School Status and its Associations among Children with Epilepsy in the Republic of Guinea

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I have reviewed this thesis. It represents work done by the author under my supervision and guidance.
# Table of Contents

Acknowledgements............................................................................................................... 3  
Abstract................................................................................................................................ 4  
Glossary................................................................................................................................... 6  
Introduction............................................................................................................................ 7  
  Education in Guinea............................................................................................................. 7  
  Education and Epilepsy in Sub-Saharan Africa................................................................. 8  
  Research on Epilepsy in Guinea.......................................................................................... 10  
  Current Study and Rationale............................................................................................... 11  
Methods.................................................................................................................................. 11  
Results.................................................................................................................................... 15  
Discussion.............................................................................................................................. 17  
Summary of Work.................................................................................................................... 23  
References............................................................................................................................... 24  
Tables and Figures..................................................................................................................... 28  
Appendices............................................................................................................................... 34  
  Appendix 1: English survey forms (reference only).......................................................... 34  
  Appendix 2: French survey forms...................................................................................... 44  
  Appendix 3: Logistic regression between wealth and school drop-out......................... 54
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Abstract

**Background:** In low income countries, more than 90% of epilepsy occurs in people younger than 20 years old. In this population, epilepsy can negatively affect education attainment. We sought to examine modifiable associations with poor school performance in children with epilepsy (CWE) in the Republic of Guinea.

**Methods:** US and African doctors performed a cross-sectional study at Ignace Deen Hospital in Conakry, Guinea in August and September of 2018. CWE were given surveys, examined by a physician, and administered the Wechsler Nonverbal Scale of Ability (WNV). Surveys included information about epilepsy history, household financial information, educational history of the child and family, and the Stigma Scale of Epilepsy (SSE). We performed four logistic regression models looking at associations between high performing (defined as going to school and having never been held back) or a low performing (defined as having either dropped out of school or been held back at least once) students. The four models each examined a different potentially modifiable variable--life time seizures, WNV score, SSE score, and household finances respectively.

**Results:** Of the 128 CWE (mean age 11.6, 48.4 %F), 11.7% (n=15) had never attended school, 23.3% (n=30) previously attended school and had dropped out, and 64.8% (n=83) were currently in school. Of CWE currently attending school, approximately half (46.9%, n=39) had been held back a grade level at least once, 53.0% (n=44) had never been held back. More than 100 lifetime seizures (OR=8.81; 95% CI=2.51-37.4; p=0.001) and lower total WNV score (OR=0.954; 95% CI=0.926-0.977; p<0.001) were significantly associated with poor school performance when controlling for potential confounders. Models examining the SSE and household wealth quintile were not significantly associated with school outcome. We subsequently modeled the number of CWE who could become “high performing” if their seizures were treated to achieve a lifetime seizure burden of <10. In our model, 38 additional CWE (33.6%) could become high functioning at school if all CWE were treated to the lowest lifetime seizure category of <10 seizures. This would bring the total percentage of the “high performing” children from 38.9% (n=44) to 72.6% (n=82).
**Conclusions:** School performance was negatively impacted by epilepsy in our sample. Over 10% of individuals had never attended school, over 20% had dropped out of school, and of those currently in school more than 40% had been held back at least once. Fewer lifetime seizures and poorer cognitive performance were significantly associated with school performance in CWE in Guinea. We provide evidence that seizure control could improve school performance in this low-income setting.
Glossary of Abbreviations

Anti-epileptic drug (AED)
Children with epilepsy (CWE)
Confidence Interval (CI)
Low income country (LIC)
Odds ratio (OR)
Stigma Scale of Epilepsy (SSE)
Sub-Saharan Africa (SSA)
Weschler Nonverbal Assessment of Ability (WNV)
**Introduction:**

More than 90% of people with epilepsy in low income countries (LICs) are younger than 20 years old (1). Given that 80% of the epilepsy world-wide occurs in LICs(2), this means that nearly all of the world’s epilepsy is occurring in children in these countries. The reasons for such high rates of epilepsy are multifactorial and include high rates of central nervous system infections, peri-natal injuries, and other head injuries (3). For these children with epilepsy (CWE), there are numerous results of their illness. Access to medications and proper treatment is difficult (4), which leads to increased morbidity and mortality (5). In addition to medical effects, epilepsy may lead to long term social consequences with some studies showing decreased employment (6), decreased lifetime earnings (7), and decreased marriage rates (6).

