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Abstract

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Keywords: Thalassemia, Caregivers, Carriers, Swabi, Social Support System

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Title

Exploring the Social Support System for Thalassemia Carriers in District Swabi, Khyber Pakhtunkhwa

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Abstract

Sociologists argue that Thalassemia is a social phenomenon. This research study explores the social support system available for thalassemia carriers in District Swabi, Khyber Pakhtunkhwa with a focus on understanding the challenges they face. Qualitative in-depth interviews were conducted with 2 thalassemia carriers and 12 caregivers to show how family members, peer groups community, and religious members help in the social and mental wellbeing of the carriers. The interviews were recorded, transcribed, and analyzed using thematic analysis to explore patterns and themes related to social support, cultural practices, and health management. It is explored that due to cousin marriages, it is spread among infants. The study concluded that social support systems prevailed for caregivers and carriers. The study concluded that due to the cultural practice of cousin marriages thalassemia is spread and community sensitization should be started to stop the spread of the disease.

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[Thalassemia](#), [Caregivers](#), [Carriers](#), [Swabi](#), [Social Support System](#)

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Introduction

Sociologists and other behavioral scientists' study chronic diseases and human illness in relation to social factors and their effects. In sociology, researchers explore the attitudes, opinions, and experiences of individuals towards illness, diseases, and the health care system. Social sciences research revealed that chronic disease patients not only suffer physically but they experience many socio-cultural and socio-economic challenges due to their illness and the poor healthcare system. Chronic disease patients are treated differently in different social settings. Chronic illness is influenced by a complex interplay of social,

economic, and cultural factors, emphasizing that health outcomes are shaped by social determinants like socio-economic status, education, and living conditions, as they may feel labeled by their conditions, while social stigma can lead to social isolation and psychological distress (Kakar.,2019).

The literature highlighted that thalassemia is one of the public health concerns around the world. Thalassemia is an inherited blood disorder caused by a defect in the gene responsible for producing the globin chains in hemoglobin (Husna et al.,2017). According to the World Health Organization, approximately 7% of the population is a thalassemia



carrier. It is estimated that around 80-90 million people worldwide are thalassemia carriers (Origa., 2005). Hemoglobin comprises Alpha and Beta (Karakochuk et al., 2015). Beta-thalassemia has two types, but the more severe form is beta-thalassemia major. An estimated 9.8 million people in Pakistan are carriers of beta-thalassemia. Approximately 50,000 patients with thalassemia are enrolled in treatment clinics throughout Pakistan while many more died without knowing that their children are suffering from thalassemia (Ehsan et al., 2020).

Mostly, thalassemia patients are considered medical patients and are treated with biomedical practices such as blood transformation to the patients. Sociological studies explained that the patients need some psychological and social support to cope with the panic treatment and situation. Much research is needed on the social and cultural experiences of thalassemia patients alongside biomedical treatment to understand thalassemia is a preventable disease and with the mitigation of some harmful traditional practices it can be reduced and minimized (Madan et al., 2010).

In the country Pakistan, Thalassemia is a social and public health concern in Pakistan. Thalassemia disease is also considered a serious health issue around the world and many developing countries are dealing with it effectively, however, in developing countries with strong traditional and cultural settings like promoting cousin marriages, lack of awareness about the disease, no proper tests, poverty among families, unemployment, and diagnose of thalassemia disease the number of patients is increasing day-by-day (Mufti et al., 2015). It is observed that due to preventable socio-cultural determinants, religious interpretations, and lack of scientific knowledge about thalassemia, the disease is rapidly repeated in newborn babies. Through observations it is explored that cousin marriages in *Pakhtun* society, illiteracy among parents, lack of community sensitization and awareness, and lack of supply-side facilities are responsible for the increase of thalassemia patients in the country (Khalid et al., 2019; Naseem et al., 2008).

