A Comparative Analysis of the Daily Challenges Encountered by Thalassemia Patients Undergoing Treatment at Rohtak PGI and Chandigarh PGIMER: An Examination from a Sociological Perspective

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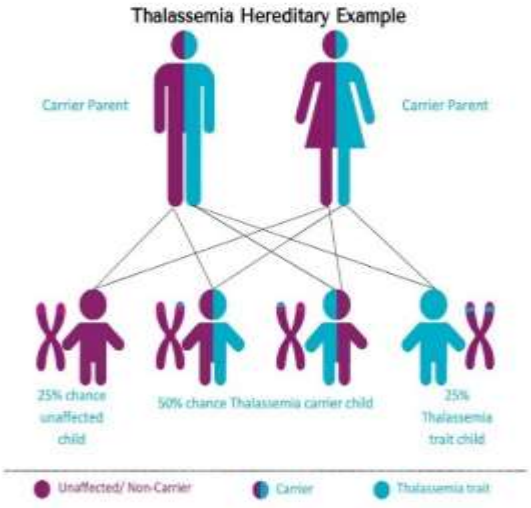
Abstract: This research paper investigates Talcott Parsons' "sick role" framework concerning thalassemia, a genetic disorder affecting many individuals. It argues that the increasing prevalence of this chronic condition is changing societal views on time and health, impacting the expectations of patients and healthcare systems. Thalassemia is common in Africa, the Mediterranean, the Middle East, the Indian subcontinent, Southeast Asia, Melanesia, and the Pacific Islands, with about 3% of the global population carrying the beta-thalassemia trait, and India having the highest number of carriers. Approximately one in every 30 births has a thalassemia mutation, with around 20% of the global population affected. India alone has around 40 million individuals with thalassemia, including 100,000 with thalassemia major, requiring regular blood transfusions. Antenatal Chorionic Villus Sampling (CVS) offers a prevention strategy during early pregnancy. This study focuses on the challenges faced by thalassemia patients in Haryana, Punjab, Uttar Pradesh, and Chandigarh, examining the disease's aetiology, clinical manifestations, and the social, economic, and psychological impacts of treatment protocols based on research from local medical institutes.

Keywords: Sick Role; Thalassaemia; Genetic Disorder; Chorionic Villus Sampling.

INTRODUCTION

Thalassaemia is a genetic blood disorder characterised by inadequate haemoglobin production, leading to anaemia (Silberstein et al., 2014; Cooley, 1925). The term originates from the Greek word "Thalassa," meaning "the sea," reflecting its historical prevalence in Mediterranean populations. Those with thalassaemia face health challenges due to reduced haemoglobin efficiency, resulting in complications (Betts et al., 2020). First described by Professor Cooley, thalassaemia is inherited and affects approximately 0.44 in 1,000 children globally, with about 10% of cases occurring in the Indian subcontinent due to a lack of awareness. In 2025, the prevalence of thalassemia is estimated to be 4.4 cases per 10,000 live births. This hereditary disorder is characterised by a defect in the synthesis of haemoglobin, which results in a range of haematological complications. Diagnosis is predominantly established during childhood, with clinical manifestations typically emerging within the first two years of life. Epidemiologically, the condition shows no significant gender disparity; however, there is a noted increase in prevalence among the elderly population, suggesting a shift in demographic trends regarding its impact (Dang, 2021). It is caused by mutations in the genes responsible for producing the beta-globin protein (Rund & Rachmilewitz, 2005).



https://mycgxlab.com/2023/07/03/thalassemia-is-not-a-gift-for-your-precious-little-angel/

Thalassaemia results from dysfunctional haemoglobin synthesis and has different forms: **Minor, intermedia, and Major** (Galanello & Origa, 2010). **Thalassaemia minor**, the least severe, is characterised by one mutated beta-globin gene and one normal gene and typically involves normal iron levels with minimal symptoms (Shafique et al., 2023). **Thalassaemia intermedia**,

or non-transfusion-dependent Thalassaemia, presents more pronounced symptoms but requires fewer transfusions than the Major form. **Thalassaemia major**, or homozygous Cooley's anaemia, is the most severe, caused by inheriting two mutated beta-globin genes, leading to severe anaemia and necessitating regular blood transfusions (Sanchez-Villalobos et al., 2022; Musallam et al., 2023).

