

Sociological Analysis of Social Support Systems among Thalassemia Carriers in Pakhtun Society: An exploratory study conducted in Pakistan

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ABSTRACT

Thalassemia is a serious public health issue in Pakistan. This paper explored sociological aspects of social support systems available for thalassemia carriers in Pakhtun society. Interpretivism was the epistemological perspective applied in the study. Researchers conducted two in-depth interviews with thalassemia carriers and eight in-depth interviews with caregivers in the study locale. The interviews were recorded, and transcription was made for all the interviews. The researchers used thematic analysis to explain the experiences and opinions of the participants. The study results explained that joint family system in Pakhtun society is one of the strong social supports available to the carrier and caregiver in the study locale. In the study area close family relatives are providing emotional, financial, and logistic support to the thalassemia carriers and caregivers. It is concluded that Pakhtunwali is a strong code of social life which is used as a support mechanism in the area.

Keywords: *Thalassemia, Social Support System, Pakhtunwali, Family, Swabi, Pakistan*

INTRODUCTION

Sociologists and other behavioral scientists' study chronic illness and human in relation with social factors and its effect. In sociology, researchers explore the attitude, opinions and experiences of individuals towards illness diseases and health care systems. It is revealed that in many social sciences researchers that chronic illness patients not only suffer physically but they experience many social, cultural and socio-economic challenges due to their illness and poor health care system. Chronic illness patients are treated differently in different social settings due to different social factors (kakar,2013). Thalassemia is an inherited blood disorder caused by a defect in the gene responsible for producing globin chains in hemoglobin (Husan at el., 2017). This disease is categorized into α , β , $\delta\beta$, and so on. This is caused of reduction or failure of globin chain production in the body (Langlois et al., 2008). This disease prevailed around the world in various regions including Southeast Asia, the Indian subcontinent and Africa), the estimated prevalence rate is 12-50% in case of alpha and 1-20% in case of beta type of thalassemia (Goh et al., 2020).

Thalassemia patients increased in many parts of the world including the developed nations like Northern America, Northern Europe, and Northeast Asia. Literature explained that one of the major reasons of international thalassemia patient's increase is migration of people to those parts of the world. It is revealed in many studies that due to lack of proper statistical databases the thalassemia prevalence and incidence rate are unknown and for active interventions and to reduce the risk of thalassemia disease the database is required (Lee et al., 2022).

Pashtunwali is the code of life among Pakhtun where family members are considered an organ of body. In families with prevalence of Pakhtunwali, women, children, old age people and family members with chronic diseases are given more attention and care. One of the traditional harmful practices in Pakhtunwali is cousin marriages where close relatives marry each other. In Pakhtun society, cousin marriages are a deeply entrenched tradition, often reinforced by cultural norms that discourage women from marrying outside their family. Similarly, in Pakhtun families when there is a person who has chronic illness, one of the family members is primarily responsible to take care of ill family members. However, the other members of the family are also taking care of the carriers. Beta thalassemia is prevalence among children in the family, so in Pakhtun culture mother or any other women are responsible for care and nursing of thalassemia carrier while the father or any male member in the family is responsible for hospital visit and financial support. Mainly women and children are engaging beta thalassemia carrier in various recreational activities within household to minimize the psychological stress to the carrier (Ahmad & Hafeez., 2011).

The societal expectation for women to conform to traditional roles, coupled with the pressures exerted by in-laws, perpetuates a cycle of dependence and discourages empowerment, thereby hindering progress toward gender equality within the community. In Pakhtun society, social support is deeply embedded in the cultural code of Pakhtunwali, where family, community, and religion collectively play a crucial role in supporting individuals, especially those dealing with chronic illnesses like thalassemia. The immediate family provides primary caregiving, with women, particularly mothers, responsible for daily care and emotional support, while male family members, especially fathers, manage medical visits and financial responsibilities. The broader community also plays an integral role, offering practical assistance and emotional comfort, reflecting the strong value placed on mutual responsibility (Khan.,2012).

