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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.

1. Introduction

Epilepsy affects millions of people in Africa and most of the cases begin in childhood (Breman 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 cllocation 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 Gazzette, 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 4.7per 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