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Community awareness of sickle cell disease and Community-Based Interventions in Tabora Region

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ABSTRACT

Sickle Cell Disease (SCD) is a major public health and social challenge in Tanzania, yet most research and services are concentrated in urban referral centres. Evidence from rural districts, where many affected families live, remains limited. Guided by the socio-ecological model and the social determinants of health framework, this study examined community awareness of SCD and the perceived effectiveness of existing Community-Based Interventions (CBIs) in Uyui and Urambo Districts, Tabora Region.

A cross-sectional household survey was conducted with a proportionate sample of 309 household heads. A structured questionnaire captured socio-demographic characteristics, SCD-related knowledge, information sources, intervention exposure and perceived effectiveness. Quantitative data were analysed using descriptive statistics, while qualitative information from key informants and documents was examined through content analysis.

Community recognition of SCD was high (93.9%), and 87.7% of respondents reported knowing at least some symptoms. Most understood SCD as hereditary, with 67.1% citing inheritance of the sickle cell trait as the cause. However, knowledge of at-risk groups was uneven (57.0% aware), and 59.2% were unsure whether SCD is curable. Information pathways were dominated by family and friends, with health workers rarely cited as first sources. Around 60.2% of respondents reported that no effective SCD interventions existed in their communities. Recognized interventions mainly included screening and nutrition services; participation across 17 types of activities was very low (72–87% rated "never"), and most interventions were rated ineffective or very ineffective.

Findings reveal a gap between a high nominal awareness of SCD and a shallow, uneven understanding of risk, inheritance and treatment, as well as weak, poorly perceived CBIs. To improve their impact, SCD responses in rural Tanzania must move beyond narrow biomedical models toward participatory, culturally embedded interventions that integrate screening and treatment with clear, low-literacy communication, psychosocial support, stigma reduction and stronger roles for frontline health workers, local leaders, and community networks.

1. Introduction

Sickle Cell Disease (SCD) in Tanzania is not only a biomedical condition but also a social reality that affects family life, education opportunities, employment prospects, and community relationships. Tanzania ranks among the five countries with the highest estimated annual number of SCD births, with approximately 11,000 affected newborns each year (Makani et al., 2018; Ambrose et al., 2020). This indicates that, for many families, SCD is a common part of daily life rather than a rare event. Nevertheless, in practice, especially outside major cities, SCD is often recognized only after repeated episodes of childhood illness and lengthy, costly journeys to referral hospitals. These patterns reflect broader social inequalities in access to information, transportation, and health services, which together delay diagnosis and hinder long-term care (Makani et al., 2018; Ndumwa et al., 2023).

These challenges occur within a broader epidemiological shift in which Non-Communicable Diseases (NCDs) are becoming more common in Tanzanian households alongside infectious diseases. Nationwide, NCDs already account for about a third of all deaths and are expected to surpass communicable diseases as the leading causes of death (Ndumwa et al., 2023; Mayige et al., 2012). Early reports noted that conditions like diabetes and hypertension were becoming "normal" in daily life, driven by rapid urbanization, lifestyle changes, and economic transition, and called for prevention strategies that reach people where they live and work, not just where they receive treatment (Mayige et al., 2012; Ndumwa et al., 2023). SCD has been included in the national NCD agenda. However, in practice, much of the expertise, infrastructure, and research remains centred in urban referral centres, leaving rural areas like Tabora with fewer resources and less prominence in national debates (Makani et al., 2018; Ambrose et al., 2020).

Recent surveillance has revealed both the scale and uneven recognition of SCD within the country. Data from dried blood spots collected through the HIV early infant diagnosis program in nine north-western regions of Tanzania reveal that around 20% of infants carry the sickle cell trait, and just over 1% have Sickle Cell Disease (SCD). In some districts, the trait rate is nearly 30% (Ambrose et al., 2020; Makani et al., 2018). This statistic shows that SCD is not just a rare disorder affecting only a few families; rather, it is a common inherited condition across many regions of the country (Ambrose et al., 2020; Ndumwa et al., 2023). However, most services, research, and advocacy remain focused on major institutions. In regions like Tabora, families often rely on local social networks, nearby health facilities, and traditional and faith-based support for SCD care, often without access to consistent, organised care (Ndumwa et al., 2023; Mayige et al., 2012).

People's understanding and responses to SCD are closely linked to their broader knowledge of chronic diseases. A study in a rural community found that just over half of adults could correctly identify which conditions are NCDs, with knowledge strongly connected to education level and place of residence (Sirili et al., 2024; Ndumwa et al., 2023). A survey in two districts preparing to implement the PEN-Plus services found that fewer than half of the participants had heard of "non-communicable diseases." While many recognized diabetes, only a small number mentioned SCD. Over 80% answered questions about SCD incorrectly, indicating limited knowledge (Kagaruki et al., 2025; Sirili et al., 2024). These findings suggest that SCD has a marginal place in common understandings of chronic illness and that awareness of it is heavily influenced by education, income, and geographic factors, especially in predominantly rural areas like Tabora (Kagaruki et al., 2025; Mayige et al., 2012).