A potential mediator between epilepsy and long term social and economic effects is education. In Sub-Saharan Africa (SSA), home to more than 800 million people, access to primary school is already challenging for many children due to absolute poverty, armed conflict, and a variety of other socioeconomic and political factors. It is likely that children with a lifelong neurological condition such as epilepsy would have additional barriers to those that already exist in Sub-Saharan Africa. Among CWE in SSA, school attendance and performance are under-studied but attending school may be the only opportunity for individuals to break the cycle of poverty in which they find themselves.

While there is limited research on education in CWE in SSA, the research that exists shows substantial obstacles. CWE in SSA have increased rates of school dropout, more missed days of school, and decreased participation in extracurricular sports (8,9). We sought to examine modifiable factors and their association with poor school performance in the Republic of Guinea, a country of 12.7 million people located in West Africa (10). The purpose of our study was both to better understand barriers to education in CWE and create targets for future interventions. We will begin by giving a brief overview of the educational system in Guinea, followed by a review of the literature on epilepsy and education in SSA. We will finally review the limited research on the epidemiology of epilepsy within the Republic of Guinea.

**The Educational System in Guinea**

Due to the changes in government, Guinea has had several different schooling systems over the last century (11). The present instructional system has been in place since approximately 1984 (11). In Guinea, schooling begins at the age of 3 years with *enseignement*
**préprimaire** (essentially preschool) (12). **Préprimaire** is not mandatory and does not receive government funding. Beginning at age 7, education receives public funding and becomes mandatory. From this point academic instruction is broken down into **enseignement primaire** (primary--ages 7-12), **collège** (secondary--ages 13-16) and **lycée** (advanced secondary--ages 17-19). Since 1984, French has been the primary language of instruction in school in Guinea, though many children continue to speak national languages at home (13).

While schooling becomes partially funded by the government starting with primary school (**enseignement primaire**), there remain a significant proportion of remunerations that are left to parents. Most schools require monthly fees from parents, and parents are expected to pay for uniforms, meals, and transportation (11). These expenses may contribute to the fact that despite primary school technically being mandatory, for many years a large number of Guinean children still could not attend (14).

Guinea has made great advances in education in recent years. In 2005 the World Bank estimated that only 79.2% of children attended primary school (14). By 2014, that number had increased to 93.9%. However, many challenges remain for the country. Despite the high rates of primary schooling, only 40.3% of children were reported to attend secondary school (**collège**) in 2014. Moreover, the country continues to have a low literacy rate—with only 22% of women over 15 and 44% of men over 15 being considered literate in 2014. Consequently, education policies continue to be challenging in Guinea.

**Research on Education and Epilepsy in Sub-Saharan Africa**

There is very little prior research on the effects of epilepsy in Guinea. Therefore, a review of research in other sub-Saharan African countries is included to assess findings in similar countries on some of the issues that we considered in our study.

Most of the research examining the interaction between epilepsy and education in sub-Saharan Africa has investigated the attitudes and perceptions of epilepsy in school teachers. Multiple surveys of teachers in Nigeria found that misbeliefs about epilepsy are common (15–18). As an example, 46% of urban and 61% of rural teachers thought that epilepsy was contagious, with most citing foaming from the mouth as the contagious agent (15). In a different study, 60% of Nigerian school teachers thought that CWE should be separated from non-epileptic children in a classroom (17). Other studies examining teachers' beliefs have been done in Ethiopia showing similar misperceptions (19,20).
There have been few studies investigating barriers to education from the perspective of children and their families. Understanding which factors are most significant from the standpoint of CWE is essential, as this would be extremely valuable for targeting future interventions. To our knowledge, only five such studies in sub-Saharan Africa exist.

