



# Women, epilepsy and HIV and AIDS in pregnancy

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A Global Campaign Against Epilepsy event at the Epilepsy centre in Hatfield, Harare. [Photo courtesy of Epilepsy Support Foundation of Zimbabwe].

**There is a relationship between HIV and epilepsy: they are both shrouded in myths and misconceptions that lead to stigmatisation of those affected by the two diseases. As Nelson Mandela once said, the reason why people are dying is not because of the diseases they suffer from, but because of stigma and discrimination.<sup>1</sup>**

This statement applies to marginalised groups, including women with epilepsy, who are also affected by HIV and AIDS. Such women find themselves between the rock and a hard place inasmuch as epilepsy and HIV continue to be shrouded in stigma and discrimination. This article addresses the triple burden of living with HIV and epilepsy and being pregnant.

People suffering from epilepsy, a chronic condition marked by recurrent seizures, mostly live in resource-poor areas especially in developing countries where epilepsy care and diagnostic options are limited. In an open letter to the World Health Organization (WHO), concerned

epilepsy specialists in sub-Saharan Africa warned of the dangers of drug interactions between antiretroviral treatment (ART) and some anti-epilepsy Drugs (AEDs). They said the co-administration of these medications leads to ART failure and resistance to other HIV drugs such as Nevirapine.

Information on the extent of interactions of AEDs with antiretroviral drugs is scarce, but if Nevirapine levels decrease to sub-therapeutic concentrations, several things are likely to happen. The decreased efficacy of Nevirapine, according to the *Lancet*, is likely to lead to the failure of ART and this in turn could lead to increased HIV resistance to Nevirapine. Moreover, since HIV itself can

cause seizures, including status epilepticus, poor viral control would be expected to increase the incidence of seizures.

On the other hand, researchers have announced that very early studies of the seizure medication Valproic Acid show that the medicine may help “flush out” HIV from remote areas in the body that are difficult to reach with conventional therapies. The very small trial combined conventional HIV medications with the seizure medication Valproic Acid.

However, during pregnancy, factors such as AED treatment, hormonal changes, and vitamin deficiency can influence seizure patterns, even for women who have had excellent seizure control in the past, the *Lancet* adds.

These complications, combined with genetic factors, also lead to a greater risk for major and minor birth defects in babies born to mothers living with epilepsy.





Although this risk is not typically significant enough for neurologists and epileptologists (epilepsy specialists) to advise their patients against pregnancy, healthcare specialists advocate a conscientious and careful pregnancy for all prospective mothers who suffer, or have suffered, from epilepsy.

For most women living with epilepsy, seizure frequency remains unchanged during pregnancy. However, some 20 per cent will suffer more seizures during pregnancy while some women experience seizures only during birth. The physiological changes that may play a role in the increased incidence of seizures for some women include changes in hormone production, metabolism, stress and alteration in sleeping patterns<sup>ibid</sup>.

The UN Summit on the Millennium Development Goals adopted a global action plan to achieve the eight anti-poverty goals by the 2015 target date and the announcement of major new commitments for women's and children's health and other initiatives against poverty, hunger and disease. They include primary education for all, alleviating extreme poverty and hunger, improving maternal health, combating HIV and AIDS, malaria and other diseases, developing a global partnership and gender equality among other goals.

Epilepsy is a critical grey area that should not be left out. Ignorance surrounding the

condition has led to many other related problems. Developing countries are mainly affected with the majority of people either receiving inadequate treatment or no treatment at all. According to the Epilepsy Support Foundation of Zimbabwe (ESFZ), women and children constitute a larger percentage of people living with epilepsy. It is estimated that almost two per cent of women with epilepsy are also infected with HIV and AIDS.

A survey carried out in India showed that women with epilepsy are affected in almost all aspects of their lives, including education, marriage, employment, household and motherhood.

Epilepsy week in Zimbabwe is an awareness period, as people from all walks of life mingle and get sensitised on the existence of epilepsy in their communities and the best ways to manage it. Awareness campaigns are promoted and members of the public are educated on the challenges of epilepsy and HIV. The week has been celebrated in Zimbabwe every last week of September since 1990.

Women with epilepsy who manage to cross the bridge to marriage often suffer silently at the hands of their husbands and relatives. The stigma of epilepsy has resulted in exploitation and physical abuse, including rape. The women, who are denied

respect, are said to be possessed by evil spirits and are often beaten up or harassed before their friends, relatives and worst of all their children. Some women might not tell their spouses about their condition until after marriage, for fear of rejection, and as a result, they are often abandoned when their condition is discovered. Most of them are illiterate and have no understanding of family planning. Also, they cannot protect themselves from HIV infection.

