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A Phenomenological Study of Psychosocial and Educational Challenges of Parents having Children with Thalassemia

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Abstract

Thalassemia is a major public health problem and the most common hereditary disease in the world. Having no permanent cure, 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. Therefore, the present study was aimed to explore the parents' experiences of thalassemia patients, particularly their educational challenges. A phenomenological research design was adopted to investigate the research questions. Through purposive sampling technique, the sample of 10 caregivers of thalassemia patients from Safe Life Thalassemia Centre Sargodha were selected. The interview guide was used to collect the data. Through thematic analysis, five major themes were generated including, Economic constraints, psychological concerns, social apprehension, impact on daily family life, and child's educational experiences. The results of the present study indicated that caregivers especially mothers of patients face multiple challenges including socio-economic problems, psychological worries, and issues of overall integration in their respective communities. This study concluded that children due to their illness, face difficulties in school and remain absent for longer period of time and consequently they suffer psychologically which further increase the severity of their illness. Moreover, due to this disease, day to day family life of patients affect too, leaving them more *vulnerable to cope with the challenges. This situation demands institutional support and mechanism for thalassemia patients to continue their education and special trainings of coping strategies for the caregivers.*

Keywords: *Thalassemia, Caregivers, Psychosocial problems, Educational Challenges, Coping Strategies.*

Introduction

In the contemporary world, thalassemia has become a prominent and excessive issue. The term "thalassemia" refers to a group of hereditary, inherited blood disorders that run-in families and cause the body to produce hemoglobin in an uneven pattern. Anemia is brought on by the disorder's excessive red blood cell breakdown. It cannot be transmitted from one person to another by direct contact and is not communicable (Reddy et al., 2022). Major and minor thalassemia are the two types of thalassemia. Minor thalassemia is thalassemia brought on by defective genes that can be inherited from either parent. Thalassemia major is a condition where the affected person inherits faulty genes from both parents. Major thalassemia is the most severe type of thalassemia and causes severe anemia in individuals as well as heart failure, exhaustion, and cachexia (Ali et al., 2021).

Additionally, this is common blood disease among children throughout several areas, including Southeast Asia, the Indian subcontinent, the Middle East, Transcaucasia, and Central Asia (Zaheer et al., 2020). There are no reliable statistics on the prevalence and fatality rates of hereditary blood disorders in Pakistan, however, according to the latest research (Khaliq, 2022), one of the greatest thalassemia loads in the world is in Pakistan. Due to Pakistan's 5.0–7.0% thalassemia major trait frequency range, there are more than 10 million thalassemia major carriers, and each year, 5,000–7,000 children are getting recognized as carriers. The reason of this catastrophic situation is that thalassemia patients have mutations in the DNA of the cells that make hemoglobin, part of red blood cells which carries oxygen throughout the body. Due to this characteristic of the disease, parents can pass on thalassemia-related mutations to their children (Clinic, 2021). A marriage between two relatives, like cousin marriage, is the most frequent reason for thalassemia in progeny. As in Pakistan, cousin marriages is quite common practice, therefore there are numerous incidences of Thalassemia in Pakistan (Sohail et al., 2020).

Contrary to other diseases, Thalassemia has no permanent cure which cause a significant load on the already overburdened and resource-constrained national health care system, particularly the blood transfusion system (Zaheer et al., 2020). Therefore, the cost of caring for a child who has thalassemia can be a significant hardship for families in terms of high expense of thalassemia treatment, which includes frequent blood transfusions, chelation therapy, drugs, and specialized care (Shafi et al., 2021). Research reveals that parents in low-paying, physically demanding occupations experience higher levels of stress and sadness (Hussain et al., 2021). In addition, the entire family of thalassemia patients commonly has psychosocial issues, with sadness, anxiety, and intellectual, emotional, and behavioral disorders being the most prevalent. Due to the extensive and demanding lifetime treatment protocol, beta-thalassemia major has an impact on patients and their caregivers mental state, everyday activities and family experiences (Afzal et al., 2023). Research document that 49% parents of thalassemia major children reported moderate to severe level of stress and emotionally invested (Inamdar et al., 2015; Nabavian et al., 2022). Further, parents of children with thalassemia encounter challenges to prioritize and manage their child's educational needs in the normal school settings along with medical support and care. It also becomes difficult undertaking for educators to carefully coordinate and support children's educational needs as well as health issues (Heidari & Ahmadi, 2020). Because children with these kinds of disabilities are frequently uncomfortable disclosing their handicaps out of concern that they may be denounced, it is crucial to give them equal opportunity to learn and thrive despite whatever obstacles they may encounter. Unfortunately, a youngster may perform poorly or completely drop out of school as a result of this lack of openness (Ogli, 2020).

