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Exploring Social Well-Being Challenges and Social Impacts Among Thalassemia Carriers

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ABSTRACT
This study explores the social well-being challenges and broader social impacts experienced by individuals who are carriers of thalassemia. Despite being asymptomatic, thalassemia carriers often face social stigma, misconceptions, and challenges in areas such as marriage, relationships, and community acceptance. The research aims to identify key social barriers, assess their effects on psychological and emotional well-being, and understand how cultural perceptions influence the lives of carriers. By highlighting these issues, the study seeks to promote awareness, reduce stigma, and inform policies and interventions that support the social inclusion and well-being of thalassemia carriers. In-depth interviews were conducted with 2 thalassemia carriers having aged above then 12 years and 8 with caregiver of thalassemia carriers having age below then 12 years. The interviews were recorded, transcribed, and analyzed using thematic analysis to identify patterns and themes related to social support, cultural practices, and health management.

Keywords: social wellbeing, social impact, social stigma, misconceptions, cultural perceptions.

INTRODUCTION
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., 2017). 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 are died without knowing that their children are suffering from thalassemia (Ehsan et al., 2020).
Social support systems are crucial in extending the value of life for individuals identified

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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 are very important in improving the mental health and reducing stress anxiety and depression. Friends offer emotional and social support by offerings companionship, understanding and encouragement. Friends provide you a social environment which also reduces the feeling of isolation. Peer group also allow to share with similar experiences to share advice, encouragement, and emotional support. Strong support from peer group 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 are important in offering to the social support network by providing resources, peer support, and awareness educational programs. Community organization foster empowerment among patients facing health challenges specially in chronic illness (Miller et al., 2021).

Religious leader have important role in all most all religion by providing comfort, guidance and spiritual heal to patients and their families. Literature revealed that Religious leaders provide support to individuals facing challenges in their difficult in managing chronic illness in which 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 ., 2024).The Healthcare providers including doctors' nurses and genetic counseling play pivotal role in wellbeing of chronic diseases patient. Healthcare professional not only provide medical treatment but they also help in guidance and emotional support to cope in managing diseases. They offer medical expertise, emotional support, and guidance on navigating healthcare systems (Smith et al., 2023).

Research 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 particular 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 researcher used interpretivist paradigm to understand the thalassemia as a social issue among thalassemia carriers. In the present study researcher used phenomenology research design. In this research design researchers studies 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., 2016). A study population means an entire group of

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individuals, items and data point from which a sample is selected for the purpose of investigation (Leedy et al., 2013). In the present study, researcher gather data from caregiver of thalassemia carriers aged 12 years or below than 12 years and thalassemia carriers aged above than 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 researcher initially proposed 10 interviews with caregivers however it was also mentioned in at the proposal stage that the saturation point will be considered. During field research, the researcher conducted total 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, 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.

Data Analysis

Awareness About 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."*

This kind of community-driven health education helps reduce the incidence of genetic disorders and empowers individuals to take preventative measures before starting a family.

In interview 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

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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:

kala cha zama mashom tabayat derr kharab v nu da mohallah khalk jumat k mola ta wai cha zma mashom sehat da para dua oka .ao da sara mata lag sukon milwe sha cha Allah masara da sakht wakht k shta.(CGI3)

"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)

This reliance on religious and spiritual support is well-documented in the literature; where the faith and collective religious practices in communities help strengthen the emotional resilience of individuals facing health challenges.

Knowledge and understanding of thalassemia as disease and thalassemia carrier;

Thalassemia is discussed in interview with study participants. The participants having traditional knowledge about thalassemia, as they don't know about that thalassemia is genetic disorder they explored in their own language that Thalassemia is often traditionally perceived as a disease where the blood "burns" the local understanding of the condition reflect a limited awareness of the genetic and medical aspect of thalassemia. (CGI 1,3,4,6)

As one of the participants share;

"Da veni swazidalo yaw bemaari da kam ta chi thalassemia wai"(CGI5)

Translator

"Burning of blood in human body is called thalassemia"