Some women living with epilepsy have been raped, and with HIV prevalence on the increase, such women are more likely to be infected. Some societies still believe that women with epilepsy are sexually inactive and not marriageable; it becomes a shock to some when the women are found to be HIV positive or having babies.

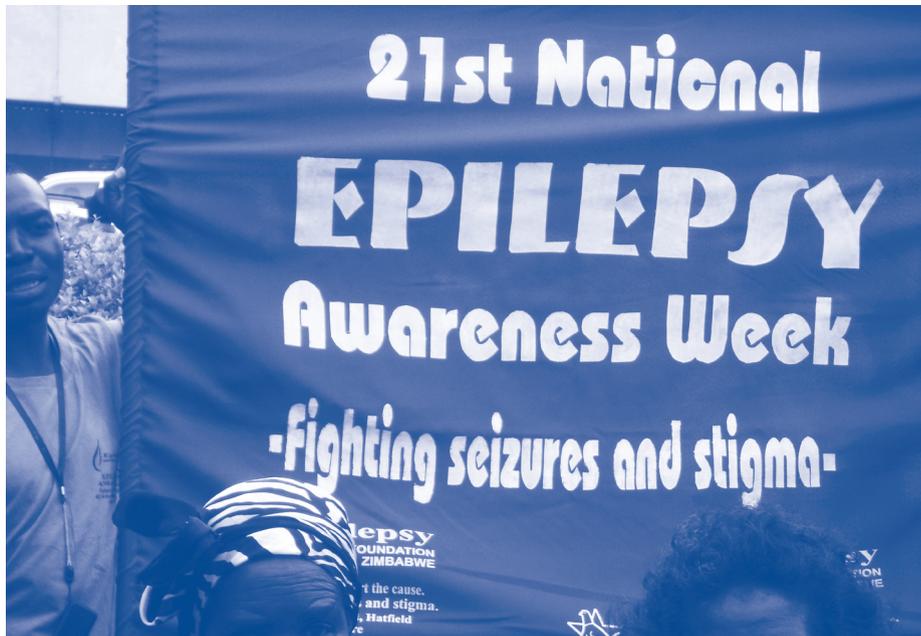
A report by the Disabled Women Support Organisation (DWSO) states that there is a high rate of HIV infection among women with disabilities in Zimbabwe. About 87 per cent have been sexually abused in the southern Africa country and of these 52.4 per cent were HIV positive.

In some cultures, women with epilepsy are not allowed to have children: some were sterilised against their will or discouraged from having a family. There is a belief that those who opt to have children have to grapple with fertility problems caused by



Nobuhle Shumba of ESFZ speaks during an epilepsy event in Harare. [Photo courtesy of ESFZ].





Members of Epilepsy Support Foundation of Zimbabwe during the Epilepsy Week in 2010. [Photo courtesy of ESFZ].

anti-epileptic drugs or irregular menstrual cycles. It is believed that one who gets pregnant will have increased seizures, which may pose some dangers for the foetus such as lack of oxygen and a possible miscarriage, depending on the type of epilepsy, as well as the medication type.

Stigma and discrimination of women living with epilepsy must be dealt with from the family level upwards. Also, programmes must be designed to sensitise communities on epilepsy and how best one can be assisted during seizures.

Management of epilepsy programmes is essential not only for those affected, but the

whole family, community and society. There is a need to establish a close link between individuals, medical fraternity, teachers, religious organisations, friends, companies and the state.

Clinics and hospitals must be friendly environments for women with epilepsy to discuss their concerns, especially about having children and being infected with HIV, and be able to be understood and treated. Confidentiality of information to patients, adequate treatment and basic medical services should be available and affordable to everyone without prejudice. ■

### Lessons learned

- During pregnancy, factors such as AED treatment, hormonal changes, and vitamin deficiency can influence seizure patterns, even for women who have had excellent seizure control in the past.
- About 87 per cent of women with disabilities have been sexually abused in Zimbabwe and of these 52.4 per cent were HIV positive.
- There is a need to establish a close link between individuals, medical fraternity, teachers, religious organisations, friends, companies and the state in order to effectively tackle epilepsy.

### References

1. Nelson Mandela spoke during the 2002 International HIV/AIDS Conference in Barcelona, Spain.
2. <http://aids.about.com/od/clinicaltrials/a/valproic.htm>
3. <http://www.healthcommunities.com/seizures/pregnancy.shtml>

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Members of ESFZ at their Harare office. [Photo courtesy of ESFZ].

