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Challenges and Lived Experiences of Mothers Caring for Children with Thalassemia: A Study of Sargodha District

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ABSTRACT

Thalassemia is a genetic disease requiring lifelong treatment, including frequent blood transfusions, drug therapy and continuous medical supervision. Despite efforts to improve thalassemia medical management in Pakistan, limited research has examined the challenges and lived experiences of mothers who are primary caregivers of children with thalassemia, particularly in District Sargodha. This study explored the experiences and challenges of those mothers using a qualitative phenomenological design. Data was collected from 32 mothers selected through purposive sampling using semi-structured in-depth interviews. The research data was analyzed using narrative and thematic analysis techniques. Findings revealed considerable emotional, physical, and psychological stress, including anxiety, fear, sadness, uncertainty, and emotional exhaustion. Mothers also reported impacts on family life, social participation, finances, and personal health, along with social isolation, gender and cultural stressors, and challenges within healthcare settings. The study recommends a family-centered, holistic approach incorporating psychosocial counseling, social support, effective healthcare communication, and community-based services to improve mothers' wellbeing and the quality of care provided to children with thalassemia.

1. Introduction

Thalassemia is a hereditary blood disorder in which patients' body is unable to make enough and healthy blood. It causes chronic anemia and

needs life time medical care (Shah & Badawy, 2024). Transfusion dependent thalassemia (TDT) children need regular red blood transfusions, iron-



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chelatron therapy, life-long medical monitoring, and specialized medical services. Despite, the significant advancement in medical research and treatment, thalassemia patients and their families faces significant physical, emotional, social and financial issues. Thalassemia carries biological effects of the disease and entails on the family functioning, psychological and social condition. It is one of the most severe inherited blood diseases in children that impacts millions of people worldwide and health-care systems and society (Baqar et al., 2026).

The prevalence of thalassemia is relatively high in Pakistan because of consanguineous marriages, low public awareness and lack of adequate preventive screening. They are confronted with extra load of care giving in a limited health care system and a wide variety of sociocultural environments. In Pakistan, recent research data indicated that there were 13.7% parents who recognized thalassemia as an inherited disease, while 91.6% were unaware of premarital and antenatal screening (Akhtar et al., 2025). Like other parts of the country, in district Sargodha, many thalassemia patients are getting treatment at public and private healthcare facilities. Although thalassemia is an important public health problem, yet comparatively little qualitative work has examined the lived experiences and challenges of mothers caring for thalassemia children in their own socio-cultural settings. In-depth analysis is vital for designing culturally responsive interventions, improving health care, guiding social work practice and creating policies to foster psychological, emotional and social health for caregivers and children.

A recent study identified that self-acceptance and personal growth were important factors associated with caregiver's well-being but in Pakistan there was a significant decrease in the quality of life of the caregivers in all domains (Hood et al., 2024). Caregivers experience ongoing uncertainty about the child's health, potential complications with treatment, education, adulthood and independence in the future. Mothers were also emotionally upset due to long-term worries about children's lives while treatment and afterwards. The research also identified that even after increasing body of research, there is a significant gap in context-specific qualitative evidence in relation to the ways mothers understand and experience the

difficulties of long-term care (Dindor et al., 2026). This quantitative study has determined the extent of the problem of caregiver burden and offers a chance to explore the mothers' view with their lived experiences, caring responsibilities' impact, family dynamics and family decision making in District Sargodha, where family structure, cultural norms, economic limitations and healthcare services impact mothers' lives with respect to caring for children with thalassemia. Hence, the present study aimed to discuss the lived experiences and challenges of mothers with the children who were suffered in thalassemia in District Sargodha, Punjab, Pakistan. Specific focus was on mothers emotional and psychosocial experiences, caring roles, financial problems, social relationships, gender roles, household decision making, health experiences and sources of support.

Research Objectives:

1. To explore lived experiences of mothers caring for children with thalassemia.
2. To understand psychosocial and financial challenges experienced by the mothers of children with thalassemia.
3. To gain insight into the perceived impact of long-term care on the physical, emotional and psychological wellbeing of the mothers.
4. To understand social challenges and support system used by the mothers of thalassemia children.

