beta	House Wife	PRCS Blood Bank	30,000
5	Rahim Gul	35	Male	Beta	Daily Wager	PIMS Hospital	15,000
6	Salem Sheikh	40	Male	Beta	Driver	PRCS Blood Bank	35,000
7	Tanzeela	34	Female	Beta	House Wife	PRCS Blood Bank	30,000
8	Akbar Ali	36	Male	Beta	Businessman	PIMS Hospital	70,000
9	Sher Ali	38	Male	Beta	Daily Wager	PRCS Blood Bank	15,000

10	Fatima Akbar	29	Female	Beta	House Wife	PRCS Blood Bank	15,000
11	Hader Ahmad	38	Male	Alpha	Livelihood	PIMS Hospital	1 lac
12	Eman Gulfraz	35	Female	Beta	House Wife	PIMS Hospital	20,000

Source: Field Data

The above table describes the demographic information from patient families in Islamabad. It became clear that these families belonged to the middle class and had limited means of income. My recommendation to the patients was that they take into consideration the possibility of receiving blood transfusions from PIMS Hospital and Red Crescent, given the financial constraints they were experiencing. These organizations are well-known for their ability to offer assistance and support, which makes the process of blood transfusion more accessible to persons who have lower financial resources.

The one below the table describes the professional doctors. In this table their name, age, gender, Occupation, and Income.

Table No.3.2: Demographics of Professional Doctors

No.	Name	Age	Gender	Occupation	Income
1	Dr. Wasifa	38	Female	Doctor	215,000
2	Dr. Kamal Khan	35	Male	Doctor	150,000
3	Dr. Bakhtawar	30	Female	Doctor	170,000
4	Dr. Hayee	32	Male	Doctor	150,000
5	Dr. Malika	36	Female	Doctor	125,000

Source: Field Data

I was concentrating on practicing physicians who are between the ages of 30 and 45. For the purposive sample method, I have chosen four physicians who are employed at the Regional Blood Center of the Pakistan Red Crescent. In addition, my sample consists of two medical experts who work at the PIMS Hospital in Islamabad.

The last table is about an administration that is working with Thalassemia Patients. In this table their name, age, gender, Occupation, and Income.

Table No.3 .3: Demographics of Administration and Nurses

No.	Name	Age	Gender	Occupation	Income
1	Tania	40	Female	Nurse	180,000
2	Abdallah Wajid	32	Female	Administration	120,000
3	Waqar Khan	31	Male	Administration and also Nurse	150,000
4	Latuf Ur Rehman	29	Male	Administration	100,000
5	Sadia	27	Female	Nurse	70,000

Source: Field Data

I am concentrating on the age range of thirty to forty-five years old among administrators and nurses. I have chosen three administrators and nurses from the Pakistan Red Crescent Regional Blood Center to conduct a sampling. Furthermore, two administrators and nurses from the PIMS Hospital in Islamabad are included in the sample collection.

3.1.6 Life History Method (LHM)

A deliberation on the life history of the thalassemia patient was done as an integral part of the study. The objective was to investigate and analyze the problems faced by thalassemia patients and their families and this information was collected from PIMS and the Pakistan Red Crescent Society. Twelve interviews for the collection of primary data on life history were held during the course of the study. Six interviews each were held at PIMS Hospital Islamabad and Pakistan Red Crescent Society. The participants were chosen based on their gender and age. The life history method is used in this research for families of Thalassemia patients in Islamabad because in-depth detailed information on this long-term disease could not have been possible in one sitting, hence interviews were conducted at different times and on more than one occasion. This technique allowed in-depth interviews for the life history method through multiple sitting with patients' families for data collection.

3.1.7 Interview Guide

Preparation of a proper interview guide before conducting an interview is mandatory for

the researcher as it will allow both the interviewer and the interviewee to stay focused on the matter at hand and not deviate from the established lines. Keeping in mind, 10 interview guides were prepared using pre-established information from available literature so that the conversation remains focused, especially about the accuracy and reliability of the data. The structured and unstructured interviews were conducted by doctors and the administration. The interview guide was closed-ended so that the interviewees don't deviate from the actual answers and provide accurate data. The interview guides were filled out by the researchers in person.

3.1.8 In-depth Interviews

The main objective of an in-depth interview is to provide the researcher with the required data to make informed decisions regarding the study. The primary data collection through in-depth interviews also enables the researchers to maintain the accuracy and reliability of the data as long as the interviews are being conducted by the researcher. These were carried out during fieldwork and were conducted for a minimum duration of 45 – 50 minutes, especially when these were done with the doctors and the administration. The researcher tried their level best to complete the study within a stipulated time.

3.1.9 Jotting

To collect more detailed information about the individuals during the interviews, the researcher used a technique known as jotting, which is a type of writing that can be carried out while on the field. This method allowed the researcher to record the various terms used in the interview. During informal discussions, the researcher was also able to get brief descriptions of the words used in the interview.

3.1.10 Daily diary

The daily diary is a set of methods utilized by researchers for data collection. The researcher must write a daily diary to describe what she has done daily. This daily dairy container has all the information related to the researcher's topic.

3.1.11 Field Notes

A field note can be used to collect data during the analysis phase. Field notes are very important for research study. It contains all the information like interviews, life history of the patient, time, place, and date of interview. During the fieldwork period, I took note of everymajor and minor point of the study. It was beneficial when conducting focus groups and interviews.

3.1.12 Audio/ Visual

The researcher took photos and audio recordings with the consent of the subjects.

3.1.13 Transcription

As an integral part of the study, I was transcribing the audio recordings made during the interviews. Transcribing the gestures and words that I observed during the interviews, were provided a complete picture of what occurred during the session.

3.1.14 Research ethics

The concept of research ethics is a set of guidelines that help guide the conduct of a study. Italso teaches the researcher about the importance of following ethical standards. These guidelines prevent the falsification of data and ensure that the research is conducted according to the highest ethical standards. To avoid being biased in the results of the study, the researcher must always strive to do the best possible work. Doing so involves staying focused on the tasks and not on other people'sopinions. The researcher is expected to follow these guidelines to conduct the study ethically. In analyzing the guidelines, the researcher is also expected to maintain a high level of trust and confidentiality.

3.2 Area Profile

The research was conducted in PIMS and Pakistan Red Crescent Blood Center, Islamabad. This location isless expensive for the researcher and an ideal place for getting a deeper understanding related to Thalassemia patients. This location is ideal because it is the first time that a researcher will be interviewing people in this area.

3.2.1 Regional Background

It is located in the northern region of Pakistan; Islamabad serves as the nation's capital and the largest city in Pakistan. The political and administrative hub, it is renowned for its well-planned infrastructure and picturesque scenery, and it serves as the center of government. An idyllic setting is provided by the city's location at the base of the Margalla Hills, which is a magnificent backdrop.

3.2.2 Demographic

Islamabad, as a metropolis, is characterized by its diverse demographic composition, encompassing individuals from a myriad of cultural, linguistic, and ethnic backgrounds (Ahmed, 2019). This diversity extends beyond those native to the city, incorporating individuals who have migrated to Islamabad in pursuit of enhanced employment prospects, educational avenues, or other opportunities for personal and professional advancement. The presence of both urban and suburban areas further accentuates the

multifaceted nature of Islamabad's population, contributing to its reputation as a hub of cultural exchange and coexistence.

3.2.3 Socio-Economic Landscape

The city has a considerable number of its inhabitants working in government services, foreign organizations, and the private sector, which contributes to the city's relatively superior socio-economic position in comparison to other regions of Pakistan. It is important to note that there exist discrepancies, and certain regions may have weaker socio-economic metrics.

3.2.4 Health Care Infrastructure

Islamabad is home to a variety of medical institutions, such as hospitals, clinics, and specialist medical centers, the city's network of healthcare facilities. To investigate the difficulties that families who are dealing with thalassemia could encounter, it is vital to have a solid understanding of the accessibility and availability of healthcare services.

3.2.5 Educational Institutes

The city is home to a wide range of educational establishments, ranging from elementary schools to institutes of higher learning. To gain a better grasp of the levels of knowledge and educational support that are accessible to families living with thalassemia, it is essential to thoroughly investigate the educational landscape.

3.2.6 Cultural and Social Dynamics

There is a rich and diverse social fabric in Islamabad, which is impacted by a combination of urban and traditional aspects being present. In the process of coping with thalassemia, the experiences of families are significantly influenced by a variety of factors, including social networks, community support, and cultural preferences.

3.2.7 Government Policies and Support System

It is of the utmost need to conduct research into the present policies and support systems in Islamabad that are associated with thalassemia. This involves having a grasp of the roles that non-governmental organizations (NGOs), government health programs, and other organizations that work in the healthcare sector play.

3.2.8 Transport and Infrastructure

Both the mobility of families and their access to healthcare services are impacted by the accessibility of the city's transportation and infrastructure structures. Investigating these factors is essential to gain an understanding of the difficulties that families who are affected by thalassemia endure.

SOCIO-EMOTIONAL ISSUES ENCOUNTERED BY FAMILIES OF THALASSEMIA PATIENTS AND THEIR FAMILIES

Thalassemia patients and their families face multiple social and emotional issues during the course of treatment and afterward. An investigation into the living experiences of these patients' social and emotional experiences and journeys shall provide insight into how these experiences affect their lives and well-being. This chapter contains an analysis of a socio-emotional issue encountered by families of thalassemia patients in Islamabad. The research is based on qualitative methodologies, such as in-depth interviews and life history studies, to gain a full understanding of the socio-emotional issues that are experienced by families of thalassemia patients in Islamabad. A further benefit of working with healthcare experts, support organizations, and policymakers is that it can provide significant insights into prospective interventions and support mechanisms.

In this chapter, the **Life History Method** was strategically employed to comprehensively explore the intricacies of thalassemia—a condition characterized by its long-term impact on individuals. Recognizing the need for a nuanced understanding of the disease's trajectory, this method facilitated the collection of detailed and insightful data over an extended period. Through spending multiple days with each respondent, often dedicating two to three days per individual, a rich tapestry of experiences and perspectives emerged, allowing for a profound exploration of the complexities inherent in living with thalassemia. This approach not only provided **depth to the information gathered** but also afforded a unique opportunity to delve into the lived realities of those affected by the condition, enriching the research endeavor with invaluable insights.

4.1 Medical Perspective

4.1.1 Medical History

A senior female, who has been dealing with thalassemia patients in her family for more than two years, described the medical conditions and symptoms of these patients in the following words:

"I saw a lot of patients having weakness as an early symptom. Even though weakness is a non-specific symptom, it is so prevalent points to the possibility that it is a common early indicator that families see. Thalassemia can result in anemia, which frequently expresses itself as feelings of exhaustion and weakness".

Elaborating her response further, she shared that although thalassemia gets diagnosed only at a certain stage of the disease, its symptoms manifest throughout the life of the patient. It is with these manifestations of the signs and symptoms of the ailment that the patients and their families observe multiple associated medical issues. She further stated that:

"Quite a lot of patients have a high fever so according to me fever may be an early indication of an underlying disease, even though it is not as widespread as other symptoms. Individuals who suffer from thalassemia may have fever as a consequence of infections or complications associated with the illness".

The fact that thalassemia can develop as a result of infections or complications associated with the sickness highlights the fact that the symptoms that manifest in the early stages of thalassemia can be quite varied and subtle. These discoveries highlight the significance of detecting a variety of symptoms to facilitate timely diagnosis and intervention in the effective management of Thalassemia.