In 2014, Ali et al. performed a descriptive study in Sierra Leone in which researchers performed a cross sectional structured interview of 50 CWE along with their caregivers and teachers (8). Most CWE reported some way in which epilepsy had impacted their education. 36% of CWE reported feeling negative attitudes from their classmates. More than 50% missed more than 5 days of school per month, and 90% did not participate in sports. Within the study, rates of school dropout were 20%. CWE self-reported that seizure frequency, pressure from teachers, and learning disabilities had caused them to drop out. In a statistical analysis, daily seizures, low parental literacy, and poor interactions with classmates were significantly associated with school dropout.

Two studies in the Hai District, in rural Tanzania, have been done. The first, conducted by Mushi et al. in 2013, consisted of structured interviews of 38 caregivers of CWE (21). While the study did not specifically focus on education, it was one of the key themes that came up during the interviews. In this study half of the children did not attend school regularly. Reasons for difficulty attending school were established through self-report and included poor seizure control, learning difficulties, and behavioral problems.

A second study in Tanzania, by Querishi et al., involved structured interviews of 19 CWE and 17 caregivers of CWE (9). In contrast to the study by Mushi et al., these structured interviews were designed to focus specifically on effects of epilepsy on education. The most common factors cited as affecting schooling were learning and behavioral problems. Less common factors that were mentioned included physical disability and lack of affordable and well-located specialist schools. Notably two children in this study reported that their fathers had prevented them from going to school, despite the fact that the mothers and the CWE wanted to attend.

Two population-based studies have been done. A cross sectional door-to-door survey in Gabon was primarily designed to look at factors affecting quality of life for CWE (22). In their sample 63% (n=51) of school age CWE were currently in school. Reasons cited for leaving school included comorbidities (11.1%), parental pressures (13.6%), and school refusal or expulsions (12.3%). In statistical analysis they found that CWE who remained in school were
more likely to have high sociability scores, take anti-epileptic drugs (AED), and have been seen by a medical specialist. Attending school was also associated with an improved quality of life for both CWE and their parents.

A second population-based study, using surveys, in rural Kenya, found that 50% of CWE did not attend school regularly (23). In bivariate analysis higher seizure frequency and cognitive impairment were associated with worse school attendance. Of note, this study took place in one of the poorest regions of Kenya, where literacy is overall thought to be low among the population (23).

These studies vary significantly from the other three in two ways. First, both Gabon and Kenya typically rank higher on development scales than Tanzania, Sierra Leone, or Guinea. In the 2018 United Nations Human Development Report, Gabon was rated as “high development” and Kenya was rated as “medium development” whereas the other three countries were rated as “low human development” (24). Second, as both of these studies are population based, this likely makes their sample of CWE more generalizable.

There are several limitations to these studies. First, both of the studies in Tanzania are entirely descriptive in nature. This limits the degree to which we can make claims about the degree of associations between their findings. The other three studies did perform a statistical analysis on their findings. Ali et al. and Munyoki et al. performed only bivariate analyses and did not control for any potential confounders. Ibinga et al. had only had 81 children who were of schooling age (51 attending school and 30 not attending school). This limits the validity of their results, especially given that they included 12 predictors in their linear regression model, which is inappropriate for this sample size.

Prior research on Epilepsy in Guinea

Despite a high rate of epilepsy in Guinea, there is limited prior research. A 2018 study from the Guinea Epilepsy Project showed 72% of the cohort, (which was comprised of more than 50% children), had poorly controlled epilepsy, defined as at least one seizure in the prior year in people with diagnosed epilepsy (25). 59% of their sample had more than 100 lifetime seizures. Seizure related injuries were common with 22% of children experiencing a head injury and 10% experiencing a burn. Only 52% of their sample was taking an anti-epileptic drug, and they noted non-adherence was common. Of note, this study found that 30% of school age children were not in school, which was higher than the national average.
Aside from this single study, our knowledge of epilepsy in Guinea stems from epidemiological studies from neighboring regions in SSA. In these regions, similarly, treatment is fragmented leading to poor epilepsy control and many co-morbidities (1).

