Tharu Community Conscience and Perception on Sickle Cell Anemia[1]

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Abstract

Sickle cell disease (SCD) is a genetic blood condition which is very common in the Terai region of Nepal among the Tharu people. The study scrutinizes about the social construction of SCD, highlighting how cultural aspects, healthcare accessibility and the extended societal views interaction affecting managerial and awareness sector in Tharu community. The study aims at examining the views of tharu community regarding SCD long with its effects. It particularly emphasizes people experienced with the illness and their awareness. The study presents the growth of awareness of SCD among people in the Tharu community. Traditional healers function seems to be changed as people tends to follow healthcare practices. Government still fail to assist the gaps in accessibility and education. One of the contributing factor for SCD prevalence is the cultural norms surrounding marriage which needs to be addressed. Focusing on intervention programs and comprehensive education can improve health outcomes. This study acknowledges insufficiency of people in reference to realization and awareness of SCD in Kailali, Nepal. Despite awareness, strategic governance is hindered by illiteracy and fallacy. In order to confront the genetic traits and sociocultural dimensions of SCD, the study focuses on the requirement of helping network and targeted educational program.

Keywords: Ghodaghodi municipality, sickle cell anemia, sickle cell disease, Tharu community

Introduction

Berger and Luckmann (1967), suggested that our accepted assumptions about society are based on specific realities, emphasizing that understanding health and illness requires recognizing their socially constructed nature. Based on this perspective, recognizing the difference between illness (the social meaning) and disease (the

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biological condition) is essential, as health is shaped by a complex blend of social and biological influences (Eisenberg, 1977). Considering this, Sickle Cell Anemia (SCA) makes a compelling case for exploring this interaction, particularly within Nepal's Tharu community, where further research is necessary to assess both awareness and genetic vulnerability to this inherited autosomal recessive condition. People are more likely to have sickle cell anemia in places where malaria is common because the sickle cell trait helps protect against it (Lawrence & Shan, 2014). Even though James B. Herrick pinpointed SCA in 1910, there is still a lack of detailed information about its occurrence in Nepal, particularly within the Tharu group (A. Amatya & R. Choudhary et al., 2007). This investigation seeks to determine the rate of SCA in individuals between the ages of 1 and 29 in the Tharu community, aiming to bring attention to health inequities within this demographic. Long-standing misconceptions, such as the belief that SCA is a disease predominantly affecting black people, highlight how societal views of the condition can strongly shape treatment outcomes, impacting the quality of care and research funding (Smith et al., 2006). Furthermore, racial disparities in healthcare expose systemic issues, as African-Americans with SCA often face longer wait times for treatment in emergency rooms compared to their white counterparts (Haywood et al., 2013). The experiences of individuals dealing with chronic diseases are heavily influenced by these societal norms and structures (Lawrence et al., 2014). Resolving the complex challenges encountered by patients and their families requires an understanding of the social environment of SCA. Managing the condition is largely shaped by elements like socio-economic position, educational background, and mental wellness (Barbarin, 1999). Cuktural and class divides between patients and healthcare providers can result in miscommunication and poor-quality care (Pinderhughes, 1989). This research intends to address the knowledge gap about SCA perceptions in the Tharu communities by illustrating how these understandings are constructed through social processes (Young & Collin, 2004). Thus, the goal of this study is to enhance awareness and provide direction for improved health outcomes within the Tharu community.

Literature Review

Origin of Sickle Cell Disease: The present knowledge of sickle cell disease (SCD) is shaped by its deep historical roots. While the disease was initially identified in the United States in 1846, it gained greater recognition in 1910 when a patient exhibited unusual elongated and sickle shaped" red blood cells, as reported by Bloom (1995). Following the reporting of more cases, SCD was officially named in 1922, highlighting a crucial development in its awareness. In populations like the Tharu community in Nepal, where genetic adaptations have provided resistance to malaria, SCD is prevalent and strongly linked to malaria (Bloom, 1995).