In interviews with participants it is explored that they have misunderstanding about thalassemia and doctors and nurse explained to them after diagnosis of their carriers that thalassemia is a lifelong condition that affects the production of hemoglobin, causing anemia. It is also explored that caregivers are often deeply aware of the challenges that come with the chronic nature of the disease, such as regular blood transfusions, iron chelation therapy, and the long-term medical attention required. This continuous need for care can be physically, emotionally, and financially burden.(CGI 2,3,6,7) Thalassemia is a lifelong condition that requires lifelong management, often involving blood transfusions, iron chelation therapy, and frequent medical assessments to prevent complications. The burden is not only physical but psychological, with caregivers often reporting feelings of stress and anxiety. (Cappellini et al.,2018)

As of the participant stated that;

"Thalassemia da wena swazado maraz nada ,da yao dasy maraz da cha kam k jasam sara wena nasha jorala wala ao da maraz k b khpl mashom wena laga"(CGI8)

"It is not a disease of burning blood but this is a disease in which body is unable to make red blood cell" (CGI8)

Furthermore, it is discussed in interviews with caregivers it is explored that thalassemia carrier and caregivers face the challenge of explaining thalassemia who are unfamiliar with the condition and they have traditional knowledge about thalassemia due to limited awareness that's why caregivers stated that they use simple terms to explaining thalassemia to others, often comparing it to anemia or other blood disorders. There is a tendency to down play the severity of diseases to make it easier for others to understand even though the disease has significant effects on the carrier and their family .(CGI,3,4,7,8). According to (Gaulton, A et al .,2017)found that caregivers often struggle with explaining the complexities of genetic diseases like thalassemia to others. They found that caregivers frequently use analogies or oversimplify to avoid causing concern or confusion.

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As one of the caregiver stated that;

"kala cha za da maraz khpl nor kor walo ao malgaro ta wam ,nu wam cha zma mashoma badan k sehatmanda wena dera na joraga ao mnga dakka maraz sara muqbala kaw" (CGI5)

Translator

"When I explained it to family or friends, I say it's like her body can't make enough healthy blood cell and we're constantly fighting tha" (CGI5)

It is explored in interview with participants they have no knowledge that thalassemia is a genetic nature of thalassemia. They were unaware of the significance of being carriers of the thalassemia gene and did not suspect that they could pass the condition on to their children. The condition was often discovered unexpectedly after routine screening tests. The genetic aspect of thalassemia became clearer to the respondents after consultations with doctors. The realization that both parents being carriers can result of passing the disease to their child helped them understand that thalassemia was not caused by their actions, but by inherited genetic factors,(CGI1,CGI3,CGI4, CGI6) thalassemia is a genetic condition ,and caregivers to grasp initially, especially when they are unaware that they or their partners might be carriers. Studies show that thalassemia is an autosomal recessive disorder, meaning that both parents must be carriers of the defective gene for a child to inherit the disease. Genetic counseling becomes a crucial part of understanding the diseases transmission. Especially for parents of children with thalassemia (forni et al.,2012).

As one of the participants share his experience;

"Mata da pata olagada cha mnga dwaro(za ao zma khaza) k thalassemia gene da, khu da rata pata na v cha da b zmnga mashom bnata asar kia''

Translator

We learned that both of us had the gene for thalassemia but we didn't know that could affect our child. (CGI2)

Risk of thalassemia is explored in interviews with participants that thalassemia is more common in people who belong to same ethnic groups having chance to increase the likelihood of being carrier or having children with the disease. Studies show that thalassemia is more common in populations with Mediterranean, Southeast Asian, Middle Eastern and African ancestry. It is explored in literature that understanding a family's ethnic background can be a key factor in identifying thalassemia carriers and at-risk individuals (Weatherall & Clegg, 2001). During interview many caregivers acknowledge the role of family history or genetic factors in the diagnosis of thalassemia. For some, the presence of carriers in their family was subtle risk factors they were unaware of until later. The lack of over symptoms in parents, despite being carriers, often led to a delayed realization of the genetic risks involved. This suggests that thalassemia not always be immediately suspected without proper genetic screening, especially in families with no prior history of the disease. (CGI, 2, 1, 5). Additionally, it is well established in the literature that early genetic screening can help identify carriers, reduce misdiagnosis, and provide a better understanding of potential risk for offspring (Sankaran et al., 2013). Without such screening, the genetic risk associated with thalassemia may not be fully understood or addressed until it is too late.

