Policy Briefing:

Beyond the Clinic Walls: Whole Person Care for Sickle Cell Disease in Cameroon

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Overview:

This policy briefing synthesizes key insights from the Cameroon Townhall for Healthcare Professionals meeting held on June 15, 2024 (103rd edition), focusing on the theme "Beyond the Clinic Walls: Sickle Cell Disease," presented by Dr. Marthe-Sandrine Mpollo.

Context:

Cameroon has a high burden of sickle cell disease, with over 5,000 affected births a year cited and more than 500,000 carriers. New therapies are unaffordable, while evidence from Jamaica and the US shows that education, screening, early care and follow up cut mortality before modern drugs existed.

Key Issues:

1. **Affordability:** Gene therapies and transplant are out of reach, and even hydroxyurea was cited at about 25 US dollars on average; penicillin stock outs occur.
2. **Gaps in early care:** Newborn screening is not universal, penicillin prophylaxis is not routine, and catch up vaccines are not covered.
3. **Workforce knowledge:** Few doctors prescribe hydroxyurea correctly and the move from paediatric to adult care is poorly managed.
4. **Social determinants:** Poverty, low health literacy and provider attitudes drive emergency visits and deaths.
5. **Data:** Little African evidence exists on social, psychological and economic burden.

Discussion Highlights:

- Faith leaders (the Council of Imams, churches) now encourage premarital screening.
- Community organisations such as the Yaoundé parents' association already provide peer support, savings funds and group purchase of drugs.
- Participants proposed starting awareness in schools rather than at marriage.

- Tanzania's compounded hydroxyurea showed a lower cost route.
- Students could take up modelling, psychological and economic research on sickle cell.

Recommendations:

- **Make newborn screening and early care standard:** MINSANTE should extend newborn screening with point of care tests, enrol positive infants in care by about two to three months, give penicillin prophylaxis and the full vaccine schedule including catch up doses. First step: add newborn screening and prophylaxis to the republished national sickle cell guidelines and pilot in one region per year.
- **Secure essential medicines:** MINSANTE, the national procurement agency and partners should ensure continuous supply of penicillin, folic acid and hydroxyurea and assess local or pooled procurement, drawing on the Tanzanian compounding model. First step: a stock and price review of these products in regional hospitals.
- **Train clinicians and plan transition:** Training schools and hospitals should teach hydroxyurea prescribing and adult sickle cell care, and set up transition clinics from paediatrics. Diaspora haematologists can support case based teaching. First step: a short online course for district doctors.
- **Fund and link community organisations:** MINSANTE and regional delegations should recognise patient associations as partners in care navigation and education, with support for outcome reporting. First step: map existing associations and agree a simple reporting format.
- **Start awareness early:** MINSANTE and the education ministries should add sickle cell to school adolescent health programmes, building on HIV programme platforms, and work with faith leaders on non-stigmatising premarital counselling.
- **Generate local evidence:** Universities, with town hall support, should take up research on cost, psychological burden, siblings and future burden. First step: share a list of research questions with the University of Buea Faculty of Health Sciences.

Next Steps: Moderators agreed to explore, with the Dean of the University of Buea Faculty of Health Sciences, student projects on sickle cell modelling and burden, and the town hall signalled readiness to support research. Participants were asked to complete the town hall survey and to mark World Sickle Cell Day on June 19.

Conclusion: The session showed that much of the gain in sickle cell survival comes from steps Cameroon can take now: education, screening, early prophylaxis, follow up and community support. Caring for the whole person, not only the cell, is within reach.

Prepared by the Co-Moderators, Cameroon Townhall for Healthcare Professionals, from the session of June 15, 2024. Recording: https://www.youtube.com/watch?v=-gayJ6xbBkM