Cameroon Townhall for Healthcare Professionals

Meeting Minutes, June 15, 2024

Host: Cameroon Townhall for Healthcare Professionals

Date: June 15, 2024

Session: No. 103

Chair: Dr. Munoh Kenne Foma

Co-Moderators: Elvis Ndansi (moderator for this session), Dr. Bryan Tegomoh, Dr. Katte Jean-Claude

Guest Speaker: Dr. Marthe-Sandrine Mpollo, PhD, Cancer and Cell Biology (University of Cincinnati); MSc, Molecular Biology (Université de Montréal), Co-founder and Executive Director, NaYa Limited; Medical Science Liaison, Janssen (dermatology, Canada); based in Quebec

Distinguished Guests: Dr. Yauba Saidu, Country Director, Clinton Health Access Initiative (CHAI) Cameroon, Dr. Mathias Fobi, Cameroonian surgeon in the US, early member of the Cincinnati sickle cell programme, A physician now in Canada, former town hall speaker on occupational health

Title: Beyond the Clinic Walls: A Whole Person Approach to Sickle Cell Disease



Agenda Items:

1. Welcome and opening remarks by the moderator, Elvis Ndansi, and the Chair, Dr. Munoh Kenne Foma
2. Introduction of the guest speaker
3. Presentation by Dr. Marthe-Sandrine Mpollo, "Beyond the Clinic Walls: Sickle Cell Disease"
4. Comments by co-moderators and participants
5. Discussion and Q&A
6. Reminder on the participant survey, closing remarks and adjournment

Opening Remarks:

- The moderator welcomed participants and noted that sickle cell disease has now been the subject of three or four town hall sessions out of 103, a sign of its importance.
- The Chair said the American Society of Hematology made sickle cell a priority, which in the last ten years has brought new drugs (voxelotor, crizanlizumab), bone marrow transplant and gene editing, none of which are accessible in Africa. He asked for the discussion to move beyond clinical care to what communities are doing.

- Dr. Yauba Saidu of CHAI Cameroon, a previous speaker on eliminating sickle cell by 2060, reported that about two weeks earlier the national coordinator of the Council of Imams in Cameroon instructed all imams to require sickle cell status checks before celebrating marriages. He called this an important civil society step towards fewer affected births.
- The moderator introduced Dr. Mpollo: co-founder and executive director of NaYa Limited, a health financing and medical education start-up in West Africa that built a health financing app for low income patients and won a 2020 Orange social entrepreneur women's prize; Medical Science Liaison at Janssen in Canadian dermatology; holder of a PhD from the University of Cincinnati and an MSc from the Université de Montréal.

Presentation Points:

Presentation by Dr. Marthe-Sandrine Mpollo: "Beyond the Clinic Walls: Sickle Cell Disease"

1. Burden of disease:

Dr. Mpollo said about 8 million people live with sickle cell disease worldwide (2021 data), a quarter of them in sub-Saharan Africa. She put prevalence in Cameroon at about 3%, with over 5,000 affected births a year, and said the disease ranks among the 12 leading causes of death in children under five. WHO recognised sickle cell awareness day (June 19) in 2008. She described the disease as systemic, driven by sickling, haemolysis, chronic inflammation and vaso-occlusion, so care must address the whole person rather than the red cell alone.

2. New therapies have not reduced the burden:

She said treatment has advanced (hydroxyurea, voxelotor, crizanlizumab, and two cell based gene therapies approved in the US in November 2023, one using CRISPR to reactivate fetal haemoglobin and one adding a normal gene), yet global sickle cell births rose by close to 14% and adults in the US still live about 20 years less than average. Guidelines remain heavily clinical and target one part of the disease at a time. Gene therapies cost millions and bone marrow transplant about 100,000 dollars, while hydroxyurea at 1,000 mg a day was shown to cost on average about 25 US dollars in the countries studied, out of reach for many Cameroonian families.

3. Lessons from Jamaica and Dallas:

She presented cohort data from Jamaica (1970s) and Dallas showing that survival improved before hydroxyurea was available. In Jamaica, counselling parents to recognise danger signs such as splenic sequestration cut mortality by about 71%, with further gains when vaccination came. In Dallas, newborn screening, a first visit

at about 60 days, penicillin prophylaxis and active follow up of missed appointments (phone calls, rescheduling, social worker visits, letters) improved outcomes. Education, attention to social determinants and early care mattered as much as medicines.

4. Social determinants of health:

She reviewed the WHO's five areas (economic stability, access to quality care, education, social cohesion and neighbourhood) and evidence that low income, low maternal education, younger maternal age and low health literacy are linked to more emergency visits, severe anaemia and higher child mortality, including in a five country African cohort. She called for more such research in Africa.

5. Whole person care: it takes a village:

She proposed a whole person care model, supported by community linkages, that addresses the biological, behavioural, social and environmental needs of patients through the doctor, patient, family and community together.

6. Community models that work:

She described a Yaoundé parents' association founded around 2005, with over 3,000 members and linked to the Chantal Biya Foundation Mother and Child Centre, which runs WhatsApp peer support groups, care navigation, a mutual savings fund for crises, provider partnerships that share health information, and group purchase of prophylaxis. Other examples: a Tanzanian pharmacy school that, with Ministry approval, compounded hydroxyurea about 11 times cheaper than commercial supply; diaspora health transfers linked to providers and outcome reporting, which support adherence; the American Society of Hematology's digital guidance for clinicians (about 80% of US family physicians said they were uncomfortable treating the disease); and a Quebec association using community nurses for blood drives, screening of newcomers, massage for children's pain, and annual education conferences.