The complications of major thalassaemia are significant. The reduced lifespan of red blood cells and frequent transfusions lead to iron overload (Taher & Saliba, 2017), affecting vital organs like the liver, kidneys, and heart, potentially resulting in cirrhosis and increased liver cancer risk (Basu et al., 2023; Lin et al., 2023). Iron accumulation also compromises bone density, increasing osteoporosis and fracture risk, particularly after age 20. Notably, over 100,000 Thalassemia patients in India die from complications before reaching their 20s (Rao et al., 2024; Isalkar, 2018). Awareness of Thalassaemia has improved since its discovery in 1925, making early detection crucial (Ali et al., 2021). Genomic technologies now facilitate preconception and prenatal screening, enabling timely interventions (Garcia-Herrero et al., 2020). Healthcare professionals, especially gynaecologists, should perform screening tests like HB Electrophoresis or HBA2 testing during pregnancy to identify Thalassaemia traits (Baxi et al., 2012). This aids in implementing preventive measures and informed decision-making for affected children (Cao & Kan, 2013). The goal is to enhance the quality of life for those affected through early detection and appropriate care (Cappellini et al., 2018).

Sociological theoretical framework: Thalassemia is a hereditary blood disorder that can be analysed through a sociological framework to understand better the social, cultural, and psychological factors influencing its prevalence and management. Talcott Parsons' **functional theory** conceptualises society as an intricate system where various components interact to ensure stability and cohesion. He delineates four critical functions necessary for the survival of a social system: adaptation to environmental demands, goal attainment for directional purposes, integration for social cohesion, and pattern maintenance for the preservation of cultural norms. Institutions and processes that facilitate these functions are deemed essential for the viability and continuity of the social system (Parsons, 1951). The "**sick role**," as proposed by sociologist Talcott Parsons, refers to the social expectations and behaviours associated with illness within society. It outlines how individuals who are ill are expected to behave and how society regards them. This concept emphasises two main aspects: the rights of the sick person, such as being exempt from regular social roles and the expectation that they will seek treatment and work towards recovery (Alderson & Scambler, 1988). Functionalist Theory emphasises the importance of cultural practices such as consanguineous marriages, where blood relatives marry each other, often leading to a higher risk of genetic disorders like thalassemia. Additionally, traditional beliefs regarding inheritance can perpetuate misunderstandings about genetic risks, further entrenching the condition within specific communities (Hyland, 1990). Sociological perspectives, such as the Social Model of Health and Illness, highlight how socioeconomic status, cultural traditions, and access to healthcare affect outcomes for individuals with thalassemia (Stam, 2000). Thalassemia is a genetic blood disorder that impairs haemoglobin production, resulting in anaemia and related health issues. In terms of the sick role, individuals with thalassemia may face stigma from chronic illness and social responsibilities for managing their condition. Analysing thalassemia through this lens helps us understand how patients deal with their illness in society, the support they receive, and the challenges of meeting societal expectations (Coloigner et al., 2016).

Karl Marx's **conflict theory** posits that the stark disparities in healthcare access, educational resources, and overall societal privileges contribute to varying outcomes for individuals affected by thalassemia. It reveals that health and illness are fundamentally intertwined with the structures of capitalism, suggesting that class struggle directly influences health disparities (Marx, 1996). This framework emphasises that the inherent inequalities of a capitalist system result in detrimental health outcomes for the working class. Factors such as exposure to hazardous working conditions, constrained access to healthcare resources, and chronic stress stemming from precarious employment significantly contribute to the poorer health status of this demographic. The theory underscores the systemic nature of these health inequities, illustrating how socioeconomic stratification perpetuates a cycle of disadvantage

and poor health (Collyer, 2015). Additionally, cultural and religious beliefs can impact families' willingness to engage in treatment and health interventions. Social support networks play a crucial role in managing the psychosocial aspects of the disorder. However, labelling theory and stigma can lead to discrimination and social isolation, ultimately affecting patients' psychological well-being. Finally, the quality of life for patients involves multiple dimensions, including physical and emotional health, social engagement, and community integration (Addison et al., 2023).

Symbolic interactionism is a sociological framework based on three core principles. It asserts that individuals interact with various entities—whether other individuals, groups, or institutions—based on the meanings they attribute to these entities. Second, these meanings are not formed in isolation; they are cultivated and refined through ongoing social interactions. Lastly, the comprehension of these meanings is dynamic, evolving through continuous negotiation and reinterpretation within specific contexts (Blumer, 1986).

This theoretical framework is particularly relevant for analysing the personal narratives and subjective experiences of individuals diagnosed with thalassemia, a genetic haematological disorder characterised by impaired haemoglobin synthesis. By employing a symbolic interactionist perspective, researchers can delve deeply into how individuals with thalassemia perceive and make sense of the health challenges they encounter (Pouraboli et al., 2017). Furthermore, this approach facilitates an examination of the nuanced ways in which the condition affects self-identity and social relationships. It investigates the ramifications of thalassemia not only for the individuals themselves but also for their interactions with family members, peers, and healthcare professionals. Through this analytical lens, the framework aims to elucidate the subtleties involved in relationship dynamics, the formation of expectations, and the establishment of support systems as individuals navigate the complexities of living with a chronic condition (Husin et al., 2021).