Literature Review

Thalassemia is a chronic blood disease that affects children and their families throughout their lives. Children with transfusion-dependent thalassemia need frequent blood transfusion, iron-chelation therapy, laboratory testing and ongoing engagement with healthcare services (Ansari, Parveen, Siddiqui, et al., 2018). The disease impacts on the child patients also caregiver's psychological, social, economic and family lives. Treatment-related stress, financial burdens, psychological distress, social restrictions and worries about the child's future are all multidimensional challenges faced by parents in Pakistan (Akram et al., 2023; Hood et al., 2024).

Literature suggests that the treatment is a lifetime process, and caring is an important and long-term commitment. Mothers and other caregivers need

to accompany children in transfusion centers, give medicines, observe the symptoms, make arrangements for transport, communicate with health care providers and care for household. According to Baqar et al., (2024), a qualitative research study conducted with 18 caregivers in Karachi highlighted that inadequate disease awareness, financial burden, high cost of chelation medication, blood shortage, complex registration process and lack of emotional and social support were identified as significant challenges for care of a patient. These duties limit the work opportunities, social life, recreational activities, and personal health care of caregivers. This is especially relevant for mothers, because the role of women is defined by culture as the one in charge of the household chores and childcare. Children with the diagnosis of β -thalassemia major need regular blood transfusion every 2 to 4 weeks of life (Dindor et al., 2026).

Literature identified that another aspect of the caregiving experience is psychological distress as anxiety, sadness, feeling helpless, emotional fatigue and decreased quality of life. Hood et al. (2024) found that caregivers in Pakistan had significantly poor quality of life compared to 100 caregivers where they showed that psychological wellbeing is linked to various domains of quality of life. Poor mental health and daily functioning observed in female caregivers with low self-acceptance in particular. Likewise, Yasmeen et al. (2024) reported the burden of caregiver and depressive concerns of parents in Pakistan as well as their impact goes beyond the child's disease to the psychosocial health of the family. Further studies have also found a negative relationship between caregiver burden and psychological functioning, with income that was found negatively related to caregiver burden (Khan et al., 2025).

Thalassemia poses extra challenges due to its genetic cause. Anxiety, misunderstanding, stigma and responsibility are the problems for parents due to limited knowledge of carrier status and genetic inheritance. Akram et al. (2023) stated that parents in Pakistan are not aware of genetic characteristics. The results showed that genetic counselling and health education are important not only for prevention but for lessening the distress and misconceptions of families. Moreover, social and family relationships can create stress or

become a support for the mothers. Mothers' participation in social activities, work and family events can be affected because of frequent hospital visits and treatment needs that leads to her isolation. Economic problems, psychological issues, social anxiety, disturbed daily lives of families, and educational difficulties were found to be important issues among caregivers in Pakistan (Abbas et al., 2023).

Another study indicated that a major part of the burden of caring for thalassemic children is the economic cost. Some transfusion services are subsidized, but on the other hand some families have to pay for medicines, chelation therapy, laboratory investigations, nutrition, and treatment of complications as well as transportation costs. A survey of parents in Quetta (2024) revealed that parents' recurring transportation and food expenses for transfusion visits. The fact that most families had single person to earn. Similarly, research conducted in Punjab has revealed physical, emotional and financial burden of caregivers (Sikandar et al., 2024). Financial pressures further exacerbated if carer reduces working hours or gets out of employment due to repeated hospital appointments and treatment needs. A recent study conducted in Hyderabad also indicates that parents have access-related, financial-related, uncertainty-related and burden of long-term treatment related issues (Junejo et al., 2026). Therefore, caring burden is a phenomenon that must be viewed in the context of health care and social services conditions, not as a problem of the caregiver's psychology.

Methodology

The study was based on qualitative research methodology by using phenomenological approach. A qualitative approach was justified for insight of thalassemic child-mothers lived with and experienced caring for children with thalassemia. The study was carried out in District Sargodha of Punjab, Pakistan. The subjects were mothers with children diagnosed to have thalassemia. There were 32 mothers as participants in the study. The participants were selected by purposive sampling. The participants shared their data on daily care and treatment problems, relationships, financial issues, social interactions and coping mechanism.

An interview guide was developed to conduct the

interviews and semi structured in-depth interviews were used to collect data. The themes related to mothers' experiences of diagnosis and treatment, emotions, everyday caregiving, finances, family relationships, social inclusion, health services and decision making were raised in different areas. For this study, semi-structured interviews were particularly appropriate to explore sensitive experiences like family problems, financial issues and social limitations. Narrative and thematic analysis was used to analyze the interview data.

