

RESEARCH FOR HEALTH IN HUMANITARIAN CRISES (R2HC) AND NODDING SYNDROME ALLIANCE PROJECTS

DISSEMINATION WORKSHOP

Juba, August 11 – 12, 2022

RECOMMENDATIONS

Research on onchocerciasis and onchocerciasis-associated epilepsy

1. To study the feasibility, safety and impact of ivermectin (IVM) administration to pregnant women, as the latter might represent a significant *Onchocerca volvulus* (OV) reservoir and contribute to keeping mass drug administration (MDA) treatment coverages below the target percentage.
2. Researchers should take into due consideration areas outside Western Equatoria, for instance, entomological surveys and studies should be conducted in other regions of South Sudan which are known to be endemic for onchocerciasis, but where the burden is currently unknown.
3. To explore the feasibility, safety and impact of IVM administration in children below the age of 5 years (once WHO deems it safe, based on specific trials being conducted elsewhere).
4. Researchers should pay adequate attention to People with Disabilities, and disability itself, while designing their studies, ensuring that no-one is left out. For instance, they could attempt to scientifically measure how disabling onchocerciasis-associated epilepsy (including Nodding Syndrome) is.
5. To investigate the efficacy of different anti-epileptic drug (AED) regimens in treating different forms of epilepsy commonly found in the study areas in South Sudan.
 - a. Efficacy in attaining seizure control.
 - b. Efficacy in preventing or slowing down the process of physical and neurological deterioration in patients.
6. To explore and assess the effectiveness of alternative awareness creation strategies in successfully fighting stigma and in positively changing behaviours, attitudes and beliefs. The main strategies currently in use are community meetings, individual household visits, radio talk shows, yearly events.

Prevention of onchocerciasis transmission and onchocerciasis-associated epilepsy

1. Extending “Slash & Clear” community-based vector control interventions to other locations in the country.
2. Ensuring bi-annual IVM MDA in high-transmission settings. For instance, the Ministry of Health of South Sudan (MOH SS) is in the process of renewing its agreement with the Mectizan Donation Program; its application includes offering bi-annual treatment in some areas characterized by high onchocerciasis transmission. However, this request needs to be well justified.
3. Concerning IVM MDAs, better engagement at the local (implementation) level is required, especially at the stage of designing the campaign plan. For instance, it is suggested that each county develops its own microplan.
4. Engagement of local chiefs (or equivalent village-level authorities) should be enhanced, in order to recruit Community Drug Distributors (CDDs) who are truly known in the community and knowledgeable about the community and the area they are assigned to.
5. Stronger and more extensive supervision is needed during MDA campaigns, which requires additional resources to be allocated to this aspect of campaign implementation. This element is key to attain larger and wider treatment coverage. For example, it has been noticed that CDDs may develop and adopt their own treatment “exclusion” criteria while carrying out MDA campaigns. This should be prevented by adequately addressing this practice during pre-campaign training of CDDs and providing adequate supervision.

6. It has been observed that motivation of CDDs during MDAs may not be always sufficient. MOH SS and partners should assess the adequacy of the incentives provided.

Service delivery

1. To increase the supply of AEDs to Maridi, Mundri West, Mundri East and Mvolo Counties. The current allocation is significantly lower than the actual needs and consumption. This recommendation is directed to the MOH SS (Pharmaceutical Dept.), and the Health Pooled Fund. At the same time, stakeholders are encouraged to foster community-based mechanisms to enable the community itself to contribute to the procurement of AEDs.
2. Pre-service training of Clinical Officers on epilepsy care should be strengthened, for instance by increasing the attention paid to epilepsy care within the training curriculum taught at Health Sciences Institutes. This recommendation is directed to: MOH SS, and the Health Sciences Institutes. Integrating WHO Mental Health Gap Action Programme (mhGAP) training modules into the regular curriculum might be a first step in this direction.
3. Human resources currently employed at the three epilepsy clinics of Maridi Hospital, Mundri PHCC and Lui Hospital need to be retained beyond the end of the current funding. These staff are already integrated in the human resource establishment of their respective health facilities. They should be considered for addition into the Health Pooled Fund incentives' scheme since they are providing crucial mental health services to the community. This recommendation is directed to: MOH SS (Mental Health Dept.), Health Pooled Fund.
4. The MOH SS, Preventive Chemotherapy Neglected Tropical Diseases (PC-NTD) Department should officially acknowledge Onchocerciasis-Associated Epilepsy (OAE) as a co-morbidity of onchocerciasis, to be addressed by Morbidity Management & Disability Prevention (MMDP) interventions. In a recent meeting of NTD Programs held in Dar es Salaam, chaired by the WHO, OAE was officially recognized as a condition to be addressed through MMDP interventions. This recommendation is directed to: MOH SS (PC-NTD Department).
5. The MOH SS, Mental Health Department should officially acknowledge OAE as a Mental, Neurological, Substance abuse (MNS) priority in South Sudan. This recommendation is directed to: MOH SS (MOH SS – Mental Health Department).
6. The Nodding Syndrome Alliance project has demonstrated that Boma Health Workers (and other cadres of community health volunteers) can be successfully employed to identify probable cases of epilepsy (including Nodding Syndrome), to refer them to a health facility providing epilepsy care, and to monitor these patients at home. A simple community case definition of probable epilepsy already exists. It is recommended that training on the identification of probable cases of epilepsy is scaled up within the framework of the Boma Health Initiative in South Sudan, especially in areas characterized by high prevalence of epilepsy.
7. The Nodding Syndrome Alliance should widen its membership to encompass agencies specialized in Child Protection and Psycho-Social Support (PSS), to acquire additional expertise in these fields.
8. To advocate for the revision of the eligibility criteria used for the provision of nutritional services to cases of Moderate Acute Malnutrition (MAM) and Severe Acute Malnutrition (SAM) at Outpatient Therapeutic Programme (OTP) centres. Children above 5 years of age with OAE should be considered eligible for treatment since their nutritional status is directly due to their epileptic condition and an optimal nutritional status contributes to the effectiveness of the anti-seizure treatment.
9. Context-sensitive Information, Education and Communication (IEC) material should be specifically developed to support awareness creation around epilepsy in South Sudan.
10. Decentralization of epilepsy care should be promoted beyond PHCCs, to bring anti-seizure treatment closer to those communities characterized by higher epilepsy prevalence. The most appropriate modalities to do so are to be explored.
11. To strengthen the engagement with local traditional healers and further enable them to identify probable cases of epilepsy and refer these cases to public healthcare facilities for diagnosis and treatment.

12. To offer vocational training opportunities for youth with epilepsy within the framework of future interventions, to economically empower them and enable them to sustainably afford epilepsy care through their own means.