The capacity and confidence of local health workers further influence the social environment surrounding SCD. In many districts, mid-level providers such as nurses, clinical officers, and assistant medical officers serve as the primary contacts for families. An assessment in Kondoa District conducted before and after training revealed that participants initially had limited knowledge about NCDs, including SCD, with fewer than 50% answering correctly on diagnosis and treatment (Karoli et al., 2024; Kagaruki et al., 2025). Although a short PEN-Plus training improved overall scores, the study highlighted the importance of ongoing education and support, especially for staff who serve long-term in rural health facilities (Karoli et al., 2024; Sirili et al., 2024). These results demonstrate that health workers are not just technical experts but also community members, whose understanding, language, and attitudes significantly shape how SCD is perceived, discussed, and managed locally (Ndumwa et al., 2023; Mayige et al., 2012).

Economic and geographic disparities play a major role in shaping how families experience and manage Sickle Cell Disease (SCD). Research from north-western Tanzania indicates that when families have to pay out of pocket for medications and clinic visits, treatment often becomes irregular and financially burdensome. In contrast, households with health insurance or external support, such as aid from health projects, generally receive more consistent and dependable care (Ambrose et al., 2023; Makani et al., 2018). Broader community-based studies on Non-Communicable Diseases (NCDs) also demonstrate that low income and limited educational backgrounds are strongly associated with poorer health knowledge and reduced access to care. This creates a vicious cycle: the families most affected by SCD are often the least equipped, both financially and informationally, to manage it effectively (Kagaruki et al., 2025; Sirili et al., 2024). In Tabora, where many people rely on subsistence farming or informal jobs, and where health facilities are often far away, these economic and spatial challenges greatly influence decisions about when and where to seek care. They also impact how families prioritize SCD treatment alongside daily survival needs and other livelihood demands (Ndumwa et al., 2023; Mayige et al., 2012).

Taken together, the literature indicates that SCD in Tanzania, especially in underserved regions such as Tabora, must be understood through social and structural lenses rather than solely biomedical ones. Frameworks such as the Socio-Ecological Model (SEM) and the Social Determinants of Health (SDH) clarify how factors like individual knowledge and beliefs, family and peer networks, local institutions, community norms and national policies interact to influence experiences of illness and care (Ndumwa et al., 2023; Kagaruki et al., 2025). Tanzanian studies demonstrate low public awareness of SCD, limited training for frontline workers on NCDs, and strong connections between poverty, geography and healthcare access, illustrating these multiple influences in real-world contexts (Sirili et al., 2024; Karoli et al., 2024).

However, there is still limited empirical evidence on how these multilevel factors actually shape the design, implementation and perceived effectiveness of community-based interventions specifically targeting SCD in rural districts like Tabora, where most families rely on primary facilities and informal networks rather than specialized centres. Existing Tanzanian work has largely focused on urban referral hospitals and biomedical outcomes, with far less attention paid to how ordinary households understand SCD, how frontline and community actors translate policy into practice, and how communities themselves judge the visibility, relevance and impact of SCD programmes. Building on this gap and on the need to operationalize SEM and SDH at the district and household levels, this study examined how community-based interventions improve awareness, reduce stigma, and promote care-seeking for SCD in Tanzania, with particular emphasis on rural and peri-urban settings in Tabora.

2. Theoretical Framework

This study is guided by two complementary perspectives: Bronfenbrenner's Socio-Ecological Model (SEM) and the Social Determinants of Health (SDH) framework. SEM views individuals as embedded within multiple, interacting levels of influence from close relationships to wider institutions and policy environments (Bronfenbrenner, 1979). In the context of SCD in Tanzania, this means that a child's experience is shaped not only by their own knowledge and attitudes, but also by family beliefs, school practices, behaviour, understanding of frontline health workers, messages from religious and community leaders, and national decisions on NCD priorities. Using SEM helps the study focus on community-based interventions that operate at multiple levels (in this case, household, school, health facility, and local leadership), rather than assuming that information given to individuals alone will change behaviour.

The SDH framework provides a structural perspective by highlighting how factors such as income, education, gender, occupation, and rural–urban location influence both exposure to risk and access to care (World Health Organisation, 2008; Marmot, 2005). For SCD in regions such as Tabora, this involves recognizing that awareness, stigma, and treatment uptake are heavily influenced by poverty, distance to health facilities, health financing systems, and broader policy implementation rather than solely individual choices. Taken together, SEM and SDH support a view of SCD as a social and structural issue as well as a health issue, and they guide this study in mapping how different actors and settings influence awareness and care-seeking, and in assessing how economic and geographic inequalities constrain or enable community-based interventions for SCD.

3. Materials and Methods

3.1. Study area

The study was conducted in the Uyui and Urambo Districts of the Tabora Region in western Tanzania, one of the country's 31 administrative regions comprising mainly rural and peri-urban settings. According to the 2022 National Bureau of Statistics, Uyui has 562,588 residents and Urambo has 260,322. The districts were purposively selected due to Tabora's relatively high SCD prevalence and their diverse settlement patterns, service access, and livelihoods, which are relevant to community awareness and care-seeking.

3.2. Study population

The target group included all households in the Uyui and Urambo Districts of the Tabora Region. According to the 2022 National Bureau of Statistics (NBS), Uyui District has 90,362 households, and Urambo District has 46,691 households, for a total of 137,053 households. This means Uyui accounts for about 65.9% of households in the two districts, while Urambo accounts for roughly 34.1%.

3.3. Study design

A cross-sectional research design was adopted, whereby data were collected at a single point in time from a selected sample of households. This design was deemed appropriate because it is relatively efficient in terms of time and cost and aligns with the study's aim to capture the current status of knowledge, attitudes, and perceptions of SCD within the two districts, rather than to assess changes over time.