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 researchers used phenomenology research design. In this research design researchers study the perception, meaning, attitude and beliefs, feelings, 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 interview, and observation notes to gather non-numerical data (Charmaz., 2021).

Purposive sampling technique is used in present study to collect data from thalassemia carriers and caregivers as participants in 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 at el., 2017). A study population means an entire group of individuals, items and data point 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 below 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 researchers initially proposed 10 interviews with caregivers, however it was also mentioned at the proposal stage that the

saturation point will be considered. During field research, the researchers conducted a total of 8 interviews as a saturation point for conducting interviews with thalassemia caregivers. The researchers 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, 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 access are permitted. After transcription and translation data analysis was conducted.

RESULTS AND DISCUSSION

The results are analyzed with role of Pakhtunwali in wellbeing of the thalassemia carriers and caregiver's. Various themes are developed and discussed below.

Reason for cousin marriage in Pakhtun society

In interviews with the study participants, it is explored that in Pakhtun culture, maintaining family honor and social status is of utmost importance. Marrying within the family, particularly to cousins, is seen as a way to preserve the family's reputation. By keeping marriages within the extended family, families are able to limit outside influences, which might jeopardize their social standing. This also ensures that the family's name remains tied to the same cultural and social values.

As one of participant told that;

"In my family my elders and we itself prefer marrying cousins because it keeps our families closely tied. No outsider can influence us or question our loyalty. It's about protecting our family's izzat (honor) and ensuring our traditions remain strong."

It is explored in interview with participants that in Pakhtun society, cultural and traditions play an essential role in shaping marital practices. Cousin marriages are not just seen as an acceptable social norm but as a practice that aligns with Pakhtunwali (the traditional Pashtun code). These marriages are thought to uphold cultural continuity, ensure compatibility of values, practices intact within the family. Families often consider cousin marriages to preserve shared traditions that might be diluted by outside influences (Khan.,2015) discusses how cousin marriages are rooted in Pakhtunwali. In many cases, these marriages are not only socially accepted but also culturally prescribed, as they are seen as a means of ensuring compatibility between the families in terms of values, norms, and customs (CGI3,5,7,8)

One of participant shared their thought;

"It's part of our tradition. Marrying within the family ensures that our customs and beliefs are upheld and passed on to the next generation."(CGI2)

In interview with study participants it is explored that there many reasons for approval of cousin marriages in pakhtun society but the most common is economic factor. Participants explored that marrying within the family helps to preserve wealth and property within the family unit and they think this is the safest way of preserving their wealth and property. It ensures that inheritance rights and assets are kept within the family and that these resources continue to benefit future generations (CGI2,3,5,7,8).

One of caregivers told that

"By marrying within the family, the elders of family ensure that our property and wealth remain in trusted hands. It's a practical decision, not just an emotional one."

It is explored in interview with study participants that in Pakhtun society, marriages between cousins are often seen as a way to ensure better compatibility between partners. As the families are already acquainted with each other's traditions, values and expectations it becomes easier for the couple to settle their roles within family. This familiarity helps minimize the likelihood of misunderstanding or cultural differences that might arise in marriages between individuals and their family's backgrounds. As a result cousin marriages are more frequently viewed as more stable and harmonious.

As of the participant told that

"It is easier to marry a cousin because we already know each other families, tradition and their way of life. We don't have difficulties of adjusting in new tradition."

In interview with study participants it is explored that in pakhtun society the cousin marriages are commonly practiced and are culturally accepted for various social and familial reasons. But in cousin's marriages there are some genetic issues, particularly with regard to inherited genetic disorders like thalassemia. It is explored by study participants that thalassemia is a genetic disorder passed down from parents to children because both parents carry one mutated gene. It is explored in interview with study participants that in pakhtun society cousin marriages especially between first cousins are frequent, and risk of passing genetic disorder are more common in cousin marriages. This is because cousins share a significant amount of genetic material, and if both are carriers of the same recessive gene for thalassemia, the risk of their children inheriting the condition increases. The cultural acceptance of cousin marriages in Pakhtun communities further complicates the situation but the people have concept that these marriages are seen more beneficial for maintaining family cohesion as they in reality they also pose significant health risks, particularly when it comes to genetic disorders such as thalassemia. (Khan et al., 2021).

