Volume 4, Issue 3, 2026

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

EXPLORING THE CHALLENGES AND BARRIERS EXPERIENCED BY PARENTS AND CAREGIVERS OF PATIENTS WITH THALASSEMIA: A CROSS-SECTIONAL STUDY OF AWARENESS, DISEASE BURDEN, AND MANAGEMENT PRACTICES

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DOI: https://doi.org/10.5281/zenodo.21410531

Keywords:
Thalassemia, Parents and caregivers, Health literacy, Disease complications, Barriers

Article History
Received on 03 February, 2026
Accepted on 16 March 2026
Published on 31 March, 2026

Abstract

INTRODUCTION: Thalassemia is a congenital hemoglobin disorder that passes from one generation to next and results in the body to make hemoglobin in a diseased pattern. The severity of the disease often remains immensely variable. Children with thalassemia suffer from the disease's consequences and treatment complications. The disease causes a negative impact on family members, who suffer mentally, socially, financially, and even physically. In this review, we explore the challenges experienced by the parents and caregivers of thalassemia patients; for instance, hindrance to get blood from donors, challenges in reaching thalassemia healthcare facilities, financial problems, difficulty in managing emotional and psychological state of their patients, socially isolation and challenges in professional life. OBJECTIVE: This cross-sectional study intents to explore the challenges and barriers experienced by parents and caregivers of thalassemia patients in District Health Quarter (DHQ) Hospital Mirpur, and Kashmir Blood Bank and Free Thalassemia Center Bhimber AJK. METHODOLOGY: This descriptive cross sectional qualitative study was conducted on 385 respondents using a self-structured questionnaire which was designed after reviewing various research articles. It was comprised of 22 questions to gather data from caregivers in wards of thalassemia center settings to explore their awareness and knowledge about thalassemia, to identify the complications of their patients and challenges and barriers experienced by caregivers of such thalassemia patients. A convenient sampling method was used where all the cases that meet inclusion criteria had been selected. RESULT: Majority

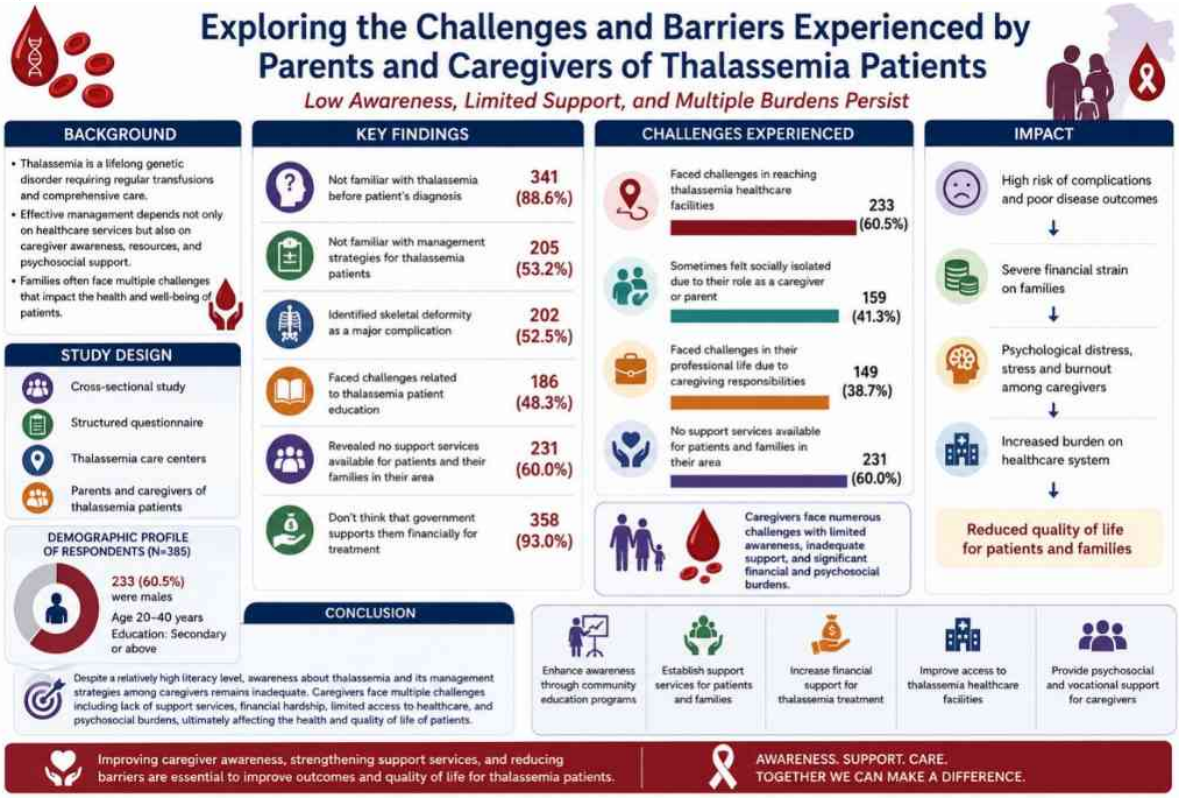
Volume 4, Issue 3, 2026

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

of respondents 233 (60.5%) were males with age between 20-40 years and education secondary or above. A higher Portion of caregivers 341 (88.6%) were not familiar with thalassemia before their patient's diagnosis. 205 (53.2) were not familiar with management strategies for thalassemia patients, 202 (52.5%) identified the complications of skeletal deformity, 186 (48.3%) faced challenges related to thalassemia patient education, 231 (60%) revealed that there are no support services available for patients and their families in their area. A significant percentage of caregivers 358 (93.0%) don't think that government support them financially for the treatment of thalassemia disease, 233 (60.5%) revealed that they faced challenges in reaching thalassemia Healthcare facilities while 159 (41.3%) sometimes felt socially isolated due to their role as a caregiver or parent of a thalassemia patient and 149 (38.7%) faced challenges in their professional life due to their caregiving responsibilities.CONCLUSION: The findings of the study concluded that despite of highest literacy rate, majority of caregivers were not familiar with thalassemia and its management strategies, significant proportion of patients suffering from complication of thalassemia i.e. splenomegaly, hepatomegaly and skeletal deformities which causes immense psychosocial, physical, and financial burdens to patients and their families. The present study concluded that the parent's awareness regarding the Thalassemia was inadequate and patients continue to suffer lot of complications ultimately leading to death. Parental knowledge regarding the Thalassemia management was limited.

Graphical Abstract



1.0. INTRODUCTION

The Thalassemia disorder is distinguished according to which of the globin chains, α or β, is impaired. These 2 major forms, α and β-thalassemia, are sub classified according to reduced (α^+ or β^+) or absent (α^0 and β^0) globin chain

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

synthesis. Another complex manifestation of thalassemia also exist which is either malfunctioning or non-functioning formation of 2-4 non-identical globin sequences (R.Yousuf *et al.*, 2022). Furthermore, where γ-chains in conjunction with α-chains comprise fetal hemoglobin (HbF) in the fetus and δ chains in combination with α-chains compose hemoglobin A_2 in adults, impaired synthesis of γ-globin or δ-globin chains can occur. Clinically, homozygotes for β-thalassemia often emerge as Thalassemia major or intermedia. Major thalassemia patients manifest extra medullary hematopoiesis and progressive severe anemia leading to poor growth, skeletal deformity, and other problems, including hepatic-splenomegaly, heart failure, and regular blood transfusion is the main therapeutic care for these patients. Homozygous individuals are those who possess two identical forms of a precise gene, one inherited from each parent; and both are abnormal genes. B-thalassemia intermedia patients in the first two years of life may or may not need blood transfusions; but, in the later life the frequency of transfusions may increase. Thalassemia minor patients are clinically asymptomatic and present in a carrier state (Toret *et al.*, 2018). The thalassemia depicts the most common monogenetic problem worldwide. Because thalassemia heterozygosis shows some immunity against malaria, there is specifically a high incidence of thalassemia (2.5-25%) in the Mediterranean basin, the tropical and subtropical regions of Africa, the Middle East, Southeast Asia, and the Asian subcontinent, where minor forms of the disease are most frequently seen (Maryam Alizadeh *et al.*, 2019). Anyhow, today thalassemia in many countries where it was not acknowledged before is very prevalent, such as North Central and South America, Northern Europe and Australia, may be due to a fast and improved transport system with huge population migration. In addition to this, thalassemia cases also occur sporadically in every geographic location and ethnic group (Maryam Alizadeh *et al.*, 2019). Children with thalassemia suffer from the disease's consequences and treatment complications. The disease also causes a negative impact on family members, who suffer mentally, socially, financially, and even physically. Parents of such patients, given that they had the thalassemia trait, hold themselves responsible for their children's disease in addition to other difficulties, bear the burden of guilt and hopelessness and worry about the health and future of their children (R.Yousuf *et al.*, 2022). Parents of children with thalassemia describe the marriage leading to the birth of this child as gray consanguineous marriage because they believe that it is neither bright nor black, and instead is a state between the two, where the current and future prospects of life are not seen (Nedruetai Punaglom *et al.*, 2019).