Current Study and Rationale

As part of the Guinea Epilepsy Project, we performed a prospective study on factors affecting education in CWE in Guinea. We hypothesized that four main patient-focused factors would relate to a child’s ability to attend and perform well in school: seizure control, cognitive ability, household finances, and perceived stigma. Our primary aim was to better characterize which factors were directly associated with poor school performance and drop out in CWE while controlling for potential confounders. We additionally wanted to identify which of these factors would be potentially modifiable to avoid missed opportunities for CWE in Guinea and similar SSA settings.

Methods

Ethics Approvals: This study was approved by the institutional review board at Ignace Deen Hospital in Conakry, Republic of Guinea and by the Partners Healthcare Inc. institutional review board at the Massachusetts General Hospital in Boston, USA. Informed written consent was obtained from children and their parents in French. For participants whose primary language was not French, verbal translation into the native language of choice by multilingual study staff was performed. The other most commonly spoken languages were Susu, Malinke, and Pular. Thumbprint was used in the place of signatures for low-literacy parents when needed. Mature children provided assent as well.

Setting: Guinea is a West African country of 12.7 million people, with an average life expectancy of 60 years in 2017(10). Until 1984, Guinea had a mostly socialized healthcare system with nearly no out-of-pocket healthcare payments by patients(26). A variety of influences, including the Bamako Initiative in 1987, led to increased privatization of healthcare(27). While this was partially in an effort to increase the country’s access to essential medications, today 93% of healthcare is outside of the public sector and most healthcare involves significant patient out of pocket co-payments(28). The Ignace Deen Hospital is one of three national hospitals in Guinea and is located in the capital city of Conakry. The hospital has a
neurology department with 4 faculty neurologists and a postgraduate residency program. All enrollment for this study was performed in August and September of 2018 in collaboration with a team of physicians at the Ignace Deen Hospital.

**Participants:** Study participants were identified by physicians at Ignace Deen Hospital when they were clinically evaluated at the Ignace Deen Hospital and kept on a study register. People with epilepsy throughout Guinea were also invited to self-refer to the study through advertisements on local and national radio and television. The study was advertised as a general study on epilepsy, and not as a study related to schooling or cognition. Children within 1 month of 4 to 19 years of age were eligible for enrollment in this study. Epilepsy was defined as the occurrence of two or more unprovoked seizures, at least 24 hours apart. Each child was evaluated by at least one U.S. neurologist as well as at least one African neurology resident and/or neurologist. Children with exclusively febrile seizures, pseudo-seizures, or other episodic or behavioral events in the absence of epileptic seizures were excluded. Participants also had the option to receive a formal consultation for treatment recommendations by the neurologist and free antiepileptic drugs. Customary hospital entrance fees were waived by the hospital in order to reach participants who lacked the ability to pay out of pocket expenses. Each participant or parent was reimbursed a total of 100,000 Guinean francs (approximately 12 USD) for travel reimbursement at the time of study completion.

**Interview:** Children were interviewed with a parent or caretaker. Older teenagers who presented alone were interviewed on their own. Participants were interviewed in their native language through a physician translator. Children and/or their next of kin, most often a parent, were interviewed using structured questionnaires on their epilepsy and medical history, school experiences, family educational history, and personal finances. Survey instruments are available as Appendix 1 (English, for review purposes only) and 2 (French)). Areas of particular interest in the education domain were determined through a review of studies of epilepsy’s effect on education reported from nearby African countries(8,21). Quality control on all survey responses was performed by U.S. based study staff. Participants with missing, inconsistent, or out of range responses that were time sensitive (i.e. seizures within the last month) were called for clarification by the African team within one month of the enrollment time. Responses that were not time sensitive (i.e. parental education level) were confirmed within 4 months of enrollment.
Cognitive Assessment: Children were given the 2-scale version of the Wechsler nonverbal assessment of ability (WNV)(29). This test was chosen because of its intent to be applicable in cross cultural settings. It does not rely on language. The WNV has been validated in non-English speaking populations in the United States(29) and used in other studies internationally including in the Democratic Republic of the Congo(30) and Malaysia(31). The 2-scale version of the test was administered by a U.S.-based investigator according to the administration directions, with children over 8 years old performing Raven’s matrices and spatial span task and children under 8 years old performing Raven’s matrices and a recognition task. For the spatial span task, a series of blocks was tapped in a particular order. In part 1 (forward span), children had to tap the blocks in the same order as the examiner. During part 2 (backwards span) the children had to tap the blocks in the reverse order as the examiner. A forward span, backwards span, and total span score was generated. Each test increased in difficulty with each level passed. Tests were scored according to the age- appropriate norms. A composite score based upon the 2-scale version was generated according to the standardized norms. As children in the pilot phase of the study in Guinea repeatedly had difficulty understanding the pictorial instructions without verbal instructions, the task was explained to all children in French or their native language. Children were tested in an office at Ignace Deen Hospital by a U.S. based examiner with a native French speaker to translate when necessary. Noise and distractions were minimized through closing the doors, however as there were two testing stations in the room and the hospital is overcrowded, some ambient noise was present during testing.