3.4. Population sample

The sample size was determined using Yamane's (1967) formula at a 95% confidence level, as shown below:

The formula is: $n = \frac{N}{1+ N(e)^2}$

Whereas,

n - Sample size;

N - Total population, and

e - Margin of error

The total population (N) was the number of households in Uyui and Urambo Districts, totalling 137,053 households (NBS, 2022).

Hence, $n = \frac{137053}{1+ 137053(0.05)^2}$

$n = 398.8$ *households*

Thus, the final sample size was set at 399 household heads, drawn proportionally from the two districts: 263 from Uyui and 136 from Urambo. Households were considered an appropriate study population because they were expected to provide relevant and reliable information on community awareness, perceptions, and care-seeking practices related to Sickle Cell Disease (SCD) in the study areas.

3.5. Sampling procedure

The study used both probability and non-probability sampling. For the household survey, stratified random sampling was applied: wards formed strata, and households were selected randomly within each ward, with sample sizes allocated proportionate to the number of households in Uyui and Urambo. Within each selected household, the household head was approached as the primary respondent; where the head was absent, another adult member responsible for household decisions was interviewed. This ensured geographic and decision-making representativeness across the two districts. In parallel, purposive sampling was used to identify key informants directly involved in SCD-related work, including Non-Communicable Disease (NCD) Officers, District Community Development Officers (DCDOs), Community Development Officers (CDOs), Ward Executive Officers (WEOs) and dispensary in-charges, based on their roles, experience, and knowledge of SCD programming and community engagement.

3.6. Data Collection

The study used a survey method with structured questionnaires to collect primary data from households. The questionnaires were mainly closed-ended and captured quantifiable information on socio-demographic characteristics, awareness of sickle cell

disease (SCD), perceptions, and experiences with SCD-related services and interventions. Secondary data were obtained through document review and engagement with key informants, including reports, guidelines, and records accessed via NCD Officers, DCDOs, CDOs, WEOs and dispensary in-charges. Insights from key informant interviews were used to interpret and enrich the survey findings, allowing for a more comprehensive understanding of SCD awareness and interventions in Uyui and Urambo Districts.

3.7. Data Analysis

Data analysis drew on both quantitative and qualitative approaches. Quantitative data from the household survey were entered into Statistical Package for the Social Sciences (SPSS) and analysed using descriptive statistics, primarily frequencies and percentages, to summarise respondents' characteristics and their responses regarding awareness, perceptions, and reported interventions related to SCD. Frequencies were used to identify common patterns, while percentages made it easier to compare how widely particular views or experiences were shared across the sample. Qualitative information from document reviews and key informant interviews was analyzed using content analysis, whereby responses were read repeatedly, coded, and grouped into emerging themes. These thematic insights were then used to complement and explain the quantitative results, highlighting contextual factors and providing depth to the numerical trends.

4. Results and Discussion

4.1. Respondent's characteristics

This study comprised 211 respondents from Uyui (80.2%) and 98 from Urambo (72.1%). As shown in Table 1, over half of the respondents were male (54.7%), while females accounted for 45.3%, indicating a slight male majority. The age distribution was mainly adult: 78.7% were between 18 and 45 years old, with the largest group being 26–35 years (33.0%), followed by 36–45 years (23.0%) and 18–25 years (22.7%). Respondents aged 45 and older made up 17.2%, while those aged 18 and younger accounted for only 4.2%. This indicates that most participants were in their economically active and reproductive years and were likely key decision-makers and caregivers in their households.

Among the 297 respondents with complete data on occupation and education, most were farmers (45.8%) and small-scale business operators (41.4%), indicating a predominantly rural, informal economy. Education levels were generally low: 53.2% had only primary education, and 20.2% had informal or no formal education. Secondary education was reported by 22.6%, with vocational training and tertiary education each at just 2.0%. Overall, more than 73% had only informal or primary education, highlighting limited formal schooling and its potential impact on health literacy. In terms of marital status, 65.4% were married, 27.2% single, 3.2% divorced, and 3.9% widowed. This mix suggests both opportunities for family-based support and the presence of potentially more vulnerable individuals with weaker household safety nets. Collectively, these characteristics emphasize the importance of community-based SCD interventions that are culturally grounded, low-literacy-friendly, and sensitive to diverse family structures.

Table 11: Socio-economic characteristics of respondents

S/N	Occupation	Education level					Total
		Informal Education	Primary Education	Secondary Education	Vocational Training	College/ University	
1	Farmer	50	71	13	2	0	136
2	Business	6	75	38	3	1	123
3	Employed	0	0	5	0	2	7
4	Student	0	6	5	0	3	14
5	Unemployed	4	6	6	1	0	17
	Total	60	158	67	6	6	297

4.2. Community's Awareness of Sickle Cell Disease

The study examined community awareness of Sickle Cell Disease (SCD) in Uyui and Urambo District by exploring several related aspects: whether people have ever heard of SCD, where they first learned about it, the symptoms they associate with the condition, their understanding of its causes, who they think is most at risk, and whether they believe it is treatable. Overall, these aspects go beyond simple recognition and offer a more complete view of how SCD is understood, discussed, and interpreted in daily life.