As one of participant explain

"Our family has always married within the family it is sad reality that we don't know that marry with cousin lead to genetic disorder like thalassemia"

In interview with study participants it is explored that in pakhtun families often have shared ancestry due to the practice of cousin marriages, particularly in rural areas where families maintain strong familial ties. Participants explored that because of these shared roots, the likelihood of both cousins carrying the same genetic mutations is higher. This means that a greater number of individuals within the community may be carriers of thalassemia, which, when two carriers marry, significantly increases the chances of having children with thalassemia. (CGI 2,4,5,7,8). According to (El-Beshlawy et al., 2019), consanguineous marriages increase the frequency of genetic disorders like thalassemia in communities, especially in regions where the prevalence of the disease is high. The study highlights that in many Middle Eastern and South Asian populations, the rate of thalassemia carriers is significantly higher in areas with a tradition of cousin marriages.

One of the participants stated that:

"Many of our people marry cousins because it's tradition. But we've realized that this increases the chance of passing on diseases like thalassemia. I have heard of several cases within our community where children have been affected." (CGII)

Role of Pakhtunwali in wellbeing of thalassemia carriers and caregivers

In interview with study participants, it is explored that in Pakhtun society, family is the emotional backbone that provides solace during tough times. The emotional and psychological support offered by joint and extended families is invaluable, especially when dealing with the burden of a chronic illness like thalassemia. It is also explored by participants that in joint family the Family members help create a sense of hope to resilience. This emotional foundation allows caregivers and patients to feel less isolated, knowing that their struggles are shared by loved ones (CGI1,3,5,7,8). (Cohen and Wills 1985; Bashir et al., 2022) suggest that social support serves as a buffer against stress, significantly improving emotional well-being. Emotional support from family members can alleviate the psychological burden on caregivers, which is particularly crucial in the context of chronic illness.

As one of caregiver stated;

"In our joint family, we all come together when son condition is not good. Even when the burden of taking care of a thalassemia patient falls heavily on one person, others step in offering comfort and strength to carry on. This sense of togetherness is what keeps us going."(CGI2)

One of the most important benefits of a joint or extended family is the ability to share caregiving responsibilities. Managing a condition like thalassemia can be physically and emotionally exhausting, and having multiple caregivers eases this burden. In interview with study participants it is explored that in joint families, caregiving is not seen as the sole responsibility of one individual. Instead, the burden is shared among family members, whether they are parents, grandparents, uncles, aunts, or older siblings. This shared caregiving system can take many forms. For instance, one family member may take the patient to regular medical checkups, while another might stay home and manage day-to-day care like ensuring the carrier is well-fed, rested, and comfortable. By dividing tasks in this way, the primary caregiver is not overwhelmed, which improves their well-being and ensures the thalassemia carrier is always attended to. The importance of shared caregiving, particularly in cultures with strong family ties (CGI 3, 4, 5, 7, 8). Study argues that shared caregiving reduces caregiver burnout and provides a more sustainable model of support for chronic illnesses (Hussain, 2014).

As one of the caregivers told that

"I may not be able to help with everything. Sometimes, it's just sitting with the daughter, other times when I am not able to do my house chores my mother in law and sister in-law do my duty."(CGI1)

Another participant stated that

"When my sister had to take care of her son's thalassemia treatment, my mother and I made sure that the house was always clean, and the food was ready. It made it easier for her to focus on the medical side of things."(CGI8)

In interview with study participants it is explored that thalassemia treatment is often costly, requiring blood transfusions, medications, and regular medical check-up. It is explored by participants that in joint family system financial contributions are often shared by all members of family and this can be especially important when a family is dealing with the long-term costs associated with thalassemia in joint family there are multiple earning members in the family which can contribute collectively making it easier to cover the high cost of medical care. This sense of responsibilities helps in reducing financial burden from parents as they have other family member to help them. (CGI2, 3, 5) (Hassan et al., 2020) examined how extended family members in collectivist societies contribute financially to ensure the well-being of a loved one with a chronic illness as their study found that extended family members are often willing to

make sacrifices to cover medical expenses demonstrating the collective nature of responsibility in caregiving.