4.1.2 Genetic History

Discussing the causes of thalassemia, there is strong evidence that there are genetic pre-dispositions of Thalassemia. A senior, female respondent with a thalassemia patient in her family stated:

"I have observed that marriages between cousins may be an indication of a possible genetic connection to thalassemia within the family. It is well known that marriages between people of the same family might raise the likelihood of developing genetic problems".

This opinion was shared by a younger, male who has also been living with thalassemia patients in his family. Based on his observation, he stated the same fact that thalassemia can be a result of some genes which are more prevalent in some families; while in others they are missing. Hence, the more genetically heterogenic a community and a family is, the lesser the chances of occurrence of the disease. The young, male respondent used the following words to describe his opinion:

"I feel that there is a genetic heterogeneity within the community, in which some families may not be genetically given to thalassemia".

The results of the themes indicate that there is a significant relationship between the marriages of cousins and the incidence of thalassemia in families. These findings offer important insights that can be used to better comprehend the involved relationship that exists between genetics, culture, and health within the population that was investigated in Islamabad.

4.1.3 Diagnosis & Types of Thalassemia

Different respondents have different types of problems related to thalassemia. Beta thalassemia is a more commonly diagnosed type and hence more respondents could elaborate on this type.

The most severe form of beta-thalassemia, also known as Cooley's anemia, is characterized by a deficiency of beta protein in hemoglobin and necessitates regular blood transfusions to maintain a patient's life. Beta-thalassemia can lead to several complications, some of which include iron overload, splenomegaly, growth retardation, problems with the immunological system, heart and kidney failure, and liver disease (Naz, 2023).

Ms. Sofia Begum, whose niece has been suffering from thalassemia, stated that her niece kept experiencing multiple minor health issues before the diagnosis. Coming from a humble background, these recurring sickness patterns affected the patient as well as her family a lot. They were always worried about the health of the child and were not sure if they were taking good care of her. Explaining the medical side of the issue, my respondent, Ms. Sofia Begum, provided information regarding beta-thalassemia.

"My niece was diagnosed with thalassemia as a result of symptoms that kept occurring like vomiting, jaundice, pale yellow skin color, and type is Beta Thalassemia."

According to (Musallam, 2024) Patients who have Alpha thalassemia should always make sure to follow the recommendations of their healthcare experts regarding the correct dosage of folic acid and any other supplements they may be following. Individuals can have different requirements, and a healthcare professional can modify the treatment plan to the specific requests of the patient.

The frequency of beta thalassemia major highlights the significance of implementing screening and awareness programs that are specifically geared towards the population, particularly in Islamabad. It is essential to have a comprehensive grasp of the obstacles

that families afflicted by thalassemia in the region encounter to have a complete comprehension of the socio-emotional impact that the disease has on families.

4.1.4 Cultural Names of the Disease and Implications

The name of the disease varies from culture to culture region, many respondents said that it is thalassemia but different backgrounds called another name. In Islamabad, the frequency with which the term "thalassemia" is used is symbolic of the fact that it is the terminology that is generally documented and used for the disorder.

One respondent coming from a rural background, with low educational degrees, shared that:

"*The common name of thalassemia is blood disease in my city. There is fear and stress associated with a diagnosis of the 'blood disease' because it is very costly to get it treated and the chances of survival of the patient are also very low. This is a huge problem from the day the patient is diagnosed, since people start developing an opinion without any valid medical advice."*

It is evidence of the widespread acknowledgment and documentation of the term "thalassemia" as the standard terminology for the condition that the term "thalassemia" is used frequently in Islamabad. However, another observation reveals that some respondents may use the phrase "**Blood Diseases**" to refer to thalassemia, either suggesting a lack of precise understanding of the condition or a broader cultural perspective that regards the illness as a general issue relating to blood health. This disparity in terminology draws attention to the fact that individuals within the community may have different ways of thinking about and communicating about health concerns. This highlights the necessity of targeted educational efforts to ensure that everyone has a common understanding of thalassemia and the implications it has within the context of the local community.

4.2 Challenges and Experiences of Thalassemia Patients

The fact that there are health problems that require surgical treatments and blood transfusions in addition to those operations makes the situation much more complicated. Another obstacle that must be overcome is gaining access to blood for transfusions; nevertheless, some of the respondents discovered relief through the free blood services provided by the Pakistan Red Crescent group.

4.2.1 Medical Issues

Thalassemia patients suffer from the pain of the disease itself and associated medical issues and troubles that are environmental. These issues start with the fact that the thalassemia patient needs regular blood transfusions. With the blood transfusion, the process of finding the right donor, accessing them, arranging the blood transfusion process, and the availability of blood in the long run. Other methods of treatment include bone marrow transplant, iron chelation, and supplements, each bringing on its difficulties.

Blood transfusions are the most common method of treatment of thalassemia in Islamabad. However, there are complications associated with the process of blood transfusion despite the common occurrence of the process. It is indicated twice a month that blood transfusions take place, highlighting the frequency with which they take place as well as the duration of time that the procedure takes. If there are too many complications with the health of the patient, or at a certain point in time with machinery and the availability of experts, a simple blood transfusion may take up to five hours to complete.

One respondent suffering from thalassemia for almost 1.5 years shared that although he is used to the process of blood transfusion, he is still nervous each time he is to get a transfusion. He said that in addition to the process of arranging blood and getting a transfusion, it is the associated troubles he is more afraid of. He said that whenever he comes for a blood transfusion, he feels the same level of difficulty as if it were the first time. However, he knows that other patients also have the same feeling. These patients may suffer from associated health and wellness issues, which may start affecting their overall quality of life. He shared his experience in the following words:

"I experienced that people have while receiving blood transfusions might vary dramatically from one another. There are a variety of adverse effects or reactions that have been mentioned by some individuals, including fatigue, loss of appetite, hair loss, and nail loss".

Describing the administrative problems he has experienced or has heard that thalassemia patients experience, he stated that:

"I have also experienced problems and issues that can be simplified for someone who is already suffering from a major disease. There are procedures such as the requirement for surgical procedures (for example, the excision of the gall bladder) and

the blood transfusions that are linked with them. There is an additional layer of complexity added to the care of thalassemia as a result of these health issues."

Another respondent, who was waiting in line to receive blood, mentioned that he has faced problems with the availability of blood. He shared that he has been in this situation a few times before and shared that it is one of the most helpless feelings, the fear of being unable to arrange blood. He shared his feelings in the following words:

"We have encountered difficulties in gaining access to the availability of blood for transfusions. There was discussion of the challenges involved in acquiring blood, as well as the eventual discovery of free blood services offered by the Pakistan Red Crescent".

The severity of this trouble is a reflection of the enormous restriction it puts on the typical activities of individuals who are getting blood transfusions for an extended period. As a result, these individuals are unable to engage in any other activities or employment during that period. These financial challenges that are linked with thalassemia not only affect the immediate medical expenses but also have a significant impact on the work chances and day-to-day activities of individuals and families who are coping with the condition. Because of the complex nature of the problems, there is an urgent requirement for comprehensive support systems that take into account both the medical and socio-economic components of thalassemia treatment.

4.2.2 Financial Issues

My respondent accounted for the various challenges of managing thalassemia, but the financial strain of the disease is another common issue among all the respondents contacted for this study. One respondent, who came from a neighboring village said that for him thalassemia is not only the disease but the costs associated with the disease which are as painful as the disease itself. Talking about traveling costs, he said that traveling from another city to Islamabad, traveling from the bus station to the hospital, and from the hospital to the blood donation site costs him a lot. He said that;

"One of the most significant challenges that I quoted in the management of thalassemia was dealing with financial concerns. This comprises the cost of transportation, the expenses incurred for medical care, and the overall financial burden that is linked with the treatment."

Elaborating on the financial hardship part, he further elaborated that:

"We *are facing an additional level of hardship as a result of the economic strain of managing thalassemia, which includes the cost of frequent blood transfusions and medical checks. Furthermore, the mention of financial concerns implies that this load adds a layer of difficulty. The thalassemia sufferers may have a more difficult time gaining access to educational resources and opportunities as a result of this financial hardship."*

A thalassemia patient shared similar views, that the disease has not only affected his physical health but has also done damage to his financial standing. The patient said that he feels responsible for adding financial burden to his family who were doing fine before his disease but are suffering now because of his disease. He said that:

"I brought up the difficult financial situation that my family faces as a result of thalassemia. This includes situations in which the patient's father places wagers regularly and in which the needs of thalassemia management have a significant impact on the patient's daily income".

This feeling of adding burden and being responsible for additional financial costs is worsened by other effects of the disease such as reduced ability to participate in educational or work life.

4.2.3 Educational Life and Prospects

Young thalassemia patients suffer on the educational front since they are unable to attend schools and other educational institutions, and at the same time, they are unable to perform well in studies they carry out at home. Although no patient account is available on this, a senior respondent shared that:

"I have observed my thalassemia patient children facing major physical obstacles, such as muscle weakness, exhaustion, and the requirement to get repeated blood transfusions throughout their lives. The patient's ability to attend school consistently and demonstrate active participation in their studies is directly hindered by the physical challenges that they are experiencing."

A senior citizen, who came from another city with his family to get his seven-year-old granddaughter treated, shared his thoughts which are similar to the previous respondent. He said that:

"My granddaughter is a thalassemia patient. She feels weak and says that she cannot sit for a longer time and study. She was very good at her studies and now I think that the disease has reduced her capacity to concentrate and gives them less energy. Because of this, they have a difficult time concentrating on their schoolwork, which negatively impacts the quality of their educational learning experience."

The Father of the same child was worried about whether she would be able to continue her education or not. He shared his fears and concerns in the following words:

"I thought that Thalassemia has a direct impact on the continuity of education, as evidenced by the fact that it is frequently said that patients are absent from school owing to medical treatments, such as blood transfusions and checkups. Lessons may be missed, students may fall behind in their coursework, and it may be difficult to catch up with their classmates if they are absent."

These difficulties extend to preventing concentration and lowering energy levels, which in turn has a detrimental effect on the overall quality of the educational experience. Families that are living with thalassemia also face financial strain as a result of the costs involved with frequent blood transfusions and medical checks, which adds a layer of difficulty to the situation. The burden of financial responsibility suggests that individuals who suffer from thalassemia may face difficulties in gaining access to educational resources and opportunities. Furthermore, the direct influence that thalassemia has on the continuation of education is clear. Patients with thalassemia frequently skip school owing to medical treatments, which results in lost lessons, falling behind in coursework, and difficulties keeping up with classmates. To summarize, the physical and economic problems that are posed by thalassemia considerably hinder the educational experiences of those who are affected by the condition. This highlights the multidimensional impact that the ailment has on numerous aspects of their lives.

4.2.4 Social Challenges

There was a significant amount of emotional stress and tension that was highlighted as a concern. This included the burden of providing care as well as the demands that came from family connections.

A senior, female having a thalassemia patient in her family for more than two years, shared that she sees other patients struggle on many fronts and feels helpless. She asserted the need for larger social support for the patients in the following words:

"We have pointed out that there is a lack of support. This assistance may be either emotional or practical. This involves the lack of emotional support as well as the requirement for aid from non-governmental organizations (NGOs), international non-governmental organizations (INGOs), Bait-ul-Mal, and hospitals".

The lack of support, both emotionally and practically, was brought to light, highlighting the importance of receiving assistance from non-governmental organizations (NGOs), international non-governmental organizations (INGOs), Bait-ul-Mal, and hospitals. In a nutshell, the difficulties comprise monetary, temporal, health-related, emotional, and support-related components, which together illustrate the complex landscape that individuals who are coping with thalassemia must navigate.

