EPILEPSY CARE IN RESOURCES-CONSTRAINED SETTINGS: THE NODDING SYNDROME ALLIANCE EXPERIENCE IN THREE CLINICS IN WESTERN EQUATORIA, SOUTH SUDAN

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INTRODUCTION

Nodding Syndrome (NS) is a degenerative neurological disease with poorly understood etiology which mainly affects children in some regions of Sub-Saharan Africa. Since 2019, a consortium of NGOs (the "Nodding Syndrome Alliance"), led by Amref Health Africa, has been working with the Ministry of Health of South Sudan to respond to the multi-sectoral needs of people with epilepsy (PWE), including NS, in three counties of Western Equatoria. Three clinics were set up, at Lui Hospital, Maridi Hospital and Mundri Primary Health Care Centre, supported by Doctors with Africa CUAMM.

METHOD

Descriptive statistical analysis was conducted from patients' databases maintained in Microsoft Excel at the clinics.

FINDINGS

Between May 2020 and August 2022, 3454 patients were enrolled, majority of them during the first year (increase of 160% of patient admissions from May 2020 to May 2021). Among all the patients, 963 (27.8%) were under 18 years old, the most represented age group was 15-24 (56.1%) and 48.2% were Female. 7 patients received a diagnosis of confirmed NS, based on the WHO case definition. Patients with probable NS accounted for 61.7% of the total (n. 2131), while the rest were diagnosed with other forms of epilepsy. Mortality rate among the enrolled patients was 1.3%. Carbamazepine was administered in 1906 (55.2%) patients, followed by Phenobarbital (787; 22.8%), Phenytoin (506; 14.6%) and Valproic Acid (252; 7.3%). The monthly average defaulter rate during the last six months of the project was 37.5%. Among all patients, 90% reported an improvement of their quality of life after receiving treatment (47% described it as «much better» and 43% as «better») and 90% reported a reduction in seizures frequency.

CONCLUSION

Epilepsy, including NS, represents a health, social and economic burden for the affected population. Further studies are needed to better investigate etiology, epidemiology, efficacy of treatments and prevention interventions.