Stigma Evaluation: Parents and children were administered the Stigma Scale of Epilepsy (SSE)(32). This is a 24-question survey that has been validated to assess stigma and used in numerous international settings. Each question was scored on a scale from 1 (not at all) to 4 (totally). All questions were translated into French by a local francophone. The SSE was scaled based upon the total number of questions answered on a total scale from 1 to 100% with 100% implying worse stigma according to the scoring system used in the original validation study(32).

Financial Survey: Children’s guardians were given a financial questionnaire using the Demographic and Health Survey model household assets questionnaire(33) These questions are intended to assess total household wealth by the United States Agency for International
Development (USAID). They assess different aspects of daily living, including electricity, housing, possessions, and access to drinking water. Questions were analyzed for participant variation across the cohort. After assessing each item for variation, it was found that questions regarding water source, toilet, bank account, electronics, transportation, and mosquito net use had significant variation across the sample. Items including cart use, electricity, telephone and boat were dropped due to the lack of variation across the sample. Participants were given a score for each item, which was ranked from lowest to highest value in ascending order. Then, polychoric principal component analysis was performed on all of the ordered and ranked asset covariates to extract a single principal component which was called “wealth score.” Participants were divided into quintiles across the sample based upon their wealth score.

Analysis: Variables of interest were described according to their mean and standard deviation for normally distributed variables or median and interquartile range for non-normal distributions. Outcomes of interest were displayed graphically to determine the distribution of the responses. For the WNV assessment, raw cognitive test scores were age adjusted by converting them to a t-score using the standard study scoring manual(29). T-scores on the two sub-tests were combined for a composite full WNV test score.

The sample was dichotomized into “high performers,” those who had attended school and had never been held back a year of school, and “low performers,” those who had either dropped out of school or been held back from at least one grade at least once. Logistic regression models were constructed with school performance status as the primary outcome variable. Directed acyclic graphs were drawn independently for each model to select potential confounders to include in each model. Four models were analyzed: one for each primary explanatory variable of interest (lifetime seizure estimate, WNV score, stigma score, and familial wealth status). A p-value of 0.05/4=0.0125 was used to correct for multiple comparisons in the method of Bonferroni.

All statistical calculations were conducted using the programming language R (Vienna, Austria).
Results:

134 children in the appropriate age range presented to the Ignace Deen Hospital during the study enrollment period and received the WNV assessment by study investigators. Of them, 3 were excluded for concerns for non-epileptic spells based upon a U.S.-based neurologist’s evaluation. Three additional children were excluded because their study files went missing after the visit. The final sample included 128 CWE participants (Figure 1). The mean age was 11.6 years (standard deviation 4.54 years). The sample was 48.8% (n=63) female. Other participant characteristics are summarized in Table 1.

Epilepsy Characteristics.