Moreover, poor health-related quality of life, maintaining a sufficient level of education and job, establishing a family, and having rewarding relationships are challenges faced by thalassemia patients. As with other chronic diseases, the medical management of thalassemia necessitates many inpatient and outpatient visits, and its complications may make it difficult to keep employment or pursue higher education (Pakbaz et al., 2010). According to findings from a different study, sociocultural variables also have an impact on how parents experience caring for children with thalassemia. Thalassemia-related social stigmas, preconceptions, and attitudes can have an impact on parents' experiences and their ability to receive support resources. Thalassemia may carry a social stigma or be linked to unfavorable perceptions in some cultures, which can make parents and their children feel ashamed or alone. These variables may have an impact on parents' experiences and their access to support resources, adding to the difficulties they face when providing care (Yousuf et al., 2022).

Behdani et al. (2015) reported that the onset of symptoms, the needs of medical treatment, and frequent absences from school place heavy demands on the children's and their families' interpersonal and emotional resources. It is possible to improve the general well-being of both parents and children by addressing and recognizing the difficulties faced by parents of children with thalassemia (Saleem et al., 2021). Therefore, this study aimed to fill this gap in the literature by exploring the lived experiences of families with thalassemia patients to see its impact on family dynamics. Additionally, Due to the symptoms and side effects of this disease, thalassemia patients confront a number of educational problems. For instance, these patients may have persistent exhaustion as a result of the disease and its treatment side effects. Their lack of sleep may interfere with their ability to concentrate, which makes studying challenging. These patients may have learning disabilities or cognitive impairments. These issues may affect their capacity to acquire and retain knowledge, making it difficult for them to comprehend and put academic principles into practice. Therefore, it was pertinent to explore the educational challenges face by thalassemia children in schools, as well as the psychosocial and economic challenges faced by their parents

Research Questions

Following were the research questions of the current study.

- What are the psychosocial and financial constraints faced by the parents of Thalassemia patients and to what extent it impacts the family dynamics?

- Which educational challenges are faced by thalassemia children in schools and what could be the effective strategies to cater their educational needs?

Theoretical Framework

The Family Systems Theory is a well-known theory that can assist in illuminating the issues that parents of children with thalassemia encounter. The goal of this theory is to comprehend how families function as a whole and how the actions and interactions of particular family members affect the dynamics of the entire family. The Family Systems Theory offers a framework for comprehending the struggles parents of children with thalassemia encounter. It underlines the effects on the emotional and psychological level, changes in roles and communication styles, and the possibility of resiliency within the family system. These aspects can help medical practitioners, teachers, and support groups offer thalassemia families comprehensive care that considers the special requirements of both parents and their affected children.

Research Methodology

According to the purpose of this research and to gain in-depth knowledge, the qualitative research method with the phenomenological research design was adopted in this study because it deals with the lived experiences of respondents. Because qualitative research aims to comprehend how individuals interpret their perceptions in light of their values and actual situations. To explore the phenomena of thalassemia the population of this study was all caregivers of the thalassemia patients in Safe Life Thalassemia Centre. Keeping in view the nature of the study the present research used a purposive sampling technique to draw the sample from the population. Out of 25 caregivers registered with Safe Life Thalassemia center, ten caregivers were interviewed till the data saturation.

An unstructured interview schedule, which was developed in the light of available literature, was utilized to record the experience, and data were gathered through in-depth interviews with caregivers of Thalassemia patients. The questions about the awareness of thalassemia disease, effect on the daily routine, social problems, financial issues, mental health, problems faced by patients in schools, teachers’ behavior etc. were asked to the patient’s caregiver.