Assumptions regarding the origin of Sickle Cell Origin: In 1940, a British colonial physician in Northern Rhodesia (now Zimbabwe), was the first to propose the link between sickle cell disease and malaria after observing that individuals with the sickle cell trait had a reduced blood parasite burden (Bloom, 1995). Subsequent studies in Zaire, where individuals with the sickle cell trait showed fewer instances of severe malaria, validated this finding. Studies like these showcase the sickle cell gene's ability to adapt in environments where malaria is common.

Sickle Cell Disease and Its Transmission: Sickle cell disease results from a defective type of hemoglobin that causes red blood cells to become misshapen into a sickle-like shape. This can obstruct blood circulation and lead to anemia (Creary et al., 2007). As stated by Muscari (2005), sickle cell trait arises when a person inherits one copy of the sickle cell gene, while sickle cell disease develops when two copies of the gene are inherited, one from each parent. The role of community and family genetics in understanding the prevalence and transmission of SCD is emphasized by its genetic consequences (Hill, 1994).

Prevalence rate of SCD: Sickle cell disease is more prevalent globally in regions with a significant African heritage. For instance, sickle cell genes are widespread in Jamaica, a country with 2.6 million inhabitants, the majority of whom trace their roots to West Africa (World Factbook, 2007). In a similar manner, consanguinity has contributed to the higher prevalence of genetic disorders such as sickle cell disease (SCD) in Saudi Arabia (Alkuraya & Kilani, 2001). However, the exact prevalence in Nepal remains largely unknown. To better understand the prevalence of SCD in the Tharu population, ongoing research aims to focus on diagnosis within the community (NHRC, 2017).

Research Problem

As stated by Alhamdan, Almazrou, Alswaidi, and Choudhry (2007), one outcome of premarital screening is better understanding of the prevalence of sickle cell disease in Saudi Arabia. With 4% of the population being carriers and 0.26% affected by the disease, the incidence is considered high. The high prevalence is attributed to the fact that more than 50% of first cousins and relatives marry within their family, (Alhamdan et al, 2007). Recent reports from various sources suggest that SCD is connected to social isolation, aggression, and depression (Anie, 2005). This study primarily focused on the connection between SCDs, social interactions, and general social practices. In 2008, the United Nations declared June 19 as "World Sickle Cell Day" recognizing sickle cell disease as a global public health issue (United Nation [UN], 2008). Each year around 400,000 children are born with sickle cell disease globally, with nearly 3,000 of these cases reported in Africa alone (Boadu & Addoah, 2018). Current estimates suggest thatn1 in 500 African American newborns in the United States are born with sickle cell anemia, with roughly 90,000 to 1,00,000 Americans affected (William, 2016). Worldwide, millions live with this condition, particularly those of descent from Sub-Saharan Africa, South America, Cuba, Central America, Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy. An estimated 72,000 people in the US are affected by the disease, with most of them having African ancestry (WHO, 2018). In India, sickle cell disease ranks as the second most widespread hemoglobin disorder, especially in the central and southern parts of the country. In certain regions, the prevalence of sickle cell diseases ranges from 2.5% to 20% (Lewis, 2014). Even though Tharu communities in Nepal and India live in areas where malaria is widespread, their incidence of malaria is seven times lower than that of individuals with sickle cell anemia ("life with sickle cell," 2014). The Tharu (91.3%), Chaudhary, and Rana ethnic gropus from Nepal's malaria-prone Terai region are more likely to be affected by sickle cell disease (Shrestha & Karki, 2013). The 2011 census recorded 1,737,470 Tharu people, accounting for 6.56% of Nepal's total population.The Tharu communities in Dang, Banke, Bardiya, Kailali, and Kanchanpur show a high incidence of the disease. The Tharu rank as the fourth largest ethnic group in Nepal by population.Tharus have a seven-fold lower prevalence of malaria compared to non-Tharus. Sickle cell disease is common in the Malaria-prone Terai region (Chaudhary, 2015). Based on the study, it is estimated that over 300,000 Tharu individuals in the nation have sickle cell anemia. Health officials in Dang, Banke, Bardiya, Kailali, and Kanchanpur districts report a high incidence of sickle cell disease among the approximately 1,730,000 Tharu people, as indicated by the 2011 census (Life with Sickle Cell Disease, June 2014). However, few studies have been done to examine the difficulties faced by the Western Tharu community as a result of sickle cell anemia. Research on sickle cell anemia in the Tharu community remains sparse, despite its widespread impact on large populations. The psychological, social, economic, marital, and educational problems arising from physical illnesses must be investigated through counseling. With this in mind, the researcher intends to investigate and address this matter by exploring the Tharu community's understanding and views on sickle cell anemia.