68.8% (n=88) of CWE had poorly controlled epilepsy (defined as at least one seizure in the prior 3 months). 80.5% (n=113) had seizures associated with loss of consciousness, and most likely representing generalized seizures. Two were noted to have partial seizures consistent with Benign Rolandoic Epilepsy with Centrottemporal Spikes. One had staring spells consistent with absence epilepsy. 61.7% (n=79) were taking an AED and 37.5% (n=48) had head imaging. The most common AEDs taken were phenobarbital 17.2% (n=22), carbamazepine 19.5% (n=25), and valproic acid 19.5% (n=25) (Table 2).

School Status

Of the 128 CWE, 11.7% (n=15) had never attended school, 23.3% (n=30) previously attended school and had dropped out, and 64.8% (n=83) were currently in school. Reasons for dropping out of school or never going to school are reported in Table 3. Of CWE currently attending school 46.9% (n=39) had been held back a grade level at least once and 53.0% (n=44) had never been held back. Due to the small sample size for children who had never attended school, and our observation that many of the children in this small sample had severe cognitive and attentional issues that would preclude them from attending school including neurodegenerative conditions from inborn errors of metabolism and epileptic encephalopathies, we excluded them from further analyses. The most common reasons cited for never attending school were parental pressure 46.7% (n=7) and developmental delay 46.7% (n=7). The most common reasons cited for dropping out of school were fear of injury 46.7% (n=14). Reasons for never attending school and dropping out of school are in Table 3. Baseline characteristics of children who never attended school are reported in Table 4.
High and Low Academic Performers

There were 38.9% (n=44) high performing children and 61.0% (n=69) low performing children. High performing children were a median age of 9.91 years old (25th, 75th percentile 7.19-14.92 years), 52.3% (n=23) female, and 59% (n=26) were on an antiepileptic drug. Low performing children were a median of age of 12.24 (25th, 75th percentile 9.64-16.14), 47.8% (n=33) female and 69.6% (n=48) were on an anti-epileptic drug. High performing students also reported on average a higher class rank and lower class difficulty than low performing students (median rank “above average” vs. “average”; average difficulty “not very difficult” vs. “sometimes difficult” for high and low performing students respectively). Descriptive statistics of high and low performing children are in Table 4. School experiences of high and low performing children are in Table 5. Since high performing children were younger than low performing children, age was adjusted in subsequent regression analyses.

Multivariate Analysis:

We constructed four models to look at our hypothesized explanatory variables of interest. Model 1 looked at the association between total seizures and school performance, controlled for current age and household wealth quintile. Model 2 looked at the association between the WNV score and school performance while controlling for current age, parental educational level (highest level of schooling of the most educated parent), and time of the child’s most recent seizure. Most recent seizure was chosen rather than total lifetime seizures for this model because it was hypothesized to more directly impact how children had performed on cognitive testing. Model 3 examined the association between stigma and school performance while controlling for age, parental educational level, WNV score, and total lifetime seizures. Model 4 examined the association between family wealth quintile and school performance while controlling for age, parental education, and total seizures.

In model 1, having greater than 100 total lifetime seizures was significantly associated with poor school status while controlling for age and wealth quintile (odds ratio (OR)=8.81, 95% CI=2.51,37.41, p=0.001). Having between 50-100 seizures did not meet our threshold after Bonferroni correction (OR=6.56, 95% CI=1.44,35.75, p=0.020). In model 2, total WNV score was significantly associated with school performance. Individuals who scored worse on the WNV more likely to perform poorly in school (OR=0.954, 95% CI=0.926,0.978, p<0.001). In
models 3 and 4, neither stigma (OR=0.993, 95% CI 0.957-1.029, p=0.693) nor wealth quintile (OR=0.846, 95% CI 0.586-1.212, p=0.364) were significantly associated with school performance (Table 6).

Additional analyses were performed with the outcome of school dropout versus attending school (Appendix 3). CWE from wealthier families were less likely to drop out of school.

Given the impact of seizure control on school performance and the missed opportunity for seizure control in Guinea compared to higher income settings, we used model 1 to estimate the number of CWE who could become “high performing” if their seizures were treated to achieve a lifetime seizure burden of <10. Based upon our regression predictions, 38 additional CWE (33.6%) could become high functioning at school if all CWE were treated to the lowest lifetime seizure category of <10 seizures. This would bring the total percentage of the “high performing” children from 38.9% (n=44) to 72.6% (n=82).

