



Determining the disability adjusted life years lost to childhood and adolescence epilepsy in southeast Nigeria: An exploratory study



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ABSTRACT

Objectives: Disease burden has always been based on associated mortality. An accurate measurement of the burden of epilepsy should rely on both morbidity and mortality. This will close any existing gap in knowledge and provide useful information to aid evidence-based decision-making. In this study, burden of epilepsy was estimated, using disability-adjusted-life-years (DALYs), using disability weights for epilepsy that were part of the Global Burden of Disease 2010 work.

Methods: The study was conducted at the University of Nigeria Teaching Hospital, Enugu. Interviewer-administered questionnaire was used to collect information from patients with epilepsy who presented to neurology clinic. The prevalence of epilepsy, and case-fatality were obtained from previous publications. The DALYs were estimated by adding together the years lost to disability (YLDs) and years lost to life (YLLs) to epilepsy (DALYs = YLD + YLL). DALYs were dis-aggregated by age group and by whether or not epilepsy was treated.

Results: A total of 134 children with epilepsy-interviews were conducted. Some 56% and 44% of the subjects had primary and secondary epilepsy, respectively. The childhood epilepsy caused 1.63 YLLs per 1000 population, 0.45 YLDs per 1000 population and 2.08 DALY per 1000 population. The highest burden was in children within the age group of 5–14 years at 2.18 DALY per 1000 people. The YLDs was higher (0.63/1000 population) among the untreated group, compared with the YLDs (0.27/1000 population) among the treated group. The YLLs lost for children with secondary epilepsy (2.23/1000 population) was higher than primary epilepsy YLLs of 1.07/1000 population.

Significance: The DALYs due to childhood epilepsy was high. The YLDs was high among children with epilepsy who were not on treatment. The YLLs were found to be the same in all children with epilepsy, irrespective of their treatment status. This imperatively necessitates the de-emphasis on just mortality as an indicator of the burden of childhood epilepsy but rather a holistic approach should be adopted in considering both the mortality and disability in monitoring the outcome of health interventions.

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1. Introduction

Epilepsy affects millions of people in Africa and most of the cases begin in childhood (Bremner and Campbell, 1988; The Global Campaign Against Epilepsy, 2000; Newton and Garcia, 2012; Epilepsy in, 2014). The impact of epilepsy is more in children than adults, and has a higher medico-social implication in children (Sillanpaa and Shinnar, 2013). Some diseases like childhood epilepsy may not commonly be accountable for premature death

but has prolonged years of life lived with disability. Disability which can be both physical and psychological, often starts early in life and if not adequately managed can continue till adulthood.

In spite of the perceived high prevalence and morbidity associated with childhood epilepsy, there is sub-optimal resource allocation for the control and management of the disease in many low income countries such as Nigeria. This is related to the low levels of computed burden of epilepsy in many studies. The traditional methods of assessment of disease burden based on mortality alone do not allow the impact of non-fatal diseases to be considered by policy makers. Due to tightly constrained resources, there is poor allocation of funds in health interventions directed to these low mortality diseases. Among the factors that contribute to the

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above scenario with regards to childhood epilepsy is the methodological weakness in computing the burden of disease (BoD) based on mortality alone. In Nigeria, most common methods quantify the number of deaths that resulted from illnesses with little or no assessment of the impact of disability on the children with epilepsy while they are still alive. Surprisingly, the estimated disability weights for epilepsy which capture the epilepsy morbidity have always been stated in Global Burden of Disease (GBD) and Injury Series GBD 2010, but the information is barely used and thus has not impacted policy-makers' decision in Nigeria. The lack of use of information from GBD in Nigeria is probably because the GBD data as it is presented is too remote and or extrapolated to be valid in the Nigerian situation.