Thalassemia is reported to create stress for the patient's families. Especially the caregivers of thalassemia children face many socio-psychological, educational, and financial challenges related to the illness of their children. The birth of a thalassemia child causes a lot of problems in the family which are divided into several categories (L.E.Rakhmilla *et al.*, 2020).

Some problems are related to child care in the family, while some are related to providing care for the thalassemia child among healthy children, hospital health care problems, relationship in the society and at the school level and connections among relatives. Some of the problems are related to parents and some to the children; Diet problems and preparing separate meals for sick children, paying attention to the special needs of these children, appearance of different skin colors and change in their facial shape, when compared with that of the healthy children (Nedruetai Punaglom *et al.*, 2019). The conditions of the thalassemia children when compared with the healthy children increase the parental feeling of love toward those sick children in the family which creates a feeling of discrimination among the children. This feeling of love is turned into jealousy among the other children. At the meantime, the injuries of the thalassemia child are exacerbated owing to more parental attention. Moreover, more level of care and attention given to the thalassemic child leads to psychological trauma, and parents unwittingly create new problems (L.E.Rakhmilla *et al.*, 2020).

All these make life harder many problems associated with keeping healthy children besides sick ones. Thalassemia children suffer from

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

physiological, psychological, social and spiritual problems because of the long treatment protocols disrupting school and social activities. Nevertheless, most parents are not skilled enough in this issue; their concerns increase and their lives will be affected (R.Yousuf *et al.*, 2022).

Thalassemia's are a group of inherited blood disorders that comes from the inheritance of mutated globin genes and it results in less production of functional hemoglobin, and eventually anemia. Carrier is a person who inherits one mutated gene and usually leads a completely normal life. Disease occurs in those who inherit two mutated genes (one from each parent). Patients with serious forms of this disease require blood transfusion regularly and iron chelation therapy adequately to survive because, except bone marrow transplantation, there is no curative treatment for thalassemia's, and it is only available for a limited number of patients due to the morbidity associated with the procedure and high cost (Hossain *et al.*, 2021). The quality of life and survival of the patients with transfusion dependent thalassemia (TDT) have been enhanced dramatically in high income countries during the past few years with safe transfusion practice, access to modern therapies and successful prevention programs. However, in the lower resource setting, the scenario is still very disappointing, where the average life expectancy of thalassemia patients is around 30 years and most of the children with TDT die before reaching 5 years (Hossain *et al.*, 2021).

Mothers play an important role in caring for a child with thalassemia. Therefore, psychosocial burden is very common in these mothers due to several challenges they faced usually. Additionally, in Iranian society and culture, mothers have the most important role in caring for a sick child. It seems that using qualitative methods, especially phenomenological approach, can provide a deeper understanding of psychosocial challenges usually experienced by mothers with thalassemia children (Nabavian, *et al.*, 2022). Although the impact of thalassemia on families has been studied extensively using quantitative approaches, there is limited evidence to evaluate the experience of psychosocial challenges faced by mothers with thalassemia children in Iranian thalassemia literature. The aim of this study was to explain the psychosocial challenges of mothers with children with thalassemia (Nabavian *et al.*, 2022).

Children and families suffering from any chronic illness have a significant impact on their mental health. Parent's anxiety about their child's illness may lead to restrictions on many normal activities of childhood and can prevent the overall development of the child. These things in the long run can make a child prone to many psychiatric disorders (Sahu, *et al.*,, 2023). Thalassemia became more prevalent disease worldwide. Here we performed a cross-sectional study by searching PubMed, National and International Journals and accessed the challenges that are experienced by caregivers of thalassemia patients. Both types of thalassemia occur but β-thalassemia is more prevalent worldwide, approximately 1.5% of people are β-thalassemia carriers. In some European countries, due to migration the prevalence of hemoglobinopathies increasing according to the study conducted recently in Southeast Asia (A. Kattamis *et al.*, 2020). Thalassemia is one of the major prevalent diseases in Pakistan, which don't affect only patients but also their parents and caregivers. The increase prevalence of the disease and challenges of caregivers are due to lack of knowledge, low socioeconomic status and unavailability of specialized thalassemia centers (Hamid Ehsan *et al.*, 2020). A study was conducted in Pakistan from 2010-2020, which assessed the awareness of people about the disease. In this study, the results were that only 15.8% patients and family members knew the importance of adequate blood screening, only 15% knew about the risk of family inheritance. There were few thalassemia centers in the region and in most cases, patients rely on ELISA and even rapid testing kits (Hamid Ehsan *et al.*, 2020).

Low health literacy, lack of knowledge about management strategies due to lack of access to healthcare professionals, low socioeconomic status, ignorance by relatives and lack of government financial support for treatment of thalassemia patients, all these factors lead to various challenges and barriers for caregivers of thalassemia patients. All these parameters provided an idea to conduct a

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

research study to explore the challenges and barriers of parents of children with thalassemia related to their family financial, social, treatment and psychological issues in two districts of Azad Jammu and Kashmir (Ali, M *et al.*, 2026). The significance of the present study is to indicate the problems face by caregivers and to improve affordable, safe and timely treatments in the area of AJK where the disease poses a huge burden. The present study will help to understand the individual needs of caregivers so they efficiently utilize the supportive and care programs for thalassemia patients, thereby preventing unnecessary morbidity and mortality among them. The objective of this cross-sectional study was to enhance awareness among caregivers for self-care and taking care of their ill children by increasing the knowledge of parents and caregivers about thalassemia.

2.0. METHODOLOGY

2.1. Study Design

The present study was a cross- sectional questionnaire based qualitative study.

2.2. Study Setting

The study had been conducted at following thalassemia centers; District Health Quarter (DHQ) Hospital Mirpur, AJK, and Kashmir Blood Bank and Free Thalassemia Center Bhimber, AJK (Basharat, H *et al*,. 2026)

2.3. Study Population

This study included all the confirmed cases of thalassemia at DHQ hospital Mirpur, AJK and Kashmir Blood Bank and Free Thalassemia Center Bhimber, AJK.

2.4. Study Duration

Study duration was from April, 2023 to March 2024.

2.5. Sampling Method

A convenient method of sampling had been used where all the cases that meet inclusion criteria was selected.

2.6. Sample Size

Sample size was calculated by Raosoft sample size calculator, with 95% confidence interval and 5% margin of error, N=385.

2.7. Data Collection Tool

A questionnaire comprises of different questions or items used to gather data from parents and caregivers about challenges and barriers they experienced during care of their patients was designed after reviewing the article "Knowledge, Attitudes, and Perceptions Towards Beta-Thalassemia among Residents of Azad Kashmir, Pakistan" (Farheen Shaffique *et al.*, 2023) to collect the data in wards of thalassemia center settings. Questions comprising of different variables including patients' demographic characteristics, history of thalassemia, treatment modalities, complications of disease and barriers was designed to collect the data from study population.

2.8. Statistical Analysis

Data had been analyzed by using Statistical Package for Social Sciences (SPSS) version 20. Statistical analysis was used to present the analyzed data for definite measures such as tables or graphs. Inferential statistics were used to determine the demographics, awareness and knowledge, and challenges and barriers experienced by the study population. Chi-square test was applied (Zafar, R *et al.*, 2026).