Social support systems are crucial in extending the value of life for individuals identified with beta-

thalassemia. Empirical research indicates that individuals possessing robust social support networks exhibit enhanced psychological well-being along with diminished levels of depression and anxiety; Social support networks are systems of family, friends, colleagues, and community members that provide various types of support to individuals. These networks play a crucial role in enhancing the well-being of patients through multiple mechanisms (Greco & Marino, 2022). Parents often provide primary emotional and instrumental support, help with daily activities, offer companionship and assist with healthcare needs. The role of family and parents is very important in improving mental health and reducing stress anxiety and depression. Friends offer emotional and social support by offering companionship, understanding, and encouragement. Friends provide you with a social environment which also reduces the feeling of isolation. The peer group also allows us to share similar experiences to share advice, encouragement, and emotional support. Strong support from peer groups will help chronic illness patients in managing their daily life activities. (Acoba et al., 2024). The role of Non-profit organizations, support groups, and community centers is important in offering a social support network by providing resources, peer support, and awareness educational programs. Community organizations foster empowerment among patients facing health challenges, especially in chronic illness (Miller et al., 2021).

Religious leaders have an important role in almost all religions by providing comfort, guidance, and spiritual healing to patients and their families. The literature revealed that religious leaders provide support to individuals facing challenges in their difficulty in managing chronic illness in which an individual can find comfort, empathy, and encouragement. Religious practices such as prayer, meditation, and rituals can serve as coping mechanisms, helping individuals manage stress and anxiety (Mandala, n.d.). Healthcare providers including doctors' nurses and genetic counselors play a pivotal role in the well-being of chronic disease patients. Healthcare professionals not only provide medical treatment but also help with guidance and

emotional support to cope with managing diseases. They offer medical expertise, emotional support, and guidance on navigating healthcare systems (Smith et al., 2023). This research study explored existing social support systems for thalassemia carriers in Swabi, a district in Khyber Pakhtunkhwa.

Methods

The present research is carried out by using qualitative methods. Qualitative research is an approach that seeks to find human experiences, social phenomena, or behavior by delving into subjective perspectives. This method emphasizes uncovering deep insights patterns and themes within context (Creswell., 2013). Interpretivism emphasizes understanding the meanings and perspectives of individuals within their social contexts, acknowledging the subjective nature of human experiences (Braun & Clarke, 2022). In the present study, researchers used interpretivist paradigms to understand thalassemia as a social issue among thalassemia carriers. In the present study researcher used phenomenology research design. In this research design researchers study the perception, meaning, attitudes and beliefs, feelings, and emotions of individuals in the real social context. Phenomenology focuses on exploring individuals' lived experiences, while grounded theory aims to generate theories based on data collected from participants. In this design, the researcher uses interviews, and observation notes to gather non-numerical data (Charmaz., 2021). Purposive sampling techniques are used in the present study to collect data from thalassemia carriers and caregivers as participants in the study locale. The primary goal of purposive sampling is to choose individuals who possess knowledge, experience, or specific traits relevant to the research, rather than aiming for a representative sample of the larger population (Etikan et al., 2017). A study population means an entire group of individuals, items, and data points from which a sample is selected for the purpose of investigation (Leedy et al., 2013). In the present study, researchers gather data from caregivers of thalassemia carriers aged 12 years or more than 12 years and thalassemia carriers aged above 12 years. An interview guide is a commonly used guide in qualitative research to

facilitate and standardize the data collection process during interviews. It outlines the key concepts, questions, and probing points that the researcher plans to cover with participants (Kallio et al., 2016). In the present study, the principal researcher initially proposed 10 interviews with caregivers. However, the sample participants are decided on the saturation point of the interviews. During field research, the researchers conducted a total of 8 interviews as a saturation point of conducting interviews with thalassemia caregivers. The researcher developed an interview guide and before starting interviews a formal written informed consent was recorded. Thematic analysis is a widely used method of analyzing qualitative data that focuses on identifying, analyzing, and reporting patterns (themes) within the data. The thematic analysis outlined a six-step process for conducting thematic analysis, which helps researchers to systematically work through the data and produce meaningful insights. (Braun & Clarke, 2006). The interviews were first transcribed and then translated into English. The recording was kept confidential and only the researcher and his supervisor's access are permitted. After transcription and translation data analysis was conducted. In the present study, verbal consent was obtained from all the participants before their interviews were recorded.

Results and Discussion

The results are analyzed with the emotional and psychological well-being of the thalassemia carriers and caregivers. Various themes are developed and discussed below.