In an effort to have a full picture of burden of diseases, the World Health Organization (WHO) introduced an index of mortality and morbidity, which is disability adjusted life years (DALY). The DALY is generated by adding together the years of life lost to premature death (YLL) and years lived with a disability (YLD) (Murray and Lopez, 1996; Murray, 1994). One DALY is one year of health life lost. DALYs is a more concise measure of BoD and helps in more objective resource allocation decisions for most diseases, including epilepsy relatively low associated mortality (Johnson, 2004) when compared to malaria and other infectious diseases, especially in countries like Nigeria where less than five percent of the annual budget allocation goes to health (Obansa, 2013).

There is a vacuum in knowledge on the BoD of epilepsy. Apart from few global studies (Wang et al., 2003; Ibinda et al., 2014) on the burden of epilepsy, there is no specific study in Nigeria on DALYs for childhood epilepsy. Although, the use of DALYs for the assessing of disease burden have been in use for several decades, only few studies (Wang et al., 2003; Ibinda et al., 2014) have been published on DALYs of epilepsy. This study evaluated the disease burden of childhood epilepsy based on disability adjusted life years, to provide a context-specific and estimate of the burden of childhood epilepsy in southeast Nigeria. A more accurate measurement of the burden of epilepsy should rely on both morbidity and mortality. This will close an existing gap in knowledge and provide useful information to aid decision-making to inform healthcare policy.

2. Methods

2.1. Study design

The study was undertaken at the University of Nigeria Teaching Hospital, Enugu, southeast Nigeria. The population of Enugu State is 3.3 million (2.33% of the national population) (Federal Republic of Nigeria Official Gazette, 2007) and children make up 41% of the entire population. (Nigeria Demographic Profile, 2012) This will give a projected children population was 1,353,000.

2.2. Sample and sampling technique

The Enugu State population census was used to estimate the proportion of children. The population of children in Enugu is estimated to be 1,353,000. The prevalence of epilepsy of 20.8 per 1000 children (rural) (Osakwe et al., 2013) and 4.7 per 1000 urban (Akinsulore and Adewuya, 2010) were used to estimate the population of children with epilepsy. Therefore, the projected number of children with epilepsy could range from 6359 to 28,143. This can be segregated in 6359, 13,530, 20,295 and 28,143 for the prevalence of 4.7/1000, 10/1000, 15/1000 and 20/1000 respectively. The age distribution was extrapolated from the age distribution of the identified subjects with epilepsy.

2.3. Data collection

Data was collected on one hundred and thirty four children with epilepsy, using interviewer-administered questionnaire that was administered to their caregivers, using a two week recall period. This ensured that the data collected was accurate.

The interviewer-administered questionnaire was used to collect data on their socio-demographic characteristics, the age of the patients, the age at the onset of their illness, the frequency of episodes of epilepsy, the last episode of epilepsy, any identifiable cause of the epilepsy, the frequency of utilization of hospital facilities, and ownership of household assets were collected, using interviewer-administered questionnaire. The information from publications on childhood and young adult epilepsy was used to build up the proportion of children with epilepsy on treatment, the prevalence and mortality associated with childhood epilepsy, the proportion of the population that were children.

The childhood epilepsy mortality rate was determined from literature. The death due to epilepsy is any death that occurred in the course of status seizure, or any sudden death in any child with epilepsy with no other possible explanation of the cause of death except epilepsy (Murray and Lopez, 1996). The case fatality was calculated as number of deaths due to childhood epilepsy as numerator and number of children with epilepsy as denominator. Global epilepsy-related mortality was reported to be 1–4.5 per 100,000 population, mortality of 3 and 7.9 per 100,000 population was reported in China (Li Sc Wang et al., 1989; Pal et al., 1999). The study in Kenya reported mortality due to epilepsy of 8.1 and 10.8 per 100,000 people per year in males and females (Pal et al., 1999). Senanayake et al. (Senanayake and Romain, 1993) reported a mortality of 6.3% from epilepsy in Ethiopia. Unfortunately, there was no study from Nigeria on the mortality of childhood epilepsy, thus average of statistics on mortality of 7.5 per 100,000 population obtained from previous study was used to calculate the YLLs.