2.9. Ethical Considerations

This study was conducted following approval from Akson College of Pharmacy, in collaboration with Mirpur University of Science and Technology (MUST), Mirpur, Azad Jammu and Kashmir, Pakistan. Institutional approval was granted under reference numbers 461/01/Ex/ACP/24 and 462/01/Ex/ACP/24. In addition, ethical and administrative permission to conduct the study was obtained from the head of each participating hospital before data collection commenced. All study procedures were performed in accordance with the ethical principles for research involving human participants, and informed consent was obtained from all participants prior to their inclusion in the study.

3.0. RESULTS

3.1. Demographic Characteristics

The present study was comprised of total 385 respondents among which 233 (60.5%) males, and 113(29.4%) females and 39 (10.1%) any other, and age of caregiver (interviewed) in years were 269 (69.9%) in range 20-40, 112 (29.1%) in range 40-50, 4 (1.0%) below 20 years, 206(53.5%)

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

respondents had educational level secondary or above, 142 (36.9%) had primary educational level, and 37 (9.6%) were illiterate, 147 (38.2%) patients were below 5 years, 126 (32.7%) patients were in 5-10 years of age, and 112 (29.1%) patients were above 10 years and 200 (51.9%) patients were males and 185 (48.1%) were female. A detailed description is given in the table 1 below.

Table 1: ***Demographic Characteristics***

Demographic variables		Frequency (n)	Percentage (%)
Caregiver interviewed	Father	233	60.5
	Mother	113	29.4
	Any other	39	10.1
Age of caregiver in years	Below 20	4	1.0
	20-40	269	69.9
	40-50	112	29.1
Educational level of caregiver	Illiterate	37	9.6
	Primary	142	36.9
	Secondary or above	206	53.5
Age of patient	Below 5	147	38.2
	5-10	126	32.7
	Above 10	112	29.1
Gender of patient	Male	200	51.9
	Female	185	48.1

3.2. Awareness And Knowledge About Thalassemia

The present study was comprised of total 385 respondents among which 341 (88.6%) were not at all familiar with thalassemia before their patient diagnosis, 44 (11.4%) were very familiar with thalassemia before their patient diagnosis, 373 (96.9%) respondents know the disease is caused genetically, 12 (3.1%) answered that disease is caused by contact with other thalassemia patient, 274 (71.2%) know the types of thalassemia, 111 (28.8%) don't know the types of thalassemia (Thalassemia major, thalassemia minor), 221 (57.4%) know about the available treatments for thalassemia, 164 (42.6%) not know about the available treatment for thalassemia. A total of 205 (53.2%) caregivers were familiar with the management strategies for thalassemia, while 180 (46.8%) were not. Regarding disease-related complications, 190 (49.4%) correctly identified splenomegaly, whereas 195 (50.6%) could not. Hepatomegaly was recognized by 243 (63.1%) caregivers, while 142 (36.9%) failed to identify it. Similarly, 202 (52.5%) identified skeletal deformity as a complication of thalassemia, whereas 183 (47.5%) did not. A detailed summary of these findings is presented in Table 2.

Table 2: ***Awareness and Knowledge about Thalassemia***

Awareness and knowledge variables	Frequency (n)	Percentage (%)

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

How familiar are you with thalassemia before your patient diagnosis?	Not at all	341	88.6
	Very familiar	44	11.4
	Genetically	373	96.9
Do you know how this disease is caused?	Contact with other thalassemia patient	12	3.1
Do you know about Types of thalassemia (thalassemia major, thalassemia minor)?	Yes	274	71.2
	No	111	28.8
Do you know about the available treatments for thalassemia?	Yes	221	57.4
	No	164	42.6
Are you familiar with management strategies for thalassemia patients?	Yes	205	53.2
	No	180	46.8
Can you identify patient complications associated with thalassemia Splenomegaly.	Yes	190	49.4
	No	195	50.6
Can you identify patient complications associated with Thalassemia Hepatomegaly.	Yes	243	63.1
	No	142	36.9
Can you identify patient complications associated with thalassemia Skeletal deformity.	Yes	202	52.5
	No	183	47.5

3.3. CROSS TABULATION

Caregiver Interviewed verses Awareness and Knowledge about Thalassemia. The present study was comprised of total 385 respondents. Based on the data gathered from them, it's evident that there was a spectrum of awareness and knowledge about thalassemia before their child's diagnosis. A significant portion comprises of 205 fathers, 99 mothers and 37 other relatives had little to no familiarity with thalassemia prior to their child's diagnosis. Conversely, only a small portion 28 fathers, 14 mothers and 2 other relatives claimed to be very familiar with the condition beforehand.

Regarding the cause of thalassemia, a significant portion comprised of 229 fathers, 109 mothers and 35 other relatives correctly attributed it to genetic factors. However, there was a minority, comprised of 4 fathers, 4 mothers and 4 other relatives, who mistakenly believed that contact with other thalassemic patients could cause the disease. In terms of knowledge about the types of thalassemia, a considerable portion, comprised of 174 fathers, 80 mothers and 20 other relatives, were aware of the distinctions between thalassemia major and thalassemia minor. However, there was still a notable portion, comprised of 59 fathers, 33 mothers and 19 other relatives, who were unaware of these differences. Regarding available treatments and management strategies for thalassemia, the data indicates a mixed level of awareness. While a significant portion, comprised of 126 fathers, 61 mothers and 18 other relatives knew about treatments and management strategies, there were notable portion, comprised of 107 fathers, 52 mothers and 21 other relatives who did not have this knowledge. When it comes to identifying potential complications or risks associated with thalassemia, there were varying levels of awareness. There were considerable numbers ranging from 122 fathers, 52 mothers and 21 other relatives,

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

who were unable to identify the complications such as splenomegaly. While a notable portion, ranging from 11 fathers, 59 mothers and 20 other relatives, who could identify complications. When it comes to identifying hepatomegaly, there were varying levels of awareness. There were considerable numbers, ranging from 152 fathers, 64 mothers and 27 other relatives, who were able to identify the complication (Hepatomegaly). While a notable portion, ranging from 81 fathers, 49 mothers and 12 other relatives, who were unable to identify the complication i.e. Hepatomegaly. Lastly, when it comes to identifying skeletal deformity, there were varying levels of awareness. There were significant numbers, ranging from 129 fathers, 50 mothers and 23 other relatives, who were able to identify the skeletal deformity. While a notable portion, ranging from 104 fathers, 63 mothers and 16 other relatives, who were unable to identify the complications associated with thalassemia i.e. skeletal deformity. A detailed description is given in the table 3 below.

Table 3: ***Caregiver interviewed verses Awareness and Knowledge about Thalassemia***

Awareness and knowledge variables		Caregiver interviewed		
		Father	Mother	Any other
How familiar are you with thalassemia before your patient's diagnosis?	Not at all	205	99	37
	Very familiar	28	14	2
	Genetically	229	109	35
Do you know how this disease is caused?	Contact with other thalassemia patient	4	4	4
Do you know about types of thalassemia (thalassemia major, thalassemia minor)?	Yes	174	80	20
	No	59	33	19
Do you know about the available treatments for thalassemia?	Yes	136	64	21
	No	97	49	18
Are you familiar with the management strategies for thalassemia patients?	Yes	126	61	18
	No	107	52	21
Can you identify potential complications/risks associated with thalassemia i. Splenomegaly	Yes	11	59	20
	No	122	52	21
Can you identify potential complications/risks associated with thalassemia ii. Hepatomegaly	Yes	152	64	27
	No	81	49	12
Can you identify potential complications/risks associated with thalassemia iii. Skeletal deformity	Yes	129	50	23
	No	104	63	16

3.4. Age of Caregiver verses Awareness and Knowledge about Thalassemia

The present study was comprised of 385 respondents. The table presents data on the correlation between the age of caregivers and their awareness and knowledge about thalassemia.

Firstly, concerning familiarity with thalassemia before diagnosis, it's notable that a significant majority of caregivers across all age groups (2 below

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

20 years, 234 between 20-40 years, and 105 between 40-50 years) were not familiar with the disease prior to their patient's diagnosis, reflecting a general lack of awareness in the population and (2 below 20 years, 35 between 20-40 years, and 7 between 40-50 years) were very familiar with the disease prior to their patient's diagnosis.