The analytical process was guided by qualitative thematic analysis. Through an organized cataloging process of coding and theme or pattern identification, the qualitative thematic analysis is a research approach for the subjective explanation of the content of text data. The first researcher recorded, transcribed, and analyzed the audio responses, read the transcripts of interviews repeatedly, and allocated codes to recurrent themes. After reviewing all the interviews, the researcher used the coding system. After the process of coding different themes was developed. Themes were used as the basic unit of analysis in this study that enables the researcher to locate and bring together similarly labeled data for investigation. The result of the data analysis is given below.

Results

In-depth interviews were conducted of total ten respondents, all were mothers of the thalassemia patients. The demographic profile is presented in the table 1.

Table 1

Demographic Profile of Participants

Participant	Age	Residence	Monthly income (Rs)	Number of children	Educational Status of Patient
R1	20 years	Sargodha	30,000	1	Not School Going
R2	31 years	Shah Pure	20,000	3	School Going
R3	23 years	91 Chak Sargodha	20,000	1	School Going
R4	35 years	Mandi Bahauddin	25,000	5	School Going
R5	28 years	Shah Pur	15,000	3	Not School Going
R6	24 years	Sargodha	15,000	1	Left the School
R7	33 years	Sargodha	25,000	4	Not School Going
R8	25 years	Jhal Chakian	15,000	1	School Going
R9	26 years	Sargodha	20,000	2	Left the School
R10	29 years	Kot Momin	25,000	3	School Going

For the sake of confidentiality of the respondents, they were coded as R1, R2 etc. Table 1 indicates that the ages of mothers ranged from 20-35 years, while the majority lying in between 20-30. This demographic profile indicates that patients belong to different regions of central Punjab who come to Safe Life Organization for blood transfusion and most of the respondents reported that they come alone with their child due to the lack of social support. Further, their income index shows that they belonged to low-income families which are insufficient according to their daily expenses and child's disease. The 60% of the mothers were having more than one child, which further demonstrates the severity of their situation to become caregiver of such patient along with the mother of other children. Besides this fact, this table also shows the educational status of the patient child. total 5 children were school going and were between age of 7 to 10 years old, 3 were not reached at school going age (less than 5 years old) and 2 children left the school due to their illness.

Thematic Analysis

The in-depth interviews of the 10 caregivers were recorded and converted into the transcripts. The transcripts were attentively reviewed in order to understand each segment as a whole and to identify the themes. Following major themes were emerged from participants' interviews.

- Economic constraints
- Psychological concerns
- Social apprehension
- Impact on daily family life
- Child's Educational Experiences

Economic Constraints

Answering the question on financial issues, the majority of the respondents reported that they face many problems and the scarcity of finances was the major concern that the participants expressed. It was included both direct and indirect costs, direct costs encompassed costs of blood transfusion, prescription, hospitalization, medical doctor visits, and laboratory test. While, indirect costs included transportation costs, and high expenses of treatments, transportation, expenses of patients, expenses of other children, besides the living costs imposed a heavy burden on families. These extra costs also included the cost of treatment, a side effect of therapies, and many indirect costs were included rent and fare charges which were playing a major role in the financial burden. As the demographic table 1 also demonstrated that most patients were belonged to rural areas or suburbs, where specialist doctors and adequate facilities for diagnosis are hard to find. Therefore, they have to come to nearby big city for the treatment of their child and many parents cannot afford the fare expenses, such situation becomes worsen when they lost wages due to missed workdays.

As many children with thalassemia major depend on regular blood transfusions thus always in a high need for blood, all respondents agreed that financial stress was a significant problem for many parents. They tell that after getting registered with NGO, they got the facility of free medical tests and even don't have to pay for medical checkup and blood transfusion charges but still they face unbearable financial burden. Other financial problems were related to the respondents living and transportation costs of visiting the hospital/NGO, food for patient and caregiver, and medicines expenses.

Psychological Concerns

According to the data, parents of thalassemia patients were highly affected psychologically. All the respondents reported that they experienced psychological distress, anxiety, frustration, and depression because of their child's disease and seeing them suffering. Answering the question on psychological problems the majority of parents explained that they are disturbed emotionally and depressed to see their child suffering from disease and pain. The parents of thalassemia patients experience a high degree of distress when compared with the parents of normal children and the parents had to face countless fears. Further, the fear of death was another main tension for mothers because they said that when people came to know about our child's disease, most people said that their child will die so their gossip disturbed us every time consequently no time to relieved. For example, R6 reported that: "*Life begins with happiness but suddenly it changes its phase when the disease was diagnosed of her child. Our tension for our child's future deprives us of the joys of life. The child's sickness is all the time tension, we do not know what will happen to them in the future. Why did her child get this disease*?". Some respondents also related this phenomenon to their unintentional sins or fate.

