

Implementing a standard-of-care clinic for stroke prevention in children with sickle cell disease in Nigeria: a feasible strategy outside a clinical trial setting

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Introduction

Stroke is a devastating, preventable complication of sickle cell anemia (SCA).¹ In a tertiary care center for children with SCA, screening for elevated transcranial Doppler (TCD) velocity coupled with regular blood transfusion therapy for those with abnormal values decreased the stroke rate from 0.67 to 0.06 strokes per 100 patient-years.² Despite evidence of preventing strokes and high morbidity and mortality associated with SCA ($\leq 30\%$),¹ primary stroke prevention teams for children with SCA are lacking in Africa.

To decrease the incidence of strokes in the general population of children with SCA, we established primary stroke prevention teams, as part of routine medical care, in 4 tertiary care hospitals in Kano, Nigeria. Collectively the 4 hospitals serve >20 000 children with SCA. We report the implementation of primary stroke prevention teams in a low-resource setting in Nigeria.

Procedure

At each of the 4 hospital-based sickle clinics, we identified the number of children with SCA and clinic personnel required to work with the team. The research team and hospital leadership identified a pediatrician, a nurse, and a radiologist to set up the primary stroke prevention teams. We initially conducted TCD training for all the radiologists using our TCD training protocol established for the SPIN trial. Each trainee radiologist and the trainer radiologist performed 40 paired TCD evaluations of the right and left middle cerebral arteries. The minimum acceptable correlation coefficient between the trainer and trainee was 0.76 for each side (85% of the trainer correlation in the same individual performed only hours apart).³ We conducted 3 education workshops based on National Heart Lung and Blood Institute sickle cell disease (SCD) management guidelines for primary care providers,^{4,5} and adapted for medical care in low-resource settings, we also trained ≥ 2 nurses and community health workers per clinic on the management of children with SCA. A child neurologist provided instructions on how to detect a stroke and stroke-related comorbidities (e.g., seizures) at 2 of 3 workshops. To ensure project sustainability and community ownership, we developed a memorandum of understanding with the Kano State government on 4 elements: (1) training hospital staff on identifying strokes with a commitment to keep the team together after the training; (2) training and certifying physicians and nurses in TCD techniques; (3) provision of free hydroxyurea therapy for children with abnormal TCD measurements; and (4) creation of an electronic patient care database for persons receiving TCD screening (no newborn screening for SCD is performed) (Figure 1).