From a sociological perspective, thalassemia highlights the interactions between genetic disorders and their impacts on individuals, families, and communities. It illustrates how cultural norms and misconceptions influence epidemiology and management and the challenges patients and caregivers face (Yousuf et al., 2022). High prevalence in areas with consanguineous marriages indicates a need for targeted genetic counselling (Saeed & Piracha, 2016), while cultural beliefs can impede premarital genetic screening, exacerbating public health issues (Suresh et al., 2023). Education is vital in addressing ignorance about thalassemia, which leads to missed prevention opportunities (Colah et al., 2017). Stigma contributes to discrimination, affecting mental health in places like Cyprus and the U.S. (Hadjidemetriou, 2020; Wong et al., 2011).

In conclusion, sociological theories are crucial for analysing social factors related to thalassemia, helping to develop tailored prevention and support strategies for affected individuals and families. Overall, this thorough exploration enhances our comprehension of the lived experiences of those dealing with thalassemia, underscoring the intricate relationships between health, identity, and social connectivity.

Psychosocial Impact on Patients and Families: Thalassemia represents a multifaceted haematological disorder characterised by its clinical manifestations and a spectrum of somatic anomalies, growth impairments, and a host of comorbidities, as noted by Colah et al. (2017). The physical complications associated with thalassemia can precipitate considerable psychological distress, adversely affecting self-esteem and overall mental health. A recent investigation by Wangi et al. (2025) underscores that the ongoing management of thalassemia—necessitating routine blood transfusions and continuous health surveillance—can contribute to heightened social isolation. Many patients report feelings of divergence from their peers, which can amplify sensations of loneliness and emotional detachment, ultimately compromising psychological well-being.

Moreover, managing thalassemia incurs significant economic burdens, encompassing treatment expenses, medication costs, and frequent healthcare interactions. This financial strain often exacerbates existing familial challenges, further jeopardising the stability of those impacted (Uchil et al., 2023). The chronicity of this disorder imposes substantial stress on family dynamics, as caregivers shoulder considerable responsibilities that may compromise their health, leading to increased conflict and strain within familial relationships (Biswas et al., 2020).

LITERATURE REVIEW

Naderi et al. (2012) reported that around 80% of patients with beta-thalassemia significantly experience psychosocial issues, including anxiety, depression, and a sense of hopelessness, alongside diminished self-esteem and social withdrawal. Yeşilipek (2014) emphasised the extensive impact of thalassemia on patients' lives, highlighting how its severe physical health challenges, coupled with psychological effects, limit autonomy and social interactions. This underlines the need for a comprehensive approach to care, integrating medical and psychosocial support. Madden et al. (2018) explored the psychosocial difficulties stemming from beta-thalassemia major, noting that physical symptoms can harm self-image, leading to social withdrawal and isolation. This creates a detrimental cycle affecting quality of life.

Malik's 2019 study of 63 individuals in Haryana and Uttar Pradesh revealed a lack of awareness about thalassemia and the risks of Hepatitis B and C due to insufficient screening. He stressed the healthcare system's strain, with one bed available for every three patients and called for enhanced governmental support to improve access to Bone Marrow Transplantation (BMT). Rashid et al. (2020) investigated socio-religious factors contributing to the psychosocial burden of beta-thalassemia, revealing that consanguineous marriages and cultural beliefs exacerbate depression and social isolation among families. They highlighted the influence of patriarchal structures on adverse outcomes in cousin marriages. Rao et al.'s study (2024), "Global Distribution of β-Thalassemia Mutations: An Update," notes that β-thalassemia varies in severity, with over 350 mutations identified, though just 20 accounts for more than 80% of cases. The disease shows geographical clustering due to population migration. In Italy’s Po Delta, prevalence is about 50%, while India has over 42 million carriers and 10,000 to 12,000 new cases annually, making up 10% of global thalassemia major births. Saudi Arabia's prevalence is 1 to 1.6 per thousand, influenced by intermarriage, and Vietnam has about 13.8% carriers, with ethnic variations. In Africa, it is rare in Kenya but more common in western Nigeria and Brazil; it affects 1-2% of the southeastern population. Awareness and genetic counselling could help reduce thalassemia’s prevalence.

In their 2024 study, "Global, Regional, and National Burden of Thalassemia, 1990–2021," Tuo et al. assess the health impact of thalassemia using global disease burden methodologies. They analyse key metrics such as incidence at birth, prevalence, mortality, and Disability-Adjusted Life Years (DALYs) from 1990 to 2021. The study reveals minimal gender disparities in disease burden, with the highest prevalence in children under five. While prevalence rates decrease with age. Significant regional differences are noted, particularly in South Asia, emphasising the need for targeted health policies and public health interventions.