Discussion

Our study shows that educational challenges are common for CWE in Guinea. Over 10% of the CWE in our study had never attended school, over 20% had dropped out of school, and over 40% of those who were still attending school had been held back at least one grade once. This suggests epilepsy remains a large barrier to childhood education in this SSA setting. One of the Millennium Development Goals determined by the United Nations was universal primary school education by 2015(34). This study suggests that epilepsy may be a significant barrier to this milestone in SSA.

Specifically, our study demonstrates that more lifetime seizures and poor cognitive test scores are associated with poor school performance in epilepsy. Multiple other studies in sub-Saharan Africa have reported that learning difficulties and poor seizure control lead children to drop out of school(8,9,21–23). However, due to a larger sample size, we have been able test this hypothesis while controlling for other variables. We hypothesized that a higher total lifetime seizure count leads to poorer cognitive performance and therefore worse school performance. However, it is also possible that underlying cortical dysfunction leads to both seizures as well as cognitive impairment. If the latter scenario is true, treatment with AEDs would be less powerful at preventing poor school outcomes.

Overall our full sample performed very poorly on the WNV, with percentile scores ranging from <0.1 to 58. The WNV was chosen because it is designed to be a culturally
sensitive test that does not rely on speaking any particular language. Though it has been used in other international settings(30,31), the overall poor performance of our sample questions whether this test is valid in a Guinean population. The study was advertised as a study of EEG and epilepsy, and CWE were only informed of cognitive testing during the consent process, making it unlikely that we obtained a sample selected for greater cognitive impairment. As we did not test any children without epilepsy, it is difficult for us to assess whether how children without epilepsy would perform on the test. Still, our results are similar to another study of CWE in sub-Saharan Africa(30). In a 2018 study in the Democratic Republic of the Congo, 73.3% of their sample had a WNV total raw score of less than 70, which corresponds to the first percentile. Using the same criteria, 72.4% of our sample would have a WNV less than 70. Thus, though the percentile may not be reflective of the full SSA population, the observation that the WNV seems to be consistent across populations in the region and correlates with success in school would suggest that it is an acceptable measure of cognition in this population.

Unlike prior studies we did not see an association with increased stigma. Interestingly, all of the prior studies that found an association with stigma evaluated reasons for school drop out by self-report through structured interviews(8,9,21). Our study differs in that we use a validated stigma scale and attempted to find associations with poor school performance rather than relying on patients’ perceptions. The mean stigma score in our sample was 51.07 (SD=14.51), which suggests that our sample was experiencing moderate stigma overall. This moderate degree of stigma, however, did not vary based upon school performance status.

There was no significant association between wealth quintile and poor school performance. While to our knowledge, prior studies have not examined this, one would expect that poverty, independent of epilepsy, would negatively affect access to education. A subset of 77 participants responded to questions about their monthly expenditures on school. In this subset of our sample school cost on average of 122,527 Guinean Francs per month—or about under $13.50. Given that the school year is 9 months, and the average gross national income in Guinea was $800 in 2017(35), this comprises a large portion of family finances. Of note, when children were grouped by school drop-out status (dropped out or not), wealth quintile was statistically significant. This suggests that, of the children who are struggling in school, only wealthier families are able have them continue to attend school.

We did not observe any differences due to gender. Girls comprised 52.3% of high performing CWE and 47.7% of low performing CWE. Gender was not a primary variable of interest, since
we did not expect gender to be in the causal chain through which epilepsy negatively affects school performance. However, this finding was still surprising given that there is a large gender gap in education in Guinea. In 2014, the most recent reported year, the World Bank published a female-to-male ratio of completion of lower secondary school in Guinea as 0.66 (36). In contrast, the mean female-to-male completion rate in other low-income nations was 0.82 that same year. This may represent the fact that our sample predominantly came from Conakry and therefore may have come from more educated families than average for Guinea. Alternatively, it may represent the fact that in this population, severe epilepsy and cognitive deficits, which would likely not vary by gender, overshadow the gender disparities that occur at baseline throughout the country.