2.4. Data analysis

The children with epilepsy were grouped into two categories: primary and secondary. Those classified as primary were those whose epilepsy had no known cause after both clinical and investigational evaluations, while the secondary epilepsy were those that could be linked to an existing metabolic or structural abnormalities such as microcephaly/macrocephaly, previous history of meningitis, or abnormal reading in electroencephalograph.

The input variables were data on gender, duration, prevalence, and mortality which were inputted in World Health Organization disease-modeling software (DisMod II) for data analysis. Since the study focused on children and adolescents, the outcome was presented in three age groups; 0–4, 5–14, 15–24 years. The duration of epilepsy was the period over which the child has been having epilepsy from its onset to the time seen.

The YLD can be computed based on factor of $I \times DW \times L$ with uniform age weights and zero discounting, where, I represents the number of incident cases of childhood epilepsy in a reference period, DW is the disability weight (0–1), and L is the mean duration of disability (years) (Murray and Lopez, 1996). In this study which was cross-sectional in design, there was no data on incident of epilepsy, and no local literature to provide such information. However, it is assumed that every child with epilepsy suffers some sort of psychological disability, thus we used information in prevalence (in range 4.7–20 per 1000). If prevalence estimates were the basic data used as input to DISMOD for calculation of incidence and duration, these prevalence data should be used directly for the calculation of YLD as follows: $YLD_x = P_x \times DW_x$, where P_x is the number of cases in age group x prevalent at any point in time during the reference period and DW_x is the disability weight (0–1). The

YLD calculation was based on prevalence range of 4.7–20 per 1000 for childhood epilepsy. The disability weights used in this study were obtained from recent large-scale studies that involved international populations to assign the weights to illnesses. According to the updated WHO global burden of disease (GBD) the average disability weight (DW) for epilepsy less than once per month was 0.263 with 95% uncertainty interval 0.173–0.367 (Murray and Lopez, 1996; Salomon et al., 2015). According to the protocol developed by Global Burdens of Diseases (GBD) (Murray et al., 2012a), the severity of disability was weighted between 0 (perfect health) and 1 (equivalent to death). The weight was established, using the person trade-off method. This is essentially comparing the claim of a particular disease on a fixed healthcare budget that is equivalent to that of 1000 healthy people. The severity weights of different disease conditions were ranged from mild to severe disabilities between 0 (perfect health) and 1 (equivalent to death).

The YLL was calculated based on factor $N \times L$, where N is the number of death in a given age group and L is the estimated standard life expectancy of each patient according to age. A death is said to be “premature” when it occurs before the completion of life expectancy age of Japanese female of 85.9 years and 79.3 years for male (Lopez et al., 2006). The Japanese are known to live long. Therefore, life expectancy is taken as the optimal and standard of reference for calculating years lost to death from an illness. Therefore, the difference between this optimal Japanese life expectancy by gender and the year at which death occurred is the year lost to death from that illness.

One DALY is one year of health life lost. Treatment for epilepsy entails diagnosis, treatment of the underlying disease condition and receiving appropriate anticonvulsant medication (Wang et al., 2003).

According to the methods applied in generating GBD data for epilepsy, only primary epilepsies were considered and the secondary epilepsies would have their burden assigned to the underlying causes and in the actual context, the same is applicable in this study. The categorization of the subjects into primary and secondary epilepsy was an effort to identify the children whose root causes of epilepsy were known (secondary) and those of idiopathic causes (primary). The reason for this was to elicit the burden of disease that could be prevented if the underlying disease conditions that caused the epilepsy were identified early and treated. However, the childhood epilepsy burden in this study was an aggregation of both the primary and secondary epilepsy, since the children involved were those whose major on-going health anomaly and the sole reason for visit to the neurology clinic was epilepsy.