4.3 Challenges and Experiences of Families of Thalassemia Patients

All patients have different types of suffering with thalassemia. Some are the result of the disease itself, and some issues arise as different organs and their working are affected by thalassemia. These sufferings are observed and to some extent are shared by the family members of these patients. We identify the emotional stress and tension as a significant problem. This includes the emotional toll that comes with providing care for a thalassemia patient, as well as the strain that it places on the relationships within the family.

Other respondents said that:

"I feel pain for my daughter, the process of receiving a blood transfusion is a painful one for patients, and the youngster may experience a rash and shivering while the treatment is being

Others also explain that:

"I mentioned that treatment procedure is actively participated in by the parents, who are present during blood transfusions and take note of any particular problems or responses that their children may experience".

A woman whose nephew has been suffering from this ailment for a few years now shared that in the effort to provide the best treatment to the child, the families often struggle, both socially and financially. It is not only the money, but the mental stress of a sick family member, their care, the burden of care, and associated social problems such as the inability to go to family gatherings that are out of the city, the responsibility of someone

being around the child 24/7, and changed family dynamics due to care duties of the child, all affect the families and patients. She stated that:

"My nephew was suffering from anemia, which is characterized by a lack of red blood cells, and was shown to be the most prevalent problem. Blood transfusions and other medical interventions are frequently required to effectively manage anemia in patients who have thalassemia. Because of this factor, families may be subjected to a greater socioeconomic load, which in turn may affect their mental well-being".

Another respondent, who was an elderly man traveling from a farther district of Punjab, described that;

"*My granddaughter's appearance up the issue of delayed growth and development was attempting to call attention to the more widespread impact that thalassemia has on the overall quality of life for patients. This may entail difficulties in the areas of schooling, social connections, and the overall development of the individual".*

It should be noted that although these patients are from different backgrounds, and their caregivers have different gender and gender roles, they all face more or less similar issues in the social and emotional domains. Both the respondents agreed that the disease comes with a social, emotional, and psychological burden for the family members. According to the findings of the themes, the socio-emotional obstacles that families of thalassemia patients in Islamabad are confronted with are multi-faceted. These concerns include both physical health challenges and broader societal repercussions related to the disease. To design tailored treatments and support networks for impacted families, it is essential to have a solid understanding of these key elements.

4.3.1 Psychological Challenges

The data includes the answers from ten participants in Islamabad reporting changes in behavior that occurred within households after the diagnosis of thalassemia. Based on the information that was provided, the following is a theme analysis. A significant number of respondents stated that they and their families have changed emotionally throughout this journey of health and sickness. Psychologically, they have suffered from stress, anxiety about the condition of the patient and health, and have also gone into depression due to associated social and financial pressures.

In several surveys, patients with thalassemia have been found to experience a significant rate of psychological discomfort. In research carried out by (Esmaeilzadeh, 2016) in Iran, children with thalassemia major were shown to have depressive moods and anxiety. A comparable study out in Singapore produced the same results. Additionally, it hasbeen found that those who have everyday limitations due to a chronic illness tend to be depressed more than people who do not. Among adult thalassemia patients, worse perceptionand sleep quality are linked to higher anxiety and depressive symptom levels. Therefore, a standard medical evaluation of this condition should include screening for anxiety and depression.

One prominent psychological theory that has influenced the field is Freudian psychoanalysis, which emphasizes the unconscious mind and its influence on behavior and mental health. Freud's work has been instrumental in shaping psychological anthropology's understanding of cultural norms, taboos, and the ways in which individuals negotiate their desires and anxieties within societal structures (Good 1994). From a medical perspective, the biopsychosocial model proposed by Engel (1977) has been influential in integrating psychological, biological, and social factors in understanding health and illness. Regarding the psychological issues discussed in psychological theory, one of my respondent Mr. Sher Ali had an opinion that was same to mine.

Mr. Sher Ali is a resident of Islamabad and is in middle age years. He works at a private company and has four children. His wife is a stay-at-home mother and has the primary responsibility of taking care of children, including the child who has thalassemia. Mr. Sher Ali has reported symptoms of stress and anxiety due to the health of his child. He has been getting his child treated for one and half years, and shared that at certain times during the treatment he lost hope, and thought there was no use even in trying. During the hospital visits, he met other parents and families and got to know their experiences. He also met relatives who sometimes said to him that the suffering of his child was a result of the parents' sins and wrongdoings. Slowly he and his wife started distancing themselves from people and avoided public interaction. This deprived the family of whatever little social interaction and support they had. He explained his feelings and realization of that time in the following words:

"My Family experiences feelings of isolation as a result of the stigmatization that this diagnosis may bring from society. This social feature has the potential to have a big impact on the emotional well-being of the family".

4.3.2 Emotional Issues

The majority of responders have experienced socio-emotional issues as a result of living with thalassemia in their families. These issues include stress, anxiety, and sadness. Many respondents said that;

Other respondents said that;

"I supposed that not only does thalassemia appear to affect the person who has the disorder, but it also appears to affect the larger family dynamics. There is a high probability that the emotional problems and stressors are experienced by all members of the family, resulting in a collective feeling of emotional strain".

Other respondents describe that;

"*I assumed that these feelings are intertwined and may be the result of a variety of variables that are associated with the difficulties that are brought about by thalassemia. These reasons include treatment, financial constraints, and societal shame".*

The fact that these emotions are connected and can be traced back to several different factors is a well-established fact. These factors include the challenges associated with treating thalassemia, limited financial resources, and societal guilt. Hence, it is vital to establish support structures that cater to the medical and social needs of these patients and their families.

4.3.3 Social Challenges: Stigma and Discrimination

In addition to the emotional and psychological issues, there is a recurrent pattern of social isolation among families, and it is believed that people in Islamabad, in particular, tend to isolate themselves as a result of the cultural shame that is linked with thalassemia. Individuals who participated in the survey stated their concern about being stigmatized and shamed by society, which might result in sentiments of isolation within families.

The complex interplay between the medical condition and its broader societal implications is reflected in the fact that this social aspect has a profound impact on the emotional health of the family. This interplay highlights the necessity for comprehensive

support systems and awareness campaigns to address the emotional challenges that are faced by families who are affected by thalassemia.

One female respondent, who is the mother of a thalassemia patient, said that;

"I believe that there are still difficulties in the community with the understanding and acceptance of thalassemia, as indicated by the fact that many patients and their families reported experiencing stigma or discrimination. The affected individuals and their families may experience feelings of marginalization as a result of this, which may be expressed as social isolation or exclusion".

The respondent described an instance of social rejection in which this family member refused to accept the clothes. This is a reflection of the larger problem of ignorance and stigma that exist in society regarding thalassemia, which can potentially lead to discriminatory behavior".

On the other hand, a male family member of another patient, who seemed to belong to a more stable economic background shared these comments:

"We have not experienced any form of discrimination or stigma in their neighborhood or social circles as a result of having a thalassemia diagnosis. This shows that there may be a supportive environment in which individuals and families who are affected by thalassemia feel accepted and integrated into their communities through the presence of a supportive environment".

Another respondent, commenting on the experience of stigma and discrimination stated:

"We advise that stigma and discrimination originate from a lack of awareness of thalassemia, which might lead to misunderstandings or worries that are not supported by evidence. It may be possible to help to the reduction of stigma by making efforts to address these misconceptions and promote accurate information".

The individual suggested that resolving misconceptions and spreading accurate information could contribute to the reduction of stigma, and they ascribed discrimination to a lack of awareness. A heartfelt family tale was also presented, which illustrated a particular instance of social rejection. The narrative described a family member who refused to buy clothes for a thalassemia patient due to ignorance and stigma. This occurrence brought to light the necessity of increasing awareness and education to create acceptance within society.

4.3.4 Guilt or Blame Due to Diseases

Some individuals place an emphasis on acceptance and credit the disease of thalassemia to a higher power, specifically Allah. In addition to highlighting the fact that they are powerless to stop the disease, they convey a sense of resignation to the course of events. We have not experienced any instances of guilt failure as a result of Thalassemia. It is Allah who is responsible for this illness, and we are treating it. My respondent said that;

"I express a perspective of acceptance, attributing the predicament to fate or nature, and a consistent theme emerges. Based on these reactions, it is clear that the belief in the divine origin of the sickness and the recognition that it is beyond the control of humans are both present".

Other respondents said that;

"We have feelings of helplessness and guilt that are associated with the limited treatment choices that are available for thalassemia is experienced by a significant number of respondents. A few of the responders have expressed their frustration and stress as a result of the absence of a clear solution and the continued difficulties associated with the management of the condition".

(Safdar, 2018) quoted that the frequency of thalassemia has historically been high in the Middle East, in part because of a high carrier rate and a propensity for Endogamy in the region. Regarding the cousin marriage, one of my respondents, Ms. Tanzela, had an opinion that was fairly comparable to mine. Shared by her:

"I believe that the thalassemia condition was caused by cousin marriage in the relative known as Family Marriages. I suggest that there is a perceived source of guilt connected to a decision made by a family member."

Others explain that;

"I emphasize that there is no responsibility for the disease, establishing a connection between thalassemia and hereditary factors and highlighting the fact that it is outside of their purview. This topic highlights how important it is to educate people on the hereditary basis of the illness and how important it is to create awareness about the need for education".

Among these is acceptance that is based on religious beliefs, emotions of helplessness as a result of restricted treatment choices, attributions of guilt to recognized causes, an

emphasis on education and awareness, and a significant concern for the well-being of the kid who is affected.

4.4 Families' Coping Mechanisms

In Islamabad, there are a variety of coping mechanisms that families who are living with thalassemia adopt, and some individuals employ an approach that is anchored in their religious or spiritual perspectives. Among those who participated in the interview, the vast majority indicated a sense of contentment with the will of God. When faced with mental, financial, and emotional stress, these families seek refuge in their faith and spirituality. Mr. Sher Ali shared that:

"*I coped with the strategy that is rooted in religious or spiritual ideas. Family members who fall into this category might consider the circumstance to be a test of faith and acknowledge that it is a component of a more extensive divine plan".*

About these families, the situation is regarded as a test of faith, and they consider it to be a part of a more comprehensive divine plan. Because of this perspective, they can discover the strength and resilience that they need in their faith, which assists them in navigating the obstacles that are affiliated with thalassemia. On the other hand, another theme shows that some families exhibit a more collected attitude, maybe originating from a sense of self-assurance in handling the condition or a lack of thorough information regarding the severity of thalassemia. It is essential to acknowledge and respect individual and cultural differences when addressing and managing the emotional impact of thalassemia among families that are impacted by the disease. These various coping techniques highlight the relevance of individual and cultural diversity.

4.4.1 Refuge in Religion

Many people find comfort and strength in their spiritual beliefs, in addition to the medical therapies and support networks that are available to them. Spirituality is examined in this article as a potential source of support and resilience for individuals who are afflicted with thalassemia treatment. Understanding and embracing one's spiritual beliefs can be a significant source of strength, resilience, and inner peace when confronted with the hardships that are associated with thalassemia. Individuals who are living with thalassemia can improve their overall well-being and build a positive view on their journey by adopting spiritual activities such as prayer, as well as mindfulness, acceptance, community support, and optimism. It is of the utmost importance that healthcare

providers and support networks recognize and respect the various spiritual requirements of thalassemia patients and that they incorporate these beliefs into a holistic approach to treatment (Rashid, 2020).

