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Newborn Screening for Sickle Cell Disease in Tanzania: The Past, Present and Future

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Abstract

Sickle Cell Disease (SCD) is an inherited disorder of the Haemoglobin molecule of the red blood cells that is associated with serious complications and reduced life expectancy. Over 75% of people with SCD live in Sub-Saharan Africa (SSA), and this proportion are projected to increase to 85% by the year 2050.

In Tanzania, approximately 11,000 babies are born with SCD each year, ranking 5th in the world. The high prevalence of SCD in SSA is compounded by the disproportionately higher mortality compared to that observed in the high-income countries. In Tanzania, SCD is a major contributor to under-five mortality and is estimated to account for 7% of all-cause mortality in this age group.

Newborn screening (NBS) is the practice of testing babies right after delivery to ascertain whether they have diseases that are potentially lethal if not treated early. Where routinely practiced, NBS has significantly reduced morbidity and mortality associated with such diseases. The Sickle Cell Programme at Muhimbili University of Health and Allied Sciences (MUHAS) in Dar-es-salaam and Bugando Medical Center in Mwanza have both conducted pilot NBS for SCD, showing that the intervention is generally feasible and acceptable in Tanzania. The successful introduction and expansion of NBS in Tanzania will require careful planning and advocacy at community to national level.

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Sickle Cell Disease (SCD) is an inherited disorder of the haemoglobin molecule of the red blood cells that is associated with serious complications and reduced life expectancy. Affected individuals require lifelong treatment [1]. Globally, the number of babies born with the disease each year is projected to increase from 300,000 in 2010 to 400,000 in 2050. The total number of individuals born with SCD in the same forty years' period is expected to reach 14,200,000 [2].

Over 75% of people with SCD live in Sub-Saharan Africa (SSA), and this proportion is projected to increase to 85% by the year 2050 [2]. Currently in Tanzania, approximately 11,000 babies are born with SCD each year, ranking 5th in the world. The high prevalence of SCD in SSA is compounded by the disproportionately higher mortality compared to that observed in the high-income countries [2]. In Tanzania, SCD is a major contributor to under-five mortality and is estimated to account for 7% of all-cause mortality in this age group [3].

Newborn screening (NBS) is the practice of testing babies right after delivery to ascertain whether they have diseases that are potentially lethal if not treated early. Such diseases include SCD, congenital hypothyroidism, galactosemia, congenital adrenal hyperplasia and disorders of amino acid metabolism such as phenylketonuria. Where routinely practiced, NBS has significantly reduced morbidity and mortality associated with such diseases. Childhood mortality due to SCD in the US and Europe has been substantially reduced following introduction of NBS and provision of comprehensive care, encompassing infection prevention through vaccination and penicillin prophylaxis, folate supplementation, access to Hydroxyurea as well as timely identification and treatment of complications [4, 5]. In malaria endemic areas, protection against malaria is also part of the prescribed comprehensive care for SCD.

Similar to other countries in SSA, NBS is yet to be routinely implemented in Tanzania. The Sickle Cell Programme at Muhimbili University of Health and Allied Sciences (MUHAS) in Dar-es-salaam and Bugando Medical Center in Mwanza have both conducted pilot NBS for SCD, showing that the intervention is generally feasible and acceptable in Tanzania. The pilot NBS project in Dar-es-salaam between 2015-2016 that involved 3,981 newborns delineated the prevalence of sickle cell trait of 12.6% and SCD of 0.8% [6]. The pilot NBS done in 2014 in Mwanza among 919 newborns reported the prevalence of sickle cell trait of 19.7% and SCD of 1.4% [7]. Currently, MUHAS is collaborating with the American Society of Hematology (ASH) to implement a five-year project on effectiveness of NBS and early intervention for SCD in Tanzania. In the period of 2020-2025, a total of 50,000 newborns are expected to be screened for SCD, with the goal to screen 10,000 babies each year. Affected babies will be enrolled in comprehensive care. With SCD recently included in the Tanzania National Non-Communicable Diseases (NCD) Program, this project will provide a large-scale proof of concept for the nation-wide roll-out of NBS in Tanzania in the future.

NBS for SCD can be done at the hospital just after delivery in order to capture babies before they are discharged home [8]. Challenges of this approach include difficulties in obtaining consent from mothers in the delivery environment and lost opportunities in case deliveries occur outside of the hospitals. Therefore, in settings in SSA, there is a need to design locally

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appropriate modalities of administering NBS to ensure inclusivity and high level of success. To this end, one thought has been to investigate the feasibility of integrating NBS with an already established National Immunization Program (NIP). Tanzania has a well-established NIP with the coverage of over 90% of babies country-wide during the first three months of life [9]. In the NIP schedule, babies attend immunization clinics at 6, 10 and 14 weeks, then at 9 and 18 months after delivery. Since complications due to SCD are usually rare before six months of age, this provides an opportunity for an extended screening for SCD during early infancy. Implementation of early infant diagnosis for SCD through screening of babies within the first 3 months of life is hoped to circumvent most challenges of screening at birth while maintaining assurance for identification of babies with SCD and their linkage to comprehensive care before they start to develop symptoms.