Objective

1. To explore the perceptions of the Tharu community regarding sickle cell disease.
2. To identify individuals with sickle cell disease within the Tharu community.

Theoretical Perspective

Symbolic interactionism, a foundational sociological perspective rooted in American pragmatism, centers on the ways in which social interactions give rise to shared meanings (Reynolds, 2003b). The theory's intellectual lineage traces back to the influential work of George Herbert Mead and the Chicago School, whose contributions significantly shaped its development. As noted by Denzin (1992), the evolution of symbolic interactionism can be understood through four distinct phases: canonical, empirical, theoretical, and ethnographic. These stages reflect the theory's progression from foundational texts to applied sociological research and ethnographic inquiry. According to symbolic interactionism, meaning is not inherent but socially constructed through interaction. Ransom (2010) underscores this b7 asserting that all social interactions are inherently meaningful (p. 168). Building on this idea, Mead posits that an individual's sense of self is shaped through social interaction, highlighting the critical role of social context in identity formation. As emphasized by De Maio (2010), a core focus of symbolic interactionism lies in understanding individual's experiences of illness. (p. 42). Freidson (1970), further argues that individuals actively assign meanings to their illnesses (p. 224). Within this theoretical framework, social reality is seen as dynamic and continuously constructed through everyday social interactions (Plummer, 1991). Mead's concept of the self, characterized by the "I" and "me," emphasizes the relationship between personal experiences and collective expressions, illustrating how societal norms influence individual actions (Blumer, 1969; Mead, 1994). Mead's self-theory (1934) further explores how a person's self-identity is maintained through a continuous, dynamic process of interaction. This relationship with oneself is important guiding social interactions (Reynolds, 2003). Mead assured the importance of communication in controlling social action and the mind, and the practical mindset reinforces consequences of meaning-making process (Meltzer et al., 1975). The distinction between "I" and "me" illustrates how individual's behaviors are shaped by their interpretations of social experiences. According to Berger and Luckmann (1996), the sociological perspective on the construction of reality is emphasized through an analysis of social constructionism asserting that all human knowledge is created, communicated and sustained within social contexrs (p. 1). Gergen (2009), argues that how we describe and explain shapes our future" (p. 11), highlighting the importance of negotiating meanings within specific contexts, while also considering social structure, individual agency, and negotiation to understand the social dynamics of the Tharu community in relation to FCD.

Methodology

A mixed-methods approach was used in this study, combining categorical and narrative methods to examine the Tharu community's knowledge and perceptions regarding sickle cell anemia (SCA). Most of the information comes from field visits, interviews, and talking with people in the community, although it also includes some reports from hospitals and other sources (Creswell, 2003). A simple random sampling method was used to select 50 respondents from Ghodaghodi Municipality, enhancing the sample's representativeness by ensuring that each individual had an equal probability of selection (Marshall, 1996). The research follows a mixed-methods design. Quantitative data were gathered through structured interviews and analyzed statistically, whereas qualitative methods were used to explore the personal experiences and interpretations of participants regarding SCA (Creswell, 2003). The qualitative data is made stronger through interviews with key informants-people who know a lot about the community (Termbly, 1995). The main findings are also supported by other sources like research articles, news reports, and information from hospitals such as Ghodaghodi Hospital and Seti Zonal Hospital. This combination of data sources contributes to a comprehensive and well-rounded understanding of the research topic.