When it comes to the topic of spiritual belief, one of my responses, Ms. Eman Gulfraz, had an opinion that was largely informed by her personality and daily life practices. She shared that she holds a graduate degree and is a stay-at-home mother. She also shared that she is a practicing Muslim, she prays five times a day and gives charity regularly. When her daughter was diagnosed with the disease, and she started looking for the reasons, she could not find any strong answer except that this disease occurs due to genetic mutations. None in her family or her husband's family had thalassemia. So she could not find any reason for her child's suffering except in fate and faith. Her words were:

"*I believed that thalassemia my child was caused by the will of God or by religious factors. It is clear from this that there is a significant connection between the condition and divine powers in the belief systems of the responding individuals".*

The investigation of these concerns reveals a wide variety of concerning thalassemia, ranging from religious interpretations to spiritual explanations from a variety of perspectives. The significance of employing approaches that are culturally acceptable in the treatment of socio-emotional issues in homes in Islamabad that are afflicted by thalassemia is brought to light by these findings.

To deal with the socio-emotional issues that they are confronted with, patients struggling with thalassemia in Islamabad adopt a variety of coping techniques that are rooted in their religious and spiritual beliefs. One respondent said that;

"*I have a significant dependence on Allah and faith as a means of coping with the situation. There is a continuous reference of participants seeking help from Allah and finding peace in their religious views within the participants. There are expressions of faith in Allah's support, as well as an acceptance that thalassemia is seen as a challenge from Allah, with the certainty that divine assistance will be delivered".*

Others describe that;

"*We view that thalassemia was caused by black magic. Some respondents feel that the ailment is caused by black magic, which is something that is considered to be prevalent in their families. It has been found by a few of the participants that to combat*

the effects of black magic, they participate in rituals like travelling on pilgrimages and seeking spiritual intervention".

The results of the thematic analysis reveal that spiritual practices, faith, and the support of family members are significant components of coping strategies for the socio-emotional challenges that families of thalassemia patients in Islamabad face.

4.4.2 Indigenous Curing Methods

Several Indigenous treatment methods may include the use of particular plants and herbs that are thought to have positive effects on health. According to (Chauhan, 2014)Home remedies are an important component for people who suffer from Thalassemia. Wheatgrass juice is consumed twice daily, and they also consume foods that are high in folic acid, such as beans, bananas, soy products, beets, and sweet potatoes. In addition to that, they incorporate four basil leaves into their routine. To support the health of their blood, grass juice is regarded to be of particular significance for patients suffering from Thalassemia about this one respondent said that;

"Based on the information provided, it appears that drinking wheatgrass juice twice a day is a major practice. The individual who responded stated that wheatgrass juice provides evidence that it plays a special role in promoting the health of the blood, which is an essential component for those who have Thalassemia conditions".

Others explain that;

"We used different natural procedures including a wide variety of foods that are high in folic acid in one's diet is the treatment that is recommended. Beans, bananas, sweet potatoes, beets, and items made from soy fiber are some examples of these. Folic acid is associated with Thalassemia, which highlights the significance of this nutrient in the treatment and management of the condition".

It is recommended that foods like beans, bananas, sweet potatoes, beets, and soy fiber be consumed because of the high folic acid content that they have. This recommendation highlights the significance of this vitamin in the therapy and management of Thalassemia. Individuals with Thalassemia and their families may incorporate dietary strategies into their daily routines, possibly as complementary measures to conventional medical treatments, demonstrating a holistic approach to health management. These natural approaches reflect an awareness and proactive engagement in dietary strategies.

4.4.3 Support Groups

Many respondents discussed that the volunteer of Pakistan Red Crescent plays a vital role in providing help for thalassemia patients.

"We appreciate Social workers or volunteers from the Pakistan Red Crescent Society (PRCS) were named by eight out of ten respondents, showing that these professionals play an important role in providing support and direction to families who are dealing with thalassemia".

Other respondents said that:

"I want to request equipped and trained pediatric psychologists that is, psychologists who specialize in working with children. This would suggest that there is an acknowledgment of the significance of providing mental health support that is specifically designed to meet the requirements of thalassemia youngsters".

The need for assistance was commonly discussed by respondents at all levels and in all families. One respondent shared that:

"We know that the fact that local hospitals and clinics were highlighted by respondents shows that a lesser emphasis is placed on these institutions in comparison to specialized thalassemia centers. The many different forms of assistance that are accessible to families that are coping with thalassemia".

These themes indicate that there is an extensive dependence on Thalassemia Centers and Clinics, which is then followed by the significant role that social workers or PRCS volunteers play. Because pediatric psychologists are mentioned, it is clear that the necessity of providing specialized assistance to children has been acknowledged.

4.5 Analysis and Suggested Techniques & Activities

The study of the social and emotional challenges that families of people with thalassemia confront in Islamabad involves a comprehensive examination of the numerous challenges that these families face in the context of the culture and social environment of the region. One of the most significant aspects of the research is the societal stigma and misunderstandings that surround thalassemia. These misconceptions frequently result in emotional distress for families who have a child who has the condition. It is essential to have a solid understanding of the regional subtleties and social dynamics to get insight

into how these families deal with societal expectations, discrimination, and the establishment of support networks.

Social awareness programs, campaigns, blood donation camps, and other variety of activities are suggested for families of thalassemia patients to participate in. These may include playing games on mobile devices, playing hide-and-seek, writing, and drawing. My respondent said that:

"We *recommended that allowing patients to participate in activities that are both entertaining and exciting is an effective way to divert their attention and cultivate a healthy environment within the family".*

Others said that:

"I suggested that the increasing knowledge about thalassemia, engaging with the community through awareness programs and activities not only helps to develop a sense of belonging and support, but it also raises awareness about the disease".

(Keun, 2023) had found that hematovigilance on the part of donors is an essential component in ensuring the safety of blood donation. To ensure that the donor would return for additional donations in the future, it is essential to provide pre-donation information and an understanding on how to handle post-donation issues. During the course of her discussion regarding blood donation, one of the respondents, Ms. Iqra Sahaheen, shared her perception in the following manner:

"I proactively commit to controlling thalassemia, which is important because regular transfusions are an essential component of treatment. Active participation in blood donation events not only raises awareness but also demonstrates a proactive commitment to controlling the disease".

This demonstrates the significance of adopting a holistic approach that takes into account not only financial considerations but also emotionally supportive measures, medical interventions, and community engagement.

CHAPTER No. 5

Doctors and Administration Perspective on Thalassemia

This chapter contains a discussion of a portion of the issue statement, as well as the introduction of a significant question concerning the variables that are driving the research. The group of this chapter can be broken down into two main sections. An overview of how thalassemia patients who are hospitalized are cared for by highly trained medical professionals is presented in the first section of this chapter. It is stated in the second section of the chapter that a brief analysis of the role that administration plays in hospitals, particularly about patients who have thalassemia, is presented. Furthermore, a comparison is made between the administration and supply of medical treatments in private hospitals and those in public hospitals, considering both the similarities and contrasts between the two.

This research employed two distinct interview guides tailored for medical professionals and administrative personnel. In-depth interviews, lasting approximately 40 to 45 minutes each, were conducted with both groups. Key informants facilitated access to participants within their respective fields.

5.1 Doctors Perspectives

5.1 .1 Experience with Thalassemia Patients

Thalassemia is a genetic blood illness that is defined by abnormal hemoglobin production. This abnormal hemoglobin production can lead to anemia as well as other issues. The experiences that the Doctor had during his career have provided him with invaluable insights into the difficulties that patients confront and the complexities of thalassemia management. He is committed to enhancing the entire well-being of people who are afflicted with thalassemia, as evidenced by his dedication to continued education and advocacy. The response statement by the doctor also shows his concern for the well-being of patients, and their families as they understand that both the patient and the family are suffering. By the statements made by the doctor during the interview that was:

"I work at the Pakistan Red Crescent Society from Monday to Friday. We care for children with thalassemia and hemophilia, among other conditions. Approximately 60 percent of the blood from our blood bank goes to thalassemia patients. When their parents come for blood they are very worried and don't know about anything, so I inform them, comfort them, and provide them clean blood".

He further added that there is a need of more specialized healthcare staff to deal with the thalassemia patients due to their complex needs. He added that:

"The other clinicians I worked with throughout the fieldwork had expertise dealing with thalassemia in the contemporary healthcare system. I have experience working with thalassemia patients in different, more conservative, and less equipped healthcare settings".

Another doctor who had immigrated to Islamabad for work explained the ordeal doctors go through during their daily life. Disclosing the news to the families of the patients is difficult for doctors as well.

"My working experience started as a house officer and I do work in the Pediatrics ward and also work with the Pediatrics surgery ward, then I joined health officer in KP. I have a lot of experience with thalassemia patients. When thalassemia was diagnosed I concealed their parents, told them the methods of treatment, and told them precautions".

He further added that:

"I had the opportunity to work with thalassemia patients during my training. A lack of proper facilities is one of the most significant obstacles that must be overcome. The most recent treatment plans are frequently unavailable or prohibitively expensive in many regions, and there are no suitable blood banks in many of these regions. The provision of the highest possible level of care to our patients is hampered as a result of this."

The majority of the time, medical professionals who work with patients who have thalassemia begin their careers by gaining practical experience during their training. This may include working in pediatric wards or surgery wards. Not only are they responsible for diagnosing thalassemia, but they are also responsible for advising parents through the many treatment techniques and precautions. There is a big impediment that exists despite their skill, and that is the lack of appropriate facilities. This hinders the execution of the most recent treatment plans, which are sometimes pricey in many places. This problem is made even more difficult by the fact that there are no suitable blood banks in many different regions, which makes it difficult to provide thalassemia patients with the best possible care.

5.1. 2 Health Care Services:

When addressing healthcare services, it is important to note that the healthcare facilities in government hospitals are insufficient. Most of the patients are from lower socioeconomic strata. When asked about a low-cost parallel system during the interviews, the majority of respondents stated that they would prefer hospitals run by the government, charities, and non-governmental organizations (NGOs/INGO). One doctor said that;

"No, Health care facilities are not sufficient because in urban areas some facilities are available but in rural are no facilities, no awareness about the diseases I will discuss some points these are Screening facilities are not available Health care providers (doctors) not sufficient in the remote areas".

When inquired about the availability of equipment and facilities for doctors to treat thalassemia patients, one of the responding doctors expressed their frustration and dissatisfaction with the current state of affairs in these words:

"No, Health care services are not sufficient because, in my experience, the hospitals I have worked at have had the necessary diagnostic tools and treatment modalities for thalassemia patients. However, there is a lack of awareness about thalassemia in Pakistan, and there is no pre-marital screening for the disease. This can lead to an increase in the number of thalassemia patients. People from the middle class and they prefer government hospitals. There are not enough healthcare facilities in government hospitals".

Patients who have thalassemia face a lot of challenges when it comes to receiving medical care, including inadequate facilities, the high expense of modern treatment choices, or the lack of availability of these options in many regions. Blood banks that are not adequate can make it more challenging to provide patients with thalassemia with the highest possible level of care. Despite the dedicated efforts of medical professionals, there is a need for improvements in infrastructure, cost, and accessibility to ensure that individuals with thalassemia receive comprehensive and adequate medical care.