Social Apprehensions

Social apprehension was regarded by respondents as a significant element that allocates the suffering of mothers. Social acceptance towards the family with thalassemic child was an important factor of a social support. On contrary, social apprehension involves three major factors. One is an absence of a support system, the second one is social stigma, and the third is rejection by the society. Participants complained about the lack of a support system for the suffering families. High financial expenses of treatment, hospitalization, and transportation besides the extra home expenses imposed a big burden on patient's families. In such situation, a support system in terms of a health care system can help in mitigating the financial impediment.

The next one is stigma, and it is a very significant factor in this study. According to the results, the participants experienced social stigma, evil eye or calamity which is attached to the family with a sick child. Wahab et al. (2011) reported that thalassemia as a reason for shame and stigmatization leading the social isolation and low self-esteem. Based on the views, during the interviews, participants reported that they face a high level of stigma and having fear of rejection and ridiculed by others for them and for their child as well. They further reported that normal children in community and schools, even their parents do not want to befriend with patient child which impedes them to integrate socially. in schools, no special educational arrangements provided to the thalassemic children nor teachers are trained enough to deal with these patients.

In addition, they stated that after the diagnosis of this disease in their child, majority of people changed their attitude towards them and their patient child. The majority of people felt pity, some blamed that family of these patients are punished by God and some people treat patients and their families as offenders. A false belief about this disease it's a big problem. Even some respondents reported that the hurting and disappointing behavior of their relatives. Therefore, families housebound the thalassemia patients to tackle with these difficulties. Therefore, the third theme was found **rejected by society.** Participants complained about the people's behavior by saying that people misbehave with them and they feel very embarrassed. The majority of the participants expressed that due *to the taunts and misbehaving of people, they are unable to go to social activities. Our social circle becomes very low because people scared us that these children do not live long and will die soon.* Having a sick child in society is considered a worry for parents. All the participants reported that they wished that their children be treated with kindness and love by others.

Impact of a Disease on Family Life

Answering the question on the effect of disease on daily life participants said that they faced many problems, so this theme was consisted of three factors, sleeping disorder, interpersonal weak relation, lack of diversion, and break. Most of the respondents expressed that they have deprived of sleep (**sleep disorder**) because they have no time for relaxation due to their child's disease.

Participants express their experiences in their relationship with their spouse, patient child, and another child. The majority of the respondents claimed that they have good relationships with their father but have very weak with their siblings. The healthy children in the family sometimes complaint of parents' negligence towards them and extra care and affection towards patient child only. This shows the weak interpersonal relationship. Most of the participants had experienced fatigue and tiredness during the care of the patient child. Apart from this, they have to perform other household duties, so they have no leisure time even if they have no time for many important tasks. It is very difficult for the patient's parents to manage the household tasks and they cannot manage their time especially their mothers feel very uncomfortable because other healthy children feel inferior as their parents couldn't give the due attention towards them. This may lead to severe disturbance of the family equilibrium or the **breaking up** of the home.

Child's Educational Experiences

This theme describes the participant's opinions about their child's educational needs and their child's academic experiences Respondents stated that children with illnesses encounter many challenges in school, absence from school is the biggest problem which effect their academic performance. This absenteeism ranges from a day to a week and they are helpless to miss their school for their follow-up appointments with doctors, medical therapies, and blood transfusions. Respondents stated that child with thalassemia had trouble in keeping up with the curriculum and making up for missing classes which effect academic performance due to child's learning difficulties. For example, R3 quoted that, "*my child has missed a large number of school days as a result of frequent doctor's appointments and medical treatments. His attendance and ability to concentrate in class are affected by the numerous blood transfusions*".