Study Area

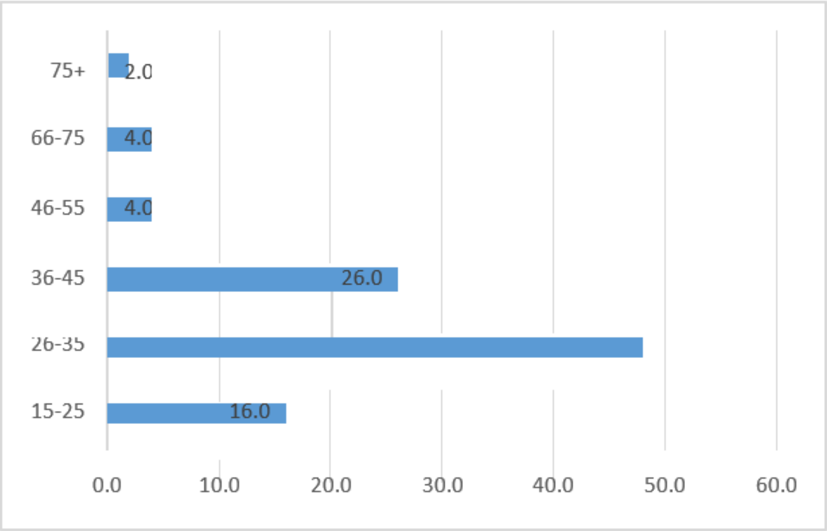
Kailali District, located in the Seti Zone of southwestern Nepal, covers an area of 3,255 square kilometers. The region features varied landscapes, with approximately 40% of the land classified as Terai and the remaining 60% comprising hilly terrain. Dhangadhi, a sub-metropolitan city of within the district, functions as the central hub not only for Kailali but for the entire Seti Zone. Notable attractions in the district include Tikapur Park-one of the largest parks in Nepal and Ghodaghodi Taal, a scenic body of water situated in Sukhad, Kailali. Dhangadi is home to Nepal's only aircraft museum, which was started in 2014 by pilot Bed Upreti (DDKailai, 2019). Kailali is also known for its rich language diversity. According to the 2011 census, people in the district speak eight different languages. Around 40% speak Tharu, and about 88% speak Doteli, Nepali, and Tharu. The Central Bureau of Statistics reports that Kailali has 73 ethnic groups, with Tharu, Kshetri, and Brahmins making up over 75% of the population. Besides the 65 other castes that make up around 1% of the population, important groups also include the Kami, Thakuri, Magar, Damai, and other socially marginalized communities. The study focuses on the Ghodaghodi Municipality, which is located in the center of Kailali District. Ghodaghodi covers an area of 354 square kilometers and has a population density of 214.3 people per square kilometer. Ghodaghodi Municipality is bordered by Bardgoria Rural Municipality to the east, Gauriganga Municipality to the west, Bhajni Municipality to the south. According to the 2011 Census, the population of Ghodaghodi Municipality is 75,965, with 37,204 men and 38,761 women. To show its commitment to education, the municipality has three campuses, 57 community schools, and 36 private schools and 12 Village Development Committees (VDCs) (Ghodaghodi Municipality, 2019).

Result

The Tharu population in the study area is particularly vulnerable to sickle cell disease, yet there is a significant lack of education regarding the the illness within the community. Sickle cell anemia poses a serious health threat to the Tharu people, making this municipality an ideal setting for the study. The limited awareness and misconceptions surrounding the disease appear to be key challenges faced by the Tharu community, contributing to their lack of understanding. This study aims to explore the knowledge and perceptions of sickle cell anemia within the Tharu population.