Thalassemia Carrier and Caregiver's Emotional and Psychological Wellbeing

In interviews with caregivers, it is explored that the emotional needs of carriers, caregivers, and family members must be acknowledged to cope with the psychological challenges of living with a chronic disease. Chronic diseases often result in feelings of stress, fatigue, and frustration. For carriers (fathers or mothers), while they may not show symptoms, knowing they carry the gene can lead to anxiety about passing it to the future generation. Caregivers often experience a mix of emotions, including fear about the

future, grief over their child's condition, and sometimes guilt about passing on the genetic condition. The emotional impact of a chronic diagnosis can be intense, with caregivers expressing feelings of helplessness and guilt. They gradually processed the information and moved toward acceptance through education and support from doctors, nurses, friends, family members, and close relatives. (CGI2, 3, 4, 5) Emotional responses can range from initial shock to feelings of isolation and helplessness, but many caregivers also go through a process of acceptance and adaptation over time (Mathew, G et al., 2021).

One participant shared their feeling.

"Upon the initial diagnosis, I experience profound emotional reactions such as shock, confusion, and guilt. These feelings are often compounded by a lack of understanding of the genetic nature of the disease. Over time, however, with adequate counseling and support, I typically come to terms with the condition, moving from a place of initial disbelief to greater acceptance and understanding of the genetic factors involved."(CGI7)

Thalassemia, as a chronic condition, brings with it long-term implications that are difficult to process in the initial stages. It is explored in interviews with study participants that emotional shock after diagnosed of thalassemia can lead to a period of disbelief, where family members may struggle to accept the diagnosis, questioning how it could have happened and what it means for the future. After this emotional period, families typically go through a period of adjustment. It is explored that a family's ability to adapt and make sense of the diagnosis is essential in determining how they manage caregiving process in the future. It is explored in interviews with caregivers that support from family members plays an important role in these emotional periods. Family members often serve as emotional anchors, offering comfort and understanding during moments of uncertainty and distress. Immediate family members, such as spouses, parents, or siblings, play a crucial role in providing emotional support. (CGI1, 6, 7, 8) .families are often the first line of defense when emotional distress occurs and offer companionship

and understanding. The bond within the family helps provide stability and reassurance in dealing with the stress of chronic disease. (Sankaran et al., 2013)

As one of the participants shared their experiences

"At first, we just couldn't believe it. We didn't know anything about thalassemia. We leaned on family for support and spent a lot of time just processing everything."(CGI2)

Another participant stated that

"We had to come together as a family. I remember we all sat down and talked about how we could handle the treatment and hospital visits."(CGI3)

Similarly, one of the thalassemia carriers stated that. My parents have been my emotional pillar; I don't know how I'd cope without them."(THI2)

Peer group support significantly enhances the well-being of both thalassemia carriers and caregivers by providing emotional understanding, empathy, and shared experiences. In interviews with participants, it is explored that Peer groups also serve as a source of practical advice, coping mechanisms, and stress-relief strategies, empowering caregivers and carriers to better manage the condition. Furthermore, peer support strengthens emotional resilience, reduces loneliness, and creates a network where both carriers and caregivers can feel empowered and understood. It is also explored by study participants that Support groups, either in-person or online, provide a space where people can share experiences, offer advice, and provide emotional validation. This can lead to increased feelings of empowerment and a sense of community. (CGI3, 5, 7, 8). (Barrera et al., 2013) discuss the positive impact of support groups for individuals managing chronic illness, emphasizing that sharing experiences fosters emotional relief and enhances coping strategies.

As one of the participants shared

"In the peer group, we laugh and cry together. It's like a family that gets what we're going through."(CGI2)

As one of the thalassemia carriers stated that

"Joining an online group for thalassemia carriers was a life-saver. Talking to people who understand makes all the difference. (THI2)

In interviews with caregivers and thalassemia carriers, it is explored that Healthcare providers, such as doctors, nurses, and counselors, play an important role in offering not only medical care but also emotional support. A compassionate, empathetic approach from medical professionals can greatly enhance the caregiver's and carrier's mental well-being. It is explored by study participants that the importance of clear communication and emotional reassurance from healthcare providers in alleviating feelings of fear and uncertainty is evident in these experiences. (CGI 2, 3, 4, 7). Tepper et al. (2017) argue that empathetic and supportive healthcare providers improve the emotional resilience of individuals with chronic illness by creating a therapeutic relationship.

As one of the participants explored that

When the doctor took the time to explain everything calmly and reassured me, it made a huge difference. I didn't feel as lost or afraid anymore." (CGI 8)

Another participant shared their experiences.