5.1. 3 Types & Symptoms of Thalassemia

Alpha thalassemia and beta thalassemia are the two primary forms of the genetic disorder known as thalassemia. One muted gene is called minor it is cured through supplements. Two muted genes are called major the treatment process is blood transfusion, iron chelation, and bone marrow. Different symptoms of thalassemia are anemia, infection, fever pale color, and delayed growth. During discussions with doctors about the types and symptoms of thalassemia, they all shared the same points of view, majorly because their educational training taught them the same information. One doctor used the following words:

"*There are 3 types of Thalassemia. Major, Minor, and Intermediate. A decrease in the production of Red Blood Cells (RBC) leads to anemia, fatigue, weakness, and other complications. Symptoms include fatigue, weakness, pale skin, shortness of breath, and slow growth among patients".*

Another doctor focused more on the symptoms than the causes of the disease:

"*Thalassemia can be categorized into major and minor types. Typically, symptoms of thalassemia appear in infants at around two to three months of age. Thalassemia major patients require ongoing blood transfusions and iron chelation therapy. Weakness, anemia, slow growth, and pale colored skin are commonly observed symptoms of this disease."*

Individuals who have a family history of thalassemia or who are experiencing symptoms should seek the advice of a healthcare practitioner to receive the right testing and treatment for their condition. In certain instances, treatment may involve bone marrow or stem cell transplantation, as well as blood transfusions, iron chelation therapy, and other similar procedures. It is also recommended that families that are genetically predisposed to thalassemia seek genetic screening and counseling before conceiving.

5.1.4 Genetic Screening

In the process of diagnosing and treating thalassemia, genetic testing is an incredibly significant component that must be considered. On the other side, treatments are intended to reduce symptoms and, in some cases, provide a cure for the condition. There is reason

for those who have thalassemia to have hope that, as a result of recent developments in gene therapy and research, thalassemia patients will experience improved outcomes and a higher quality of life.

The blood disorder known as thalassemia is a hereditary condition that alters the production of hemoglobin, which ultimately results in anemia. Because standard medical therapies, including blood transfusions and iron chelation therapy, are frequently required for the management of thalassemia, it is possible that traditional medicine alone will not be sufficient to control the condition. Nevertheless, there are some traditional practices and nutritional choices that might be supplemented by conventional therapy. It is essential to have a conversation with a healthcare provider about any alternate courses of action (Cappellini, 2014) . Dr. Wasifa shared similar ideas. She mentioned the financial side of the testing and stated different treatment options that are available to the patients:

"*Thalassemia is diagnosed through blood tests, including a complete blood count (CBC), hemoglobin electrophoresis, and DNA mutation testing. The main treatment options for thalassemia are blood transfusions, iron Chelation, and bone marrow transplants. Other treatments include folic acid supplementation and iron chelation therapy. The cost of the test is 2000-3000 PKR".*

5.1. 5 Treatments and Associated Pros and Cons

Another respondent doctor mentioned the same tests and their costs but expanded more on the available treatment options. He elaborated on the treatment options in detail but did not mention the costs of these treatments. One reason can be that these treatments are not available in Pakistan, or he has not been a part of some of these treatments like gene therapy and bone marrow transplant.

"There are two types of genetic test for thalassemia: Certain invasive techniques, such as amniocentesis and chorionic villus sampling (CVS), have the capability of identifying thalassemia mutations in the fetus while the mother is pregnant. The non-invasive prenatal testing, also known as NIPT, is a relatively recent technique that looks for thalassemia mutations in the maternal blood by analyzing cell-free DNA. This method does not involve any intrusive procedures. Treatments are blood transfusion, gene therapy, and bone marrow transplant."

When a patient is diagnosed with thalassemia, the attending physician recommends a genetic test to identify the specific globin gene abnormalities, the root cause of the condition. This test assists in determining the kind of thalassemia as well as the severity of the condition, which in turn assists in determining the treatment plan.

People who have beta-thalassemia major are commonly required to undergo regular blood transfusions to keep healthy levels of hemoglobin. The physician may additionally suggest iron-chelating medications to manage iron excess that is the result of repeated transfusions. There is a possibility that patients with severe thalassemia could benefit from receiving a bone marrow transplant.

Genetic counseling is a crucial component of the treatment process because it assists the patient and their family in gaining an understanding of the hereditary aspects of thalassemia and in making well-informed decisions on family planning.

One of the respondent doctors said:

"Blood transfusions, while essential, can lead to complications such as iron accumulation in the body. Major drawbacks are cardiac issues, delayed puberty, and transfusion reactions".

Another respondent also elaborated on similar pros and cons associated with blood transfusions in the following words:

"*Treatments for thalassemia, which may involve blood transfusions, drugs, and the possibility of complications, might result in large financial costs".*

Financial costs are one major deciding factor when choosing between certain available treatments for the disease. The medical professionals, like the doctors interviewed for this research, are also well aware of this fact and have included this aspect in their discussions multiple times. These professionals must have suffered stress and anxiety when dealing with situations where people cannot get their loved ones treated beyond a certain point of time because they cannot afford the treatment option that is best suited for a certain stage of the disease.

Blood transfusions are an essential component of the care of thalassemia, particularly in the more severe forms of the disease. This is especially true in cases when the disease is more severe. It is common for patients who suffer from thalassemia to require regular

blood transfusions. This is done to ensure that their hemoglobin levels remain at a sufficient level and to prevent the complications that are associated with anemia. Transfusions are administered to patients to provide them with healthy red blood cells that contain normal levels of hemoglobin. As a consequence of this, there is an increase in the quantity of oxygen that is transported to the tissues of the body. One Doctor elaborated that:

"*People who have severe thalassemia frequently need to receive blood transfusions regularly, typically once every two to four weeks. The frequency of treatment is determined by the severity of the ailment as well as the specific requirements of the client. The potential for transfusion responses is always present, even though blood transfusions are generally considered to be safe. There is a reduction in these hazards by the use of pre-transfusion testing and regular monitoring".*

Patients who suffer from thalassemia can benefit from regular blood transfusions because they help refill their hemoglobin levels, which in turn improves their overall health and quality of life. To reduce the likelihood of problems, the process requires carefully matching blood types.

According to the discussion by medical professionals, patients who suffer from thalassemia, have to choose between the available treatments based on their respective pros and cons which can be summarized as follows:

Table No 5.1: Benefits & Drawback

Benefits	**Drawback**
Blood Transfusion	
Provide Healthy RBCs and improve o2 delivery	Iron overloaded
Iron Chelation	
Remove excessive iron and also prevent iron overload.	It requires long-term adherence and may have side effects.
Folic Acid Supplements	
It helps in the production of RBC.	It does not address the underlying cause.

As a result of breakthroughs in medical therapies, including blood transfusions and iron chelation therapy, the quality of life of a considerable number of thalassemia patients

has significantly improved, and they are now able to lead relatively normal lives. However, the requirement for regular blood transfusions and ongoing medical supervision can be difficult to handle. This presents a disadvantage in terms of the financial burden that it imposes as well as the possibility of consequences such as iron overload. Furthermore, the emotional toll of chronic sickness and the ongoing need for medical attention can influence the mental well-being of thalassemia patients. This highlights the significance of comprehensive care and supports to address both the physical and psychological elements of the condition.

5.1. 7 Associated Complications

5.1.7.1 Iron Overload

No medical intervention for thalassemia patients is free from associated complications and medical professionals are well aware of this fact. Explaining the effects of blood transfusions, one respondent doctor compared the pros and cons of blood transfusions as a treatment in the following words:

"*The transfusion contributes to the improvement of the patient's overall well-being by alleviating the symptoms that are linked with anemia (low red blood cell count). On the other hand, receiving regular blood transfusions can result in an accumulation of iron in the body because the excess iron that is present in the blood that is being transfused is difficult to clear".*

Another doctor explained the effects of iron overload in these words, explaining more of what accumulation of iron does to essential body organs:

"*The bone marrow, the liver, and the spleen are the key organs that are accountable for the storage of unnecessary amounts of iron. Over time, these organs have the potential to become overloaded with iron, which could lead to major problems".*

5.1. 7.2 Enlargement of Organs:

Discussing the enlargement of organs, one doctor affirmed that:

"*As a result of increased workload, the spleen, which is responsible for filtering and eliminating damaged blood cells, becomes enlarged. Similarly, the liver, which is responsible for the storage of blood and the cleansing of toxins, undergoes expansion. From a physiological standpoint, these enlarged organs might result in issues such as*

discomfort, pain in the abdomen region, and the possibility of a reduction in the function of the organs".

Another Doctor revealed that;

"*In patients with thalassemia, the management of organ enlargement typically involves a mix of blood transfusions, iron chelation therapy, and, in more severe situations, splenectomy. There are difficulties associated with these therapies, even though they are designed to ease symptoms and improve organ function".*

The extra iron that is present in transfused blood is difficult to clear, which is why frequent transfusions can cause the body to experience iron overload. Iron chelation therapy is frequently provided in conjunction with blood transfusions to solve this issue. The presence of an excessive amount of iron runs the danger of causing damage to organs such as the heart, liver, and endocrine glands, which could result in numerous major health problems.

5.1. 8 Emotional & Psychological Impact

Stress is a huge problem for thalassemia patients and their families. However, this study shows that none dealing with this ailment is immune to stress, including medical professionals. Since these doctors deal with patients, existing and new, all day long, they face significant levels of stress in their jobs and even during after-work hours. One of the Doctors asserted that:

"*There is a possibility that medical professionals are aware of the fact that thalassemia may have a significant influence on the quality of life of a patient who is receiving medical treatment. There are a variety of variables that might lead to feelings of stress and anxiety, some of which include the probability of difficulties, as well as frequent medical visits and treatments".*

Another doctor declared that:

"*It is possible that medical professionals are aware of the fact that the treatment for thalassemia, which includes chelation therapy and regular blood transfusions, can be quite taxing. Maintaining these treatments and coping with the possibility of experiencing adverse effects may be a contributor to mental discomfort".*

It is common for medical professionals to emphasize the significance of providing patients with psychological support to assist them in coping with the physical problems

and potential complications that are connected with the condition. It is possible that the patient would experience a sense of vulnerability as a result of the need for continuing medical management, which, when combined with the possibility of restricted daily activities, may affect the patient's overall quality of life. When it comes to addressing these emotional components, doctors play a significant role. They also emphasize the necessity of taking a holistic approach to care, which involves not only medical treatments but also psychological assistance and counseling to improve the overall well-being of those who are living with thalassemia.

5.1. 9 Need for Holistic Care

One of the doctors asserted the need for a comprehensive approach to treatment and said that:

"*The medical management of thalassemia, which may include blood transfusions, iron chelation therapy, and the possibility of bone marrow transplantation, is the basic component of holistic treatment for the disease. Maintaining a consistent schedule of medical follow-ups and monitoring".*

Another doctor described the situation from the patient's perspective in the following words:

"*Being a person who lives with a chronic ailment such as thalassemia can be very difficult emotionally. If a physician acknowledges the significance of mental health, they might suggest that their patients seek assistance from psychologists or counselors. When it comes to teaching patients about their disease, treatment options, and whether or not they should make changes to their lifestyle, doctors may play a role. It is possible to improve patients' abilities to effectively manage their health by providing them with knowledge".*

When a clinician describes holistic treatment for a patient with thalassemia, they are referring to an approach that is not only complete and integrated, but also addresses not only the physical symptoms of the individual, but also the emotional, social, and psychological components of the person.

5.1. 10 Support Groups

Just like families of patients, the doctors also asserted the need for social support for patients. One respondent doctor used the following words to assert this need of the patients and their families:

"Support groups and educational initiatives are crucial. They provide a platform for patients and their families to share experiences and receive guidance. Blood donation drives, awareness programs, and collaborations with organizations contribute significantly to the overall support system".

