

Oral Health-Related Quality of Life in Tanzanian Adults with Sickle Cell Disease

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Abstract:

Background: Sickle Cell Disease (SCD)-related orofacial manifestations are exacerbated by poor oral hygiene practices, malnutrition, and poverty and disproportionately affect people of color. The study aimed to compare self-reported oral health-related quality of life between persons diagnosed with SCD and known sickle cell trait (SCT) carriers to the general population residing in Burere, Nyambogo, and Roche villages, Rorya district, Tanzania, East Africa.

Methods: Purposive sampling was used to recruit participants from Rorya district who received SCD or SCT-related health services at Bugando Medical Center. Additional participants were recruited from villagers receiving non-SCD or non-SCT-related health services. All participants completed the oral health-related quality of life (OHRQoL) measure.

Results: A nonrandomized convenience sample ($n=74$) of mostly female-identified participants ($n=44$; 59%) were recruited. Participants reported an average age of 30.83 ($SD=10.22$; min to max 18-57) with no differences in age between groups. Compared to the general population ($n=51$; $\bar{x}=9.16$; $SD=3.86$; min to max 3-14 with higher scores indicating decreased QoL), persons in combined SCD and SCT groups ($n=23$; $\bar{x}=11.13$; $SD=2.58$; $p=0.03$) indicated significantly reduced QoL. Independently, the average OHRQoL score for the SCD group ($n=10$; $\bar{x}=13.20$; $SD=0.92$; $p<0.05$) was considerably higher when compared to the SCT group ($n=13$; $\bar{x}=9.54$; $SD=2.30$), indicating greater decreased QoL in persons with SCD. No statistical differences were found in OHRQoL between the general population and the SCT group.

Conclusion: Oral health-related quality of life is compromised in SCD and SCT. Socio-dental impact on quality of life is substantially worse for those diagnosed with SCD and SCT than the general population.

Keywords: sickle cell disease; oral hygiene practices; malnutrition; poverty; disproportionately affect people of color

Introduction

Sickle cell disease (SCD) is a genetic blood disorder prevalent in Tanzania that affects the shape and function of red blood cells.¹ SCD is a genetic blood disorder characterized by abnormal hemoglobin S (HbS) protein, which leads to the deformation of red blood cells from a disc-like shape to a sickle or crescent shape. This process is known as sickling and is responsible for the vascular occlusions and tissue damage associated with SCD.² These sickling blood cells cause vaso-occlusive crisis in individuals with SCD, leading to acute ischemic injury, excruciating pain, and other chronic complications like nephropathy, bone necrosis, skin lesions, and lung lesions disorders.³⁻⁵

SCD can cause a range of oral manifestations, including delayed tooth

eruption, enamel hypoplasia, increased risk of caries, periodontal disease, salivary gland dysfunction, and mucosal ulceration. These oral complications are believed to result from vaso-occlusive episodes and chronic inflammation associated with SCD.⁶ Individuals impacted by SCD also experience dental discomfort due to poor dental and bone formation.⁷ If left untreated, these SCD-related dentofacial complications can result in dental decay, pulp infections, periodontitis, temporomandibular joint pain, orofacial pain, osteomyelitis of the jaw bone, enamel hypoplasia, paresthesia of the mental nerve, and severe blood disorders.⁸⁻¹⁰

The oral manifestations of SCD are diverse and can impact the oral health-related quality of life (OHRQoL) of individuals with the disease. Previous research has shown that sickle cell disease (SCD) and sickle cell trait (SCT) follow distinct geographic and genetic characteristic common throughout sub-Saharan Africa and dramatically influences the quality of life.³⁻⁵ Confounding this severity are low rates of dental screening, particularly in low-resource settings, like sub-Saharan Africa, where routine dental care is scarce. Individuals with SCD may experience a significant decline in their oral health-related quality of life due to the combined effect of untreated dental pathologies. Therefore, it is crucial to investigate the relationship between routine oral hygiene practices, oral health disease, and their impact on quality of life.

This study aims to investigate the OHRQoL of individuals with SCD in individuals residing in the Burere, Nyambogo, and Roche villages off Rorya district of East Africa, Tanzania, in partnership with community partners Village Life Outreach Project (VLOP), Roche Health Center (RHC) and Shirati Health and Education Development Foundation (SHED), Bugando Medical Center (BMC).