Age of Respondents

Figure 1: Respondents Age



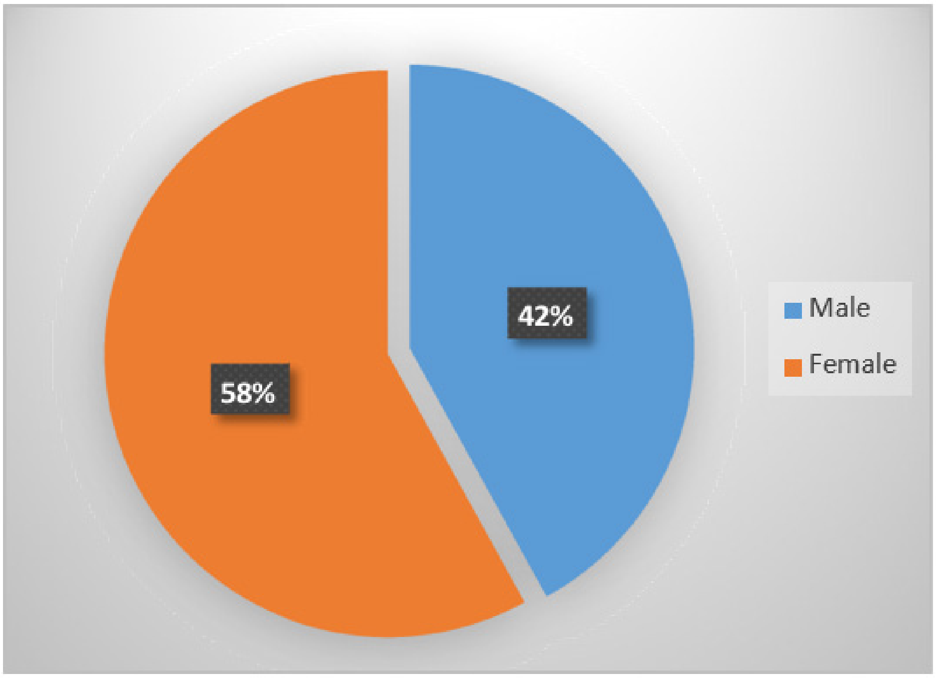
Source: Field Survey

According to the 2019 field survey, respondents in the 15–25 age range are less aware of sickle cell disease than those in the 26–45 age range. However, respondents in the 46–55, 66–75, and 75+ age groups know very little about sickle cell disease. Figure 1 also showed that respondents in the 26–45 age range have access to social media, health care facilities, and education to learn about social reality. Respondents in this age group are taking part in political and health-related programs together. Accordingly, respondent age affects their understanding and perspective of sickle cell disease.

Gender of Respondents

According to the 2019 field survey, women make up the majority of respondents (58%) compared to men (42%). This indicates that in the study area, women are more likely to suffer from sickle cell disease (SCD) in Ghodaghodi Municipality, while men are less likely to do so. The data also shows that women are more likely than men to seek a sickle cell disease checkup from the Tharu community, while men undergo fewer examinations due to foreign employment and international migration.