Isolation was frequently mentioned as an issue that children experienced in school. They claimed that because of this illness, their child feels alienated from their peers. Their social connections at school and sense of self-worth are affected by this illness. They require support and accommodations in the classroom. Observing our children go through this stage of feeling different from their classmates has been quite upsetting. one respondent reported that, "*my child has conveyed to me that he feels excluded and cut off from their peer group. His/her attempts to interact with others appear to have gone unappreciated, which causes them to feel excluded and alone*".

Respondents who were asked what modifications are normally required for thalassemia students in the classroom? were stated that these students need special accommodation like, more time for assignments and tests. To control their exhaustion, they require a longer time to finish tasks. But regrettably, some kids lack access to these resources, which is bad for them because they require more care and attention from their instructors, peers, and school administration.

Discussion

The main purpose of the study was to investigate the lived experience, challenges, and constraints faced by the parents or caregivers of Thalassemia patients. Results indicated that parents' life is exceedingly affected due the thalassemia in their child in term of psychological, financial, sociological and educational aspects. The finding signifies that stigma, rejection by society, economic burden, and lack of social relations, psychosocial worries, and sad emotions in parents increased by the patient's illness. As Ali et al. (2012) support the same findings, they showed that the parents had to deal with a variety of issues, including the child's psychosocial adjustment, financial difficulties, the supply of treatment, and social issues. These findings synchronize with the study of Aziz et al. (2012) in which they concluded that since there is currently no cure for this illness, the majority of patients only receive blood transfusions. This puts a strain on the healthcare system and the afflicted families, who are more susceptible to social and psychological issues. Ogli (2020) proposed that educational institutions are responsible for ensuring that the provisions of the disabled are followed and appropriate conditions are supplied. As the results of this study showed that children with thalassemia encounter many health concerns and hence need more educational accommodation and special attention in school.

In addition, the results of this study showed families with thalassemia encounters problems in maintaining the family system. It is quite difficult for a woman to manage the whole work including all household duties, taking care of a sick child, and husband responsibilities. As reported by the respondents that their other children feel jealous and complain that they are deprived of the pleasure and love of their parents which ultimately disturb their family life. These finds are aligned with that of Abu Shosha & Al Kalaldeh (2018) who found that Thalassemia disease may lead to severe disturbance of the family equilibrium. Family members and other children are affected because the illness of a family member directly affects the whole family.

Further, the results revealed that thalassemia disease damaged the financial condition of the patient's families. Financial issues were the most important concern that increased the burden of the family having child with thalassemia. Increased expenses associated with treatment, transportation, and other living cost were the most cause of the burden for families. Previous findings support this research(Abu Shosha & Al Kalaldeh, 2018), all parents thought that the problem of financial stress was crucial. Some parents experienced financial difficulties as a result of the costs associated with hospital visits and blood transfusions.

Conclusion & Suggestions

In the light of the findings of this study, it was concluded that caregivers of children with thalassemia face psychosocial, financial difficulties during their treatment and children face the learning difficulties as well which in result disturb their family life and fear about the future of their children. A reasonable amount should be specified in the health budget by the government for the treatment of thalassemia to reduce the economic constraints on parents of thalassemia patients. To mitigate the spread of this disease, social citizens, societal administrations, and civil societies should initiate the awareness campaigns and arrange a seminar in every city and town to make people aware of this disease and its causes. As the findings showed that all the participants were reported psychological disturbance due to this disease, hence counseling programs must be arranged by the civil society organizations for the parents/caregivers of thalassemia patients and for the community to play the positive role in dealing with social isolation and psychological issues of these families.

Results also showed that parents and children suffer with the social isolation due to less time spending in social activities or the non-supportive and negative behavior of the people. Due to these challenges, either children exhibit poor academic performance or leave their schools in case of not coping up with the difficulties and long absenteeism from school. Therefore, they must be provided educational accommodation and a conducive learning supportive environment in schools. As Ogli (2020) argued that educational institutions must see that the rights of the disabled are upheld and that reasonable accommodations are made. Last but not least, drop out or absenteeism can be controlled by educating these children through educational gadgets, learning software and by arranging online classes by the schools so that the children may be able to study at home. Counselors should also be arranged in schools for the counseling and educating coping up strategies to thalassemia children and their parents. Further, special training sessions and knowledge sharing seminars must be integrate in the teachers' training programs to enable the teachers to teach the patient students as well parallel to the healthy students.

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