Another doctor also took an empathetic stance and shared that:

"*Living with thalassemia can be a very challenging experience, both for the patients themselves and for their families. Patients may face physical limitations, social stigma, and emotional distress. Families may also experience financial strain and emotional stress due to the ongoing care required for their loved ones. Therefore, emotional and psychological support is crucial for thalassemia patients and their families. This can include counseling and support groups".*

Individuals and families who are impacted by this genetic blood condition can benefit greatly from the emotional, educational, and practical aid that is provided by support groups for thalassemia patients. When it comes to the establishment of these support networks, non-governmental organizations (NGOs) and international non-governmental organizations (INGOs) frequently work together with medical experts and other medical professionals. Patients have the opportunity to discuss their experiences, methods of coping, and information regarding the most recent developments in medical technology through the use of these groups.

5.1. 11 Research and Future Remedies

Recent advancements in the management of thalassemia have resulted in the introduction of novel medications and treatments. One example of this is the pharmaceutical Luspatercept, which is designed to increase the production of red blood cells. One doctor explained that:

"There are several advances in the management of thalassemia, including new medications and treatments. One example is Luspatercept, a new drug that helps to increase the production of red blood cells".

These attempts to improve the therapeutic alternatives that are accessible to people who have thalassemia are continuous, and the creation of novel medications is a reflection of

those efforts. Individuals who are committed to maintaining their knowledge of the most recent advancements in the management of thalassemia are actively participating in continuing education (CE) programs at the same time. One responding doctor added that:

"I stay up-to-date on the latest developments in thalassemia management by participating in continuing education (CE) programs. These programs are offered both online and offline and they provide updates on new treatments, approaches, and medications".

Professionals have access to a crucial platform that allows them to receive updates on novel treatments, methods, and pharmaceuticals through these programs, which are available with both online and offline access. This dedication to continuous education ensures that both individuals and healthcare practitioners continue to be well-informed about the ever-changing environment of thalassemia care, which in turn fosters a proactive and well-informed approach to the condition.

5.1. 12 Analysis

It is possible to acquire a thorough picture of the challenges that are encountered by families of thalassemia patients in Islamabad by doing a thematic analysis of the perspectives of doctors on these families. This will allow for the acquisition of more information. It has become abundantly evident, as a consequence of conducting interviews and surveys with healthcare professionals in the region, that medical professionals place a significant emphasis on the significance of giving families who are coping with thalassemia comprehensive support networks. As a result of the current research, several issues have been brought to light. These issues include the need for more knowledge about hereditary illness, as well as financial challenges and emotional stress. On the subject of the necessity of multidisciplinary care, which includes psychological support and educational resources, a consensus has been formed among medical professionals about the importance of providing families with the skills to effectively manage thalassemia syndrome. The analysis highlights the significance of collaborative efforts between healthcare professionals and policymakers to increase accessibility to specialized care and genetic counseling, which will ultimately lead to improved outcomes

for thalassemia patients and their families in Islamabad. This is an additional point of interest that is highlighted by the analysis.

5.2 Administration Role & Perspective on Thalassemia

The majority of thalassemia treatment and prevention programs are managed and overseen by the administration and care facilities where the disease is administered. Among their roles are the dissemination of information regarding thalassemia, the promotion of early detection through screening programs, and the provision of access to medical professionals who are experts in the field. From an administrative point of view, one of the primary focuses is to make certain that the necessary resources and infrastructure are available for the treatment of thalassemia. This includes the establishment of well-equipped treatment centers, guaranteeing a constant supply of blood and blood products for transfusions, and the incorporation of mental health assistance into comprehensive thalassemia care programs.

5.2.1 Working Experience with Thalassemia Patients

The working experiences of administrators and nurses who deal with thalassemia patients are very important to discuss, hospital in charge said that:

"*I am the charge of administration for the Pakistan Red Crescent that pertains to the problem of thalassemia. In addition to ensuring that healthcare professionals are taught to assist families with a wider range of difficulties than just medical concerns, He has contributed to the writing of guidelines for thalassemia clinics. During his discussion, he discusses the need for the community to be involved and educated about thalassemia to eliminate the bad perceptions that are associated with the disease. Additionally, I am collaborating with non-governmental organizations (NGOs) to provide financial assistance to families whose lives have been affected by the calamity".*

One of the nurses stated that:

"I work as a Pediatric Hematology Nurse at a PIMS hospital in Islamabad that serves children. For several years, I frequently found myself in the position of offering emotional support and being a reassuring presence during therapeutic procedures that

are difficult. As a result of my observations regarding the resiliency of these families, my opinion is that it is necessary to take a holistic approach to care, which includes providing psychosocial assistance".

According to (Druzy, 2016) in any group of medical professionals that are involved in the treatment of patients who have chronic diseases, including hemoglobin (Hb) abnormalities like sickle cell disease and thalassemia, the nurse is an essential member of the team. There is, nevertheless, the possibility of efficiently managing these illnesses through the dissemination of expert knowledge regarding their prevention and treatment. A nurse's education is comprised of both theoretical and practical training that is delivered to nurses to prepare them for the responsibilities that they will have as nursing care providers. While talking about the challenges of working with thalassemia, Ms. Tania shared:

"I worked as a specialized faculty of nurses at a thalassemia clinic. The administration of treatments, the monitoring of patients, and the provision of education to families are all areas in which I play an essential role. I am actively involved in connecting families so that they can receive assistance services because I have personal experience with the financial burden that families are under. I am a firm believer in the efficacy of community support groups in facilitating the sharing of individual experiences and coping mechanisms among families".

To ensure that individuals with thalassemia receive comprehensive and empathetic care, nurses and office staff play a very essential role. To manage the symptoms and effects of thalassemia, nurses are required to do routine tasks such as monitoring their patients' vital signs, administering blood, and ensuring that their patients adhere to their prescribed medication schedules. In addition to providing patients and their families with emotional and psychological care, they are also trained to create a supportive environment and to educate patients and their families about the disease. Additionally, the administration collaborates with medical personnel to ensure that the system continues to function smoothly and effectively. This involves the establishment of follow-up meetings regularly, the facilitation of specialized treatment for individuals who have thalassemia, and the implementation of measures that bring about an overall improvement in the

quality of life for patients. The management and nurses must collaborate to accomplish the goal of improving the overall health and quality of life of thalassemia patients.

5.2.2 Observations on Emotional Responses of Families

As discussed previously, families of thalassemia patients in Islamabad face social and emotional challenges. However, this phenomenon is not limited to the patients or their families only. Healthcare workers and administration of the healthcare facilities also witness the suffering and stress of the patients and families which leaves a profound impact on them. One nurse informed that:

"When members of the family were informed for the first time that a member of their family had thalassemia, I will never forget how they felt. Statements of disbelief, numbness, and attempts to dismiss or minimize the severity of the situation are examples that are associated with this subject".

Another administration staff member explained the variety of emotional responses he observed in patients and families of those suffering from thalassemia. His response to the question clearly showed how deeply he was affected by these responses and the reactions of families. While discussing the emotional reactions of families, he shared that:

"A variety of emotional responses that include dread, grief, and anxiety exists. It may include details of occasions that caused tears to fall, sentiments of anxiety about the future, and the emotional toll that it took on members of the family".

According to the observations made by the nurses and the administration, the reaction of the family showcases a range of feelings, beginning with initial shock and distress and progressing to resilience and determination. In addition to providing emotional support and information, nurses play a significant role in enabling communication between the family and the healthcare personnel who are treating the patient. As part of its duties, the administration is responsible for creating thorough care plans, ensuring that therapies are easily accessible, and cultivating a supportive environment. Despite the constant medical problems that are connected with thalassemia, families demonstrate an extraordinary level of resilience and solidarity, which highlights the significance of holistic healthcare approaches and compassionate support networks.

Many different people are involved in the caregiving and support network, and it is essential to take into consideration their points of view. I will now discuss some of the potential emotional problems that families may experience. One administration team member shared the observations of parents and primary caregivers of thalassemia patients in these words:

"*The parents of children who have thalassemia frequently endure unrelenting anxiety for their child's health and future development. Increased levels of anxiety may be caused by several factors, including the requirement for consistent medical attention, the strain on one's finances, and the lack of certainty over the effectiveness of therapies".*

A less discussed element of the emotional suffering of patients' families is the experiences of younger family members such as siblings. A respondent from the administration team highlighted this element and stated that:

"There are instances when siblings of thalassemia patients may experience feelings of emotional neglect as a consequence of the attention and resources that are devoted to the sibling who is impacted by the disease. This can result in a variety of feelings, such as bitterness, guilt for feeling that way, and a desire to be validated".

Because they are intimately involved in the day-to-day care of thalassemia patients, nurses and administration can experience firsthand the hardships and resiliency of both patients and their families. It is common for them to witness the psychological impact of chronic therapies, the financial difficulties, and the uncertainties that are involved with the management of a condition that lasts a lifetime.

5.2.3 Healthcare System and Safe Blood

Several individuals work in the healthcare system for thalassemia patients. These individuals include an administrator, a nurse who specializes in providing care for people who have thalassemia, a general healthcare administrator, and a mental health staff member. Considering the nature of the disease, these staff must be trained in dealing with thalassemia patients, since like every disease, thalassemia also requires a certain skill set. However, from responses, it appears like neither the medical nor the administrative staff is trained to provide specialized care to these patients. One respondent elaborated on this response in the following words:

"*The nurse who provides care for patients with thalassemia emphasizes the significance of providing specialized care to patients and their families. They examine the difficulties that families of thalassemia patients have in gaining access to specialist treatment, highlighting the pressing requirement for a system that is both more streamlined and more easily accessible. Also, the nurse understands the emotional toll that is placed on families and advocates for holistic care that goes beyond the interventions that are provided by medical professionals".*

The administrative staff also discusses the significance of community relationships, to establish a straightforward experience for families dealing with thalassemia within the context of the larger healthcare network. Another staff member added that where there is realization of the issue, there are only limited efforts to address the issue both at the healthcare facility and the community level:

"*Healthcare supervisory at the thalassemia center acknowledges the necessity of enhancing accessibility and support services. They talk about the ongoing efforts that are being made to improve care coordination, cut down on wait times, and provide families with more support in every aspect. Additionally, the administrator highlights community service programs that are intended to decrease the stigma that is associated with thalassemia and increase knowledge of the disease".*

These various discussions provide light on various aspects of the health care system in Islamabad, which is of particular interest to individuals who have thalassemia. The results demonstrate that families require specialized treatment, enhanced accessibility, healthcare professionals who collaborate, and a significant amount of assistance with their mental and social health.

Safe blood is very important for thalassemia patients, as their lives are dependent on the availability and transfusion of safe blood. One of the nurses said that:

"*Patients who have thalassemia need to have regular blood transfusions, and the blood that they receive must be subjected to periodic testing for infectious illnesses. This is done to ensure that the blood is free of infectious agents such as HIV, hepatitis B and C, and other viruses that are spread by blood transfusions".*

It is necessary to perform thorough screening and testing of given blood to eradicate potential infectious agents such as HIV, hepatitis B and C, and other blood-borne viruses. Another respondent emphasized the need for strict screening procedures before supplying blood. He explained that:

"*There is a complete necessity for the implementation of rigid screening and testing processes for donated blood. This involves conducting exhaustive tests for infectious diseases and ensuring that the blood supply is of high quality to reduce the extent to which thalassemia patients are exposed to the danger of developing infections".*

The administration also stated that:

"It is of the utmost importance that hospitals, blood banks, and other health institutions that are tied to one another work together more effectively. Through the efforts of this cooperation, the procedures of blood collection, testing, storage, and distribution are ensured to function well, so contributing to an overall improvement in the health of the blood supply".