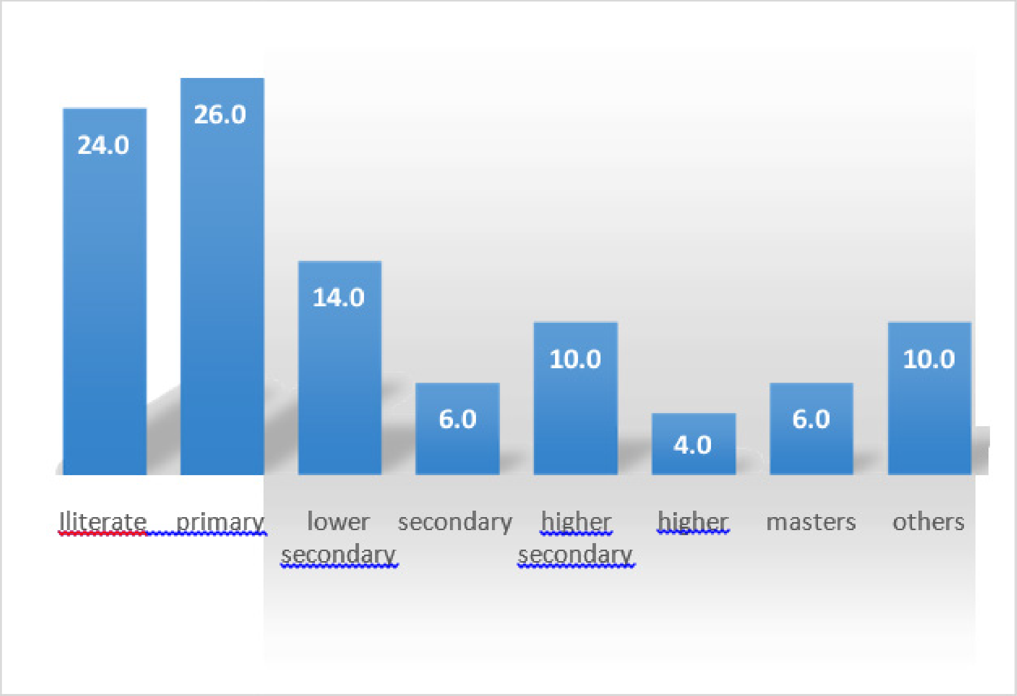
Figure 2: Respondent Gender



Source: Field Survey

Education of Respondents

Figure 3: Education of Respondents



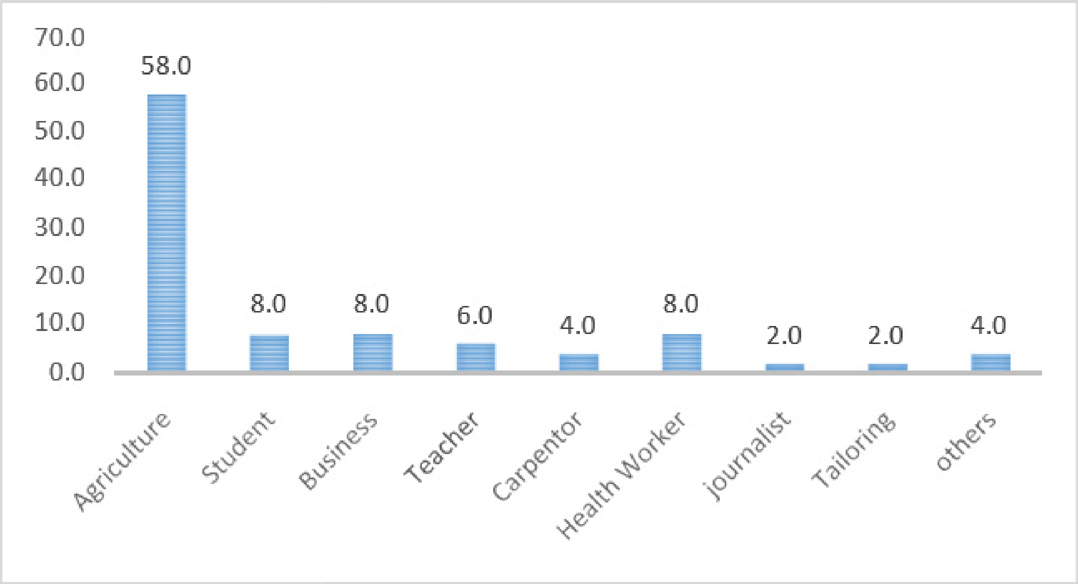
Source: Field Survey

The 2019 field survey found that the percentage of respondents with illiteracy and primary level is high (24% and 26%, respectively), followed by higher secondary level and others (10%), secondary and master level respondents equal 6%, and respondents with higher education level 4%. The data also shows that a large proportion of respondents (nearly 50%) have less education and awareness of sickle cell disease, while a smaller percentage of respondents have more education and awareness of sickle cell disease. This is because education is a key component of understanding and perception of sickle cell disease, which provides insight into social reality.

Occupation and Economic Background of the Respondents

The study area is based on the 2019 field survey regarding the economic background and occupations of the respondents. 58 percent of respondents were employed in agriculture. Similarly, 42 percent come from the business, teaching, carpentry, health, journalism, and tailoring sectors. Additionally, the data shows that the primary occupation of the Tharu community in the Terai is agriculture. Because agricultural occupational respondents are only involved in the agriculture sector and other occupational respondents are involved in multiple sectors and acquire multiple types of knowledge, the economic background of business and health workers is superior to that of agricultural occupational respondents. Therefore, respondents with agricultural occupational economic backgrounds are less likely to be aware of and perceive sickle cell disease, whereas respondents with other occupational economic backgrounds are more likely to do so. The Tharu community's primary source of information about sickle cell disease is their lack of education and stable economic situation. As a result, the Tharu community's economic background greatly depends on their level of awareness and understanding of sickle cell anemia.