Secondly, knowledge about the causes of thalassemia predominantly attributed the disease to genetics, with 4 of caregivers below 20 years, 262 between 20-40 years, and 107 between 40-50 years recognizing its genetic origin. However, only a small fraction with (0 of caregivers below 20 years, 7 between 20-40 years, and 5 between 40-50 years associated it with contact with other thalassemic patients. Thirdly, awareness of the types of thalassemia varied across age groups, with younger caregivers demonstrating slightly higher awareness levels. Specifically, (3 of caregivers below 20 years, 194 between 20-40 years, and 77 between 40-50 years) were aware of thalassemia types, while a small portion comprised of (1 of caregivers below 20 years, 75 between 20-40 years, and 85 between 40-50 years) were not aware of thalassemia types. Fourthly, understanding of available treatments and management strategies for thalassemia patients showed similar trends, with younger caregivers exhibiting higher levels of awareness compared to older counterparts, although knowledge gaps persisted across all age groups. A significant portion of respondents comprised of (2 of caregivers below 20 years, 154 between 20-40 years, and 65 between 40-50 years) were aware of available treatment for thalassemia while (2 of caregivers below 20 years, 115 between 20-40 years, and 47 between 40-50 years) were unaware of available treatment for thalassemia.

A significant portion of respondents comprised of (2 of caregivers below 20 years, 140 between 20-40 years, and 63 between 40-50 years) were aware of management strategies for thalassemia while (2 of caregivers below 20 years, 129 between 20-40 years, and 49 between 40-50 years) were unaware of management strategies for thalassemia.

Lastly, regarding the identification of potential complications associated with thalassemia, older caregivers tended to display better recognition, particularly in identifying complications like splenomegaly and hepatomegaly. A group of respondents comprised of (2 of caregivers below 20 years, 143 between 20-40 years, and 45 between 40-50 years) identified the splenomegaly complications while (2 of caregivers below 20 years, 126 between 20-40 years, and 67 between 40-50 years) did not identify the splenomegaly complications. A significant group of respondents comprised of (1 of caregivers below 20 years, 177 between 20-40 years, and 65 between 40-50 years) recognized the hepatomegaly complications while (3 of caregivers below 20 years, 92 between 20-40 years, and 47 between 40-50 years) did not recognize the hepatomegaly complications.

However, across all age groups, there were notable proportions of caregivers (2 below 20 years, 146 between 20-40 years, and 35 between 40-50 years) who were unable to identify complications like skeletal deformity, highlighting areas where education and awareness efforts could be targeted to improve caregiver knowledge and understanding of thalassemia-related risks. A detailed description is given in the table 4 below.

Table 4. ***Age of Caregiver verses Awareness and Knowledge about Thalassemia***

Awareness and knowledge variables		Age of caregiver in years		
		Below 20	20-40	40-50
How familiar are you with thalassemia before your patient's diagnosis?	Not at all	2	234	105
	Very familiar	2	35	7
Do you know how this disease is caused?	Genetically	4	262	107
	Contact with other thalassemia	0	7	5

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

patient				
Do you know about types of thalassemia (thalassemia major, thalassemia minor)?	Yes	3	194	77
	No	1	75	35
Do you know about the available treatments for thalassemia?	Yes	2	154	65
	No	2	115	47
Are you familiar with the management strategies for thalassemia patients?	Yes	2	140	63
	No	2	129	49
Can you identify potential complications/risks associated with thalassemia i. Splenomegaly.	Yes	2	143	45
	No	2	126	67
Can you identify potential complications/risks associated with thalassemia ii. Hepatomegaly	Yes	1	177	65
	No	3	92	47
Can you identify potential complications/risks associated with thalassemia iii. Skeletal deformity.	Yes	2	123	77
	No	2	146	35

3.5. Age of Caregiver in years verses Challenges and Barriers Experienced by the Parents and Caregivers of Thalassemia Patients

The present study comprised of total 385 respondents. The data provided offers insights into the challenges and barriers faced by parents and caregivers of thalassemia patients across different age groups. Firstly, regarding the impact of thalassemia on social activities, a substantial proportion of caregivers reported difficulties faced by patients in playing or participating in social activities, particularly among the 20-40 age group 102, followed by the 40-50 age group 63 , indicating the significant social limitations imposed by the disease, while a small portion particularly among the below 20 age group 3, 20-40 age group 130, followed by the 40-50 age group 33 reported no difficulties faced by patients in playing or participating in social activities, and a significant portion comprised of 1 below 20 age group, 37 20-40 age group, and 16 in 40-50 age group reported that they sometimes faced difficulties by patients in playing or participating in social activities.

Secondly, logistical challenges related to obtaining blood from donors were prevalent across all age groups, with approximately a quarter of caregivers experiencing hindrances, particularly in the 20-40 age group 102 and 40-50 age group 47, reflecting the ongoing struggle to secure necessary resources for treatment and management, and a considerable portion including the below 20 age group 3, 20-40 age group 164 and 40-50 age group 59 don't faced hindrance to get blood from donors. Thirdly, accessing thalassemia healthcare facilities posed significant challenges, with the majority of caregivers reporting difficulties, especially in the 20-40 age groups 156, underscoring the critical need for improved healthcare infrastructure and accessibility, while a portion in the 20-40 age groups 60; 40-50 age groups 15 had not faced any challenges in reaching healthcare facilities.

Fourthly, availability and adequacy of support services varied, with a higher portion of caregivers in the 20-40 age group 151, in 40-50age group 78 reported the absence of support services, while a small portion of caregivers below 20 age group 2, in the 20-40 age group 84, in 40-50 age group 22 reported the presence of support services, highlighting the importance of community resources in addressing the multifaceted needs of thalassemia patients and their families. A significant portion of respondents comprised of 149 of age group 20-40, 32 of age group 40-50 had no challenges related to the thalassemia patient

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

education (school, policies). A considerable portion of 108 of age group 20-40, 78 of age group 40-50 had challenges related to the thalassemia patient education (school, policies) and portion of 12 of age group 20-40, 2 of age group 40-50 preferred not to say. Further availability and adequacy of healthcare professionals varied, with a higher portion of caregivers in the 20-40 age group 179, in 40-50age group 85 reported that there are not enough healthcare professionals in their region, while a small portion of caregivers in the 20-40 age group 80, in 40-50 age group 24 reported the presence of healthcare services, and a portion of caregivers in the 20-40 age group 10, in 40-50 age group 3 reported the presence of healthcare services sometimes. A significant portion of respondents comprised of 252 of age group 20-40, 102 of age group 40-50 had answered that government had not support them financially for the treatment of thalassemia disease of their children, while a small portion of respondents comprised of 14 of age group 20-40, 6 of age group 40-50 had answered that government had support them financially for the treatment of thalassemia disease of their children.

A significant portion of respondents comprised of 168 of age group 20-40, 68 of age group 40-50 had answered that they had not ignored by relatives due to blood demand, while a considerable portion of respondents comprised of 82 of age group 20-40, 36 of age group 40-50 had answered that they had ignored by relatives due to blood demand. Furthermore, emotional and psychological burdens were evident among caregivers, with a notable portion reporting challenges in managing the emotional and psychological states of patients, particularly among the 20-40 age group 150, among the 40-50 age group 72, indicating the need for comprehensive psychosocial support programs tailored to the specific needs of caregivers across different age groups. Social isolation was another parameter, which is particularly among the 20-40 age group 116, among the 40-50 age group 43, sometimes feel socially isolated due to your role as a caregiver or parent of a thalassemia patient, while a small portion among the 20-40 age group 98, among the 40-50 age group 34, feel socially isolated due to your role as a caregiver or parent of a thalassemia patient always.

Lastly, caregivers faced challenges in their professional lives due to caregiving responsibilities, with 108 among the 20-40 age group, 39 among the 40-50 age group reporting such difficulties, while a small portion of respondents comprised of 94 among the 20-40 age group, 37 among the 40-50 age group responded that they faced challenges in their professional lives due to caregiving responsibilities sometimes. A detailed description is given in the table 5 below.

