The double burden of epilepsy and HIV in sub-Saharan Africa calls for a more suitable medical education

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Dear Editor,

The Sub-Saharan Africa (SSA) population almost doubled in the last 20 years and life expectancy increased by more than 10 years, contributing to re-shape the disease spectrum of the continent; nowadays, 45% of the SSA disease burden is due to non-communicable diseases (NCDs) including neurological disorders [1]. From 1990 to 2017, the disability-adjusted life years (DALYs) attributed to epilepsy increased by 68.8% [1] and the estimated number of people living with epilepsy in SSA grew from 15 million in 2005 to 22 millions in 2021. About two-thirds of epileptic patients have no access to treatment and the disease related mortality is six times higher than in other continents.

Along with malaria and onchocerciasis, HIV is a major contributor to epilepsy in SSA; there are more than 25 million people living with HIV, which is a leading risk factor for epilepsy [2] due to the persistence of the virus in patients'

brain throughout their life. Longer life expectancy due to improved access to antiretroviral treatment and reduced funding to fight HIV produce a constant increase of people living with HIV (https://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf) so that the double burden of epilepsy and HIV continues to rise.

More than 60% of the SSA population live in rural areas, far from medical care, and hospitals are often located in urban areas affected by poverty, lack of human resources and poor education. Public transportation is lacking, fuel is expensive, more than half of the population live with less than 2 USD per day and many patients seek assistance in rural health centres. These are the backbone of primary care in SSA where a huge proportion of patients with epilepsy are treated. The HIV epidemic has deeply transformed primary care centres in SSA that have become the main sites where HIV + patients receive treatment. The worrying double burden of epilepsy (and other NCDs as well) and HIV led the United Nations to recommend integrating the two diseases at HIV centres to reduce troubles to the patients; on the other side, integrating epilepsy and HIV raises some challenges.

SSA has the lowest density of doctors and nurses, only 3% of the global health work force, but has the highest disease burden, 26%. Neurologists are exceptionally rare and only about 1 for every 3–5 million people is available. Hence, in health care systems, up to 91% of epilepsy and neurological care is provided by non medical health care providers (NMHCP) who have variable medical education regarding both diseases. There is some concern about epilepsy education of NMHCP; and in primary care/HIV centres, the quality of care relies on their education; good education on epilepsy increases quality of care, which, in turn, favours epileptic patient satisfaction encouraging patients to regular follow up visits and to follow advices to obtain good retention. Patients retention is important for long term seizures monitoring and ascertainment of regular intake of antiepileptic drugs (AEDs) and side effects monitoring. In rural areas, a relevant proportion of

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patients with epilepsy do not take drugs regularly or they take them with inadequate dosages or may stop taking drugs at all leading to uncontrolled epilepsy. Insufficient follow up/poor retention does not allow ascertainment and correction of wrong patient behaviours thus limiting efficacy of large scale epilepsy care programs and contributing to increase the burden of the disease.

In SSA, low patients' retention affects many care programs for chronic diseases as epilepsy, HIV, arterial hypertension and diabetes; about 40 to 60% of these patients are lost to follow up within 2–4 years after treatment starts and many resources and lives are lost. To sum up, inadequate education of NMHCP contributes to worsen patient retention and weakens chronic care programs.

In a recent teaching course that authors (ML) offered to 40 NMHCP in Malawi, it emerged that all of them treated epileptic patients but no one had previously received education from neurologists. An assessment about knowledge was made in a pre-course questionnaire, where more than half of the participants (55, 3%) answered that epilepsy is a psychiatric condition — instead of a brain disorder — and 85.3% neither recognized HIV as a major risk factor for epilepsy nor that the disease is more frequent in children than adults (personal observations, data presented at the World Congress of Neurology Rome, 3–7 October 2021).

More training alone was supposed to improve quality of care — and patients' retention as well. In one large study at primary care level in India, 74% of trained health care providers were able to report on how to deal with patients suffering from angina, asthma or diarrhoea. But when visited by “*mystery patients*” presenting with exactly these symptoms, just 31% treated them correctly; this is called the *know-do gap*. Training alone is not enough to grant sufficient quality of care. Quality of care is also related to consultation length. Average consultation length with primary care physicians is 5 min or less for about 50% of the global population, particularly in low-income countries (LIC) as SSA. *Know-do gap* and short consultation length at primary care may be caused by health care providers not receiving feed-back of their work and being left working alone. These conditions and the lack of simple quality measures predispose to the *burn out* of health professionals.

As a consequence, disease-specific knowledge alone may not be enough for education programs; experienced neurologists in the field of epilepsy and HIV can teach disease-specific knowledge but how to improve health care providers' accountability when integrating epilepsy and HIV in SSA? It has been reported that ability — and accountability — of health workers to provide integrated services in low- and middle-income countries (LMIC) is improved when the education programs are followed-up after training in terms of high quality supervision and site visits, and peer support by including mentoring by more experienced health workers.

Conversely, brief stand-alone training and longer gaps between supervisions are associated with poor performance.

European academic institutions education programs in LIC are somehow far from adhering to the above reported performance indicators and some changes have been proposed: education programs of longer duration, funding extended residencies in LIC, encouraging candidates to teach and mentor in LIC. Adequate funding for LMIC institutions is also indicated [3]; during the last Ebola epidemic in western African countries, almost all the funding to fight the disease was allocated mainly for research to European and American institutions, and poor attention was given to strengthen the SAA primary care systems that play a crucial role in preventing threats as now is COVID-19.

Education models adopted from international institutions in SSA are questioned by the *brain drain* phenomenon: the migration of young and educated workers from Africa and LMIC to high income countries. *Brain drain* takes a toll in SSA where human capital is already scarce: 25% of the 10,000 graduated in health works (doctors, nurses, clinical officers, midwives) every year in SSA will emigrate within 5 years or less [4]. In the attempt to limit the growing migration trend, the WHO has issued a key recommendation, the WHO Global Code of Practice on the International Recruitment of Health Personnel, a global framework adopted in May 2010 to address health workforce retention in resource-limited countries and the ethics of international migration. But in 2013, African doctors migrating to the USA were more than those working in Africa: 11,787 vs 11,519 — a similar proportion could involve the figures for European Union countries. This costs \$2 billion in lost educational investments and an unknown additional financial burden caused by the illnesses which cannot be treated in SSA. Only 16% of graduates may work longer than 5 years in rural environment.

Well established education programs may help the development of teleneurology in SSA so to bring neurologists where there are none. Such programs on epilepsy could allow NMHCP to send appropriate questions to specialists in local centres and even remote countries. Good communication between remote neurologists and local workers can motivate NMHCP to stay in their country to limit the *brain drain*.

Epilepsy, HIV related or not, is increasing in SSA; however, the vast majority of patients with epilepsy are managed at primary care/HIV centres by NMHCP with insufficient education in this illness. Unfortunately, this situation will last for decades; hence, it seems reasonable to offer more education on the disease to NMHCP. This can improve quality of care to millions of patients. International and academic institutions educational programs should improve their attention on NMHCP education. This promises to be a powerful tool to reduce the increasing burden of epilepsy in SSA.

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Declarations

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