

Feasibility and acceptability of hydroxyurea-based treatment for children with Sickle Cell Disease in remote rural areas of Niger, 2024–2026

Delphine Sauvageot, Epicentre, France; Fara Temessadouno, Epicentre, Senegal

Background

Sickle cell disease (SCD), characterized by recurrent pain episodes and premature mortality, is highly prevalent in sub-Saharan Africa. Hydroxyurea (HU) reduces complications and improves survival, but its high cost limits access in many countries. In Niger, Médecins Sans Frontières (MSF) follow-up approximately 3,000 SCD children in rural district hospitals, including 70 receiving HU through pilot programs. We assessed HU feasibility and acceptability in rural settings.

Methods

In 2025, 30 children from MSF Diffa program completed the PedsQL™v3.0 quality of life (QoL) questionnaire at HU initiation and after 6 and 12 months of treatment (study 1). QoL scores were calculated globally and across nine domains. In 2026, 49 semi-structured interviews were conducted with children on HU, parents, health professionals, and health authorities involved in the MSF programs in Madarounfa and Diffa (study 2). Data were analyzed using thematic content.

Results

In study 1, the overall QoL score increased from 67 [95% CI: 63–70] at initiation to 90 [95% CI: 87–92] after 12 months, with major improvement in the pain impact domain (+39 points, $p < 0.001$). In study 2, participants reported improved pain control, reduced healthcare utilization, and increased socialization. Traditional medicine use and community influence were identified as barriers to healthcare access, while HU-related infertility affected treatment acceptability. Awareness-raising among fathers helped mitigate this concern. Prolonged caregiver absence from home, transportation costs and difficulties related to the 500mg/kg drug

formulation were identified as barriers to adherence. The reference medical team perceived itself efficient, but laboratory tests were associated with long waiting times.

Conclusion

HU treatment showed good feasibility and acceptability in rural Niger and was associated with substantial QoL improvement. Strengthening community awareness, improving pediatric drug formulation, increasing laboratory capacity, and decentralizing care could support future scale-up efforts.

HU improved QoL. Acceptability barriers included economic, traditional, and social issues. Drug formulation and laboratory capacity influenced feasibility. Scale-up can be envisaged with tailored actions.