Ethical Considerations

The principles of ethical research including voluntary participation, informed consent, confidentiality and anonymity were adhered. Participants were given information regarding the purpose of the study and their right to take part in the study voluntarily. Reporting of the findings did not include identifiers and participants were referred to by numbers. Moreover, ethical approval was formally obtained from Ethical Review Board, University of Sargodha, before conducting the research.

Results and Data Analysis

The analysis resulted in narrations and a series of research themes related to mothers' experience of caring for children with thalassemia. These themes were based on individual issues and an illustration of the interaction between the medical needs and emotional health, family responsibilities, economic circumstances and social relationships.

Theme 1: Emotional and Psychological Burden

Emotional and psychological distress was the most striking aspect of mothers' experience. Participants shared the fears, anxiety, sadness, emotional exhaustion and ongoing worry about their children's health.

A Participant (Age 28) from Urban area at the shared her concern by saying;

“Since my son was diagnosed with thalassemia, my whole life has changed. Now I am concerned about his condition every day. Even when he is doing well, I remain anxious and keep thinking about what might happen tomorrow. I have so many questions about his illness. Will we be able to arrange his blood transfusion on time? Will we

have enough money for his treatment? Sometimes I wake up during the night because I worry about my son's future. I keep thinking whether he will be able to attend school like other children, whether he will have a normal life, get married, and become independent when he grows up. Before my son became ill, I was very active and social. I enjoyed spending time with my family, communicating with others, and laughing. Now, most of my attention is focused on my son and his illness. I try to hide my emotions in front of him because I want to remain strong for him, but inside I feel scared”.

These findings are consistent with research conducted in Pakistan, where caregivers of children with thalassemia have been reported psychological difficulties and reduced quality of life. Hood et al. (2024) reported problems related to caregivers' quality of life, concerns about children's future, financial difficulties and inadequate emotional and social support as important challenges for caregivers. In this context, the present finding suggests that the psychological burden of thalassemia is not limited to concern about the child's current health but also involves uncertainty about the child's long-term future.

Another participant (Age 32), from rural area, described the emotional and psychological burden of caring for her child with thalassemia. She shared that her child's illness had made her more worried and emotionally sensitive in her daily life. She expressed her feelings by saying;

“I remain worried about my child most of the time. Whenever his health changes, I become nervous and start thinking about whether something serious might happen. His treatment has become a regular part of our life, but I still find it difficult emotionally. Sometimes I feel tired and helpless, especially when I see my child suffering. I try to stay strong in front of my family, but inside I feel very worried. I also think about his future and whether he will be able to live an independent life”.

The participant's experience shows that caring for a child with thalassemia can create continuous psychological pressure. Her concerns were not only related to the child's present health but also to his future well-being and independence. The need to remain emotionally strong while

managing the child's treatment also contributed to her feelings of exhaustion and helplessness. These findings are in line with Yasmeen et al. (2024), who reported that caregivers of thalassemia patients experience psychological and social difficulties associated with the demands of long-term caregiving. Similarly, Abbas et al. (2023) identified psychological concerns and social difficulties among parents of children with thalassemia in Sargodha. The present finding therefore suggests that the emotional burden of thalassemia is closely connected with the mother's ongoing caregiving responsibilities and uncertainty about her child's future.

Theme 2: Continuous Caregiving and Disruption of Everyday Life

The research explored that there was a routine in the mothers' life that was focused on their children's needs. It also took a lot of time and planning to arrange for blood transfusions, medical appointments and hospital visits as well as medicines. Another Participant from urban area and (Age 29) shared her emotional and physical ambivalence caused by these responsibilities. She said;

“After my child was diagnosed with thalassemia, my entire daily routine changed. I used to be a very relaxed person, but now I wake up early to prepare meals, make sure my child takes medicines on time, and follow every instruction given by the doctor. Before every hospital visit, I spend hours arranging transportation, collecting medical reports, and making sure that everything is ready because I do not want anything to delay my child's treatment. Even after coming back from the hospital, there is hardly any time to rest. I have to manage household responsibilities while continuously observing my child's condition and checking for fever, weakness, or discomfort. Sometimes I feel physically exhausted because there is always something that needs my attention”.