Figure 4: Occupation and Economic Background



Source: Field Survey

Discussion

Early ethnographies on Nepalese health-seeking behavior suggest that shamans were traditionally the sole providers of medical care. Over time, their role evolved alongside cultural challenges, and they eventually became recognized as Traditional Medical Practitioners (TMPs) integrating into the Western allopathic system (Justic, 1986) due to the influence of Western development (bikash). Recently, a new trend has emerged in how the Tharu people seek health care, with many now avoiding medical shops before visiting a hospital. The study identifies key themes based on informants responses, with each theme having subcategories derived from the data analysis.

Management of the Sickle Cell Disease

Education plays an important role in improving the quality of life for sick individuals. Tharu people are instructed on how to handle their health issues at home before consulting a doctor.

One of the respondents says that*:*

She frequently loses consciousness due to excruciating pain in her hands, feet, and stomach. “The pain becomes less severe only after I take medicine,” she claims. Her father, who works as an office assistant and makes only 8,000 rupees a month, claims he has no debt because he paid for medicine to ease his daughter’s discomfort. Her family wasn’t getting any help until a year ago. Thanks to her sickle cell identity card, she received treatment at Seti Zonal Hospital in Dhangadhi a month ago.” The money that the government provided for the trearment has eased the burden for my father,”she says. She tells me that at that point, every member of the Tharu community should have their blood tested and have a sickle cell identity card. (Respondent participant).

Due to financial constraints, the respondent cannot afford treatment and is unaware of the government’s free SCD treatment facilities. However, she received treatment at Seti Zonal Hospital a month ago, and believes the government provides free SCD patient care. Some respondents also express dissatisfaction, stating that the government fails to manage sickle cell disease properly, saying at the time:

> However, the government has never prioritized sickle cell research, awareness, or medical services in the western Tharu community. The Tharus, who have been neglected by the state, have been forced to endure the brunt of its indifference. Additionally, some people with sickle cell disease are content with the government services that are provided. (Two male respondents and one female respondent participated.)

Some respondents appreciate the government’s free SCD treatment, while others criticize the lack of research and culturally tailored programs for the Tharu community. Government policy mandates a sick-ling test and health card for Western Tharu people before marriage. The paragraph emphasizes that improved education, research,and community-specific management could help address SCD more effectively.

Cultural Boundaries

The Tharu people, an indigenous group, are originally from southern foothills of the Himalayas. Traditionally, the cultural practices of the Tharu community, including their marriage customs, were closely tied to their ethnic identity. Consequently, approximately 90% of Tharu individuals marry within their own ethnic group.

According to two respondents says that in this context:

> Marriages in the traditional Tharu community were frequently arranged during two women's pregnancies. If they had opposite-sex children, they were expected to marry them if they became friends as adults. If a boy or girl reached adulthood and refused to accept their assigned finance, that was problematic. Since the majority of girls and boys were already engaged, finding a replacement was challenging. Nowadays, the majority of Tharus engage in conventional arranged marriages. In the Tharu community, they also engage in eloping due to sickle cell disease, love marriages, intercaste marriages, and marriages following courtship. (Respondents of 2 participants).

The Tharu community's traditional marriage system, based on ethnic exchange, is linked to the prevalence of sickle cell disease. While some Tharu individuals are exploring inter-caste and love marriages, the traditional system persists, and some individuals are affected by sickle cell anemia.

> The prevalence of the disease has grown among the Tharu people because customer requires that they marry within their ethnic group, and sickle cell disease is a recessive triat and requires both parents to carry gene. (Respondents, five participants).

The discussion in this study underscores the complex connection between awareness of Tharu culture and the prevalence of sickle cell disease (SCD). Given that sickle cell disease is genetic, the Tharu's community long standing practice of arranged marriages within their caste has inadvertently facilitated the spread of the condition. As emphasized by Dr. Anjani Kumar Jha, the risk of a child inheriting sickle cell disease significantly increases when both parents carry the sickle cell trait. This highlights the urgent need for educational programs to inform the community about how genetic inheritance affects marriage choices.

