



Impact of epilepsy on children and parents in Gabon



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ABSTRACT

Children with epilepsy and their parents face many social and psychological difficulties that remain insufficiently studied in sub-Saharan Africa. The aim here was to assess the quality of life of children with epilepsy and their parents.

A community-based cross-sectional survey was conducted in two urban areas and four rural areas of Gabon. Children were screened through key informants, medical sources, and a door-to-door survey. They were clinically selected based on their medical history and a clinical exam conducted by the investigating physician. Electroencephalography had not been carried out because of a lack of material and financial resources. The quality of life of children and their parents was assessed by a structured interview of parents using a questionnaire.

Of 317 suspected cases on screening, 83 children with epilepsy were identified. Their mean age was 11.9 ± 4.4 years. Twelve percent of the children had neurosensory abnormalities on clinical exam. Sixty-three percent of them attended school; factors associated with schooling were higher score on the sociability subscale, specialized medical advice, and antiepileptic drug treatment. Sociability difficulties, anxiety, cognitive impairment, and behavioral disorders were suspected in 39.8%, 45.8%, 49.4%, and 42.2% of children, respectively. A total of 48.2% of parents expressed a poor quality of life related to their children's illness. A higher score on the cognition subscale, urban residence, specialized medical advice, and a stable income in the household were predictive of poor parental quality of life.

Epilepsy influences many aspects of a child's life and the life of the child's parents. Care should incorporate a cognitive assessment of the child and emphasize information for patients and their relatives.

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1. Introduction

Epilepsy is the most common childhood neurological disorder [1]. Approximately half of epilepsy cases occur during childhood [2]. The

Abbreviations: AET, Antiepileptic drug treatment; IENT, Institute of Neurological Epidemiology and Tropical Neurology; ILAE, International League Against Epilepsy; PAANS, Pan-African Association of Neurological Sciences; QOL, Quality of life; QOLCE, Quality of life of children with epilepsy; RERENT, Study and Research in Tropical Neurology Network.

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reported prevalence of childhood epilepsy varies from 3.6 to 4.2 per 1000 in developed countries. In developing countries, the prevalence of lifetime epilepsy is highest in rural areas, whereas that in urban areas is somewhere between the figure seen in rural areas and in developed countries [3]. Exposure to injury or infection or lack of adequate care leads to more cases of symptomatic seizures and explains at least in part the differences between developing rural regions, developing urban areas, and developed countries [3]. People with epilepsy are, like children, more likely than others to report symptoms of depression, anxiety, and behavioral problems worldwide [4,5]. The prevalence of behavioral disorders in children with epilepsy varies from 20% to 60% in developed countries [4,6,7] which is lower than what is reported in sub-Saharan Africa [8,9]. Regardless of region, risk factors for

neurocognitive disorders occurring in association with epilepsy appear to be identical. Most reported risk factors are early-onset seizures, increased seizure frequency, a family history of epilepsy, medication side effects, and polytherapy.

In recent decades, quality-of-life (QOL) scales have been used in evaluating children with epilepsy, their parents, and their interaction. Defining health status on the basis of clinical and biomedical criteria does not describe the burden of physical illness on children [10]. Hence, health-related QOL is an important health outcome parameter in the management of chronic diseases such as epilepsy. Western QOL scales assess specific areas of neurological, cognitive, and psychological comorbidities related to the experience of chronic disease. Some scales are synthesized from others in order to adapt them to wider neurocognitive assessment in different age groups and offer simultaneous evaluation of children and their parents and siblings [9]. Certain of these scales have been validated in some sub-Saharan African countries, but they are still scarcely used given the number of studies assessing QOL in this region [8,9,11,12].

Like many developing countries, Gabon is characterized by a lack of neurologists, uneven distribution of human resources and equipment between urban and rural areas, scarcity of epidemiological data, and the absence of national guidelines on epilepsy treatment. Awareness of the experiences faced by children with epilepsy and their parents may help with the implementation of initiatives to promote health. The aim of the present study was to assess the QOL of children with epilepsy and their parents in Gabon.