Another respondent (Age 35) shared,

“I have gradually stopped attending family gatherings, visiting relatives, and spending time with friends because my child's health is always my first priority. Although these responsibilities have changed my personal life completely, I do not complain because my child depends on me. As

a mother, I believe caring for my child is my greatest responsibility, even if it means sacrificing my own comfort, rest, and personal happiness”.

The findings are consistent with the qualitative study conducted among Pakistani parents that reported the disruption of family-life, treatment related issues and psychosocial side-effects are significant aspects of thalassemia's impact on living. Moreover, the parents have been reported to struggle to keep up with family and social relationships, as the continuous needs of treatment can exacerbate family responsibilities, impact on their relationships with other children and family members, and interfere with their activities and routines (Aziz et al., 2012; Rehman et al., 2024). Qualitative research also shows that mothers may need to sacrifice some of the activities they had planned for their households for their sick child, causing family tensions and emotional stress (Nabavian et al., 2022). Evidence from Karachi that is more recent also points to a burden on caregivers' roles, problems with family bonds, and the neglect of other children as major consequences of caring for a child with thalassemia major (Baqar et al., 2024). Therefore, the role of a mother with thalassemia can reach beyond the mother-child relationship, impacting family roles, family norms, family relations, and mothers' integration into family life.

Theme 3: Financial Challenges

The most significant part of mothers' experiences was financial strain. Expenses incurred due to treatment, transportation, medication, investigations and repeated hospital visits were described by participants. A participant from rural area (Age 38) said,

“Since the moment my daughter was diagnosed with thalassemia, our financial situation has worsened considerably when we compare before and after the diagnosis situation. Now we cannot spend money without thinking about it in detail because most of our money is directed to the process of treating my child. While there are several types of medical service, we still have to pay a lot of money for medications, testing and transportation needed to get to the hospital, special food, and lots of other unexpected expenses. We usually plan the family budget together every month so that we make sure there will be enough money for the treatment. Sometimes, it happens

that we have to postpone some purchases meant for us because it is more important to take care of our child's health. Sometimes the expenses we have to handle are beyond our means, and we need to ask for help from relatives or family members. It is not an easy thing to do because I dislike the idea of putting myself into somebody's debt. On the other hand, when my son health is at stake, I have to accept the help whenever I get it".

The finding therefore illustrates that the economic burden of thalassemia is not restricted to medical expenses alone. Transportation, repeated hospital visits, medicines, investigations, and other associated needs can collectively create financial pressure for families. For families with limited economic resources, these recurring expenses may require continuous adjustments in household spending and may increase dependence on relatives or other sources of support.

A participant from rural area (Age 40) shared, *"My husband is a laborer and he puts in an amount of hard work daily to ensure that our family does not financially suffer, and I, on my part, trying to support him. Despite my husband's daily hard work, our earnings do not suffice to cover child treatment-related expenses"*.

Another respondent shared,

"Every month, we have to come up with funds for medicines and transportation to the hospital, not to mention blood transfusions, laboratory tests, and sometimes additional procedures in case of any complications. While expenses keep rising, we receive the same amount of money. Ultimately, our family financial situation compels us to restrict or postpone our own needs and purchases. Seeing my husband work all day, I find it painful to realize that he strives to earn more without being sure if he will be able to pay for his next trip to the hospital. Additionally, I feel guilty, since I do not earn money either, but I try to save as much as I can. Our top priority is our child's health, and we will spare no expense to allow our child to receive proper treatment, which ensure her survival in the battle against thalassemia".

These narrations highlight the financial strain caused by the ongoing costs of thalassemia care, including medicines, transportation, blood transfusions, and laboratory investigations. Despite having a working husband, the family

struggles to meet these expenses and often sacrifices their own needs. These findings are consistent with Abro et al. (2022), who identified economic problems as a major psychosocial concern among parents of children with thalassemia. Similarly, Hassan et al. (2023) and Hood et al. (2024) reported financial and treatment-related challenges among Pakistani families.

Theme 4: Gender Roles and Maternal Caregiving Responsibilities

The results revealed the effect of gender roles on the care giving. The participants usually referred to the mother as the one who would take the main care of the sick child. This was in addition to the household and family chores. A Participant lived in urban area (Age 36) clearly articulated this cultural expectation as,

"In society, people think that it is mainly the duty of the mother to look after a sick child. In my case, after my child was diagnosed with thalassemia, everybody expected me to become the primary caregiver. Although my husband is willing to help me as much as he can, most of the daily responsibilities, such as giving medications, preparing special meals, taking my child to the hospital, and staying with my child during the blood transfusion process are considered my responsibility".