Overall, it is widely accepted that scaling-up of NBS is timely for Tanzania. The Ministry of Health, Community Development, Gender, Elderly and Children has admirably embarked on addressing NBS and other priorities in SCD in collaboration with stakeholders. The successful introduction and expansion of NBS in Tanzania will require careful planning and advocacy at community to national level. Partnerships with national and international organizations, public and private, will be required for the sharing of resources and expertise. Through MUHAS, Tanzania is currently a member in a number of SCD consortia in SSA, including the Sickle Pan African Research Consortium (SPARCO; funded by NIH, US where MUHAS is prime awardee), Sickle Pan African Network (SPAN) and SickleInAfrica [10]. Notable areas of need for future collaborations include manufacturing and testing of diagnostic equipment (including affordable point-of-care diagnostic tests for SCD), provision of low-cost antibiotics, local compounding of Hydroxyurea, health education and exploration of the feasibility of integrating NBS with the NIP as well as its coverage by the National Health Insurance Fund. As NBS for SCD takes root, the platform can be utilized in the future for screening of other inborn illnesses.

References

1. Karnon J, Zeuner D, Ades AE, Efimba W, Brown J, Yardumian A: **The Effects of Neonatal Screening for Sickle Cell Disorders on Lifetime Treatment Costs and Early Deaths Avoided: A Modelling Approach.** J Public Health Med 2000; 22(4): 500-11.
2. Piel FB, Hay SI, Gupta S, Weatherall DJ, Williams TN. **Global Burden of Sickle Cell Anaemia in Children under Five, 2010-2050: Modelling Based on Demographics, Excess Mortality, and Interventions**. PLoS Medicine 2013; 10(7): e1001484.
3. Makani J, Soka D, Rwezaula S, Krag M, Mghamba J, Ramaiya K, Cox SE, Grosse SD: **Health policy for sickle cell disease in Africa: Experience from Tanzania on interventions to reduce under-five mortality.** Tropical Medicine and International Health 2015; 20(2): 184-7.
4. Quinn CT, Rogers ZR, Buchanan GR: **Survival of children with sickle cell disease**. Blood 2004; 103(11): 4023-7.
5. Telfer P, Coen P, Chakravorty S, Wilkey O, Evans J, Newell H, Smalling B, Amos R, Stephens A, Rogers D, Kirkham F: **Clinical outcomes in children with sickle cell disease living in England: A neonatal cohort in East London**. Haematologica 2007; 92(7): 905-12.
6. Nkya S, Mtei L, Soka D, Mdai V, Mwakale PB, Mrosso P, McHoropa I, Rwezaula S, Azayo M, Ulenga N, Ngido M, Cox SE, D'Mello BS, Masanja H, Kabadi GS, Mbuya F, Mmbando B, Daniel Y, Streetly A, Killewo J, Tluway F, Lyimo M, Makani J: **Newborn screening for sickle cell disease: An innovative pilot program to improve child survival in Dares Salaam, Tanzania.** International Health. 2019; 11(6): 589-595.
7. Ambrose EE, Makani J, Chami N, Masoza T, Kabyemera R, Peck RN, Kamugisha E, Manjurano A, Kayange N, Smart LR: **High birth prevalence of sickle cell disease in Northwestern Tanzania**. Pediatric Blood and Cancer 2018; 65(1): 10.1002/pbc.26735
8. Streetly A, Sisodia R, Dick M, Latinovic R, Hounsell K, Dormandy E. **Evaluation of newborn sickle cell screening programme in England: 2010-2016**. Archives of Disease in Childhood 2018; 103(7): 648-653.
9. Lyimo D, Kamugisha C, Yohana E, Eshetu M, Wallace A, Ward K, Mantel C, Hennessey K: **Improving the efficiency and standards of a national immunization program review: Lessons learnt from United Republic of Tanzania**. Pan African Medical Journal 2017; 28: 209.
10. Makani J, Sangeda RZ, Nnodu O, Nembaware V, Osei-Akoto A, Paintsil V, Balandya E, Kent J, Luzzatto L, Ofori-Acquah S, Olopade OI, Pallangyo K, Minja IK, Jonas M, Mazandu GK, Mulder N, Ohene-Frempong K, Wonkam A: **SickleInAfrica**. The Lancet Haematology 2020; 7(2): e98-e99.