The significance of genetic counselling and the implementation of prenatal testing protocols for Thalassemia is paramount. Many prospective parents opt for genetic counselling prior to conceiving a second child. They may undergo Chorionic Villus Sampling (CVS) during gestation to ascertain whether the foetus has inherited the Thalassemia alleles (Bhattacharya et al., 2019). Thalassemia's pathophysiological mechanisms highlight the bone marrow's critical function in haematopoiesis, synthesising erythrocytes, leukocytes, and platelets. Allogeneic bone marrow transplantation remains the cornerstone of curative treatment for patients diagnosed with Thalassemia major. However, this intervention is fraught with complexities and significant financial implications (Lucarelli et al., 2012). Optimal transplant outcomes are generally observed in cases where the procedure is performed before the patient attains the age of 14 (Caocci et al., 2017).

The study highlighted the critical need for iron chelation therapy, particularly in light of the elevated ferritin concentrations frequently observed in patients. Research by Cianciulli (2009) and Wang et al. (2010) indicates that a majority of affected individuals present with ferritin levels between 1000 and 3000 ng/ml, with a noteworthy 42% exceeding levels of 3000 to 5000 ng/ml. Participants provided crucial perspectives on both dietary and pharmacological approaches to manage these heightened ferritin levels. Key recommendations included avoiding iron-rich foods, adhering to specific pharmacotherapy protocols, and increasing the intake of citrus fruits, which may significantly improve long-term patient outcomes.

Regular blood transfusions, iron chelation therapy, strict medication adherence, and a well-rounded diet are important to ensure Thalassaemia patients' good quality of life. There is growing optimism among patients about the potential of gene therapy and CRISPR gene editing, with many expressing reservations about continuing current medications due to undisclosed risks and benefits (Frangoul et al., 2020).

Research gaps: Despite the substantial literature on beta-thalassemia, notable deficiencies persist in comprehensively understanding the psychosocial support requirements of affected individuals. There is an urgent need for rigorous identification and evaluation of specific interventions designed to enhance these support systems for patients with beta-thalassemia. Cultural attitudes and practices concerning thalassemia exhibit significant variability across different geographical regions; however, there is a paucity of research addressing the influence of these cultural variations on patient care and clinical outcomes. Investigating the psychosocial ramifications of beta-thalassemia within diverse cultural frameworks is crucial for optimising supportive interventions.

Additionally, the ongoing prevalence of consanguineous unions in populations affected by thalassemia necessitates further examination, particularly regarding the long-term health implications for patients resulting from such marital practices. It is imperative to devise targeted strategies to enhance awareness and educational initiatives about thalassemia in endemic regions, as these efforts could markedly improve prevention and management practices.

The impact of healthcare policies on the accessibility of quality treatment for thalassemia patients across various countries remains an underexplored area, which could significantly influence patient outcomes. Moreover, there is a pressing need for research to elucidate the long-term consequences of living with thalassemia on quality of life and mental health, as this understanding is critical for fostering a holistic approach to patient care that integrates medical and psychosocial considerations.

In parallel with these identified research gaps, the current study will delve into the multifaceted challenges faced by patients with thalassemia major, encompassing social, mental, economic, and health-related dimensions of their daily lives. These challenges include logistical difficulties in securing blood for transfusions, psychosocial and financial stresses on transfusion days, the availability of screened blood, the management of elevated ferritin levels through painful chelation therapy, and the social stigma associated with thalassemia. The study will also proffer potential solutions to mitigate these challenges.

THE OBJECTIVE OF THE RESEARCH

1. This research employs a qualitative methodology to deepen the understanding of thalassemia, a multifaceted hemoglobinopathy characterised by the dysregulation of globin chain synthesis.

2. The study's primary objective is to elucidate the myriad social, economic, and psychosocial challenges encountered by individuals with thalassemia major in their daily experiences. By systematically documenting these issues, the research aims to enhance community awareness and facilitate the development of culturally and contextually relevant interventions to mitigate the prevalence of this haematological disorder.

METHODOLOGY

This study implemented a comprehensive methodology for systematically collecting data from a cohort of 120 patients diagnosed with thalassemia major, divided evenly between 60 males and 60 females. The participants were selected via purposive sampling from treatment centres at the PGIMER, Chandigarh and PGIMS in Rohtak. We employed a descriptive research design complemented by thematic analysis to explore the multifaceted challenges encountered by this demographic, with a particular emphasis on socio-economic and psychological complications that substantially affect their quality of life. The study aims to foster a nuanced understanding of thalassemia major's complexities by employing a meaning-making framework that synthesises qualitative data from various methodologies. This approach facilitates a thorough exploration of the intricate meanings and interpretations of the social phenomena affecting these patients, enriching the qualitative findings and enabling a holistic comprehension of the identified themes.