Community knowledge of sickle cell disease: Out of 309 respondents, 93.9% reported having heard of SCD, 3.6% had never heard of it, and 2.5% did not respond, giving a 97.5% item response rate. This indicates that SCD is widely recognized by name in Uyui and Urambo, and basic awareness is relatively high in these districts, which have a high burden. However, national studies show that although many Tanzanians have heard of NCDs, understanding, especially of conditions like SCD, is often limited: fewer than half of adults in two PEN-Plus districts can correctly define "NCD," and only 25.2% recognized SCD as an NCD (Kagaruki et al., 2025). Similarly, community surveys in rural areas reveal only moderate NCD knowledge, strongly influenced by education and residence (Sirili

et al., 2024). Overall, the finding suggests that in Uyui and Urambo, many people recognize SCD by name but may lack detailed knowledge of its inheritance, prevention, or management. The small group that has never heard of SCD, though a minor number, likely includes those with limited access to information, such as individuals with low literacy, social marginalization, or weak links to health services. Previous research in Tanzania highlights how these gaps can lead to delays in diagnoses and missed opportunities for counselling and screening (Ndumwa et al., 2023; Ambrose et al., 2020). Therefore, future community interventions should go beyond simple name recognition to promote a deeper, actionable understanding of SCD across all household groups.

Responding to the First Source of SCD Information: Most respondents (78.0%) first heard about SCD from family and friends, with far fewer citing radio (12.6%), community meetings (1.3%), healthcare workers (1.0%) or television (0.3%) as their initial source; see figure 1. This confirms that informal interpersonal networks are the dominant pathway for SCD information in these districts, echoing other rural Tanzanian findings, where people often depend on neighbours, relatives, and peers rather than formal health education channels (Sirili et al., 2024; Kagaruki et al., 2025).

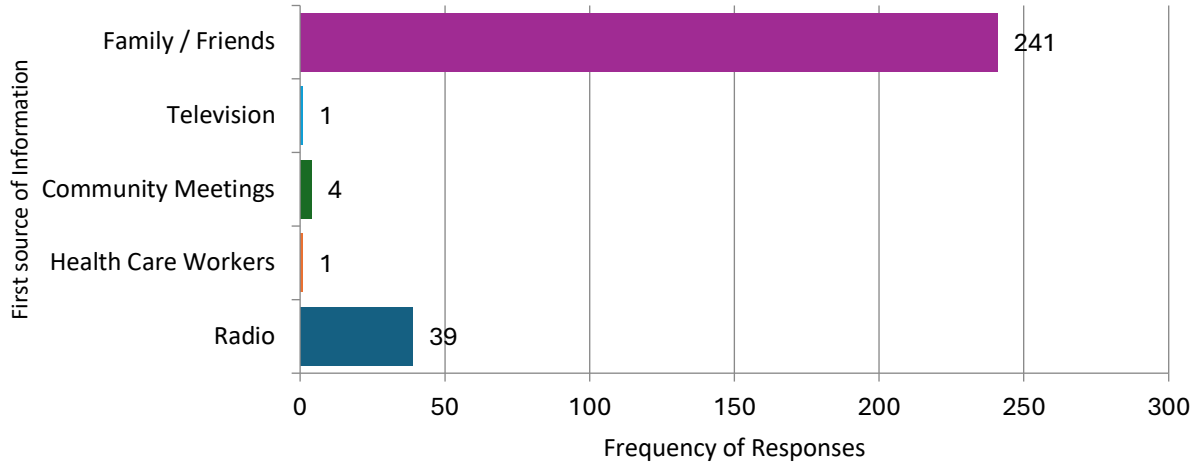

Figure 1: First source of information about sickle cell disease

While community networks are effective for rapid, cost-efficient dissemination of information, they also risk spreading incomplete or inaccurate messages without clear, consistent guidance from the health system. Few respondents reported learning about health issues directly from health workers, which is concerning given that many mid-level providers at district hospitals reportedly lack sufficient training and confidence in managing NCDs and SCD (Karoli et al., 2024). In line with the Tanzanian NCD policy's emphasis on health promotion (Ndumwa et al., 2023), these findings reveal a significant opportunity: to enhance training for frontline healthcare workers and involve them more actively in community communication efforts. This approach could include outreach activities, public meetings, and partnerships with respected local figures to ensure the adequate flow of accurate, trustworthy health information.

Community Knowledge of SCD Symptoms: Among 301 respondents, 87.7% reported knowing symptoms of SCD, while 9.7% said they did not. The most commonly recognized symptoms included delayed growth, and puberty, anaemia, and recurrent pain episodes. Less frequently, complications such as vision problems and ulcers were identified. This pattern emphasizes obvious and disruptive symptoms but shows a limited awareness of more subtle or long-term health issues. Similar research in African contexts indicates that while communities often acknowledge pain and visible signs of illness, there is less awareness of complications like stroke, organ damage, or risks from chronic infections (Coetzee et al., 2022; Elendu et al., 2024). The nearly 10% of respondents who reported no knowledge of symptoms, together with partial recognition of more complex manifestations, indicate that significant gaps remain in symptom literacy. In situations where families face travel time, income loss, and healthcare expenses, a limited understanding of symptoms can delay seeking medical help and reduce the likelihood of early diagnosis (Ambrose et al., 2023; Bossy et al., 2024). To improve this, targeted education is essential. These efforts should go beyond just describing common signs of SCD and incorporate less obvious complications using simple, relatable language and everyday examples. Education materials should emphasize symptoms that communities already identified. Sharing this information through local networks and trained healthcare professionals can ensure consistent, repeated messaging, thereby enhancing understanding.