Another respondent (Age 39) shared,

"Sometimes, even when I feel physically tired and my head is full of many thoughts, I have to continue carrying out my duties, because society expects the mother to sacrifice everything for her child. If I ask for help or say that I am tired, there are people who think that I am not a good mother. All these social requirements weigh me down even more, because I feel responsible not only for the health of my child but also for meeting the expectations of my family and the society. There are times when I wish I could share these duties with somebody else. In spite of the difficulties, I keep on looking after my child with great care and love, as I believe that this is my best gift for my child. I also think that mothers of thalassemic children deserve more empathy, support, and help from their families and society".

Participant's narrative illustrates the social norms and expectations around maternal care that are

gendered. Since her child's diagnosis, she was expected to be the main carer with tasks being thrust upon her, including taking her child's medication, preparing special meals, visiting him in hospital and staying with her child during transfusion. Moreover, cultural norms can make caregiving a moral obligation rather than a family obligation. This is similar to studies indicating that mothers of children with chronic conditions often take on more responsibility for their care and have more psychological and practical burden than fathers (Cousino & Hazen, 2013; Pinquart, 2018). Similarly, in the context of thalassemia, Pakistani studies have also reported significant psychosocial and caregiving problems of parents such as disruption in daily activities and family life (Aziz et al., 2012; Anum & Dasti, 2016). Prasomsuk et al. (2007) also discovered that mothers of children with thalassemia feel the disease to be an on-going duty that has an impact on both their personal and family lives.

A participant from urban area (Age 29) shared the emotional and physical ambivalence caused by these responsibilities as,

“After, my child was diagnosed with thalassemia, my entire daily routine has flipped now. I was a very lazy person but now I wake up early in the morning to prepare meals, make sure my child takes medicines on time, and keep track of every doctor's instruction. Before every hospital visit, I spend hours arranging transport, collecting medical reports, and making sure everything is ready because I don't want anything to delay my child's treatment. Even after returning home from the hospital, there is hardly any time to rest. I continue taking care of household responsibilities while closely observing my child's condition, checking whether there is any fever, weakness, or discomfort”.

Another respondent (Age 37) shared,

“Sometimes I feel physically exhausted because there is always something that needs my attention. I have gradually stopped attending family gatherings, visiting relatives, or spending time with friends because my child's health is always my first priority. Although these responsibilities have changed my personal life completely, I never complain because my child depends on me. As a mother, I believe that caring for my child is my greatest responsibility, even if it means sacrificing

my own comfort, rest, and personal happiness”.

The experience of the research participant highlights how thalassemia impacts the day-to-day life of mothers and their personality, requiring a constant burden of caring, such as giving medicines, watching for symptoms, arranging hospital visits, doing household tasks and transportation. The signs of physical fatigue and isolation from family and social contacts revealed the psychological and social costs of intensive care-giving. A research study results are similar to the ones reported by Yasmeen et al. (2024), who found that the parents of thalassemic children in Pakistan experienced disruptions to routines, problems with sleep, psychological distress and social difficulties. Likewise, Hassan et al. (2023) reported physical, emotional, financial, and familial issues faced by the parents in Pakistan, and Hood et al. (2024) noted that Pakistani caregivers experienced poor quality of life and psychological problems. Other international studies have also shown that the long-term treatment needs of thalassemia significantly impact mothers' emotional, physical and social function (Prasomsuk et al., 2007).

Theme 5: Family and Peer Support

Social support was identified as an important protective resource. Husbands, sisters, relatives and friends assisted mothers in their emotional and practical support. The support of other thalassemia mothers was especially significant because they had experienced the same or similar experiences. Instead of feeling supported, mothers felt like they were criticized by the people closest to them. A participant from the rural area (Age 41) described her experience with family support as follows,

“After the diagnosis of my child with thalassemia, I expected all my relatives to come together and support us during that tough time. However, there were very few relatives who actually helped us in real terms. Even those who expressed their sympathy to us said things like, “This is your fate,” or asked us repetitively as to why it happened to us. Such comments only made me feel worse”.