Contemporary newspaper articles were reviewed to underscore the socio-economic and psychological barriers faced by individuals with thalassemia major. Additionally, qualitative insights were gathered through in-depth interviews with affected individuals, providing precious firsthand accounts of their experiences. Furthermore, a systematic review of both published and unpublished literature was conducted to delve deeper into the complexities associated with this disorder. This integrated approach has been meticulously crafted to address key research questions and to formulate actionable recommendations grounded in the study's findings.

RESULT AND DISCUSSION

The current research involved a cohort of 120 participants diagnosed with Thalassemia Major, comprising 60 males and 60 females. The subjects were drawn from two primary treatment facilities: PGIMS in Rohtak and the Thalassemia Welfare Society at the Advanced Paediatric Centre in Chandigarh. The sample consisted of 60 individuals from the Thalassemia Welfare Society (30 females and 30 males) and another 60 individuals from PGIMS, Rohtak (30 females and 30 males). This stratified selection allows for a balanced gender representation across both treatment settings in the study.

Table 1: Gender of the Respondents

Gender	Frequency	Percent
Male	60	50.0
Female	60	50.0
Total	120	100.0

The study identified a diverse demographic of participants from several regions, including Haryana, Chandigarh, Punjab, and Uttar Pradesh. Most of the patient cohort was relatively young, predominantly within the age spectrum of 3 months to 10 years. A more granular analysis of the age distribution revealed that approximately 25% of participants were adolescents aged 11 to 15, while over 10% were in the 16 to 20 age brackets. Additionally, 13% of the respondents were categorised as young adults aged 21 to 25. It is noteworthy that two patients were above 35 years of age; both required consistent blood transfusions, approximately every 20 days, to effectively manage their underlying conditions.

Table 2: Age of the Respondents

Age	Frequency	Percent
3 Months to 10 Years	44	36.66
11 Years to 15 Years	28	23.33
16 Years to 20 Years	13	10.83
21 Years to 25 Years	16	13.33
26 Years to 30 Years	11	9.16
31 Years to 35 Years	6	5.00
Above the age of 35	2	1.66
Total	120	100.0

In sociology, the concept of "geographic location" is examined within the context of how social phenomena are distributed and influenced by space and place. The geographical distribution of patients illustrates a varied demographic landscape. A notable 14.20% of the patient cohort originated from Rohtak, while Bhiwani contributed 9.2%. The combined representation from Panipat and Sonipat was significant, accounting for 17.5% of the total patient population, underscoring their relevance in this analysis. Among the cases analysed, Thalassemia major was diagnosed in five patients from Jind and six from Hisar, constituting 9.16% of all cases, thereby highlighting the prevalence of haematological disorders in this region.

Table 3: Which State/district do you belong to?

State/District	Frequency	Percent
Rohtak	17	14.2
Bhiwani	11	9.2
Panipat	11	9.2
Sonipat	10	8.3
Jind	5	4.2
Hissar	6	5.0
Chandigarh	11	9.2
Mohali	14	11.7
Patiala	12	10.0
Sangrur	10	8.3
Fatehgarh Sahib	9	7.5
Uttar Pradesh	4	3.3
Total	120	100.0

Additionally, the data indicated that 9.2% of patients were from Chandigarh, with substantial inputs from Mohali (11.66%), Patiala (10%), Sangrur (8.3%), and Fatehgarh Sahib (7.5%). In stark contrast, only 3.3% of patients were reported from Uttar Pradesh. Acknowledging that thalassemia cases were identified across other districts within these states is crucial. However, a significant knowledge gap in specific areas requires further investigation and focused research efforts.

Table 4: Time of diagnosis Thalassemia Major

Time	Frequency	Percent
After the birth of 3 to 6 month of child	69	57.5
6 months of age or older	51	42.5
Total	120	100.0

Almost 60% of respondents reported that they learned about their child's thalassemia diagnosis when the child was between 3 and 6 months old. Meanwhile, nearly 40% of parents were informed of their child's genetic disorder only after the child turned 6 months. This delay in diagnosis underscores the challenges associated with the early detection of certain genetic conditions.

Table 5: After receiving a blood transfusion, how many days until the next one

Time	Frequency	Percent
after 15 days	53	44.2
after 20 days	54	44.0
after 25 days	8	6.7
after 30 days	5	4.2
Total	120	100.0

The study's results revealed that nearly 88% of the respondents needed blood transfusions approximately every 20 days. This statistic emphasises the importance of consistent and thorough medical care to manage their health conditions effectively. Regular transfusions are crucial for maintaining their well-being, suggesting that a structured care plan and ongoing medical support are essential for these individuals.