Knowledge of SCD Causes: Most respondents correctly identified SCD as a genetic condition: 67.1% attributed it to inheriting the sickle cell trait, and a further 20.2% mentioned a genetic mutation in the

HBB gene (see figure 2). This result shows that many community members understand that SCD "runs in families," which aligns with findings from other SCD-endemic areas where heredity is broadly recognized, even if the biological details are not fully understood (Tatipamul et al., 2024; Coetzee et al., 2022). In Tanzania, national NCD knowledge surveys similarly reveal that while some individuals acknowledge the hereditary aspect of chronic diseases, their detailed understanding of the mechanisms remains limited (Kagaruki et al., 2025).

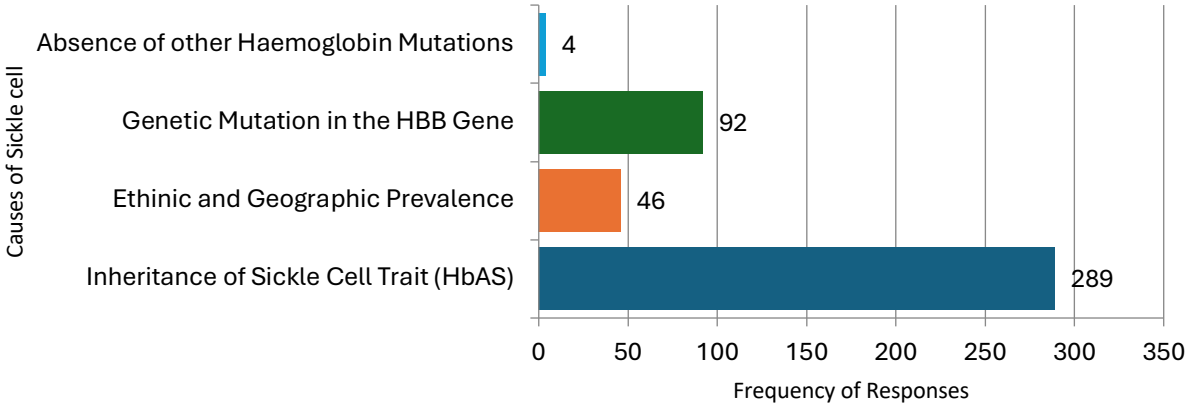

Figure 2: Causes of sickle cell

At the same time, the limited reference to autosomal recessive inheritance and the small proportion that mentions specific genes suggest that the understanding of how SCD is inherited is incomplete. This finding has implications for reproductive decision-making, premarital screening and family planning, especially in regions like Tabora, where SCD trait prevalence is likely to be high (Ambrose et al., 2020). Without clear information on carrier status and risk probabilities for offspring, couples may underestimate or misinterpret their chances of having a child with SCD. Strengthening community-level genetic counselling, integrated into existing reproductive and youth interventions, could help translate general awareness of heredity into more informed, equitable choices (Ndumwa et al., 2023; WHO, 2008).

Knowledge of At-Risk Groups: As shown in Figure 3, just over half of respondents (57.0%) reported knowing who is most at risk of developing SCD, while 40.5% said they did not. When multiple responses were considered, the most frequently mentioned at-risk groups were people with a family history of SCD and children of parents with SCD or sickle cell trait, followed by pregnant women in high-risk populations. These responses indicate a reasonable appreciation of hereditary risk and the intergenerational nature of SCD, echoing broader Tanzanian and regional literature showing that families often connect SCD with bloodlines and kinship (Kilonzi et al., 2022; Adigwe et al., 2023).

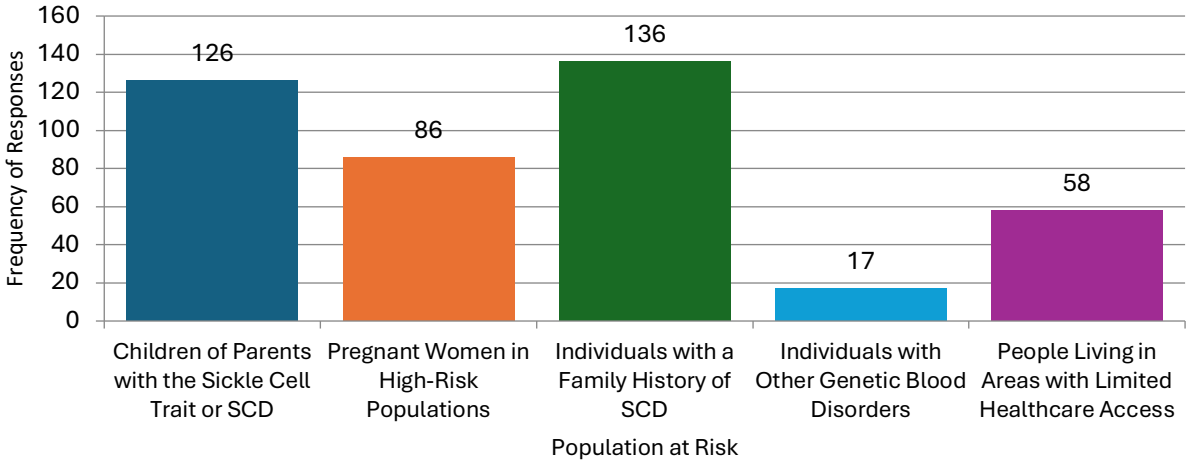

Figure 3: Population at risk

However, a significant number of respondents were unable to identify any at-risk groups, and there was limited mention of other relevant categories, such as carriers without symptoms or individuals in high-prevalence areas. These gaps might weaken prevention and early detection strategies. In high-burden areas without universal newborn screening, awareness of risk groups is crucial for deciding when to seek testing and when to visit health facilities (Ambrose et al., 2020; Makani et al., 2018). Integrating clearer,

context-appropriate explanations of "who is at risk" into antenatal care, community meetings and youth initiatives could therefore help bridge this gap and support more proactive health-seeking behaviour.