Another respondent (Age 38) shared,

“At family functions, instead of treating my child like any other children, people looked at him with

pity. Sometimes, I was made to feel guilty for not taking care during my pregnancy when I knew that it was a genetic condition. I expected to find comfort in such statements, but they did the opposite. There were situations when I needed support to either go to hospitals or do some chores at home, but there were a very few numbers of people ready to help. Their empathy lasted few minutes, while our pain continued".

Another Participant from rural area (Age 26) shared a similar experience,

"The family's support was merely to express verbal sympathy rather than providing any support practically or emotionally. The family members understood the family's issues. They share care-giving duties or assist in visiting the hospital or taking care of the child. A mother has to suffer from comments, reproaches, and interpretations of her child's disease....it worsened the state of my mental health. I used to be hurt by more sayings from other people and hearing undesirable recommendations. I started to keep silence about what was happening with my child in family circle. There is absence of real support from the family and negative attitude of the relatives increased my burden of care".

The participant's narration illustrates a difference between verbal sympathy and real family support. While the family's struggles were recognized, primarily by family members, no practical support was offered with regards to care giving, hospital visits or care taking children. Rather, comments, criticisms and unasked- explanations of the child's sickness, only added to her emotional distress and feelings of disappointment and isolation. It also indicates that mothers do not respond positively regarding their child's condition, they discouraged from seeking support from relatives. The results are in line with Aziz et al. (2012) who reported social and psychological problems of Pakistani parents with thalassemia like disruption of family and social life. Dewi et al., (2024) also determined that the caregiver burden was related to psychological wellbeing suggesting that poor support exacerbate the emotional burden of caregiving. Emotional, family and social problem have also been mentioned as significant issues in living with thalassemia by the qualitative research done among the parents of Pakistan (Hassan et al., 2023).

Discussion

The present study demonstrates that caring for a child with thalassemia is a multidimensional and demanding experience that extends far beyond the provision of medical care. Mothers in the present study described caregiving as an ongoing responsibility that affected several areas of their lives, including their psychological well-being, financial condition, family responsibilities, social participation, and everyday routine. The continuous need to manage blood transfusions, medical appointments, medications, investigations, and other treatment-related requirements placed mothers under considerable caregiving pressure. At the same time, mothers had to maintain their household responsibilities and response to the emotional and developmental needs of their children. These findings indicate that thalassemia affects not only the child living with the disease but also the family members who provide continuous care. Treatment challenges, financial issues, psychological stress, and familial issues are other challenges found in Pakistani studies involving thalassemic children (Anum & Dasti, 2016; Rehman et al., 2023; Baqar et al., 2024). In addition, it was found that mothers could also experience fatigue, social limitations, changes in the role of parents, and a decrease in their quality of life due to the continuous demands on the mother as a carer (Zakiyah et al., 2018; Setiyowati et al., 2025). Evidence also shows in recent times, that caregiving burden, family relations, economic hardship and parental burnout are not experienced separately, but are interconnected (Özkan et al., 2026). Therefore, the care of thalassemia impacts the mother, the child, family function as well as family well-being.

The psychological findings of the present study are consistent with previous research conducted in Pakistan, which has shown that caring for children with thalassemia can have a substantial impact on caregivers' quality of life. According to Hood et al. (2024), Pakistani caregivers experienced difficulties across different domains of quality of life, while factors such as self-acceptance and personal growth were associated with greater caregiver well-being. The findings of the present study build upon this evidence by illustrating how psychological distress is experienced in the context of everyday caregiving. Mothers reported feelings of fear, worry, sadness, emotional

exhaustion, and uncertainty regarding their children's health and future. Their concerns were not limited to the child's current medical condition but also extended to questions about the child's future treatment, health, education, independence, and overall quality of life. Thus, psychological distress appeared to be closely connected with the continuing and uncertain nature of thalassemia care. The findings further suggest that mothers' emotional experiences cannot be separated from their caregiving responsibilities. The continuous need to remain attentive to the child's health created a sense of responsibility that could be emotionally exhausting. Mothers were required to remain prepared for transfusions, medical consultations, investigations, and treatment-related needs, while also managing their normal family responsibilities. This situation may create a constant state of concern because the child's condition requires long-term medical management rather than a short-term intervention. In this regard, the present findings support the argument that chronic childhood illness can influence the emotional well-being of the entire family system. The mother's emotional condition is therefore an important component of the overall caregiving experience and should not be considered separate from the child's medical needs.