Table 6: Do you know the Nucleic Acid Amplification Test? (NAAT)

Response	Frequency	Percent
Yes	82	68.33
No	38	31.67
Total	120	100.0

Moreover, the study shed light on issues surrounding the awareness and accessibility of the nucleic acid amplification test (NAAT) technique, which is vital for diagnosing and managing Thalassemia. It was found that nearly one-third of Thalassemia patients remained uninformed about the NAAT, primarily due to the limited availability of testing services in certain regions.

Table 7: The blood from the hospital transfusion is entirely negative for HIV, HCV, and HBsAg.

Response	Frequency	Percent
Yes	84	70.0
Not Completely	36	30.0
Total	120	100.0

This significant gap in testing not only raises alarms regarding the effective management of Thalassaemia but also poses serious health threats, such as the potential transmission of serious infections like HIV and HCV among patients who may not receive timely and adequate screening. Research findings indicate that nearly two-thirds of respondents were aware of HIV, HCV, and HBsAg infections resulting from infected or untested blood transfusions.

Table 8: How long does the entire blood transfusion process take, from when you leave your house until you return home?

Time	Frequency	Percent
9 to 10 hours	47	39.2
10 to 12 hours	32	26.7
12 to 14 hours	33	27.5
14 to 16 hours	8	6.7
Total	120	100.0

Recent research from Chandigarh PGI and Rohtak PGI indicates that patients with thalassemia major are subjected to significant delays in receiving essential blood transfusions, with wait times averaging 10 to 14 hours. These prolonged waiting periods not only contribute to physical discomfort but also heighten emotional distress as patients navigate the uncertainty and anxiety associated with their condition. Such extended intervals can exacerbate their psychological burden during an already taxing treatment process. Identifying and addressing these lag times is imperative to enhance the patient experience and optimise the overall quality of care within these healthcare institutions.

Table 9: Availability of beds for every patient receiving blood transfusions

Response	Frequency	Percent
Yes	48	40.0
No	72	60.0
Total	120	100.0

At the Rohtak Postgraduate Institute (PGI), we observe an average daily demand for blood transfusions ranging from 15 to 20 patients. However, the institution is constrained by a critical infrastructural deficiency, with only seven dedicated beds for transfusion procedures. This limitation leads to the significant patient backlog, as approximately 40% of individuals requiring transfusions cannot secure a bed promptly, resulting in prolonged waiting periods at the facility. In contrast, the Chandigarh PGI is equipped with superior resources and infrastructure, effectively mitigating patient congestion and enhancing the overall efficiency and accessibility of transfusion services.

Table 10: An active member of a committee or organisation that supports Thalassemia patients

Response	Frequency	Percent
Yes, With NTWS	17	14.2
Yes, With PTWS	21	17.5
Both	22	18.3
No	60	50.0
Total	120	100.0

Patients with thalassemia frequently encounter challenges in securing adequate blood transfusions, which can lead some to the distressing necessity of purchasing blood due to persistent shortages. Research indicates that approximately 50% of surveyed individuals express significant appreciation for the support provided by various thalassemia advocacy organisations, such as the Haryana Thalassemia Welfare Society, Panipat Thalassemia Welfare Society, and the National Thalassemia Welfare Society. These organisations play a crucial role by organising targeted blood donation drives, facilitating access to medications at subsidised costs, and conducting blood screening camps, thereby substantially aiding individuals affected by this hemoglobinopathy.

Table 11: Facilities provided by the government for free

Facilities	Frequency	Percent
Free bus and train passes	9	7.5
Access to free blood and medicine	13	10.8
No	10	8.3
Ten lakh Rs. under the TBSY for BMT under CSR	26	21.7
All of the above	62	51.7
Total	120	100.0

Many stakeholders acknowledged the presence of various government-sponsored initiatives designed to support individuals affected by thalassemia. Key among these programs are complimentary transportation passes for buses and trains, which enhance access to essential healthcare services and support systems for patients and their families. Furthermore, free blood donations and medications ensure that patients can obtain critical treatments without financial constraints.

In addition, the Thalassemia Bal Sewa Yojana offers substantial financial aid, providing up to ten lakh rupees for patients undergoing Bone Marrow Transplantation (BMT). This financial assistance is crucial in mitigating the prohibitive costs often associated with thalassemia-related medical care. These various initiatives are integrated into the Corporate Social Responsibility (CSR) framework, underscoring the government’s commitment to improving thalassemia patients' overall welfare and

support networks. The Haryana government has included 18 chronic diseases, including thalassemia major. The people suffering from it have been provided free bus passes, blood transfusions to Thalassaemia patients, free medicines, pension facilities, etc., which is an important step,

Table 12: Socio-Economic challenges faced by patients with thalassemia Major

Socio-Economic challenges	Frequency	Percent
Financial burden	22	18.3
Job in security	28	23.3
Travel and Accommodation costs at the hospital	15	12.5
Social isolation	7	5.8
Discrimination and stigma	25	20.8
All of the above	23	19.2
Total	120	100.0