Table 5. ***Age of Caregiver in years verses Challenges and Barriers Experienced by the Parents and Caregivers of Thalassemia Patients***

Challenges and barriers variables		Age of caregiver in years		
		Below 20	20-40	40-50
Does your patient face difficulty to play or participate in any social activity due to thalassemia major disease?	Yes	0	102	63
	No	3	130	33
	Sometimes	1	37	16
Do you face hindrance to get blood from the donors?	Yes	1	102	47
	No	3	164	59
	Prefer not to say	0	3	6
Have you faced any challenges in reaching thalassemia	Yes	3	156	74

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

healthcare facilities?	No	1	60	15
	Sometimes	0	53	23
	Yes	2	84	22
Are there support services available for individuals with thalassemia and their families in your area?	No	2	151	78
	Sometimes	0	34	12
	Yes	0	108	78
Do you have any challenges related to the thalassemia patient education (school, policies)?	No	4	149	32
	Prefer not to say	0	12	2
	Yes	0	80	24
Are there enough specialized healthcare professionals for thalassemia in your region?	No	4	179	85
	Sometimes	0	10	3
	Yes	0	14	6
Does government support you financially for the treatment of thalassemia disease?	No	4	252	102
	Sometimes	0	3	4
	Yes	1	82	36
Are you ignored by relatives due to blood demand?	No	3	168	68
	Sometimes	0	19	8
Do you have difficulty in managing emotional and psychological state of your patient?	Yes	1	150	72
	No	3	108	35
	Prefer not to say	0	11	5
	Yes	2	98	34
Do you feel socially isolated due to your role as a caregiver or parent of a thalassemia patient?	No	2	55	35
	Sometimes	0	116	43
	Yes	2	108	39
Have you faced challenges in your professional life due to your caregiving responsibilities?	No	2	94	37
	Sometimes	0	67	36

3.6. Educational Level of Caregiver verses Awareness and Knowledge about Thalassemia

The present study comprised of total three hundred and eighty-five respondents. The table presents a comparison between the educational levels of caregivers and their awareness and knowledge about thalassemia, a genetic blood disorder. It shows responses categorized based on

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

the caregivers' educational background: illiterate, primary education and secondary education or above. The first set of data pertains to the familiarity of caregivers with thalassemia before their patient's diagnosis, with responses ranging from "Not at all" to "Very familiar." Among illiterate caregivers, 36 responded as not familiar at all, while only 1 claimed to be very familiar. Among primary education caregivers, 137 responded as not familiar at all, while only 5 claimed to be very familiar. Among secondary education caregivers, 168 responded as not familiar at all, while only 38 claimed to be very familiar.

Similarly, the table provides information on the causes of thalassemia, knowledge about types of thalassemia, among illiterate caregivers 33 responded that disease genetically caused and 5 responded that disease caused due to contact with other thalassemia patients, among primary level caregivers 139 responded that disease genetically caused and 3 responded that disease caused due to contact with other thalassemia patients, among secondary level caregivers 201 responded that disease genetically caused and 5 responded that disease caused due to contact with other thalassemia patients.

Regarding about available treatments, a higher proportion of secondary level caregivers 135 had awareness about the treatment but a small portion 71 were unaware of available treatment, and primary level caregivers 75 were unaware and 67 were aware of treatment, while a small portion of illiterate caregivers 18 knew about the treatment available.

Understanding of available management strategies for thalassemia patients showed similar trends, with secondary level caregivers exhibiting higher levels of awareness compared to primary and illiterate counterparts. A significant portion of secondary level respondents comprised of 122 exhibited awareness and 84 were unaware, while among illiterate respondents 18 exhibited awareness about management strategies and 19 were unaware.

Regarding the identification of potential complications associated with thalassemia, educated caregivers tended to display better recognition, particularly in identifying complications like splenomegaly and hepatomegaly. A group of respondents among secondary level education 109 were knew about splenomegaly, while among primary educators 65 recognized and among illiterate only 16 recognized. Among secondary level respondents 138 identified potential Hepatomegaly associated with thalassemia, among primary level respondents 86 identified, and illiterate respondents identified only 19. Among secondary level respondents 92 identified potential skeletal deformity associated with thalassemia, among primary level respondents 86 identified, and illiterate respondents identified only 24. For instance, it can be observed that higher education levels generally correspond to greater awareness and knowledge about the disease and its management. A detailed description is given in table 6 below.

Table 6. ***Educational level of Caregiver verses Awareness and knowledge about Thalassemia***

Awareness and knowledge variables		**Educational level of caregiver**		
		Illiterate	**Primary**	**Secondary or above**
How familiar are you with thalassemia before your patient's diagnosis?	Not at all	36	137	168
	Very familiar	1	5	38
Do you know how this disease is caused?	Genetically	33	139	201
	Contact with other thalassemia patients	4	3	5
Do you know about types of thalassemia	Yes	17	100	157

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

(thalassemia major, thalassemia minor)?	No	20	42	49
	Yes	19	67	135
Do you know about the available treatments for thalassemia?	No	18	75	71
	Yes	18	65	122
Are you familiar with the management strategies for thalassemia patients?	No	19	77	84
Can you identify potential complications/risks associated with thalassemia i. Splenomegaly.	Yes	16	65	109
	No	21	77	97
Can you identify potential complications/risks associated with thalassemia ii. Hepatomegaly	Yes	19	86	138
	No	18	56	68
Can you identify potential complications/risks associated with thalassemia iii. Skeletal deformity	Yes	24	86	92
	No	13	56	114

3.7. *P*-Values of Caregiver Interviewed verses Awareness and Knowledge about Thalassemia

The Chi-square test was conducted to assess the association between demographic variable i.e. caregiver interviewed versus awareness and knowledge variables. The awareness and knowledge variables i.e. cause of disease (0.017) and type of thalassemia (0.012) with p-value less than 0.05 indicates significant association with demographic variables i.e. caregiver interviewed. The variables with p-value above 0.05 indicate that there is no significant association between study variables and objectives of study. The detailed description is given in table 7 below.

Table 7. ***P-value of Caregiver Interviewed verses Awareness and Knowledge about Thalassemia***

Awareness and knowledge variables		Caregiver interviewed		
		Father	Mother	Any other
How familiar are you with thalassemia before your patient's diagnosis?	Not at all Very familiar Genetically	0.425		
Do you know how this disease is caused?	Contact with other thalassemia patient	0.017		
Do you know about types of thalassemia (thalassemia major, thalassemia minor)?	Yes No	0.012		
Do you know about the available treatments for thalassemia?	Yes No	0.853		
Are you familiar with the management strategies for thalassemia patients?	Yes No	0.645		

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Can you identify potential complications/risks associated with thalassemia i. Splenomegaly	Yes No	0.704
Can you identify potential complications/risks associated with thalassemia ii. Hepatomegaly	Yes No	0.211
Can you identify potential complications/risks associated with thalassemia iii. Skeletal deformity	Yes No	0.258

3.8. P-value of Caregiver Interviewed verses Challenges and Barriers experienced by the Parents and Caregivers of Thalassemia patients

The association of caregiver interviewed and challenges and barriers experienced by parents and caregivers of Thalassemia patients was found using chi-square test. The challenges and barriers experienced by parents and caregivers of thalassemia patients i.e. difficulty in managing emotional and psychological state of patient (0.007), social isolation (0.001) and challenges in professional life (0.002) have significant association with caregiver interviewed with p-value less than 0.05, and the other variables with p-value above 0.05 indicates that there is no significant association between study variables and objectives of study. A detailed description is given in table 8 below.