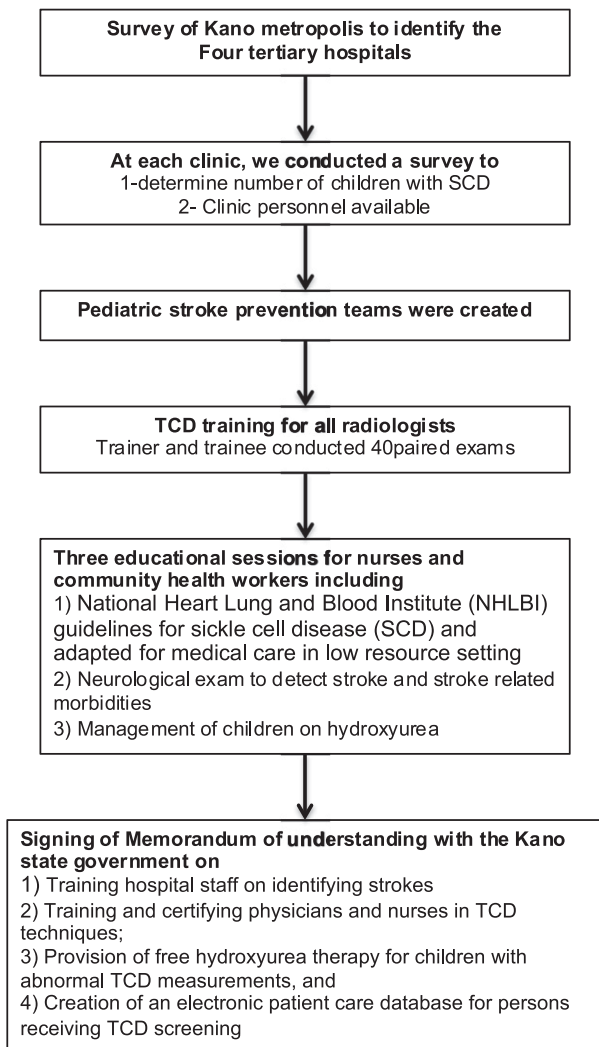


Figure 1. Establishment of the primary stroke prevention clinics and multidisciplinary team.

Results

A survey of medical leadership at each hospital in the fall of 2016 indicated that TCD screening was not standard of care for children with SCA. Outside of the clinical trial setting, none of the radiologists had extensive experience in performing TCD evaluation in children with SCA. Only 1 of 4 hospitals provided hydroxyurea therapy regardless of the ability to pay, but leadership at each hospital agreed that screening for strokes and providing hydroxyurea should be an important component of standard care. The primary stroke prevention clinics opened in January 2017. Each of the hospitals trained a multidisciplinary team. The government of Kano State agreed to provide free hydroxyurea to all eligible patients and provided 2 full-time permanent nurses for each of the 4 clinics.

We have trained and certified a hospital radiologist at all 4 participating hospitals. Since January 2017, 1249 children with SCA have been screened using TCD; all children were entered in a database with basic clinical information facilitating medical care. Abnormal TCD values (TAMMV ≥ 200 cm/second in middle cerebral artery confirmed independently by 2 radiologists) were reported in 7% of patients (n = 82); 73 were referred to participate in the SPRING Trial (www.clinicaltrials.gov identifier NCT02560935). As standard care, 7 of the remaining 9 children were started on ~20 mg of hydroxyurea per kg per day (Figure 2). We fully anticipate that the primary stroke prevention teams will continue screening and identifying children with SCD in 4 major hospitals in Kano, Nigeria, beyond the funding period of the SPRING Trial.

Conclusions

Community ownership and partnerships with leaders of participating hospitals and with local governments facilitate the establishment of sustainable primary stroke prevention teams for children with SCA in low-resource settings.

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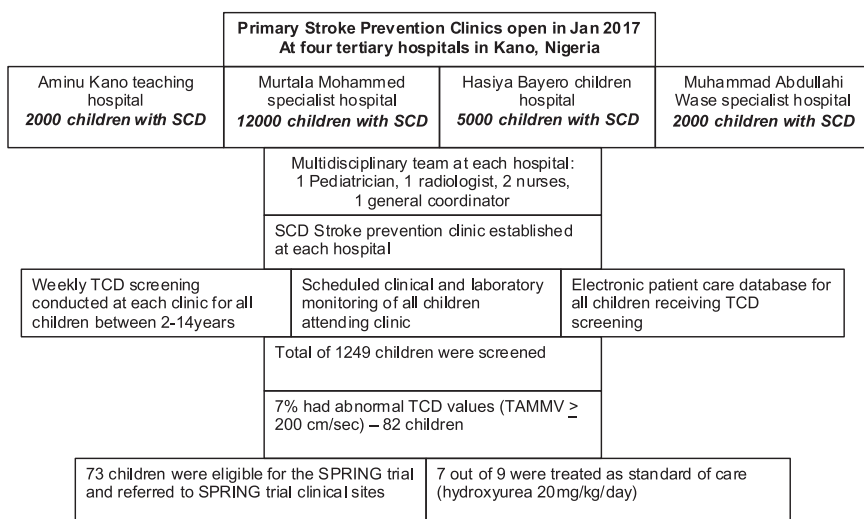


Figure 2. Flow diagram showing results of the primary stroke prevention clinics.

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