According to WHO estimation, the proportions of cases of patient with epilepsy that are receiving treatment for sequel in sub-Saharan Africa, was 0.10 (10 percent) of patient with epilepsy (Meyer et al., 2010; Mbuba et al., 2008).

The principal component analysis (PCA) was used to calculate the socio-economic status (SES) based on ownership of household assets and household weekly spending on food. The households were grouped into four equal SES groups (quartiles): poorest, very poor, poor and least poor.

Table 1

Demographics characteristics and socio-economic status of the pediatric patients.

| Variables | n = 134 | % |
|---|----------------|------|
| Sex | | |
| • Male | 94 | 70.1 |
| • Female | 40 | 29.9 |
| Mean age of patients in years (range) | 6.31 (1–19) | |
| Mean duration of illness in years (range) | 3.56 (0.5–9.5) | |
| Additional diagnosis (n = 52) | | |
| • Cerebral Palsy | 32 | 61.5 |
| • Hydrocephalus | 4 | 7.7 |
| • Post-meningitic neurological disorder | 4 | 7.7 |
| • ADHD | 2 | 3.8 |
| • Tuberous Sclerosis | 2 | 3.8 |
| • Others ^a | 8 | 15.5 |
| Socio-economic status | | |
| • Poorest | 34 | 25 |
| • Very poor | 33 | 25 |
| • Poor | 34 | 25 |
| • Least poor | 33 | 25 |

^a Others: mental retardation, speech defect, congenital blindness.

2.5. Ethical considerations

The University of Nigeria Health Research Ethics Committee gave ethical clearance before the study was commenced. The respondents gave written informed consent before participating in the study.

3. Results

One hundred and thirty four children with epilepsy were studied. There were more males (70.1%, 94/134) than females (29.9%, 40/134) (see Table 1). Their mean age was 6.31 years, with age range of 1–19 years. The average duration of illness was 3.56 years, with range of 0.5 years to 9.5 years. Some 56% (75/134) of children with epilepsy had primary epilepsy, and 44% (59/134) had secondary epilepsy. Among the secondary causes of epilepsy, 61.5% (36/59) had cerebral palsy, 7.7% (5/59) had hydrocephalus, 7.7% (5/59) had post-meningitic neurological disorder.

Table 2 shows that epilepsy caused 1.63 YLLs per 1000 population. The YLDs caused by epilepsy was 0.45 per 1000 population. The DALYs due to epilepsy were 2.08 per 1000 population. Table 2 also shows that 21.6% of overall DALYs, were due to YLD, while 78.4% were due to YLL. The highest burden of childhood epilepsy was in children within the age group of 5–14 years at 2.18 per 1000 people. The YLLs lost for males (1.92/1000) were higher than those for females (1.31/1000), as well, the YLDs lost for males (0.57/1000) were higher than those for females (0.33/1000).

Table 3 shows the difference in DALYs at varied prevalence of childhood epilepsy. The DALYs was highest (2.20) at prevalence of 20 per 1000 and lowest (1.88) at the prevalence of 5 per 1000.

Table 4 shows the distribution of disease burden according to children with epilepsy on active treatment. There was equal YLLs (1.63/1000 population) for both those on treatment and those not on treatment. But the YLDs was higher (0.63/1000 population) among the untreated group, compared to the YLDs (0.27/1000 population) among the treated group. The overall DALYs/1000 was

Table 2

YLL, YLD and DALY lost per 1000 population by gender due to childhood epilepsy in Enugu, Nigeria.

| Age group (years) | YLL/1000 | | | YLD/1000 | | | DALY/1000 | | |
|-------------------|----------|--------|-------|----------|--------|-------|-----------|--------|-------|
| | Male | Female | Total | Male | Female | Total | Male | Female | Total |
| 0–4 | 2.41 | 0.82 | 1.61 | 0.5 | 0.1 | 0.3 | 2.91 | 0.92 | 1.91 |
| 5–14 | 1.77 | 1.58 | 1.68 | 0.6 | 0.4 | 0.5 | 2.37 | 1.98 | 2.18 |
| 15–24 | 1.58 | 1.63 | 1.60 | 0.6 | 0.5 | 0.55 | 2.18 | 2.13 | 2.15 |
| Total | 1.92 | 1.31 | 1.63 | 0.57 | 0.33 | 0.45 | 2.49 | 1.68 | 2.08 |

higher among the untreated group (2.26/1000 population) compared to the DALYs (1.9/1000 population) among the treated group.