As one of caregiver explained

"When my child was diagnosed with thalassemia my brothers help me in hospital financing of my child as he told that we are one family and that we would rather spend it on a loved one's health than let them suffer due to a lack of resources. "(CGI 1)

In interview with participants, it is explored that in pakhtunwali, spirituality plays an important role in managing health crises. The joint family system provides spiritual and cultural support, which may help individuals cope with the emotional challenges of chronic illness. It is explored by caregivers that spiritual practices such as prayers, religious rituals, and community gatherings provide a sense of hope, meaning, and strength for the family. These practices help reduce feelings of helplessness or despair, which can accompany a chronic health condition. Extended family members may organize prayer sessions or engage in rituals designed to invoke blessings for the patient's recovery or at least to provide them with strength. This sense of collective faith can be deeply reassuring to both the patient and the caregiver (CGI 3, 4, 5, 8) (Sadeghi et al., 2021), found that religious rituals and prayer groups have been shown to reduce caregiver burnout by providing emotional comfort and a sense of collective responsibility. These practices also offer a means of maintaining hope, even when medical treatments may not provide immediate results.

As one of caregiver stated that

"When my son was diagnosed, the elders in our family organized prayers. They believed that spiritual support would help heal him, and it made all of us feel that someone doing something, even if we couldn't cure the disease."(CGI2)

In interview with study participants, it is explored that in Pakhtun culture, the extended family is a central source of emotional support. The strong family bonds within Pakhtun society create a support system that helps caregivers cope with the emotional toll of caring for someone with thalassemia. Participants explored that in pakhtun societies, individuals are not only seen as part of a family unit but also as integral members of a broader community, which helps share the emotional burden. In collectivist societies, individuals are seen not only as members of a nuclear family but also as part of a broader social unit that includes extended family and the community. This collective identity helps caregivers feel supported and reassured, as they know that they have a network to turn to for emotional assistance, even during the most challenging times. Studies have shown that such community-based support structures are particularly effective in alleviating the emotional stress associated with caregiving (Hassan et al., 2020; Razi et al., 2022).

Caregivers often describe their experiences as follows:

"Whenever my child has to go through a blood transfusion or a difficult time, my relatives are always by my side. It feels comforting to know that we are not alone in this struggle."(CGI3)

It is explored in interview with study participant that the given the ongoing medical costs associated with managing thalassemia, financial support from the community becomes critical. It is explored in interview with study participants that in Pakhtun society, communities often come together to pool resources to assist families facing medical burdens. This practice of shared financial responsibility is common in collectivist cultures where communal solidarity is emphasized. Research has shown that in such societies, the collective effort to address individual needs, particularly in health-related situations, can ease financial

strain. Fundraising events, financial contributions, and informal monetary assistance are common ways communities help each other. (CGI 1,3,4,7,)(Hassan et al., 2021) found that financial assistance from family, extended family, and even neighbors is vital in managing chronic illnesses like thalassemia in collectivist societies. This assistance often comes in the form of monetary gifts, food donations, or the provision of essential medical supplies.