7. Four pillars to scale whole person care in Africa:

She proposed: convening to define the social determinants that matter in the African context; data integration to document interventions and outcomes; collaboration to share best practice and inform policy; and accountability, with community organisations trained to measure and report outcomes. These need IT infrastructure, funding for incentives, and trained care coordinators.

8. Call to action:

She asked participants to find and support community organisations, volunteer IT or care coordination skills, share evidence on social media, champion whole person

care in their practice, consider ventures such as local hydroxyurea formulation, and ask for accountability on outcomes when sending remittances for care.

Discussions and Q&A Session:

- **A physician now in Canada: what does this mean for Cameroon?** He said no country can afford all of health care, so new therapies are 'nice to know' for sub-Saharan Africa, and the realistic route is holistic care using simple tools such as WhatsApp. He recalled caring for children with sickle cell in Cameroon and said the gains from simple measures gave him hope.
- **Dr. Yauba Saidu (CHAI): how does this fit with elimination by 2060?** He described two pathways: reducing affected births through premarital counselling with civil society and community health workers, and newborn screening (being expanded through the PEN-Plus initiative) with follow up. This needs regulation, working supply chains, funding and incentives for manufacturers, since hydroxyurea and blood products are hardly available, and robust data systems. He said political will is present.
- **Dr. Katte Jean-Claude: what role do faith communities play?** He said pastors in his Christian community now check whether couples have been screened, which has become good practice, though how couples handle discordant results remains unresolved. He called for open public discussion.
- **Chair (Dr. Munoh Kenne Foma): what does the evidence mean for physicians?** He said hygiene, sanitation, vaccination and antibiotics have done more for mortality than most hospital treatments. He noted that Cameroon has all the main sickle cell subtypes, including the Cameroon haplotype, and more than 500,000 carriers. He stressed the transition from paediatric to adult care, training family doctors and internists as the American Society of Hematology does, better transfusion medicine, and thanked Dr. Saidu for pushing the Ministry to revive its sickle cell unit and republish guidelines.
- **Dr. Mathias Fobi: what was learned from early prevention work?** He said he helped start the sickle cell centre at Children's Hospital in Cincinnati in 1972 with Dr. Marilyn Gaston and was a leader of the sickle cell awareness group there, whose main work was premarital screening and genetic counselling. He has the milder sickle cell variant he described as 'SD trait', had his family tested in Cameroon in 1973, and said family members with the disease reached adulthood through preventive care. He said in the 1970s patients spent about four months a year in hospital and lived to about 16 or 17 in the US, and that the pain of not marrying is less than that of raising a child with the disease.

- **A participant (by chat): what prevention is possible at individual and community level?** Dr. Mpollo said individuals should attend early visits, stay hydrated, watch weather and personal triggers and eat well; the Yaoundé association sends weather advisories. At community level, awareness should start in primary and secondary schools, as for HIV, because people close to marriage resist screening. She urged empathy for couples who carry on, who face stigma. Dr. Saidu added that school adolescent health programmes have missed the chance to include sickle cell, and suggested women's groups, households and social media materials.
- **Dr. Yauba Saidu: should future burden be modelled?** He noted projections that by 2045 to 2050 the world will reach about 10 billion people, two billion in sub-Saharan Africa, with more migration, and proposed scenario models for advocacy. The Chair said such modelling would be fascinating, since malaria elimination and better survival will change the gene pool, and that more than ten new drugs are in the pipeline. Dr. Tegomoh offered to connect University of Buea students with modellers.
- **Dr. Katte Jean-Claude: when will gene therapies reach Cameroon?** Dr. Mpollo said not for at least 15 years: US payment is still being worked out under a 2024 presidential executive order, the FDA requires 15 years of follow up, and Cameroon lacks basic transfusion services. Hydroxyurea and L-glutamine are available now. She asked who is best placed to counsel couples. The Chair, as 'devil's advocate', argued that a shared gene and cell therapy platform would serve many diseases and that Africans should keep investing in it.
- **Dr. Yauba Saidu: what data are missing?** He called for psychological and health economics research, such as household spending on care, and proposed that the town hall frame policy questions for MSc, MPH and doctoral students at the University of Buea, with support for design and data collection. The moderator said the town hall would be ready to offer scholarships for sickle cell research.

Call to Action and Closing:

- Dr. Katte Jean-Claude said he learned he carries the trait from a note in his father's Bible at about age 12, and that education in families, churches and associations is the cheapest prevention.
- Dr. Mpollo proposed using platforms built for HIV for premarital and newborn screening, an African rather than national response to stock outs of basic drugs such as penicillin, local production of penicillin, and attention to the siblings of affected children.
- The moderator reminded participants to complete the town hall survey shared by email and in the chat.

- The Chair described sickle cell in his own family, noted that fewer than 5% of doctors he assessed in Cameroon prescribe hydroxyurea correctly, and called for premarital screening, newborn screening, penicillin, extended and catch up vaccination, health education and better transition of care. The theme for the year is 'Hope through progress: advancing sickle cell disease care globally'.
- Participants were asked to post about sickle cell on World Sickle Cell Day (June 19).

Next Meeting

In two weeks (late June 2024).

Recording: https://www.youtube.com/watch?v=-gayJ6xbBkM

Submitted by: Co-Moderators, Cameroon Townhall for Healthcare Professionals