The comprehensive therapy of thalassemia patients includes regular blood transfusions requiring the elimination of these potential infectious agents. There was a strong emphasis placed on the significance of rigorous screening procedures, which highlighted the requirement for high-quality blood to reduce the likelihood of infection for thalassemia patients. The administration emphasized the need to counter the myths that are associated with blood donation to attract a greater number of individuals to routinely participate in blood drives. In addition, they emphasized the significance of effective collaboration between hospitals, blood banks, and other health institutions to optimize the procedures of blood collection, testing, storage, and distribution, which would ultimately lead to an improvement in the overall health of the blood supply system. This all-encompassing strategy guarantees the security and dependability of blood for patients suffering from thalassemia and other individuals who are reliant on receiving frequent transfusions.

5.2.4 Social Problems

Family members of thalassemia patients face a variety of socio-emotional challenges, including emotional anguish and the requirement for assistance. These various points of

view, when taken together, offer light on the complex social problems those families of thalassemia patients in Islamabad are confronted with. These concerns include financial difficulties, emotional difficulties for parents, the influence on siblings, and the stigma that is associated with the disease. One of the nurses shared the social aspect of caregiving in the following words:

"*It is possible for families to experience social isolation from their extended social circles as a result of the stigma and misunderstandings that are connected with thalassemia in society. This isolation can make the emotional issues that the nuclear family and the extended family are already facing much more difficult".*

Another respondent focused on the lack of facilities, resulting in late diagnosis, and increased burden of care on the family members. He used the following words to describe his observations:

"Because there are not many thalassemia treatment clinics that specialize in the disease, not many people are aware of the sickness. This can result in delays in diagnosis as well as inadequate medical care. The fact that families have to deal with the healthcare system and make sure that their children receive the appropriate therapy consistently makes it difficult for them to deal with their sentiments and the social challenges that they are facing".

A nurse working in the psychological ward shared her experience and observations in these words:

"I observed the emotional difficulties that families go through and the significance of including mental health services within thalassemia treatment. To address the socio-emotional aspects of living with thalassemia, the professional pushes for the provision of counseling services, support groups, and educational programs".

The financial cost of treatment and care is an unavoidable part of caring for thalassemia patients. Where families pay both emotional and financial costs of the treatment, the administration staff is completely aware of these costs. A responding administration team member stated that:

"*Families that are coping with thalassemia frequently face considerable financial challenges throughout their journey. A person may experience financial strain as a result of the expenses that are connected with receiving regular blood transfusions, medications, and specialized care. In addition, the social stigma that is connected with thalassemia in many societies makes the difficulties much more difficult to deal with. Having to deal with discrimination and solitude can hurt the social well-being of families. It becomes clear that addressing worries regarding finances and striving to eliminate misunderstandings held by society are essential components in providing help for these families".*

As nurses have seen and experienced directly, the chronic nature of thalassemia causes a significant emotional strain on parents, resulting in feelings of anxiety, helplessness, and loss. This is something that nurses have watched and experienced firsthand. The holistic approach to treating thalassemia emphasizes the importance of providing good emotional support, acknowledging that this is an essential component of the treatment process. As a result of limited awareness and clinics, families in Islamabad who are coping with thalassemia face difficulties in gaining access to specialized medical treatment. This leads to delays in diagnosis and poor care. The financial burden that is involved with monthly blood transfusions, medications, and specialized care further enhances the challenges that these families are confronted with, which are compounded by the stigma that is associated with the condition in society. To provide effective assistance to these families, the administration places a strong emphasis on addressing concerns regarding finances and setting the record straight regarding societal misconceptions. These viewpoints, when taken as a whole, give light on the complex socioeconomic concerns that families of thalassemia patients in Islamabad are confronted with. These issues include financial limits, emotional obstacles for parents, the influence on siblings, and the stigma that is connected with the condition.

5.2.5 Cultural & Language Barrier

The socio-emotional challenges that families of thalassemia patients confront, as well as the cultural and language difficulties that exist within hospitals, can have a substantial impact on the lives of both patients and their families. The healthcare professionals that are involved in the treatment of thalassemia patients, which includes a dedicated head nurse, another nurse, and an administrative focal person, jointly underline the impact that

cultural elements have on communication and emotional well-being among families who are dealing with thalassemia.

This holistic approach acknowledges the interconnectedness of mind, body, and environment, emphasizing the importance of considering cultural beliefs and practices in medical diagnosis and treatment (Kleinman 1980). In the realm of psychological anthropology, cultural psychology has emerged as a key framework for studying how cultural context shapes cognitive processes, emotions, and behavior. This perspective highlights the role of culture in shaping individual and collective psychological phenomena, challenging universalistic assumptions about human nature and cognition (Shweder 1991). My one respondent nurse shared the same idea she stated:

"*I am, a dedicated head nurse, I have observed the cultural reluctance that relatives of thalassemia patients have when they express their concerns to medical personnel through conversation. When it comes to discussing their concerns, I am aware that certain families may experience discomfort due to the cultural norms and expectations that they have".*

The head nurse recognizes the discomfort that arises from societal conventions and accepts the cultural reticence of families to communicate feelings of concern. During hospital encounters, the nurse draws attention to the difficulties that are associated with language and suggests potential solutions, such as the provision of translation services or the employment of multilingual staff, to improve communication. He stated that:

"During the process of appointment, booking, and questions, a receptionist at the hospital frequently observes language-related issues that thalassemia families confront due to the language barrier. To improve communication, I propose either the provision of translation services or the employment of staff members who are fluent in multiple languages at the front desk".

The admin focal person said that:

"*During hospital visits, I saw situations in which families, who were not familiar with medical terminology and cultural shades, expressed frustration and fear. So, I recommended that counseling services that are sensitive to cultural norms be incorporated into healthcare to assist families in coping with the emotional issues that*

are connected with thalassemia. This would help to create a supportive and kind environment for medical care".

After observing instances of frustration and fear among families who are not familiar with medical terminology and cultural nuances, the administrative focal person advocates for the incorporation of counseling services that are sensitive to cultural norms to assist families in coping with the emotional aspects of thalassemia. In conclusion, these realizations highlight the significance of overcoming cultural barriers and improving communication to establish a hospital environment that is helpful and empathic for families who are afflicted with thalassemia.

5.2.6 Stigma & Discrimination

My respondents share their experiences working with families of people who have been diagnosed with thalassemia. The admin stated that;

"*I brought your attention to this issue that certain families experience feelings of discrimination during their trips to the hospital. These families have reported instances of extended wait times, a lack of privacy, and insensitive comments provided by other patients".*

The administrator explained that:

"I am an administrator at Pakistan Red Crescent Blood Bank, and I describe occasions in which I have witnessed families of thalassemia patients being subjected to discrimination at the entrance of the hospital. Some guests stare or make offensive comments, which contributes to an uncomfortable environment. I feel that teaching both employees and visitors about thalassemia can make a substantial contribution to decreasing the stigma and discrimination that are associated with the disease".

Nurses also had similar observations and one respondent nurse stated:

"To address these issues and make certain that all patients receive care that is both equal and courteous, I take an active part in patient support groups that are held within the hospital. I place a strong emphasis on the necessity of providing ongoing

education and maintaining open communication to effectively overcome stigma and discrimination".

When these topics are addressed through education, awareness campaigns, and sensitivity training for hospital staff, it is possible to create an environment that is more sympathetic and understanding for families who are living with thalassemia.

5.2.7 Religious Beliefs as Coping Support

Patients with Thalassemia are more likely to rely on non-medical treatments, such as prayers and magic, than they are on medical treatments, such as blood transfusions. The nurse said that;

"It is possible for families to believe that thalassemia is the product of divine intent or fate. To help them deal with the difficulties, some people may find comfort in the rituals and practices of their religious faith. There is a possibility that stigma will be connected to thalassemia because some people may view it as a divine test or a sort of punishment".

Others also explained that;

"It is possible that families will have a sense of relief when they pray, attend religious gatherings, and seek assistance from other people in the neighborhood. How families deal with the challenges they confront daily may be altered if they have faith in God and pray".

There is a possibility that the belief that thalassemia is the result of divine purpose or fate may affect how families perceive the disease and the methods they employ to deal with it. Some individuals may find solace in the rituals and practices of their religious beliefs, viewing thalassemia as a divine punishment or examination, which may result in feelings of embarrassment. On the other hand, other people might discover comfort and relief via the practice of prayer, participation in spiritual gatherings, and aid from the community. Religious beliefs and medical decisions are connected because decisions about interventions and treatments, including moral ones such as the utilization of blood transfusions, can be impacted by religious beliefs. It can be challenging for many families

dealing with thalassemia to find a middle ground between adhering to religious convictions and seeking the advice of medical professionals.

5.2.8 Need for Social Support Systems

Considering the complex social, emotional, and psychological experiences of patients and their families, the healthcare staff in administrative roles also assert the importance of social support systems. This statement was reiterated from the leadership level to the healthcare staff and nurses, who all advocated for the need to develop such systems that can help the patients, their families, and caregivers during treatment. A respondent in a management position shared that:

"*I am an administrator at a thalassemia support center in Islamabad, and I think it is important to underline the significance of support services. I am responsible for coordinating therapy sessions and support groups for families, thereby providing a secure environment in which they may discuss their experiences and methods of coping. Over time, I have noticed that families who participate actively in these services demonstrate increased resilience and the ability to cope with difficult situations".*

This view was common at the middle management level, where an administrator shared his thoughts in the following words:

"I work as an administrator in a hospital in Islamabad, and my primary responsibility is to establish a supportive community network. To bring together families affected by thalassemia, I organize community gatherings and fundraising activities. According to me, cultivating a sense of community enables families to connect with others who are experiencing issues that are comparable to their own, so establishing a support network that extends beyond the confines of the therapeutic setting".

A nurse advocated for the use of a holistic approach to treatment including the psychological and social aspects. She stated that:

"*A holistic approach to care is something that I, as a nurse working in a pediatric thalassemia unit, take into consideration. The provision of not just medical care but also emotional and psychological assistance to families is something that he makes certain of. I am working in conjunction with social workers and psychologists to address the various*

requirements that families deal with when dealing with thalassemia. Based on his personal experience, it appears that a holistic approach to care facilitates the development of more effective coping strategies".

For these families to be able to deal with the social and emotional issues that they are experiencing, it is essential to have an understanding that coping mechanisms are complicated and that they require specialized assistance.

5.2.9 Analysis

The administration of thalassemia requires ensuring that quality healthcare services are easily accessible, conducting public awareness campaigns to dispel misunderstandings around the condition, and establishing regulations that make it easier for families to receive financial support for managing the condition. It is necessary to delve into the complex dynamics of familial ties, take into account the perceptions of society, and investigate the psychological impact of managing a chronic genetic illness. Families who are coping with thalassemia may experience increased levels of stress, emotional strain, and financial constraints as a result of the numerous medical treatments and specialized care that are required. In addition to the person who is directly impacted, the emotional impact extends to include the individual's parents, siblings, and other members of the extended family. The stigmatization of thalassemia and the widespread misconceptions about the disease that are pervasive in society add a degree of difficulty, which can result in social isolation and intense mental pain. To establish targeted support mechanisms and interventions that would improve the overall well-being of thalassemia families in Islamabad, it is vital to have a comprehensive understanding of the complex socio-emotional terrain that these families face.

CHAPTER NO. 6

CONCLUSION AND RECOMMENDATIONS

The objective of the study was to investigate the challenges that are encountered by families of thalassemia patients. Islamabad is the country that gave rise to a distinct treatment and belief system. The comprehensive requirements of the people living in Islamabad, in addition to those of neighboring communities in Punjab and Pakistan generally.