The responses from participants reveal evolving attitudes toward marriage practices among Tharu community. One respondent highlighted that doctors have recommended inter-caste marriages in regions with high disease prevalence to reduce the spread of sickle cell disease (SCD), reflecting a growing willingness to adapt cultural norms for health protection. Additionally, another respondent from the Pahalmanpur Sub-Health Post noted that sickle cell disease is more common in malaria-endemic areas, as the sickle cell gene provides carriers with resistance to malaria. This illustrates the complex interplay between the Tharu community's environmental adaptation and the prevalence of SCD

The studies reviewed indicate a significant lack of awareness about SCD among different segments of the Tharu community, underscoring the need for comprehensive educational initiatives. While some individuals recognize the preventive potential of inter-caste marriage, many remain unaware of the hereditary nature and implications of SCD. To break the cycle of transmission and support informed reproductive choices, the research advocates for improved access to genetic counseling and targeted health education within the community.

Finding

The study explored Tharu community in Kailali's knowledge and attitudes toward sickle cell disease (SCD), highlighting its genetic nature and prevalence in Nepal's Western Terai. Many lack awareness, increasing health risks. Tharu people show diverse health-seeking behaviors, blending traditional and modern treatments, including allopathic care and consultations with shamans. The rise of private healthcare suggests a shift toward western medical practices. The Tharu community encounter challenges linked to the social implications of SCD, including stress, loneliness, and a poor quality of life, despite having some understanding of how to manage the illness. These factors complicate social connections and marriage, particularly for unmarried youth facing a vulnerable phase of life. The research indicates that while there is some awareness of sickle cell disease, the depth of understanding-especially regarding its impact on reproductive planning-is often limited. The study of 50 respondents using statistical analysis found that education is key to reducing the prevalence of SCD. However, it emphasizes that awareness alone is insufficien and a more nuanced approach considering [personal experiences and cultural context is necessary. The Tharu community's ongoing efforts to understand SCD reveal the need for targeted counseling and education before and after marriage. The study highlights SCD as both socially constructed issue and a genetic condition, emphasizing the importance of integrating sociocultural perspectives into health education strategies. This comprehensive approach can lead to improved health outcomes and more informed decisions about marriage and family planning.

Conclusion

This study provides valuable insights into the knowledge and attitudes of the Tharu community in Kailali, Nepal, regarding sickle cell disease (SCD). While there is partial awareness of the condition, significant gaps remain in understanding its hereditary nature and available treatments. The lack of comprehensive knowledge places many individuals at heightened risk, hindering their ability to protect themselves and their families. The findings also reveal a gradual shift toward Western healthcare practices, alongside the continued influence of traditional medical approaches. Social consequences such as anxiety and isolation, particularly among unmarried youth, further compound the challenges posed by SCD. The study underscores the superficial nature of existing awareness and emphasizes the urgency for culturally tailored education and support systems. Ultimately, the research positions SCD not only as a genetic illness but also as a socially constructed phenomenon shaped by cultural beliefs and social dynamics.

Brief Recommendation: To enhance the Tharu community's understanding and management of sickle cell disease (SCD), it is essential to implement targeted educational initiatives that clearly explain the genetic and clinical aspects of the condition, while emphasizing the importance of both pre-marital and post-marital counseling. Promoting collaboration between modern healthcare providers and traditional healers can support a more integrated and culturally appropriate approach to health-seeking behaviors. Additionally, the development of mental health resources is crucial to address the social isolation and anxiety often experienced by individuals with SCD, particularly among youth navigating personal relationships. Reducing stigma through community-based awareness campaigns involving local leaders and stakeholders can foster open dialogue and support. Ongoing research is also necessary to monitor changes in community understanding, ensuring that educational interventions remain relevant and effective. Through these strategies, the Tharu community can improve health outcomes and empower individuals to make informed decisions about their health and family planning.

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