Thalassemia poses significant clinical challenges and profoundly affects the educational trajectories of affected individuals, often impeding their academic advancement. The study reveals that most participants reported encountering socioeconomic challenges and strongly desired specific governmental interventions to support these populations. Chandigarh has identified that patients with thalassemia major face formidable barriers related to the stringent protocols for blood transfusions. Specifically, before each transfusion, patients must provide a financial contribution and obtain a subscription from a designated non-institutional organisation associated with PGI Chandigarh. This requirement highlights patients' considerable financial burden in managing their lifelong treatment, compounded by their routine living expenses. In addition to medical hurdles, these patients also face substantial social challenges. They often experience job insecurity, incur costs related to travel and accommodation for hospital visits, and grapple with social isolation, discrimination, and stigma. These factors contribute to the complex landscape of living with thalassemia, highlighting the need for a multifaceted approach to support affected individuals both medically and socioeconomically.

Table 13: Physical challenges faced by patients with thalassemia Major

Physical challenges	Frequency	Percent
Anaemia	6	5.0
Bone Deformities	17	14.2
Organ Damage	3	2.5
Enlarged Spleen	9	7.5
Heart Problems	30	25.0
All of the Above	55	45.8
Total	120	100.0

Patients with Thalassemia Major encounter multifaceted challenges that significantly impact their quality of life. From a physiological perspective, these individuals may experience a range of complications, including growth retardation, skeletal malformations, and progressive organ dysfunction. Chronic anaemia is a central issue characterised by persistent fatigue, pallor, and impeded growth, adversely affecting paediatric development. As thalassemia progresses, bone marrow hyperplasia may occur, leading to changes in bone architecture that predispose patients to fractures and deformities. Regular blood transfusions, necessary for managing anaemia, introduce the risk of secondary hemochromatosis due to excessive iron deposition in critical organs such as the heart and liver, heightening the risk of severe complications, including cardiomyopathy. An expanded spleen exacerbates anaemia by phagocytosing transfused red blood cells, complicating the patient's clinical status. Cardiovascular complications, such as congestive heart failure and arrhythmias, are closely linked to the severity of the thalassemia phenotype. Additionally, patients may develop extra-medullary haematopoiesis, gallbladder dysfunction, renal enlargement, diabetes mellitus, and hypothyroidism, all contributing to the complexity of management.

Table 14: Psychological challenges faced by patients with thalassemia Major

Psychological challenges	Frequency	Percent
Anxiety and depression	9	7.5
Guilt and shame	7	5.8
Low self-esteem	2	1.7

Difficulty with school and work	11	9.2
Impact on family dynamics	28	23.3
Body image issues	13	10.8
All of the above	50	41.7
Total	120	100.0

On the psychosocial front, the emotional and psychological burden of living with thalassemia is profound. Patients often contend with heightened levels of stress, anxiety, and depressive symptoms stemming from the chronicity of the condition and the continuous need for medical intervention. The somatic changes associated with thalassemia can adversely impact body image, self-esteem, and overall sense of identity. Moreover, regular hospital admissions and limitations on physical activity can foster social isolation, complicating the maintenance of peer relationships and engagement in normative social interactions. The uncertainty regarding long-term health outcomes and the potential for future complications can exacerbate anxiety, making it difficult for patients to envision a stable future.

Table 15: Ways to address the challenges faced by patients with thalassemia Major

Responses	Frequency	Percent
Government Financial Assistance	24	20.0
Improved Diagnostic Facilities	16	13.3
Public Health Programs	16	13.3
Promotion of Awareness about education and Campaigns	10	8.3
Community Engagement and Blood Donation	19	15.8
All of the above	35	29.16
Total	120	100

The consequences of thalassemia extend well beyond the individual, significantly impacting families and caregivers. The financial burden associated with treatment—such as the costs of blood transfusions, regular medical appointments, and necessary medications—can place a heavy strain on household finances, leading to increased family stress. Caregivers often find themselves in a difficult position, trying to balance their own health needs with those of the patient, which can result in physical exhaustion and psychological distress. Frequent medical treatments and the fatigue caused by the illness may hinder educational attainment, making it challenging for patients to maintain a consistent school routine and impairing academic progress. These complexities underscore the urgent need for robust support systems that address medical needs and the emotional and educational aspects of care for patients and their families.

Furthermore, patients and their families hope for supportive government initiatives, including financial assistance, improvements in diagnostic facilities, public health programs, education and awareness campaigns, community engagement, and promotion of blood donation.

