Designing an Educational Brochure for Malawian Families of Children with Sickle Cell Disease

Maureen Nwizu, BA[1]; Emmalee Barrett, BS[1]; Douglas Postels, MD[1,2]; Peter Moons, MD[3]

[1] The George Washington University, [2] Division of Neurology, Children's National Medical Center, [3]Department of Paediatrics, Queen Elizabeth Central Hospital, Blantyre, Malawi

Introduction:

- Annually, there are approximately 400,000 children born with sickle cell disease (SCD) of which 90% are in sub-Saharan Africa.[1] 1 to 3% of Malawian children are affected.[1,2]
- Silent or overt strokes are feared complications of SCD that can be monitored using transcranial Doppler ultrasound (TCD).
- TCD has recently become available in Malawi but since this technology is new to this region, there are concerns that families do not understand why TCD was being performed.

Methods:

- We reviewed educational brochures about SCD and other disease processes in use in other African countries.
- Following these models, we developed questions and answers related to SCD and TCD using simple language. The narrative was translated into Chichewa, a regional, native language.
- We obtained feedback on the pilot version after review by Malawian nurses and parents for content validity and ease of understanding.
- We then revised the brochure accordingly. The final product was illustrated and printed, creating a deliverable, educational brochure focused on Malawian families of children with SCD.

Results:

Sample Brochure Content

Ndichifukwa chani tikuyenera kumamujambula mwana wanu pogwiritsa TCD

- Madotolo amagwiritsa TCD ngati njira imodzi yowunikira ana amene ali pa chiwopsyezo chokhala ndi mavuto omwe amadza kamba ka matenda a sickle cell. Izi zimathandizira kuti iwo adziwe ngati mwana wanu akuyenera kulandira mankhwala apadera.
- Kujambulidwa kwa pafupi pafupi pogwiritsa ntchito TCD kumathandizira kuti mwana wanu akhale ndi zotsatira zolondola za matendawa.

Why must we monitor your child using TCD?

Doctors use TCD to identify children with the highest risk of complications from sickle cell disease. This will help them recognize when your child needs different drugs. Regularly receiving TCDs will increase the likelihood that your child will have a good outcome.

Kodi pali ndondomeko zanji zomwe zimatsatidwa pa nthawi yojambula?

- Panthawi yoyeza mwana wanu amayenela kuti agone pa bedi/kama.
- Adotolo amayika kilimu/mafuta ku kachipangizo kojambulira (probe) komwe azayike pambali pa mutu wa mwana wanu.
- Kujambulaku sikumapweteka, koma nthawi zina ana ena amamva kuzizira pang'ono chifukwa cha kilimu kapena mafuta aja. Kenako a dotolo azatenga zithunzi, ndondomekoyi imatenga pakati paphindi zisanu (5) ndi khumi (10).
- Ngati mwana angavutike kukhazikika panthawi, adotolo amamuyatsira kanema (video) pa thenifolo pofuna kumuthandizira kudekha.

What happens during the exam?

Your child will be asked to lie on a bed. The doctor will put cream on a probe and touch the side of your child's head with it. This is not painful. Sometimes it feels a bit cold. Then the doctor will take some pictures. In general, it takes about 5-10 minutes. If your child finds it difficult to lie still, we will try to show them a video and this often helps your child stay still.

Conclusion:

- Future directions may include interventional clinical trials to ascertain whether family education using this brochure improves compliance with medications, clinic attendance, and SCD outcomes.

References:

1. Chimbatata CS, Chisale MR, Kayira AB, et al. Paediatric sickle cell disease at a tertiary hospital in Malawi: a retrospective cross-sectional study. *BMJ Paediatr Open*. 2021;5(1):e001097.
2. Cook J, Jefferis O, Matchere P, Mbale E, Rylance J. Sickle-cell disease in Malawian children is associated with restrictive spirometry: a cross-sectional survey. *Int J Tuberc Lung Dis*. 2013;17(9):1235-1238.