Newborn Screening Program for Sickle Cell Disease in Western Kenya

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Statement of the Problem: Lack of newborn screening (NBS) for sickle cell diseases (SCD) contributes significantly to increased infant mortality rates especially in Sub Saharan Africa, where majority of the affected children die undiagnosed under the age of 5. Sickle cell disease (SCD) is a life-threatening genetic disorder that affects the red blood cells. Identification of hemoglobinopathies in some countries like Kenya is usually delayed until clinical signs of the disease appear, yet, little has been done to encourage NBS programs for SCD. Such delays in diagnosis hinder prompt intervention resulting in clinical complications as well as irreversible organ damage or death. The purpose of this paper is to describe the critical role played by NBS program for SCD in Western Kenya.

Methodology & Theoretical Orientation: AMPATH-Moi Teaching and Referral Hospital NBS program for SCD was established in the year 2012 with the support from Indiana Hemophilia and Thrombosis Center (IHTC). Laboratory personnel were trained on screening for hemoglobinopathies using isoelectric focusing (IEF) technique. Children with abnormal screening results were recalled for confirmatory testing using Hb Electrophoresis. Those who were diagnosed with SCD were referred to SCD clinics for treatment and further management. Findings: Over 10,000 newborns were screened for SCD. Out of these, about 100 were diagnosed with SCD and close to 500 were found to have sickle cell trait. Those with SCD were enrolled to the clinics and are currently on follow up treatment. Conclusion & Significance: Newborn screening program for SCD plays a major public health role that complements and enhances clinical services through reduction in mortality and improved developmental outcomes for the screened conditions. Training more lab personnel and the use of a point of care screening tools as well as nationwide efforts involving all stake holders are needed for policy development and system change.

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