Beliefs about SCD curability: Community beliefs about SCD curability showed significant uncertainty. Only 15.2% believed SCD could be cured, 23.0% thought it could not, and the majority (59.2%) were unsure. This situation highlights a harsh reality: although advanced treatments, such as stem cell transplants and gene therapy exist, they are accessible to only a small fraction of patients treated at specialized hospital centres. For many families, Sickle Cell Disease (SCD) remains a chronic condition managed with supportive care and disease-modifying treatments (Makani et al., 2018; Ambrose et al., 2023), rather than a cure. This persistent uncertainty about the possibility of a cure heavily impacts how families view the significance of early diagnosis, regular check-ups, and consistent treatment. If people believe there is no hope, they may see no point in seeking care. Conversely, if they expect a complete cure but only see partial improvement, that can lead to disappointment or mistrust.

Given earlier findings, such as the fact that many people are aware of SCD but rely on informal sources and have only a basic understanding of the risks, it becomes evident that our messaging needs improvement. Communities require clear, honest information about the realistic outcomes of SCD care. This messaging should be integrated into broader NCD awareness campaigns and community engagement initiatives, as recommended by Tanzanian policy (Ndumwa et al., 2023; Mayige et al., 2012). Such efforts can foster trust in the healthcare system and motivate individuals to remain engaged in their care over time.

4.3. Effectiveness of existing community-based interventions

SCD interventions available in the community: When respondents described the types of SCD-related activities present in their communities, they most frequently cited screening and diagnosis (34.6%) and nutrition programmes (23.6%), followed by maternal and child health and general health services, while education campaigns, anti-stigma work and support groups were rarely mentioned. This pattern reflects a strong biomedical focus, emphasizing early detection and clinical follow-up but giving much less attention to psychosocial support, stigma reduction, and community involvement. It mirrors Tanzania's national approach to SCD, which has made notable progress in surveillance, clinic-based care, and access to treatments such as hydroxyurea, but has invested less in community-level, family-centred, or peer-support initiatives (Ambrose et al., 2020; Ambrose et al., 2023). However, research on chronic illness and SCD demonstrates that social support, mental health, and community acceptance are essential for adherence and long-term coping (Berghs et al., 2020; Bossy et al., 2024). The low visibility of support groups and anti-stigma initiatives in Uyui and Urambo suggests that current programming is too narrow to match the full spectrum of needs experienced by affected households. In the future, community-based SCD responses will need to deliberately combine biomedical services with education, counselling, stigma reduction and participatory spaces if they are to be experienced as meaningful and effective by residents.

Of the 304 people surveyed, over 60% said there were no effective sickle cell interventions in their community, and only 38.2% felt the existing interventions made a real difference. This shows that in places like Uyui and Urambo, SCD efforts are either missing, poorly known, or not meeting local needs (see Figure 4). This lines up with what national research has found: even though sickle cell disease is officially recognized as a priority in Tanzania's NCD strategy, most specialized services and trained professionals are still based in major urban hospitals like Muhimbili and Bugando (Makani et al., 2018; Ambrose et al., 2020). Rural areas are often left with weak, uncoordinated programs. Policy reviews also highlight a significant gap between what is outlined in national plans and what actually occurs on the ground, due to underfunding, poor integration with regular health services, and confusion about district-level responsibilities (Ndumwa et al., 2023; Mayige et al., 2012).

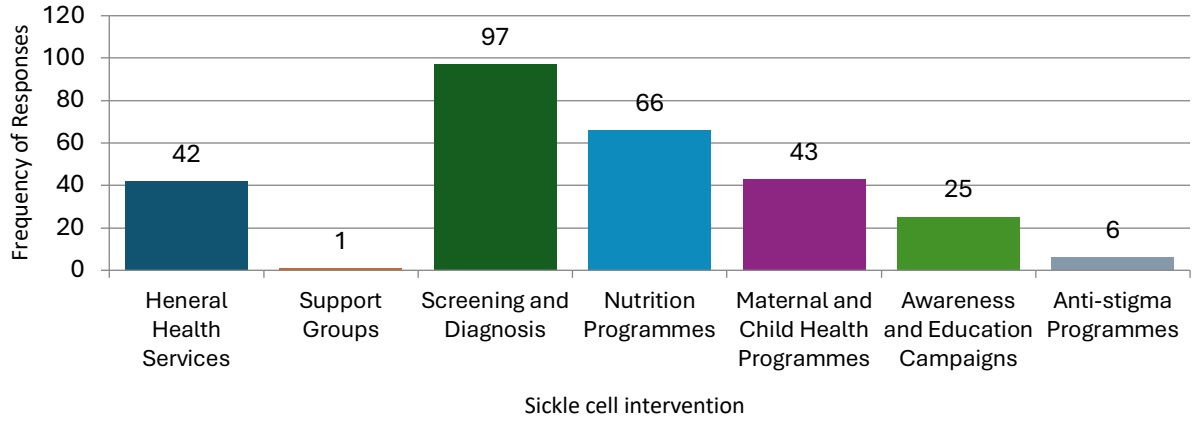

Figure 4: Sickle cell interventions in the community

In this context, the minority who report positive experiences may be those with direct contact with specific clinic-based or project-supported activities. At the same time, most households never encounter clearly identified SCD initiatives. The findings therefore underline the need for more coherent, well-communicated and locally rooted SCD interventions that communities can see, name and participate in rather than ad hoc or facility-bound efforts.