Summary and conclusion: The research involved 120 participants with Thalassemia Major, evenly divided by gender, from PGIMS in Rohtak and the PGIMER in Chandigarh. The majority were young, aged 3 months to 10 years, with a smaller percentage in adolescence. Most patients required blood transfusions every 20 days. Geographically, participants were primarily from Haryana, with 14.2% from Rohtak and notable numbers from Bhiwani, Panipat, and Sonipat. Around 60% of parents learned about the diagnosis when their child was 3 to 6 months old, indicating challenges in early detection. Awareness of the nucleic acid amplification test (NAAT) was low, with nearly one-third uninformed, raising concerns about the risks of untested blood transfusions, though about two-thirds recognised the potential dangers, including infections like HIV and HCV. Research indicates that patients with thalassemia major at Chandigarh PGIMER and Rohtak PGI experience wait times of 10 to 14 hours for essential blood transfusions, leading to physical discomfort and emotional distress. Rohtak PGI faces critical infrastructural challenges, with only seven beds available for an average demand of 15 to 20 patients, resulting in a 40% backlog.

Patients with Thalassemia Major face significant challenges affecting their quality of life. **Physiologically**, they may experience complications such as growth retardation, skeletal deformities, and organ dysfunction. Chronic anaemia leads to persistent fatigue and growth issues, impacting paediatric development. Bone marrow hyperplasia can cause changes, increasing fracture risk, while regular blood transfusions raise the risk of secondary hemochromatosis, potentially

resulting in severe complications like cardiomyopathy. Additional complications include splenomegaly, cardiovascular issues, extra-medullary haematopoiesis, and various endocrine disorders.

Psychosocially, the emotional burden is profound, with patients experiencing stress, anxiety, and depression due to the chronic nature of the condition. Body image changes and regular hospital visits may lead to social isolation and hinder peer relationships. Uncertainty about health outcomes heightens anxiety regarding the future. Moreover, thalassemia affects families, creating financial strains from treatment costs and impacting caregivers' health due to the demanding nature of care. Frequent medical needs can also disrupt the educational progress of patients. This highlights the necessity for comprehensive support systems addressing medical, emotional, and educational needs. Families seek government support through financial assistance, improved health services, awareness campaigns, and community engagement.

In conclusion, the study affirmed the remarkable resilience of Thalassemia patients and their families, illustrating the proactive measures they undertake to manage their condition. It highlighted essential areas for improvement: healthcare infrastructure, public awareness initiatives, and the establishment of comprehensive supportive services. These enhancements are vital for developing a more effective and continuous care continuum for individuals with Thalassemia, ultimately improving their overall quality of life.

Recommendations to Address the Sociological Challenges: Implementing comprehensive public health campaigns to heighten awareness and educate communities about thalassemia is critical. Such initiatives empower individuals to make informed choices regarding premarital screening and prenatal diagnostics, potentially lowering thalassemia's prevalence. Developing targeted, community-oriented programs is essential to provide support and resources to patients, their families, and healthcare professionals. These programs foster environments conducive to sharing experiences and disseminating crucial information, ultimately enhancing community cohesion and understanding of the condition. Furthermore, establishing robust social support networks is highly beneficial for both patients and their families. These networks play a vital role in addressing the emotional and social complexities associated with thalassemia, offering indispensable support and validation to enhance overall quality of life.

The government must also prioritise free HBA2/HPLC/HB electrophoresis testing in public healthcare facilities to streamline the detection of thalassemia cases. Accredited Social Health Activists (ASHA) should actively engage with expectant mothers, advocating for thalassemia screening within the first trimester to mitigate the risk of gene transmission. Additionally, promoting the submission of genetic profiles during the UID card application process or educational institution enrolment will contribute to a more informed populace, thereby aiding in the prevention of thalassemia transmission.

Contribution to literature and practice: The research paper significantly advances the academic discourse and practical applications regarding thalassemia, a complex hereditary haematological disorder with broad implications for patient quality of life. It comprehensively examines the sociological factors associated with thalassemia, presenting a comparative analysis of patient experiences from two prominent medical institutions in North India.

This study enhances our understanding of the psychosocial challenges faced by individuals with thalassemia, highlighting critical issues such as stigma, social support structures, economic barriers, and disparities in healthcare access. The research addresses a substantial gap in the existing literature by elucidating the influence of geographic and institutional variations on patient experiences.

From a practical standpoint, the findings have significant implications for healthcare practitioners and policymakers. The research lays the groundwork for targeted interventions to improve patient care and support frameworks by pinpointing specific challenges faced by thalassemia patients in Rohtak and Chandigarh. Recommended strategies include establishing community education programs to mitigate stigma, optimising healthcare delivery systems, and advocating for enhanced resource allocation that aligns with the unique needs of thalassemia patients. This research is a vital resource for scholars and practitioners, providing insights to guide future investigations and practical implementations within healthcare settings.

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