The present findings are also consistent with recent qualitative evidence from Karachi. Baqar et al. (2024) identified financial constraints, limited knowledge about the disease, concerns about the future, and inadequate emotional and social support as major challenges experienced by caregivers. Their findings also highlighted barriers related to healthcare access, blood availability, and treatment costs. Similar concerns were reflected in the present study, where mothers described the difficulties associated with managing the continuing requirements of thalassemia treatment. These similarities suggest that caregiver' difficulties are not restricted to one particular family or setting. Instead, they may reflect broader social, economic, informational, and healthcare-related challenges faced by families caring for children with thalassemia in Pakistan.

The financial findings of the present study are particularly important from a social work perspective. The economic burden of thalassemia

does not arise only from the direct cost of treatment. Families may also experience indirect expenses related to transportation, investigations, medicines, food, hospital visits, and the time required for caregiving. When treatment is required repeatedly over a long period, even relatively small expenses can accumulate and place considerable pressure on household resources. For families with limited income, these continuing costs may require them to adjust other household priorities. The findings therefore demonstrate that financial hardship should be understood as part of the broader social impact of chronic illness rather than simply as an issue of medical expenditure.

The findings related to gender roles provide another important perspective on caregiver burden. In the present study, mothers were primarily responsible for caring for their children while also being expected to continue their household responsibilities. This dual responsibility increased the pressure associated with caregiving because mothers had to balance the child's treatment needs with domestic work and other family obligations. From a social work perspective, this finding highlights the importance of examining how caregiving responsibilities are distributed within families. When most caregiving responsibilities are concentrated on mothers, their own physical, emotional, social, and personal needs may receive less attention. Consequently, interventions should consider the well-being of the caregiver alongside the medical needs of the child.

The findings can also be understood through Bronfenbrenner's Ecological Systems Theory (1979), which emphasizes the influence of different environmental systems on an individual's experiences. The immediate family environment plays an important role in shaping how mothers experience and manage caregiving responsibilities. Family expectations, household duties, availability of support, and relationships with other family members may influence the mother's ability to cope with the demands of caring for a child with thalassemia. At the same time, these family experiences are connected with broader cultural expectations regarding women's roles and responsibilities (Bronfenbrenner & Morris, 2006; Suksiri et al., 2007; Ali et al, 2024). Therefore, the mother's caregiving experience

cannot be understood in isolation from the family and social environment in which she lives.

An important finding of the present study is that caregiving was not only associated with vulnerability but could also become a source of knowledge, confidence, and agency. Some mothers developed greater confidence through repeated interaction with healthcare providers and through their continued involvement in the child's treatment. Over time, mothers became more familiar with the child's treatment requirements and learned how to communicate with healthcare professionals, organize treatment-related activities, and respond to different caregiving demands. This suggests that mothers should not be viewed only as recipients of support. They are also active participants in the management of their child's illness and possess valuable knowledge based on their lived caregiving experiences.

The findings also have implications for social work practice. Since the challenges experienced by mothers are interconnected, support services should not focus exclusively on the medical condition of the child. A family-centered approach is needed in which the psychological, social, economic, and informational needs of mothers are also considered. Social workers can contribute by providing psychosocial support, facilitating communication between families and healthcare providers, identifying available community resources, linking families with financial or welfare services, and strengthening social support networks. Such interventions may help reduce some of the pressures associated with long-term caregiving and enable mothers to manage their responsibilities more effectively. The results of a multi-disciplinary intervention also highlight a practical role for social workers in assisting families to access blood donors and financial assistance, in supporting children's education and in connecting families with other community resources (Huang et al., 2024). Social work can therefore help to establish a model of thalassemia care that is not only holistic and family-centered, but also focuses on the needs of the child and considers the mothers' role as a career, the family functioning, financial struggles, social support and access to services.

Overall, the present study indicates that the experience of caring for a child with thalassemia

involves an ongoing interaction between medical needs, psychological stress, financial pressure, family responsibilities, gender expectations, social circumstances, and coping resources. The findings reinforce the importance of recognizing mothers as an essential part of the caregiving system whose well-being is closely connected with the well-being of the child. Therefore, the needs of maternal and other family caregivers should be addressed alongside the medical needs of children with thalassemia. A holistic and family-centered approach may provide more meaningful support by recognizing not only the child's treatment requirements but also the emotional, social, economic, and practical realities of the people providing that care.