Frequency of participation in interventions: Across 17 different forms of SCD-related activities, including workshops, school programmes, media campaigns, faith-based outreach, and village meetings, between 72% and 87% of respondents reported never participating, with only small minorities indicating that activities occurred even "rarely" (see Table 2). This extremely low participation indicates that, for most households, SCD interventions are not a visible or regular part of community life, despite the high underlying burden of disease.

Table 12: Frequency of SCD Interventions (Activities)

Sn	Activities Conducted	Rarely		Never		Total
		f	%	f	%	
1	Community Workshops and Seminars	40	13	267	87	307
2	Radio Campaigns	85	28	222	72	307
3	Television Campaigns	81	26	225	73	307
4	Social Media Campaigns	70	23	237	77	307
5	School-Based Awareness Programmes	62	20	245	80	307
6	Community Drama and Street Theatre	62	20	245	80	307
7	Religious and Faith-Based Outreach	65	21	242	79	307
8	Pamphlets, Posters, and Billboards	70	23	237	77	307
9	Community Health Fairs and Mobile Clinics	66	21	241	79	307
10	Peer Educator programmes	65	21	242	79	307
11	Partnerships with Celebrities and Influencers	69	22	238	78	307
12	SMS and Mobile Phone Campaigns	69	22	238	78	307
13	Cultural Events and Festivals	59	19	248	81	307
14	Workplace Awareness programmes	79	26	228	74	307
15	Advocacy Walks and Public Rallies	64	21	243	79	307
16	Health Apps and Websites	62	20	245	80	307
17	Village and Household Meetings	65	21	242	79	307

Similar trends are seen in rural Tanzania, where many adults report having little or no contact with formal health education programs and instead depend on friends, family, or community chatter for information (Sirili et al., 2024; Kagaruki et al., 2025). National reports highlight some clear causes: fragmented planning, insufficient resources, and weak integration of NCD efforts into everyday healthcare and community life (Ndumwa et al., 2023). Specifically, regarding sickle cell disease, research indicates that most interventions are associated with short-term projects, specific clinics, or research environments and seldom develop into long-term, district-wide programs (Ambrose et al., 2020; Tutuba et al., 2023). In places like Uyui and Urambo, the data show that it is time to move beyond one-off campaigns and start integrating SCD services and messaging into everyday, trusted spaces such as schools, religious events, village meetings, and routine health visits, using familiar formats and local languages to connect with communities and make a lasting impact.

Perceived Effectiveness of SCD Interventions: Using a five-point Likert scale (very ineffective, ineffective, moderate, effective, very effective), respondents were asked to rate the effectiveness of 17 types of SCD-related interventions. Across all activities, ratings clustered at the negative end of the scale: for example, 97% rated community workshops as either very ineffective or ineffective, and similar patterns were observed for radio, television, school-based activities and community events, with very few respondents selecting "effective" or "very effective" for any intervention (see Table 3).This widespread scepticism aligns with the very low participation levels and the perception among 60.2% of respondents that SCD interventions in their communities are ineffective, pointing to interventions that are either poorly adapted, too infrequent or insufficiently participatory to be recognized as applicable.

Table 13: Effectiveness of sickle cell intervention

S/N	Effectiveness of the sickle cell intervention	Very ineffective		Ineffective		Moderate		Effective		Total
		f	%	f	%	f	%	f	%	
1	Community Workshops and Seminars	76	64	39	33	3	3	0	0	118
2	Radio Campaigns	23	19	70	59	25	21	0	0	118
3	Television Campaigns	28	24	75	64	15	13	0	0	118
4	Social Media Campaigns	43	37	50	43	23	20	1	1	117
5	School-Based Awareness Interventions	34	29	67	57	17	14	0	0	118
6	Community Drama and Street Theatre	46	39	53	45	17	14	2	2	118
7	Religious and Faith-Based Outreach	30	25	69	58	18	15	1	1	118
8	Pamphlets, Posters, and Billboards	38	32	61	52	18	15	1	1	118
9	Community Health Fairs and Mobile Clinics	38	32	63	53	17	14	0	0	118
10	Peer Education interventions	37	31	62	53	19	16	0	0	118
11	Partnerships with Celebrities and Influencers	39	33	67	57	12	10	0	0	118
12	SMS and Mobile Phone Campaigns	38	32	56	4	24	2	0	0	118
13	Cultural Events and Festivals	35	30	63	53	20	17	0	0	118
14	Workplace Awareness interventions	38	32	62	53	18	15	0	0	118
15	Advocacy Walks and Public Rallies	28	24	69	58	20	17	1	1	118
16	Health Apps and Websites	41	35	53	45	23	19	1	1	118
17	Village and Household Meetings	41	35	59	50	18	15	0	0	118

Research on Non-Communicable Diseases (NCDs) and Sickle Cell Disease (SCD) in Tanzania and nearby regions reveals a clear pattern: top-down approaches such as pamphlets, lectures, or general media messages often fail when they are not grounded in local communities' realities. To truly succeed, these efforts must be co-created with the people they aim to serve and implemented by well-trained, motivated teams (Ambrose et al., 2023; Tutuba et al., 2023). National policy experts also agree that effective responses to NCDs need to be grounded in local evidence and driven by strong district-level leadership, rather than by national campaigns alone (Ndumwa et al., 2023).
In Uyui and Urambo Districts, the overwhelmingly negative ratings of effectiveness therefore signal the need for a fundamental reorientation toward participatory, culturally embedded models that engage community leaders, peer educators, families and frontline health workers in designing, delivering, and refining SCD interventions over time.