Our nurse is so kind. She knows how stressful this can be and always makes sure that my child doing well to make me mentally relaxed. (CGI1)

In interviews with participants, it is explored that religious leader often serves as a source of emotional support for thalassemia carriers and caregivers. Through their teachings, prayers, and counsel, they can offer comfort in times of distress, helping individuals to cope with the emotional burden of the condition. Many religious leaders emphasize the importance of patience, trust in a higher power, and the value of enduring hardship with faith. It is explored by study participants that religious leaders help instill spiritual resilience, offering hope that can uplift carriers' and caregivers' mental and emotional well-being during difficult times. (CGI1.3.6.8) Participants in the study noted that such spiritual resilience helped instill a sense of hope and strength, which is in line with literature on the positive effects of religious coping on mental and emotional well-being (Buchbinder et al., 2010).

As one of the caregivers stated that

The Imam often tells us that taking care of a sick child is a noble task. This reminder helps us stay strong

and feel like we're doing the right thing, both in terms of religion and family duty. (CGI2)

In interviews with study participants, it is explored that emotional support from close family relatives is essential because it helps them deal with stress, anxiety, or the difficulties of controlling the condition. It is explored in interviews that close relatives reassure carriers, lessen their sense of loneliness, and support them in making educated decisions regarding their hereditary risks. Understanding, support, and shared responsibility are beneficial for caregivers, who frequently suffer from emotional tiredness. For both carriers and caregivers, a robust emotional support network promotes mental health, builds resilience, and raises general quality of life. (CGI3.4.5.6) the findings of this study align with existing literature that emphasizes the importance of a strong emotional support system, particularly from close family members, in promoting the mental health and well-being of both thalassemia carriers and their caregivers (Baqar et al., 2024; Utami et al., 2023).

As one of the participants shared her experiences;

"Whenever I feel overwhelmed, my sister just listens. She never judges me, and she understands how hard it is to see my child go through pain. It means everything to me."(CGI 2)

As one of the carriers stated that

I know my parents feel the weight of my illness. But they never show their worry, and that makes me want to stay strong for them. It's hard sometimes, knowing how much they carry too."(THI1)

Thalassemia Carrier and Caregiver's Practical Support

It is also explored in interviews with caregivers that the Practical support for thalassemia carriers comes from various sources, each providing valuable contributions to health management. It is also explored in interviews with caregivers that the family members help with daily tasks like scheduling medical appointments, accompanying the carrier to transfusions, and managing medications. Caregivers and families play a central role in offering emotional and tangible support, ensuring timely medical care and daily assistance.(CGI1,2,4,7,8) Close family members take specific responsibilities to help with

daily tasks involved in managing thalassemia, ensuring that the logistics side of caregiving runs smoothly (Vella et al., 2019).

As one of the participants said;

"My brother is the one who handles all the medical appointments. He keeps track of when the next transfusion is due and even calls the hospital to confirm the schedule. It takes a lot of stress off my shoulders because I don't have to worry about that part." (CGI3)

As one of the thalassemia carriers stated;

"Managing the medications is tough, especially with all the different prescriptions. My cousin helps me by organizing them into a weekly pill box" (TH11)

Practical support is available on a recurring basis for thalassemia carriers, but it varies depending on the type of support needed. Support systems must be responsive, with caregivers often needing to adapt based on the patient's immediate needs. (Brancati et al., 2018) It is also explored in interviews with caregivers that medical practitioners provide support on a regular schedule for blood transfusions and check-ups, which is predictable and well-coordinated. It is explored in interviews with participants Practical support provided by medical practitioners for thalassemia carriers plays a crucial role in ensuring that they receive the proper care required to manage the disease. Medical practitioners such as doctors, nurses, and specialists offer consistent, structured, and well-coordinated care that is critical for maintaining the patient's health over time. The recurring nature of certain interventions, such as blood transfusions and regular check-ups, allows caregivers to predict and manage the treatment schedule. (CGI4, 5, 6, 7)

As one of the participants shared experiences that "The doctor calls every few months to schedule regular check-ups, and they always let us know well in advance when it's time for a follow-up. It helps because we know the next appointment is coming up, and we can prepare in advance for any changes in the treatment plan." (CGI1)

Practical support provided by peer groups is an essential component of managing chronic conditions like thalassemia. It is explored in interviews with study

participants that Peer groups, which include individuals who share similar experiences with thalassemia whether they are other patients or caregivers offer a unique form of support that combines practical advice, shared resources, and sometimes help in transportation. It is explored in interviews with participants that Peer groups can share practical strategies on how to organize and manage medications more effectively, such as creating medication schedules, setting up reminders, or sometimes when we are not free they bring medicines for our children or visit with us in hospitals. (CGI3,5,7,8). Interviews with study participants revealed that peer groups, composed of individuals who share similar experiences with thalassemia whether patients or caregivers offer a unique form of support. This support includes practical advice, shared resources, and sometimes assistance with transportation (Berglund et al., 2022).