Implications for Social Work and Healthcare Practice

The results have a number of implications for social work and health care practice. Firstly, mothers are recognized as primary source of affection and a player in healthcare. They have personal experience of how the child has been treated, symptoms and daily activities and can play a part in effective care planning. Secondly, psychosocial support needs to be integrated into the care plan of thalassemia. Thirdly, peer-support groups can be an easily accessible source of emotional and informational support. Fourth, social workers can perform family assessments at the economic, social and psychosocial level to links with welfare and financial support programs and resources in the community. Lastly, healthcare providers should promote shared decision-making and communication. Raising the awareness of mothers can help build their confidence and better involvement in the process of treatment decision.

Conclusion

The study concluded that caring for a thalassemic child is a multidimensional and continuous family experience, which changes the day-to-day lives of mothers. Having to provide blood, medication, hospital visits and oversee treatment puts mothers under continuous care, and financial, household and social demands add to this. In each of these areas, mothers felt fear, anxiety, sadness, exhaustion, and ongoing worry and uncertainty about their children's health and future. The cumulative demands affected not only the mother-

child relationship, but affected household routines, family relationships, social participation, employment and the well-being of other family members. The results also show the relevance of the "gendered" patterns of care-giving. Mothers were primarily expected to take care of the child with a continued role in the household. They were also able to gain knowledge about the disease and build confidence in their ability to communicate with health care professionals and become more involved in the planning of their children's care while engaged in intensive treatment. Mothers are therefore not just caregivers who suffer the effects of thalassemia but should be acknowledged as partners who show their own skills and knowledge in caring for the child in the long term. The combined results confirm the fact that the welfare of a child with thalassemia is directly related to the welfare of the mother and the extended family. Therefore, a sustainable response to thalassemia should be broadened from a strictly biomedical and child-centered model, to a family-centered and caregiver responsive approach. This should include systematic psychosocial assessment, counselling for the caregivers, family support, education on care, financial and social resource connections and meaningful participation of mothers in care planning and decision making. Supporting mothers is an integral component of supportive care for children with thalassemia; supporting the caregiver and the family's system is crucial to sustaining treatment and the health and quality of life of children with thalassemia.

Recommendations

There are following recommendations on the basis of research findings;

- Regular counselling, stress-management sessions, as well as psychological services at thalassemia treatment centers should be offered to mothers of thalassemia children.
- Peer support groups for mothers should be set up at thalassemia centers. The results demonstrated that mothers found it was helpful to share with other mothers facing the same issues.
- Caregivers, especially husbands, should be encouraged to share in the care-giving burden. The results showed that mothers have a significant share of the daily care

responsibility.

- Financial support should be provided to help families who are struggling financially. Government institutions, welfare organizations, NGOs and healthcare facilities should offer support to families for transport, medication, investigations, or any other treatment costs.
- Facilities providing healthcare services should enhance the access and structure of thalassemia services. Sufficient blood provision, medicines, investigations and follow-up services should be provided.
- Awareness about the disease should be reinforced for parents and caregivers. Regular education through healthcare professional should be given about thalassemia, treatment options, medication adherence, transfusion management, thalassemia's complication, and the long-term treatment.

Limitations

The study has several limitations. First, it was conducted in District Sargodha; therefore, the findings are context-specific and should not be statistically generalized to mothers in other districts or provinces of Pakistan. Differences in healthcare access, socioeconomic circumstances, family structures and cultural environments produce different experiences elsewhere. Second, the study used purposive sampling and a relatively small qualitative sample of 32 mothers. This approach was appropriate for obtaining rich descriptions of lived experiences but was not designed to produce statistical representation. Third, data were collected through semi-structured interviews and depended on participants' willingness and ability to discuss their experiences. Sensitive issues such as financial difficulties, family conflict, emotional distress or dissatisfaction with healthcare not have been fully disclosed by every participant. Fourth, the study focused specifically on mothers. The perspectives of fathers, children, siblings, healthcare professionals and social workers were therefore not included. Future research incorporating multiple perspectives could provide a more comprehensive understanding of caregiving and family decision-making.

Conflict of Interest

The authors showed no conflict of interest.

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