5. Conclusion and Recommendation

5.1. Conclusion

This study shows that the effectiveness of Community-Based Interventions (CBIs) for Sickle Cell Disease (SCD) in Uyui and Urambo Districts is shaped as much by social and structural realities as by the interventions' content. The surveyed population is mainly working-age adults involved in farming and small businesses, with low levels of formal education and a firm reliance on informal rural economies. Within this context, awareness of SCD is high at the level of name recognition, and many respondents can identify common symptoms and understand that the disease is inherited. However, knowledge is often shallow and uneven: almost half of the respondents could not clearly identify who is most at risk, many were unsure whether SCD is curable, and understanding of inheritance mechanisms and long-term complications remained limited. Information flows are dominated by family and friends, with radio as a secondary source, whereas formal health education and frontline health workers are only marginally trusted as information providers.

At the same time, existing SCD-related interventions are perceived as fragmented, clinic-centred and largely invisible at the community level. Screening and nutrition services are the primary interventions people recognize, reflecting a narrow biomedical focus, while psychosocial support, anti-stigma activities and peer groups are barely known. Participation in a wide range of potential platforms, such as workshops, school activities, religious outreach, media campaigns and village meetings, is extremely low, and most interventions are rated as ineffective or very ineffective. For many households, SCD initiatives are either absent from everyday life or poorly adapted to local priorities, languages, and social structures; as a result, they feel neither relevant nor valuable. A further limitation is that these findings are drawn mainly from household heads and institutional key informants; the voices and lived experiences of people living with SCD were not directly captured, suggesting the need for future qualitative work (such as focus groups or in-depth interviews) with affected individuals and families.

In summary, these findings highlight the need to rethink SCD and CBIs in the Tabora Region through a socio-ecological and social-determinants lens. Future interventions should be co-designed with communities and integrated into familiar platforms, such as schools, religious institutions, village assemblies, and primary care contacts. These efforts must integrate medical care with clear, easy-to-understand communication, especially for communities with low literacy levels. They should also focus on reducing stigma, providing emotional and social support, and using peer-led education to build trust and understanding. Strengthening frontline health workers as local

educators is essential, but it also requires strong district-level support and coordination to ensure alignment with national health policies and goals. To ensure that future programs are both conceptually sound and grounded in the realities of those most directly affected, it is crucial to include the perspectives of people living with SCD in the design and evaluation of such interventions.

5.2. Recommendation

Enhancing the response to Sickle Cell Disease (SCD) in rural areas such as Uyui and Urambo Districts requires coordinated efforts among the government, communities, and civil society. However, these recommendations should be considered within the context of the study's scope and data limitations. The survey focused on household heads and a small group of institutional key informants and did not include a detailed assessment of facility readiness, NGO capacities, or staffing levels. Despite these constraints, the findings on low intervention visibility, limited educational roles for health workers, and heavy reliance on informal information still indicate clear directions for action.

At the policy and health system levels, the government should prioritize strengthening rural healthcare facilities by ensuring a reliable supply of essential SCD medicines, basic diagnostics, and laboratory services. Supporting people with SCD begins with guaranteeing that key medicines such as painkillers, antibiotics, and, where feasible, hydroxyurea are consistently available, as well as training mid-level health workers to recognize SCD signs, provide accurate advice, and support long-term management. Expanding access to specialized care through regional centres, mobile clinics, or integrated PEN-Plus models can help connect remote areas with the broader national health system. However, for these efforts to be sustainable, strong policy support and dependable funding are necessary so that SCD care becomes a permanent component of the national chronic disease response rather than a temporary initiative.

Furthermore, awareness and education initiatives need to be revised to reflect local languages, cultural norms, and communication styles, recognizing that this study captures community perceptions of interventions but is not an exhaustive map of all existing actors. Public campaigns through radio, school programmes, community gatherings, and faith-based platforms, should share clear, accurate information about SCD, its symptoms, inheritance, risks, and available treatments while challenging harmful stigma and the belief that nothing can be done. These outreach efforts should also connect families to genuine support, such as counselling and peer groups, acknowledging that the current study found very limited awareness of such services.

Communities themselves play a vital role: family networks and informal communication channels can be used to share accurate information, practical caregiving strategies, and stories that normalize seeking help. Training community members as peer educators or SCD "champions" and collaborating with NGOs, community-based organizations, and religious institutions can strengthen outreach and trust, though further research is needed to map these actors in detail. Coordinating the efforts of government, communities, and civil society around locally grounded strategies is essential to shift from fragmented, low-impact activities to community-based interventions that are recognized, trusted, and genuinely responsive to the needs of people living with SCD and their families.

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