As one of the caregivers stated that

"When I had to take my daughter in for a transfusion last month, a member of our peer group came along with me for company. It really helped having someone there to chat with while we waited. It made the experience much less stressful for both of us." (CGI4)

Another participant stated

"When I was recovering from surgery and needed help with my son's thalassemia treatments, one of the women from our peer group brought my son to the hospital for a routine checkup and even helped clean my house." (CGI1)

In interviews with participants, it is explored that community organizations sometimes provide access to essential medical equipment like oxygen masks or medical syringes, sometimes arranging blood for thalassemia carriers. Transportation to and from medical appointments is a common challenge for thalassemia carriers and their caregivers. It is explored in interviews with participants that Community organizations sometimes arrange free transport services for those who are financially weak to ensure that carriers can get to their medical appointments, especially when regular treatment such as blood transfusions or check-ups is needed (CGI2.4.5.8). A significant challenge for thalassemia carriers and their

caregivers is transportation to and from medical appointments, particularly for those with limited financial resources. Participants shared setting that community organizations sometimes offer free transport services to ensure that carriers can attend necessary medical appointments, such as regular blood transfusions or check-ups (Yousuf et al., 2022).

As one of the caregivers stated that

The community offers free transportation to hospital visits for blood transfusions for my son .it's such a relief when I am already overwhelmed with other responsibilities. (CGI7)

In interviews with study participants, it is explored that Hakims (traditional healers) are highly respected figures, particularly in rural areas (swabi).it is explored that before diagnosis of thalassemia, most of the participants first visited hakims for treatments They play a role in offering alternative healing practices, including herbal remedies and treatments for various conditions, including thalassemia, Though thalassemia is a genetic disorder that cannot be cured through traditional medicine. (CGI 1,3,4,7,8) Caregivers often seek comfort in the support and advice provided by Hakims, particularly for managing symptoms and promoting overall well-being (Shahid et al., 2018).

One of the caregivers told me that.

"We go to a local Hakim for general health advice. While he can't cure thalassemia, his herbal treatments help with some of the symptoms and boost my child's overall health."(CGI5)

In interviews with study participants, it is explored that religious leaders play an important role in the mental and social well-being of individuals, including thalassemia carriers. It is explored in interviews with caregivers that religious leaders provide practical support by offering spiritual guidance, encouragement, and support to both the affected individuals and their families. (CGI2, 4, 5, 6).In a culture where religious beliefs hold a significant place, support from religious figures is a source of emotional comfort, helping families cope with the challenges

posed by chronic health conditions (Tariq et al., 2019). Religious leaders may also encourage community members to show empathy, solidarity, and care, promoting a collective responsibility for the well-being of individuals in need.

One of the caregivers in this study stated that;

"Our local Imam has been very supportive. He reminds the community that we are all responsible for helping one another. He often prays for my child's health and encourages others to show kindness."(CGI7)

Conclusion and Recommendations

The study concludes that family is the basic and first contact for thalassemia carriers and mostly the thalassemia caregivers belong to close family members like father, mother, brother, sister, aunt, cousin, etc. The study explored that family members provide emotional support to the thalassemia carrier at times of anxiety, isolation, and emotional strain. The family manages financing for the treatment and searches for the best treatment place for thalassemia carriers. It is concluded that thalassemia carriers not only get support and facilitation from their family members but also peer groups play a vital role in the social well-being of the carrier. The community provides information about the available health facilities and establishes links between carriers and caregivers with such kinds of networks who are working for the prevention and response to thalassemia disease. The religious leader's role is explored significantly in connection with the social and mental well-being of the carriers and caregivers. The health care centers are not only used for treatment and blood transfusion rather they enhance the awareness of thalassemia caregivers and other family members.

The study results recommended that community-based awareness raising programs should be started to prevent cousin marriages among thalassemia major and minor couples. Healthcare providers should educate and inform couples about pre-marital screening options and benefits.

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