Table 8. *P*-value of Caregiver Interviewed verses Challenges and Barriers Experienced by the Parents and Caregivers of Thalassemia patients

Challenges and barriers variables		Caregiver interviewed			
		Father	Mother	Any other	
Does your patient face difficulty to play or participate in any social activity due to thalassemia major disease?	Yes No Sometimes	0.176			
Do you face hindrance to get blood from the donors?	Yes No Prefer not to say	0.249			
Have you faced any challenges in reaching thalassemia healthcare facilities?	Yes No Sometimes	0.599			
Are there support services available for individuals with thalassemia and their families in your area?	Yes No Sometimes	0.349			
Do you have any challenges related to the thalassemia patient education (school, policies)?	Yes No	0.148			

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

	Prefer not to say	
Are there enough specialized healthcare professionals for thalassemia in your region?	Yes	
	No	0.314
	Sometimes	
Does government support you financially for the treatment of thalassemia disease?	Yes	
	No	0.081
	Sometimes	
Are you ignored by relatives due to blood demand?	Yes	
	No	0.914
	Sometimes	
Do you have difficulty in managing emotional and psychological state of your patient?	Yes	
	No	0.007
	Prefer not to say	
Do you feel socially isolated due to your role as a caregiver or parent of a thalassemia patient?	Yes	
	No	0.001
	Sometimes	
Have you faced challenges in your professional life due to your caregiving responsibilities?	Yes	
	No	0.002
	Sometimes	

3.9. P-Value of Age of Caregiver in years verses Awareness and Knowledge about Thalassemia

The association of age of caregiver and awareness and knowledge about thalassemia was found using chi-square test. The awareness and knowledge variables i.e. familiarity with disease (0.009) and skeletal complications (0.002) with p-value less than 0.05 indicates significant association with demographic variables i.e. age of caregiver interviewed and the other variables with p-value above 0.05 indicates that there is no significant association between them. A detailed description is given in table 9 below.

Table 9. ***P-value of Age of Caregiver Interviewed verses Awareness and Knowledge about Thalassemia***

Awareness and knowledge variables		**Age of caregiver in years**	
		Below 20	**20-40**	**40-50**
How familiar are you with thalassemia before your patient'sNot at all diagnosis?	Very familiar			0.009

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Do you know how this disease is caused?	Genetically Contact with other thalassemia patient	0.595
Do you know about types of thalassemia (thalassemia major, thalassemia minor)?	Yes No	0.792
Do you know about the available treatments for thalassemia?	Yes No	0.946
Are you familiar with the management strategies for thalassemia patients?	Yes No	0.749
Can you identify potential complications/risks associated with thalassemia i. Splenomegaly.	Yes No	0.070
Can you identify potential complications/risks associated with thalassemia ii. Hepatomegaly	Yes No	0.102
Can you identify potential complications/risks associated with thalassemia iii. Skeletal deformity.	Yes No	0.002

3.10. P-Value of age of Caregiver in years verses Challenges and Barriers Experienced by the Parents and Caregivers of Thalassemia Patients

A chi-square test was conducted to assess the association between demographic variables i.e. age of caregivers in year's verses challenges and barriers experienced by parents and caregivers of thalassemia patients. The challenges and barriers experienced by parents and caregivers of thalassemia patients i.e. difficulty to play or participate in any social activity (0.003), challenges related to the thalassemia patient education (0.001) have strongly associated with age of caregiver interviewed with p-value below 0.05 except the variables with p-value above 0.05 indicates that there is no significant association between study variables and objectives of study. A detailed description is given in table 10 below.

Table 10. ***P-value of Age of Caregiver in years verses Challenges and Barriers Experienced by the Parents and Caregivers of thalassemia patients***

Challenges and barriers variables		**Age of caregiver in years**		
		Below 20	**20-40**	**40-50**
Does your patient face difficulty to play or participate in any social activity due to thalassemia major disease?	Yes No Sometimes Yes	0.003		

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Do you face hindrance to get blood from the donors?	No Prefer not to say	0.098
Have you faced any challenges in reaching thalassemia healthcare facilities?	Yes No Sometimes	0.282
Are there support services available for individuals with thalassemia and their families in your area?	Yes No Sometimes	0.104
Do you have any challenges related to the thalassemia patient education (school, policies)?	Yes No Prefer not to say	0.001
Are there enough specialized healthcare professionals for thalassemia in your region?	Yes No Sometimes	0.284
Does government support you financially for the treatment of thalassemia disease?	Yes No Sometimes	0.559
Are you ignored by relatives due to blood demand?	Yes No Sometimes	0.969
Do you have difficulty in managing emotional and psychological state of your patient?	Yes No Prefer not to say	0.281
Do you feel socially isolated due to your role as a caregiver or parent of a thalassemia patient?	Yes No Sometimes	0.084
Have you faced challenges in your professional life due to your caregiving responsibilities?	Yes No	

Volume 4, Issue 3, 2026

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

	Sometimes	0.447

-value of Age of Patient in years verses Awareness and Knowledge about Thalassemia

All the variables of awareness and knowledge were significantly associated with age of patient in years with p-value below 0.05 familiarity with Thalassemia (0.005), knowledge about available treatment (0.001), familiarity with management strategies (0.004), identification of complications like splenomegaly (0.002), hepatomegaly (0.001), and skeletal deformity (0.001), except the variables i.e. cause of disease and types of disease is not associated with age of patient in years with p-value above 0.05.A detailed description is given in table 11 below

Table 11. *P*-value of Age of Patient in years verses Awareness and Knowledge about Thalassemia

Awareness and knowledge variables		Age of patient		
		Below 5	5-10	Above 10
How familiar are you with thalassemia before your patient's diagnosis?	Not at all	0.005		
	Very familiar			
	Genetically			
Do you know how this disease is caused?	Contact with other thalassemia patients	0.120		
Do you know about types of thalassemia (thalassemia major, thalassemia minor)?	Yes			
	No	0.120		
Do you know about the available treatments for thalassemia?	Yes			
	No	0.001		
Are you familiar with the management strategies for thalassemia patients?	Yes			
	No	0.004		
Can you identify potential complications/risks associated with thalassemia i. Splenomegaly.	Yes			
	No	0.002		
Can you identify potential complications/risks associated with thalassemia ii. Hepatomegaly	Yes			
	No	0.001		
Can you identify potential complications/risks associated with thalassemia iii. Skeletal deformity.	Yes			
	No	0.001		

***3.12. P*-value of Age of Patient in years verses Challenges and Barriers Experienced by the Parents and Caregivers of Thalassemia patients**

All the variables of challenges and barriers experienced by parents and caregivers of thalassemia patients were significantly associated with age of patient in years with p-value below 0.05

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

i.e.; difficulty to play or participate in any social activity (0.002), challenges related to the thalassemia patient education (0.001), ignored by relatives due to blood demand (0.033), difficulty in managing emotional and psychological state (0.014), socially isolated due to your role as a caregiver or parent (0.001) except the variables i.e. hindrance to get blood challenges in reaching thalassemia healthcare facilities, support services, availability of health care professional, government support and challenges in professional life were not associated with educational level of caregiver with p-value above 0.05.A detailed description is given in table 12 below.

Table 12. *P*-value of Age of Patient in years verses Challenges and Barriers Experienced by the Parents and Caregivers of Thalassemia patients

Challenges and barriers variables		Age of patient		
		Below 5	5-10	Above 10
Does your patient face difficulty to play or participate in any social activity due to thalassemia major disease?	Yes No Sometimes	0.002		
Do you face hindrance to get blood from the donors?	Yes No Prefer not to say	0.125		
Have you faced any challenges in reaching thalassemia healthcare facilities?	Yes No Sometimes	0.842		
Are there support services available for individuals with thalassemia and their families in your area?	Yes No Sometimes	0.281		
Do you have any challenges related to the thalassemia patient education (school, policies)?	Yes No Prefer not to say	0.001		
Are there enough specialized healthcare professionals for thalassemia in your region?	Yes No Sometimes	0.867		
Does government support you Financially for the treatment of thalassemia disease?	Yes No Sometimes	0.623		

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Are you ignored by relatives due to blood demand?	Yes No Sometimes	0.033
Do you have difficulty in managing emotional and psychological state of your patient?	Yes No Prefer not to say	0.014
Do you feel socially isolated due to your role as a caregiver or parent of a thalassemia patient?	Yes No Sometimes	0.001
Have you faced challenges in your professional life due to your caregiving responsibilities?	Yes No Sometimes	0.098

4.0. DISCUSSION

The study was carried out to explore the challenges experienced by the parents and caregivers of thalassemia patients in two districts (Mirpur and Bhimber) of Azad Jammu and Kashmir.