One participant explains:

"When i faces such a challenge, duration of my son treatment. The people collect money from the neighborhood, and sometimes the people of community even organize small events to help with medical expenses. They can't leave me alone."(CGI8)

In interview with study participants it is explored that in addition to emotional and financial support, practical help is a crucial form of community assistance. Community members often assist with daily chores, take on caregiving responsibilities for other children, or provide transportation to medical appointments. These practical contributions are an essential part of it is also explored by participants that Pakhtun culture, where communal responsibility and cooperation are valued. Families in Pashtun communities are often able to manage caregiving tasks through the collective effort of extended family and neighbors. Studies on caregiving in collectivist cultures have shown that the distribution of caregiving tasks among multiple family members and community members can help lighten the load for primary caregivers. (CGI2, 4, 6, 7)A study by (Razi et al., 2022) found that in collectivist societies, caregiving is often a shared activity, with multiple family members taking on different roles to ensure that no single individual bears the full responsibility.

Caregiver has shared:

"My neighbors come over to help me with household work, especially when I have to take my child to the hospital. It is a great relief to have others stepping in when things get overwhelming."(CGI8)

Such practical support, as noted in studies, reduces the day-to-day stress that caregivers face, making it easier to manage the challenges of caring for someone with a chronic illness like thalassemia.

It is explored in interview with participants that in some Pakhtun communities, awareness about thalassemia and its genetic implications is increasing, and the community plays a role in spreading this knowledge. Educational efforts often come from local healthcare providers, community leaders, and elders who promote awareness of genetic risks and encourage genetic screening. It is also explored by participants that community-driven education about health risks can lead to more informed decision-making, particularly in communities where genetic diseases are prevalent. Recent studies emphasize the important role of community leaders, including elders and religious figures, in educating populations about the genetic risks of diseases like thalassemia.(CGI 1,3 5 ,7) In Pakistan, community-based programs have been effective in increasing knowledge and participation in genetic screening. These efforts are particularly impactful in communities where traditional beliefs and practices influence health behaviors (Tariq et al., 2021).

A doctor might explain:

"We are trying to educate people about the importance of genetic screening before marriage. Thalassemia is a common issue here, and we want people to understand the risks so they can make informed choices."

In interviews with study participants, it is explored that Pakhtun society places great importance on religious practices, and for many caregivers, spiritual support is an essential component of coping with the challenges of managing thalassemia. Religious leaders, such as Imams, often play a role in providing

spiritual guidance and prayers for healing. Many families rely on prayer as a way to cope with the emotional and physical tool of thalassemia, and the community's involvement in these religious practices reinforces a sense of shared responsibility. (CGI1, 2, 4,6,8) Research has also demonstrated that families of individuals with thalassemia often turn to religious practices to cope with the ongoing challenges of managing a chronic genetic disorder. Spiritual support, including prayer and seeking divine intervention, is an established practice in many cultures for managing the emotional and spiritual toll of such illnesses (Mirehie et al., 2016).

A caregiver might say:

"When condition of my child is critical, the people of community requested to local imam to pray for my child's health. It brings peace to my heart, knowing that God is with us in this trial."(CGI8)

CONCLUSION AND RECOMMENDATIONS

The study concluded that Pakhtunwali is a code of life plays two roles in the study locale. In Pakhtunwali as a culture close relatives' marriage is encouraged. The people living in joint families and cousin marriages are socially approved practice in the study area. The scientific research studies in biological sciences explained that thalassemia is increased among couples and their newborn babies due to cousin marriages which are largely practiced in the study locale. In Pakhtun family's cousin marriages are acceptable to both the families. It is also concluded that discouragement of cousin marriages is a western agenda to break the joint family bond in Pakhtun society. It is also concluded that Pakhtunwali is also providing a strong supportive ground for thalassemia carriers and caregivers. In this code of life, the neighbors and families with good financial health support the poor thalassemia carriers and arrange blood for transfusion at the time of need. This code of life also establishes strong integration among community members to support families having thalassemia carriers. The study concluded that due to this code of life the caregivers are appreciated, and all the community is encouraged to support them.

The study results recommended that the Government should start awareness program on digital media i.e. television, radio and social media to educate youth of society. Government should develop a mechanism to ensure the implementation of the law "THE KHYBER PAKHRUNKHWAI PREVENTIVE HEALTH ACT, 2009" to prevent spread of thalassemia among newly married couples in the province.

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