Some 56% (75/134) of children with epilepsy had primary epilepsy, and 44% (59/134) had secondary epilepsy. Among the secondary causes of epilepsy, 61.5% had cerebral palsy, 7.7% had hydrocephalus, 7.7% had post-meningitic neurological disorder.

The YLLs lost for children with secondary epilepsy (2.23/1000 population) was higher than primary epilepsy YLLs of 1.07/1000 population) see [Table 5](#). The YLDs lost for primary epilepsy (0.56/1000 population) were higher than those for secondary epilepsy (0.37/1000) population. The DALYs due to secondary childhood epilepsy were 2.6/1000 population, while that from primary childhood epilepsy were 1.63/1000 population.

4. Discussion

The DALYs lost of childhood epilepsy that was found in this study was high. This was higher than the estimated DALYs in a study in rural China ([Murray et al., 2012b; Ding et al., 2006](#)), but lower than what was reported in a study in Kenya ([Ibinda et al., 2014](#)). The difference could be attributed to the all children population studied in this study since most diseases carry large burden when they occur in young population. The YLLs lost to childhood epilepsy was higher among males compared to females. There is no obvious explanation for this finding. Since the conditions: tobacco, alcohol and occupational injury ([Murray and Lopez, 1996](#)), which explain the slightly lower life expectancy observed in males are not obtainable in children. The recent report by institute of health metrics and evaluation reported DALYs of 137.8/1000 for all age groups. The reason for these wide discrepancies could not be ascertained.

The YLDs among the children with epilepsy that were not on treatment was high, but there was no difference in the YLLs between the two groups. Therefore, narrowing of treatment gap for childhood epilepsy by provision and compliance with recommended anticonvulsant drugs, may not significantly reduce mortality associated with epilepsy, but will significantly reduce overall disability associated with childhood epilepsy. This finding is very revealing, especially in sub-Saharan countries, where over the years, disease burden has been based on extent of mortality caused by a disease. The decision by programme managers to implement an intervention often depends on the relative mortality to avert. Although some studies have reported high DALYs among subjects not on anticonvulsant drugs, this high DALYs may be due to high YLDs among the group not necessarily high YLLs and YLDs. Therefore, epidemiologists should understand that improvement in adherence to childhood epilepsy treatment may not adequately

Table 3

DALYs lost per 1000 population at different prevalence of childhood epilepsy in Enugu, Nigeria.

| Age group (years) | DALYs at different prevalence of Epilepsy per 1000 | | | |
|-------------------|--|---------|---------|---------|
| | 5/1000 | 10/1000 | 15/1000 | 20/1000 |
| 0–4 | 1.66 | 1.91 | 1.98 | 2.10 |
| 5–14 | 1.98 | 2.18 | 2.21 | 2.24 |
| 15–24 | 2.00 | 2.15 | 2.22 | 2.27 |
| Total | 1.88 | 2.08 | 2.14 | 2.20 |

be evaluated with change in mortality but overall reduction in the burden of disease; mortality and disability.

The relative contribution of primary childhood epilepsy was lower than that from secondary childhood epilepsy. This is similar to what was reported in a study in Kenya ([Ibinda et al., 2014](#)). This could be due to the fact that children with secondary epilepsy already have extra morbidity with varied severity ([Ibinda et al., 2014](#)). In this study, the common underlying disease among those children with secondary epilepsy were cerebral palsy, hydrocephalus, and post-meningitic neurological disorder. These diseases on their own, have associated mortality and disability.