We conducted a qualitative cross-sectional questionnaire-based study and asked questions to the caregivers to achieve the objectives of this study. The results of the study showed that the disease has affected parental psychosocial and financial state very badly. The majority of the affected patient's families were poor and unable to afford the costly treatments. The present study has revealed the challenges faced by thalassemia patients. These challenges affected many aspects of life of patients and their caregivers, such as education, difficulty to play or participate in any social activity, differences from family adjustments, ignorance by relatives and social isolation. A similar study conducted in Iraq showed that caregivers who are mainly mothers (55%) feel afraid of the complications of the disease, feel guilty, and are frustrated, causing a loss of pleasure in life. Caregivers suffer from low-level quality of life with low physical and mental health and a sense of guilt due to the inheritance of this genetic disease. It is necessary to provide support to these caregivers by relatives, family members, community people, and also the health care providers by providing counseling to enhance their self-care knowledge (Yousuf *et al.*, 2022). In present study, regarding the cause of thalassemia, the majority correctly attributed it to genetic factors, with percentages ranging from 3.1 to 96.9%. However, there was a minority, comprising around 4% across the board, who mistakenly believed that contact with other thalassemia patients could cause the disease. A similar study conducted in Department of Zoology University of Azad Jammu and Kashmir, Muzaffarabad showed same results aimed to quantify the public's awareness, attitude, perception and prevention among the population of Azad Jammu and Kashmir. A descriptive cross-sectional was conducted from Mar-Sep 2021. Approximately 75% of the participants (1677) had heard of thalassemia. Around 48% of the people interviewed were unaware that one might be a thalassemia carrier (Farheen Shaffique *et al.*, 2023). In present study, the majority of the respondents 231 (60%) revealed that there are no support services available for individuals with thalassemia and their families in their area. Similar findings had been reported in the study conducted by at Department of Physiology Islamic International Medical College Peshawar Road Rawalpindi, Pakistan. In that study psychological distress and

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

coping strategies among parents of β-thalassemia patients showed that all the parents of these thalassemia patients experienced severe parental stress and no support services available for individuals however, psychological distress was reported by 27 (67.5%) parents. Beta thalassemia is an unending illness that can lead to excessive psychological burden to the patients and their families (Rehman *et al.*, 2023).

Education was one of the major difficulties thalassemia patients faced. Among the total respondents, a higher Portion of caregivers 186 (48.3%) faced challenges related to thalassemia patient education (school, policies). These findings correlated with the study conducted at Nehru Hospital Chandigarh, 35 (70%) major Thalassemia disease adolescents expressed that the disease had an adverse impact on their education performance (Prajapati, *et al.*, 2021). Similarly another study mentioned that most of the thalassemia major patients education is affected due to attending the regular hospital for blood transfusion and chelation therapy (Yadav *et al* ., 2022). The present study revealed the relatives behavior regarding blood demand towards thalassemia patients and their caregivers. In response to the questions regarding ignorance by relatives due to blood demand, 239 (62.1%) revealed that they didn't ignore by relatives due to blood demand. They had no problem in family relationships and not ignored. They normally share their worries the relatives regarding blood demand. Similar, results had been reported in other studied conducted by in Antalya, Turkey. The study was undertaken at thalassemia center Antalya state hospital which revealed a weak positive correlation of 0.23 between pediatric patients and their parent's psychosocial burden (Lai, Huang, Su, & He, 2017). The present study revealed that a significant percentage of caregivers 358(93.0%) don't think that government support them financially for the treatment of thalassemia disease. These findings of our study were consistent with the study conducted in 2004 which demonstrated that the disease has affected parental financial state very badly worldwide. A study conducted in 2015 in northern Punjab demonstrated that average cost for treatment of a thalassemia patient is around 10,000 PKR (100 USD) per month apart from blood arrangements, which is too high for a poor family and it clearly demonstrated the financial burden of caregivers (Siddiqui *et al.*, 2015). In present study, 233(60.5%) respondents revealed that they faced challenges in reaching thalassemia Healthcare facilities. The results of our study were consistent with those reported in Gomel Journal of Medical Sciences which also revealed that though, the Government is providing blood transfusion facilities; subsidize and free medicines in public teaching hospitals, which are only limited to big cities. So, there is a need to focus more on reducing the financial burden by providing health care facilities in their areas. Financial support by exempting hospital bills and some support from the government would be helpful (Rehman *et al.*, 2023).

Present study founded that majority of caregivers 159 (41.3%) sometimes felt socially isolated due to their role as a caregiver or parent of a thalassemia. These results are consistent with the study conducted in northern Punjab, Pakistan to find Thalassemia Major Impact on patients' Families which also reported that the social activities of the affected family members are restricted due to regular transfusion (Siddiqui *et al.*, 2015). A review of the challenges to the families and caregivers that the social attitude, shame, and stigmatization towards the patient cause the parents to conceal the disease and secretly pursue the treatment and care of their children. The parents and the family become socially isolated and communicate poorly (Yousuf *et al.*, 2022).

Thalassemia is a preventable disease; there is a need for anti-thalassemic educational exhibits and awareness programs. The only effective way to overcome the prevalence of Thalassemia is to stop the birth of Thalassemic children by making pre-marital screening compulsory for the general public and counseling to the affected families. Thalassemia has already been addressed successfully in many countries like Iran, Greece, Italy, and Cyprus by running educational campaigns; making people aware of the disease and highlighting its preventive measures to get rid of the disease. It is the need of time to realize the density of the disease and practical steps should be

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

taken to reduce the prevalence of the disease. Therefore, it is important to make people aware of the disease, its complications and preventive measures. It was found that educated parents were more worried and tended to cure the disease. But the majority of the parents in Pakistan are illiterate and they have little awareness about the disease.

5.0. CONCLUSION

The study concluded that the parents and caregivers of thalassemia patients experienced several challenges in their lives. This study demonstrated the caregivers' psychosocial problems and concerns related to thalassemia which contributed to the impaired quality of life of caregivers. Having physical impairments, social stresses, financial burdens and problems with the education of their patients make them very much vulnerable to psychological trauma very early in their life.

Overall, caregivers with lower educational levels seemed to encounter more challenges across various domains related to thalassemia care, including patient education, financial support, emotional management, and social isolation. This underscores the importance of targeted interventions and support programs tailored to the specific needs of caregivers, especially those with limited educational backgrounds, to alleviate the burdens associated with caring for thalassemia patients and improve overall outcomes for both caregivers and patients (Mahmood *et al.*, 2017).

The study revealed the complex and demanding nature of caring for Individuals with thalassemia, emphasizing the need for comprehensive support services and resources to alleviate the burdens faced by caregivers and improves the quality of life for both patients and their families (Alshehri,*et al.*, 2022). Efforts to address these challenges should prioritize comprehensive support services, enhanced healthcare infrastructure, and targeted interventions to alleviate the burden on caregivers and improve the quality of life for both patients and their families. The study also revealed the significant challenges and barriers faced by caregiver, s of thalassemia patients, including difficulties in accessing healthcare, obtaining blood donations, managing emotional and psychological states, and navigating social isolation. These findings emphasize the need for comprehensive support services, enhanced healthcare infrastructure, and targeted interventions to alleviate the burdens faced by caregivers (Waheed *et al.*, 2022).

As thalassemia causes immense psychosocial, physical, and financial burdens to patients and their families and the present study concluded that the parent's awareness regarding the thalassemia was inadequate. It is required to enhance awareness by increasing the knowledge of the parents and caregivers about thalassemia. Educational programs are required to enhance caregivers' awareness about self-care and taking care of their ill children. The data suggests a need for increased education and awareness campaigns about thalassemia, particularly regarding its causes, types, available treatments, management strategies, and associated complications. Such efforts could empower caregivers with the knowledge necessary to provide better care for thalassemia patients and potentially mitigate risks associated with the condition. Further research in this area with a larger sample size, a control group, and multiple assessments should provide greater insights into the problems faced by caregivers and their patients and strengthen the case for an integrated approach to management. There is a need to understand the density of the problems and educate the general public and create awareness among thalassemia families in order to reduce the burden of thalassemia disease in this area (Shahzadi *et al.*, 2023). Awareness among close family members, relatives, friends, and the community should also be extremely helpful for social support. Financial support is required to lessen their stress. A multidisciplinary approach to managing the disease and psychosocial support is required for the management of thalassemia and to minimize the burdens on both patients and families. Prevention by making premarital screening and carrier identification through pre-implantation, and genetic diagnosis for β-thalassemia with or without HLA typing as well as genetic counseling for the parents to take appropriate measures will help to lessen the propagation of this disease (Mahnashi *et al.*, 2022).