Study Design

The study used a cross-sectional research design to quantitatively assess the self-reported oral health-related quality of life in persons diagnosed with SCD and known carriers of SCT compared to the general population. Informed consent for participation in the study was obtained through a research information sheet that was collaboratively written with and approved by our community partner (i.e., Village Life Outreach Project -VLOP) and written in simple, readable language that communicated the study's purpose. It was made available in both English and Swahili and designated VLOP staff used the research information sheet to inform participants about the risks, benefits, and procedures involved with the study. All consent procedures were aided by a language interpreter, independent of the research team, who spoke fluent English and Swahili. Eligibility criteria set for individuals to participate in the study were: 1) persons 18 years of age and older; 2) persons who resided in the Burere, Nyambogo, or Roche villages of the Rorya district of Tanzania, East Africa; and 3) persons who spoke and could read either fluent English or Swahili. Participant recruitment was conducted via purposive sampling methods through the community partner by the executive director at SHED and the clinical officer and nurse midwife at the RHC from patients receiving health services at the Bugando Medical Center (BMC) for SCD and SCT-related complaints and from the general population of Rorya District villagers receiving health services at

the RHC and SHED sites for non-SCD and non-SCT-related complaints.

Study Method

To assess and compare the self-reported oral health-related quality of life among individuals with SCD and SCT carriers to the general population of Rorya District, a single administration of the OHRQoL measure was conducted using a paper-and-pencil format (**Table 1**).

Table 1. Demographic Questionnaire and OHRQoL measure ¹²

1. Age:
2. Sex:
3. Name of Residential Village:
4. Date:
5. 6-digit identifier

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Have problems with your teeth or mouth affected your daily life (e.g., going to school or work)?

Always	Frequently	Occasionally	Rarely	Never
5	4	3	2	1

2. Have problems with your teeth or mouth affected your ability to socialize (e.g., playing outdoors, meeting with friends, seeing family)?

Always	Frequently	Occasionally	Rarely	Never
5	4	3	2	1

3. Have problems with your teeth or mouth affected your ability to talk?

Always	Frequently	Occasionally	Rarely	Never
5	4	3	2	1

Participants who received SCD or SCT-related services at the BMC completed the measure once using the paper-and-pencil form and were assigned a unique identifier to differentiate between SCD patients and SCT carriers. However, participants from the general population who received non-SCD and non-SCT related health services from the RHC or SHED sites did not receive any identifier as their SCD or SCT status was unknown during the survey.

Data Analysis

The data collected from participants (n=74) who completed the OHRQoL measure were subjected to data cleansing, verification, and consistency checks to ensure accuracy and reliability. The OHRQoL measure was based on a 5-point Likert scale (1=Never, 2=Rarely, 3=Occasionally, 4=Frequently, 5=Always), and participants selected the number that best reflected the self-perceived impact of oral health on daily activities (Q1), social activities (Q2), and conversations (Q3). All quantitative data were entered into IBM SPSS Statistics (Version 22) for data analysis ¹¹, and an OHRQoL score was obtained by summing the scores

derived from the three questions. Participant confidentiality was maintained throughout the data collection and analysis process.

Results

Participants and Demographics. A nonrandomized convenience sample ($n=74$) of mostly female-identified participants ($n=44$; 59%) were recruited into the study. Participants reported an average age of 30.83 ($SD=10.22$; min to max 18-57) with no differences in age between SCD/SCT ($n=23$) and the general population of non-SCD/SCT groups ($n=51$).

Quantitative Findings. Compared to the general population ($n=51$; $\bar{x}=9.16$; $SD=3.86$; min to max 3-14 with higher scores indicating decreased OHRQoL), persons in the combined SCD and SCT groups ($n=23$; $\bar{x}=11.13$; $SD=2.58$; $p=0.03$) implied significantly decreased oral health-related quality of life. Independently, the average OHRQoL score for the SCD group ($n=10$; $\bar{x}=13.20$; $SD=0.92$; $p<0.05$) was significantly higher when compared to the SCT group ($n=13$; $\bar{x}=9.54$; $SD=2.30$), indicating decreased oral health-related quality of life in persons diagnosed with SCD when compared to this with SCT. No statistical differences were found in OHRQoL between the general population ($n=51$) and the SCT group ($n=13$).

Conclusion

In conclusion, our study found that individuals with SCD in the Rorya District of Tanzania reported a significantly lower oral health-related quality of life than known carriers of SCT and the general population. Despite the significant burden of SCD in Tanzania, there is limited research on the country's OHRQoL of individuals with SCD. Understanding the impact of SCD on OHRQoL is critical for developing effective oral health interventions for this population. The study highlights the need for targeted oral health interventions for individuals with SCD in this region, including routine oral hygiene practices, preventative measures, and timely access to oral healthcare services. Health education programs to improve oral health literacy and address the unique challenges associated with SCD should be implemented. The findings of this study can inform the development of comprehensive oral health programs for individuals with SCD in Tanzania and other low-resource settings where this disease is prevalent. Future research should also focus on evaluating the effectiveness of these interventions in improving the oral health-related quality of life of individuals with SCD.

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