The limitation to this study was the determination of epilepsy case-fatality rate from literature rather than survey of the population. Since with the recent introduction of highly effective new anticonvulsant drugs, there is likely to be improvement in mortality rate. However, the epilepsy mortality of 7.5 per 100,000 population that was used to calculate the YLLs in this study was very low. Hence even if there would be any further reduction in mortality rate, it would not make any significant change in the outcome of the estimation of YLL. Another limitation is the clinic-based design of the study, this will cause bias towards children with epilepsy that are better catered for compared to what would have been obtainable if the study was population-based. Since many people with epilepsy in low-income countries, especially those that live remotely or are from the lowest socio-economic class will not attend health-care facilities, it is among these groups that some barbaric practices like burning of body parts: hands, feet, or abdomen, are frequently observed and these cause more disability. Thus, higher DALY of all people with epilepsy was covered in the survey. Since among the variables used: the gender, age, whether primary or secondary epilepsy and history of drug, it was only the drug history that can obviously differ if the study was conducted in the community. Also, the mortality due to epilepsy was used in the study because there was no available data on mortality that was not attributed to any known cause to be able to calculate the excess mortality due to childhood and adolescent epilepsy.

Table 4

YLL, YLD and DALY lost per 1000 population due to treated and untreated childhood epilepsy in Enugu, Nigeria.

| Age group (years) | YLL/1000 | | | YLD/1000 | | | DALY/1000 | | |
|-------------------|----------|-----------|-------|----------|-----------|-------|-----------|-----------|-------|
| | Treated | Untreated | Total | Treated | Untreated | Total | Treated | Untreated | Total |
| 0–4 | 0.7 | 0.64 | 0.67 | 0.17 | 0.45 | 0.31 | 0.87 | 1.09 | 0.98 |
| 5–14 | 0.08 | 0.07 | 0.08 | 0.28 | 0.67 | 0.48 | 0.36 | 0.74 | 0.56 |
| 15–24 | 4.11 | 4.17 | 4.14 | 0.35 | 0.79 | 0.57 | 4.46 | 4.96 | 4.71 |
| Total | 1.63 | 1.63 | 1.63 | 0.27 | 0.63 | 0.45 | 1.9 | 2.26 | 2.08 |

Table 5

YLL, YLD, and DALYs per 1000 population due to Primary and Secondary childhood epilepsy in Enugu, Nigeria.

| Age group (years) | YLL/1000 | | | YLD/1000 | | | DALY/1,000 | | |
|-------------------|------------------|--------------------|-------|------------------|--------------------|-------|------------------|--------------------|-------|
| | Primary Epilepsy | Secondary Epilepsy | Total | Primary Epilepsy | Secondary Epilepsy | Total | Primary Epilepsy | Secondary Epilepsy | Total |
| 0–4 | 0.73 | 0.45 | 0.59 | 0.3 | 0.4 | 0.35 | 1.03 | 0.83 | 0.93 |
| 5–14 | 0.05 | 0.08 | 0.07 | 0.7 | 0.4 | 0.55 | 0.75 | 0.48 | 0.61 |
| 15–24 | 2.42 | 6.16 | 4.3 | 0.7 | 0.3 | 0.50 | 3.12 | 6.46 | 4.8 |
| Total | 1.07 | 2.23 | 1.65 | 0.56 | 0.37 | 0.46 | 1.63 | 2.6 | 2.1 |

5. Conclusion

This study highlighted that childhood epilepsy generally has high DALY in Nigeria. There were higher YLDs and relatively the same YLLs among treated and untreated subjects, thus the need to de-emphasize focus on only mortality as an indicator in monitoring drug intervention in the management of childhood epilepsy but rather adopt a holistic approach of considering both the mortality and disability in monitoring the outcome of drug treatment.

Conflicts of interest

The authors declare that there was no conflict of interest.

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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