Based on the findings of the study, it was discovered that families face a wide variety of obstacles, ranging from financial obligations to psychological and social forces that cause stress. When it comes to their general well-being, families must navigate a complex web of emotions, coping methods, and cultural perceptions, all of which have a substantial impact on their condition. Because of the limited accessibility of healthcare, their financial obligations are made even more difficult, which results in a cyclical pattern of stress. At a time when Islamabad is struggling with issues related to its healthcare infrastructure, authorities need to take into consideration measures that address the financial part of thalassemia care to alleviate the economic hardships that these families are experiencing.

Family members are subjected to a significant amount of emotional strain, with caregivers experiencing increased levels of worry and anxiety. The stigmatization of these issues makes them even more difficult to manage, which in turn leads to feelings of alienation and marginalization. To address the psychosocial well-being of thalassemia patients and their families, it is necessary to implement not just medical interventions but also community-based awareness initiatives. These programs aim to dispel misconceptions and build empathy.

One of the most important findings highlights the critical role that support systems have in minimizing the socio-emotional obstacles that these families are confronted with daily. It becomes clear that one of the most important strategies is to create and strengthen support networks, not only within the family but also within the larger community around them. An important factor that can considerably contribute to the resilience of thalassemia families is the encouragement of discussion, the promotion of understanding, and the provision of platforms for emotional expression.

The socio-emotional issues that families of thalassemia patients in Islamabad are confronted with, the findings of this research highlight the necessity of a comprehensive and multi-faceted strategy. This approach will contribute to the larger discourse on healthcare and social well-being in the region.

In conclusion, the findings of this study not only contribute to a more in-depth comprehension of the socio-emotional issues that families of thalassemia patients in Islamabad are confronted with, but they also urge for holistic therapies that take into account medical, financial, and psychosocial elements. By tackling these concerns together, we can work toward creating a society that is more compassionate and inclusive, one that gives families afflicted by thalassemia the ability to negotiate the challenges they face with dignity and resilience.

RECOMMENDATIONS

My research on the socio-emotional challenges that families of Thalassemia patients in Islamabad, Pakistan face is particularly important and delicate because of the nature of the subject matter. A few suggestions are provided below, which are derived from the results of my research.

1. Support Programs for the Community:

Workshops should be held regularly within the community to dispel common myths and offer advice on how to effectively manage the social and emotional elements of individuals with Thalassemia. Obtain the participation of psychologists and healthcare professionals to exchange ideas.

2. Assistance program for financial matters:

a) To reduce the financial strain that families suffering from Thalassemia are experiencing, it is important to establish financial aid programs. The provision of financial assistance for medical treatments, prescriptions, and other associated costs may fall under this category.

b) Individuals who have Thalassemia should be provided with employment possibilities and supportive workplaces, and this should be accomplished through collaboration with local businesses and organizations. This has the potential to contribute to the financial stability of families that have been affected.

3. Health Care Facilities

It is important to encourage regular contact and collaboration between the families of Thalassemia patients and the medical professionals who treat them. The organization of frequent forums or gatherings in which families can openly share their concerns, ask questions, and receive updates on the most recent treatment options and research advancements represents one possible approach to accomplishing this goal. Establishing a solid network with service providers in the healthcare industry can help to cultivate feelings of trust and confidence.

4. Organizational Support System:

Establish and encourage the development of a support network for families of patients suffering from Thalassemia in Islamabad. Support groups, online forums, or community gatherings could be utilized in this context to enable the sharing of experiences and ideas for coping with emotional distress.

5. Educational Programmers for Families:

Encourage the development of programs that are expressly geared toward educating family members about Thalassemia, its management, and the necessary emotional support. When it comes to overcoming difficulties, can help the family unit become stronger. These programs must address a variety of facets of the condition, such as the hereditary origin of the ailment, the therapeutic options available, and the socio-emotional issues that families confront. The reduction of stigma and misconceptions can be aided by increased consumer awareness.

6. Services for mental health:

Improve mental health assistance to the system for caring for people with thalassemia. A lot of the time, families deal with worry, anxiety, and depression. Giving patients and their families access to counseling services and mental health support can make a big difference in their general health.

7. Conducting Research

In Islamabad, it is important to encourage continued research on the socio-emotional elements of thalassemia research. The gathering and analysis of data regularly can provide valuable insights for future actions and help to ensure that support services continue to be successful and relevant.

8. Campaigns for communities

The social stigma and misunderstandings that are connected with thalassemia should be reduced by the implementation of community outreach efforts. Increasing public awareness has the potential to create an environment that is more accepting and understanding of others. The promotion of positive narratives surrounding thalassemia, to foster empathy and support, should involve community leaders, influential individuals, and the media.

It is important to keep in mind that the success of these proposals will be contingent on the circumstances and the particular requirements of the Thalassemia community operating in Islamabad. It is necessary to work together with local stakeholders, healthcare professionals, and community leaders to properly execute these recommendations.

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APPENDICES

Appendix 1: Life History Method for Families of Thalassemia Patients

Demographic Information:

Name of interviewee		Name of interviewer	
Head of Family name		Relation with Head of Family.	
Age of interviewee		Age of Family Head	
Gender of interviewee		Gender of Family Head	
Occupation of Interviewee		Occupation of Family Head	
Ethnicity		Ethnicity	
Education		Education	
Area/ Location		Area/ Location	

Background Information:

1. Can you please introduce yourself and provide some background on your connection to thalassemia?
2. Describe your medical history?
3. Describe your family history?
4. Describe your employment background?
5. How and when was the thalassemia diagnosis made? Also describe the type of thalassemia?
6. What are the sufferings of the patients?
7. Is there any behavior or emotional change after diagnostic thalassemia?
8. What is the reaction of family members when the symptoms of thalassemia appeared?
9. In your area what is the cultural name of the disease?
10. What are the religious aspects of the diseases, like any medical condition, magic, belief or myth? explain your cultural belief of the disease?

11. What are the social sufferings of such patients before treatment?
12. What are the emotional aspects of patients and their family related to future?
13. Who give financial support to such patient and how?
14. What challenges has the family faced in managing thalassemia?
15. How has thalassemia affected the education of the patient?
16. How has thalassemia impacted your family and daily life?
17. Describe the patient's experiences with medical treatments, including blood transfusions, chelation therapy, and bone marrow transplantation?

Socio-Emotional Challenges:

1. Can you describe the emotional reactions and challenges you or your family experienced when the thalassemia diagnosis was first confirmed?
2. What emotions or difficulties have you encountered related to the ongoing medical treatments and care of the thalassemia patient?
3. Have you or your family members experienced feelings of stress, anxiety, or depression because of living with thalassemia? If so, how have you coped with these emotions?
4. What feelings or challenges have you faced because of the patient's ongoing medical care and therapies for thalassemia?
5. Have you faced any stigma or discrimination in your community or social circles due to thalassemia, and how did you handle it?

Psychological Impact:

1. How does the thalassemia diagnosis influence the emotional and psychological well-being of the family members?
2. Can you share any specific moments or situations that have been emotionally challenging for your family due to thalassemia?
3. Are there any specific cultural or religious beliefs that influence how thalassemia is perceived or managed within your family?
4. Are there any specific support groups, organizations, or resources that you have found valuable in dealing with the psychological impact of thalassemia? Please share your experiences?
5. Have you or your family members experienced feelings of guilt or blame related to the condition? If so, how do you cope with these feelings?

Support System:

1. What types of support systems have been helpful for you and your family in coping with the challenges of thalassemia?
2. Can you describe the current support system available for families of thalassemia patients in your community or region?
3. Have you encountered any challenges or limitations with the current support system for thalassemia patients' families?
4. Based on your experiences, what types of support or resources do you believe would be most beneficial for families dealing with thalassemia?

Coping Mechanism:

1. Can you describe any specific managing techniques or activities that have been particularly helpful for you?
2. Have you sought support from friends, family, or support groups? How has this support been beneficial?

Closing:

1. Discuss the patient's goals, aspirations, and concerns for the future.

- Thank the participant for their time and willingness to share their experiences.

Appendix 2: Interview Guide: Doctors' Perspective on Thalassemia Patients

Demographic Information:

1. Interview's Name:
2. Age:
3. Gender:
4. Area/Location:

Section 1: Background Information

1. Briefly introduce yourself and your experience working with thalassemia patients?
2. Do you think health care services are sufficient for providing facilities to thalassemia patients?
3. Do you think there is an increase in the number of thalassemia patients in Pakistan?

Section 2: Diagnosis and Treatment

1. What are the different types of thalassemia, and how do they affect patients?
2. How the severity of Thalassemia determined and what are the typical symptoms of Thalassemia?
3. Are there any genetic tests available to determinant thalassemia carrier status? In addition, what are the costs of the tests?
4. How do you determine the appropriate treatment plan for thalassemia patients?
5. What are the main treatment options available for thalassemia patients? Please explain their benefits and drawbacks.
6. How long will each transfusion session typically take?
7. What are the potential risks and side effects associated with blood transfusions?
8. What are the blood screening and safety measures in place to prevent infections or other complications?

Section 3: Disease Management

1. How do you monitor thalassemia patients' health and response to treatment over time?
2. What are the common complications or health issues that thalassemia patients may face, and how are they managed?

3. How do you address the emotional and psychological well-being of thalassemia patients and their families?
4. Are there any dietary or lifestyle recommendations for thalassemia patients to manage their condition effectively?

Section 4: Supportive Care and Patient Education

1. How do you engage with thalassemia support groups or organizations to provide holistic care for patients?
2. What educational resources or materials do you provide to thalassemia patients to enhance their understanding of the condition and treatment options?
3. What are the key issues concerning thalassemia that may be discussed during a support group session?
4. How do you involve thalassemia patients and their families in decision-making processes regarding their treatment and care?

Section 5: Research and Advances

1. Are there any recent advancements or research findings that have affected the management of thalassemia?
2. How do you stay updated with the latest developments and best practices in thalassemia management?

Section 6: Closing

1. Is there anything else you would like to add regarding thalassemia management or patient care?

- Thank you for sharing your expertise.

Appendix 3: Interview Guide for Administration

Demographic Information:

5. Interview's Name:
6. Age:
7. Gender:
8. Area/Location:

Socio-Emotional Challenges:

1. Briefly describe your role and responsibilities in the administration of hospital or any organization, particularly in relation to patient-family interactions and support during a loved one's illness?
2. How many Thalassemia patients are approximately served by the hospital?
3. What are the common treatment modalities and procedures for thalassemia patients at your hospital?
4. In your experience, what are the common emotional phases that families of patients typically go through during their loved one's illness?
5. How do family members emotionally react when they first learn about their loved one's illness? Are there specific coping mechanisms that they commonly employ during situation?
6. How does the hospital currently support the emotional needs of patient's families? Are there specific programs or resources in place to address their emotional well-being?

Discrimination, Stigma & Mental Health Issues:

1. How does discrimination and stigma influence the mental health and well-being of Thalassemia patients?
2. In your experience, what level of stigma do the Thalassemia patients face in their daily lives, including healthcare settings and the community?
3. How can healthcare providers and the hospital improve services to ensure a more inclusive and supportive environment for Thalassemia patients?

Social Problems:

1. Have you observed or received feedback regarding the social challenges faced by the families of thalassemia patients during their treatment journey?

2. In your view, what could be the financial burdens faced by thalassemia patients' families in terms of treatment costs, medications, and other related expenses?

3. Are there cultural or language barriers that families often encounter when seeking treatment for thalassemia patients, and how do we address them?

4. What suggestions or recommendations do you have for further improving the social support and services for thalassemia patients and their families within your hospital?

- Thank the participant for their time and willingness to share their experiences.