2. Materials and methods

2.1. Study sites

The study was conducted in six localities in Gabon, two urban (the third Libreville borough and Mouila) and four rural (Nende, Lebamba, Moabi, and Mayumba), all randomly selected. The Gabonese population is around 1.6 million, mostly urban (85%). Over 42% of the inhabitants are under 18 years of age. Life expectancy at birth is 63 years. Gross enrollment rate in primary school is around 94%. Adult and youth literacy rates are 88% and 99%, respectively [13]. The third borough of Libreville has 160,000 inhabitants and is home to the Central University Hospital of Libreville (CUHL), a referral hospital for a medical center, and two clinics. The district has 20 primary schools and four secondary schools. Mouila, the fifth largest city in Gabon, has around 30,000 inhabitants and contains a regional hospital and a medical center. The medical staff consists of a surgeon, an obstetrician/gynecologist, a pediatrician, six general practitioners (GPs), midwives, nurses, and a senior psychiatric nurse. Mouila has eleven primary schools and six secondary schools.

The four rural communities – Lebamba, Ndende, Mayumba, and Moabi – have populations of 8000, 6000, 3600, and 3200, respectively. Each locality has a public medical center run by a GP (with the exception of Moabi where there is no GP). Lebamba has (in addition to the medical center) the Evangelical Hospital Bongolo run by American missionaries. Lebamba has six primary schools and two high schools. Each of the other three localities has four primary schools and one high school.

2.2. Participants

We used the International League Against Epilepsy (ILAE) epidemiological definition of epilepsy: two or more unprovoked afebrile seizures occurring within 24 h in the absence of an acute underlying cause [14].

We conducted a population-based cross-sectional survey among children with epilepsy 18 years of age or less and their parents or custodians. Children who had only experienced neonatal seizures, febrile seizures, or an isolated episode of seizures were excluded. The study was carried out from January to October 2013 in two steps: screening and the selection of cases with childhood epilepsy.

Screening made use of three sources of information:

- medical sources consisting of hospital records and physicians' own records. We checked the medical records available in hospitals and medical centers covering the past 15 years. All children consulting for seizures were identified.
- nonmedical sources included teachers and traditional and religious leaders. Traditional healers not previously recognized as such were not used as informants. We met heads and teachers of all schools, religious leaders, and traditional leaders and asked them to report cases of children who had experienced episodes of seizures or loss of consciousness at school and those whose parents had reported similar events occurring at home.
- a door-to-door survey was conducted by fieldworkers recruited from among health personnel, volunteers from the Gabonese Red Cross (GRC), and community workers from the local municipalities at each study site. The screening questionnaire for epilepsy in the tropics designed by the Neurological Institute of Epidemiology and Tropical Neurology, University of Limoges, France, was used to detect children with epilepsy [15,16]. Before starting the survey, fieldworkers underwent 8 h of training. The survey questionnaire was not translated into local languages. We explained each question by searching synonymous keywords in local languages so that each fieldworker understood the questionnaire and were able to administer the questionnaire in French and in the local language to the population. In each household, we noted the name of the head of household, the telephone number, the number of people, the number of children, and the number of children 18 years of age or less. The screening questionnaire for epilepsy in the tropics was then administered [15].

To select cases, the GP met children with suspected epilepsy in their respective households in the presence of their parents. Parents and/or children were interviewed to collect their family history and the history of the disease, and then the children were examined. Additional information was obtained from the previous health records when available. At the end of the clinical examination, the survey questionnaire on the quality of life of children and parents was completed by interviewing the parents. The selection of children with epilepsy in the community is described in Fig. 1.

2.3. Measures

2.3.1. Screening questionnaire

The screening questionnaire for epilepsy in the tropics was developed in collaboration with the Study and Research in Tropical Neurology (RERENT) network with the support of the committee on tropical diseases of the International League Against Epilepsy (ILAE) and the Pan-African Association of Neurological Sciences (PAANS) [15]. The questionnaire has four objectives: to screen people with epilepsy, to describe clinical forms of epilepsy, to identify etiologies of epilepsy, and to assess treatment for epilepsy. It consists of nine modules, one or more of which may be used independently in a survey. We used the screening module, which had already been validated in a tropical environment [16]. The screening questionnaire is shown in Appendix 1 and 2.

2.3.2. Parental quality-of-life assessment

We used a quality-of-life assessment questionnaire derived from the synthesis of other scales after a French study on quality of life that used a questionnaire with tools for parent assessment [17]. The adaptation was obtained from several scales including Herranz and Casas' scale, Hoare and Russell's scale for the impact of disease, Goodman's psychosocial and behavioral questionnaire, Achenbach's Children Behavior Checklist, and Goyette's questionnaire [18–22]. After analyzing all parents' responses, they found several items in the "Quality of Life in Children

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