One of participants shared their experiences

Awal mata dasy lagadala cha sa teak nada ,khu bad k mata pata olagada cha zmnga dwaro family k thalassemia maraz shta .

Translator

I had a feeling something wasn't right and then we found out that both sides of our family

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had thalassemia. (CGI7)

Recreational activities provided to thalassemia carrier

In interview with caregivers it is explored that by participants that at-home activities for thalassemia carriers are adjusted to suit their energy levels and health status. It is also explored by Caregivers that small activities in home like drawing, reading stories to them, watching informative cartoons and playing with soft toys that don't take more energy was helping in coping with this chronic condition. These activities are often low-impact but still offer a sense of normalcy and inclusion.(CGI1.3.5.6) Literature shows that routine includes recreational and leisure activities are crucial for mental health and emotional stability (Gottfried et al., 2016).

One of caregiver stated that;

"At home, my child loves drawing and playing simple board games. These activities keep them entertained without tiring them out. It's crucial to create a comfortable environment where they don't feel restricted by their condition."(CGI7)

In interview with caregiver it is explored that role of family members and close friend play important role in physical and mental wellbeing of thalassemia carriers. The study participants explored the importance of family and close friends in encouraging their child to participate in social and recreational activities. It is also explored that close friends arrange a trip or any other social gathering to engaged carrier with their own children .These social networks often adapt activities to ensure inclusivity, helping to create a supportive environment.(CGI3,4,6,7) Research support that familial support significantly contributes to the emotional well-being of children with chronic conditions (Balk et al., 2006).

One of caregiver stated that;

"Our family and friends always try to include my child in social activities. In summer my friend takes my son with their children on sea side."(CGI8)

In interview with caregivers, it is explored that there is no specific activities for thalassemia carrier, but community people engaged carriers in their social gathering although due to their physical condition it is not easy but community people try to involve our thalassemia carrier in social events, including wedding events, or when there is local cricket tournament. (CGI2,4,5,7)However, there is often a need for careful management of energy levels to avoid exhaustion; which is supported by studies on the importance of moderating physical exertion for children with chronic conditions (Borgna-Pignatti et al., 2015).
One of care giver reported that;

"There is wedding in our neighborhood and they insist that my son must attend this function. However, we have to be careful with how much activity is involved. My child loves the outdoors, but we always make sure there are spaces to rest.''(CGI1)

Conclusion

The study concludes that family is the basic and first contact for thalassemia carrier and mostly the thalassemia caregivers are belongs to the close family members like father, mother, brother, sister, aunt, cousin etc. The study explored that family members provide

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emotional support to the thalassemia carrier at the time of anxiety, isolation, and emotional strain. The family manages financing for the treatment and searching for the best treatment place for thalassemia carriers. It is concluded that thalassemia carriers not only get support and facilitation from their family members rather peer group also play a vital role in the social wellbeing of the carrier. The community provides information about the available health facilities and establish link of carriers and caregivers with such kind of networks who are working for the prevention and response to thalassemia disease. *Mulla*-religious leader's role is explored significant in connection with social and mental wellbeing of the carriers and caregivers.sThe health care centers are not only used for treatment and blood transfusion rather they enhance the awareness of thalassemia caregivers and other family members.

Recommendations

Government should start an awareness raising program on thalassemia as a social phenomenon at community level and educational institutions to sensitize about the outcome of thalassemia as diseases.

Government should start awareness program on digital media i.e. television, radio and social media to educate youth of the society.

Government should develop a mechanism to ensure the implementation of "THE KHYBER PAKHRUNKHWAI PREVENTIVE HEALTH ACT, 2009"

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