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

It is essential that psychosocial support as well as medical help should be provided to the thalassemia major patients to minimize their burden. Healthcare professionals i.e. Doctors, Nurses, and Social Worker, must provide the psychosocial support to the caregivers of thalassemia patients and encourage them. It is the need of time to realize the density of the disease and practical steps should be taken to reduce the challenges associated with this disease which include awareness about thalassemia, its complications and preventive measures. All of this creates a hindrance in their way of developing into autonomous functioning caregivers. Thus, caregiver support in the form of education, self-help groups, psychological interventions and/or medication should be an integral part of management of thalassemia in order to optimize outcomes.

ACKNOWLEDGMENT

The authors sincerely acknowledge Dr. Rehman Zafar for his valuable guidance, critical review, and continuous support in the preparation and writing of this research manuscript. His academic expertise and constructive suggestions significantly contributed to improving the quality and scientific presentation of this work.

CONFLICT OF INTEREST

The authors declare that there are no conflicts of interest regarding the publication of this manuscript. The authors have no financial, personal, or professional relationships that could have inappropriately influenced the work reported in this study.

REFERENCES

Ahmed, M. M., Salaria, S. M., Qamar, S., Soaz, M. A., Bukhari, M. H., & Qureshi, A. H. (2016). Incidence of β-thalassemia carriers in Muzaffarabad, Azad Kashmir. *Annals of Punjab Medical College, 10*(1), 11-19.

Ali, M., Raja, W., Ali, M. H., Khan, J. M., Akbar, H. S., Siddiq, M., & Zafar, R (2026). Prevalence of Overactive Bladder Syndrome (OAB) among Individuals and its Prevention through Improved Strategies, a Cross-Sectional Study. *Prevalence*, *3007*(3197), 3007-3189.

Basharat, H., Waseem, A., Mukhtar, A., Ali, M. H., Khan, J. M., Chaudhry, B., ... & Hadi, F. (2026). Breast cancer side effect evaluation using Naranjo Algorithm, A Cross-sectional questionnaire based descriptive study. *Phytopharmacology Research Journal*, *5*(1), 110-127.

F. Mahmood, M.S. Jan, S. Ahmad, U. Rashid, M. Ayaz, F. Ullah, F. Hussain, A. Ahmad, A.-u.

Khan, M. Aasim, 5 (2017) 119. Ethyl 3-oxo-2-(2, 5-dioxopyrrolidin-3-yl) butanoate derivatives: anthelmintic and cytotoxic potentials, antimicrobial, and docking studies, Frontiers in chemistry,

Charoenngam, N., Rittiphairoj, T., & Ponvilawan, B. (2021). Fracture prevalence in thalassemia: A systematic review and meta-analysis. *Archives of Osteoporosis, 16*, 1-11.

Farheen Shaffique *et al.* (2023). Knowledge, Attitudes, and Perceptions Towards Beta-Thalassemia among Residents of Azad Kashmir, Pakistan. *Journal of Zoology, 38*(1).

Ishfaq, K., Diah, N. M., Ali, J., Fayyaz, B., & Batool, I. (2018). Psychosocial problems faced by thalassemia major patients of district Multan, Pakistan. *Pakistan Pediatric Journal, 42*(1), 22-26.

Khan, A., Bukhari, S. S., Alvi, M. I., & Qazi, A. (2011). Seroprevalence of hepatitis B, hepatitis C and HIV in blood donors of Peshawar. *Gomal Journal of Medical Sciences, 9*(1).

Khaliq, S. (2022). Thalassemia in Pakistan. *Hemoglobin, 46*(1), 12-14.

Kattamis, A., Forni, G. L., Aydinok, Y., & Viprakasit, V. (2020). Changing patterns in the epidemiology of β-thalassemia. *European Journal of Haematology, 105*(6), 692-703.

Lee, K. H., Yu, K., Al Ba'ba'a, H., Xin, A., Feng, Z., & Wang, Q. (2020). Sharkskin-inspired magnetoactive reconfigurable acoustic metamaterials. *Research*.

Lai, K., Huang, G., Su, L., & He, Y. (2017). The prevalence of thalassemia in mainland China: evidence from epidemiological surveys. *Scientific reports, 7*(1), 920.

Prajapati, N. K., Samani, M. J., & Jani, A. M. (2021). Caregiver burden and psychiatric morbidity among caregivers of children with

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

thalassemia major: A cross-sectional study. *Annals of Indian Psychiatry, 5*(1), 43-49.

Rasheed, M. A. B., Ashraf, N., Khan, J. M., Sohail, K., Zafar, R., & Fahid, M. (2026). Assessment of Infectious Healthcare Waste Disposal Practices Across Different Wards of Public and Private Hospitals: A Questionnaire-Based Cross-Sectional Study. *Pakistan Journal of Medical & Cardiological Review*, *5*(2), 4794-4813.

Rehman, I. U., Khan, T. M., Bukhsh, A., Munawar, K., Suleiman, A. K., Ming, L. C., . . . Choudhry, F. R. (2023). Challenges of having a child with thalassemia in Pakistan: A phenomenological study. *Journal of pediatric nursing, 72*, e179-e186.

Siddiqui, M., Rehman, F. U., Nazir, I., Khan, M. M., Zafar, S., Ali, Z., & Qadir, I. (2015). Thalassemia Major Impact on patients' Families in Northern Punjab, Pakistan. *PJMHS, 9*(3), 870-875.

Töret, E., Karadaş, N. Ö., Gökçe, N. Ö., Kaygusuz, A., Karapınar, T. H., Oymak, Y., & Gözmen, S. (2018). Quality of life and depression in Turkish patients with β-thalassemia major: A cross-sectional study. *Hemoglobin, 42*(5-6), 326-329

Yadav, S. S., Panchal, P., & Menon, K. C. (2022). Prevalence and management of β-thalassemia in India. *Hemoglobin, 46*(1), 27-32.

Yousuf, R., Akter, S., Wasek, S. M., Sinha, S., Ahmad, R., Haque, M., & Salam, M. W. (2022). Thalassemia: A Review of the Challenges to the Families and Caregivers. *Cureus, 14*(12).

Zafar, R., Zafar, I., Waseem, W., Shahid, K., Jan, M. S., Khan, A. A., & Hadi, F. (2026). A Retrospective study of Hepatitis B and C Viral Infection Predominance among illiterate Individuals of Capital Islamabad, Pakistan. *Phytopharmacology Research Journal*, *5*(1), 135-145.

O.M. Alshehri, M.H. Mahnashi, A. Sadiq, R. Zafar, M.S. Jan, F. Ullah, M.A. Alshehri, S. Alshamrani, E.E. Hassan, 2022 (2022) 6726438. Succinimide Derivatives as Antioxidant Anticholinesterases, Anti-α-Amylase, and Anti-α-Glucosidase: In Vitro and In Silico Approaches, Evidence-Based Complementary and Alternative Medicine.

B. Waheed, S.M. Mukarram Shah, F. Hussain, M.I. Khan, A. Zeb, M.S. Jan, Synthesis, 2022 (2022) 1445604, antioxidant, and antidiabetic activities of ketone derivatives of succinimide, Evidence-Based Complementary and Alternative Medicine.

K. Shahzadi, S.M. Bukhari, A. Zaidi, T.A. Wani, M.S. Jan, S. Zargar, U. Rashid, U. Farooq, A. Khushal, S. Khan, 16 (2023) 1552, Novel coumarin derivatives as potential urease inhibitors for kidney stone prevention and antiulcer therapy: from synthesis to in vivo evaluation, Pharmaceuticals.

M.H. Mahnashi, Y.S. Alqahtani, B.A. Alyami, A.O. Alqarni, M. Ahmed Alshrahili, M.A. Abou-Salim, M.N. Alqahtani, S. Mushtaq, A. Sadiq, M.S. Jan, 2022 (2022) 7921408, GC-MS Analysis and Various In Vitro and In Vivo Pharmacological Potential of Habenaria plantaginea Lindl, Evidence-Based Complementary and Alternative Medicine,