While 61.7% of our sample was on AEDs, we did not control for this in our analyses. The majority of CWE were on sub-therapeutic doses of anti-epileptic drugs that were doing little to control their epilepsy. This percentage of treated epilepsy is likely higher than the average for Guinea as some of these individuals had been started on AEDs during a prior trip of our group. Specifically, while levetiracetam is not typically available in Guinea, 12.5% (n=16) of our sample was taking it.

**Limitations**

Our study has several limitations. First, our study sample is not population based since it was more urbanized than the population of Guinea in general. 72.6% (n=82) of the participants included in our analysis were from Conakry, the largest city in Guinea which is home to just 15.8% of the total Guinean population(37). According to the World Bank’s 2014 data, 93% of children in Guinea are enrolled in primary school(10). However, children in urban environments, such as Conakry, are more likely to attend school (37). In addition to changing the prevalence of schooling, it is possible that certain factors that might be more important for education in a rural environment, such as stigma, were less important in our sample. We attempted to make our sample more representative of Guinea as a whole by advertising on national radio and television; however, our location in Conakry and in a hospital likely biased our sample to more urbanized patients.

Second, our population may have tended towards having more severe epilepsy and worse seizure control, given that patients were presenting to a major health center. CWE who had well-controlled seizures may have had less motivation to present to a research study. As the only
prior studies of epilepsy in Guinea are from our center, we cannot compare our patients' epilepsy characteristics to any other known epidemiology of epilepsy in Guinea.

Similarly, our sample included many etiologies of epilepsy. Due to the lack of prior usable medical records and limited access to EEG, it was impossible to consistently make a confident syndromic diagnosis in all cases, despite the fact that all patients were seen by both a U.S.-based neurologist and a Guinean neurology resident or neurologist. It was beyond the scope of our study to perform head imaging and laboratory testing in each participant, although clinical data and histories were carefully recorded. Nearly all patients had generalized seizures with loss of consciousness; patients with only staring spells (i.e. absence seizures) would be anticipated to perform better than other epilepsy syndromes, but these cases were infrequent in this cohort. Only 2 individuals were noted to have focal seizures possibly representative of Benign Epilepsy with Centrotemporal Spikes and only one child was noted to be having staring spells most likely consistent with absence epilepsy, though even this patient had a remote history of generalized seizures as a young child. Still, as we did not have full EEG data, our characterization was based solely on patient report. This is a limitation of all of the prior education in epilepsy research in West Africa and is important to explore in future studies.

Additionally, while we had a larger sample than most prior studies, we did not have a large enough sample to stratify by age. We examined our sample across all school age groups. It is possible that there are different factors influencing education at different age levels. Future research should investigate factors based upon age, which would better allow us to appropriately target interventions. Furthermore, recruiting children at the age of entry to school (between 4 and 7 years) would allow us to both intervene and observe factors affecting education early on when interventions would likely have the greatest impact.

Our study used a self-reported measure of school performance—a combination of self-reported school drop-out and being held back. We selected these measures as we thought they would be objective measures that could be understood accurately through self-report. It is possible that parents wanted to either inflate or deflate their child’s degree of education and exaggerated degree of success or impairment in school. Reassuringly, self-reported school difficulty and rank are consistent with our performance categorizations. This suggests there is internal consistency within our sample.

We performed participant-level quality control of our data. During this process, we realized that there may have been some misunderstandings regarding questions about school
status in our CWE participants due to Guinean schools being on vacation while we were collecting data. We called all participants who seemed to have discordant answers on their questionnaire clarify their answers. However, it is possible that there were other misunderstandings that we were not able to identify, or that we inadvertently overlooked a participant who had misunderstood the questionnaire.

A final limitation to our study that parents and children responded to the questionnaires together. This inconsistency could have added noise to our data, especially the SSE that lessened the significance of our results.

*Study Strengths*

There were several strengths of our study compared to prior studies. First, as we focused on modifiable factors, our results are more actionable than prior studies, and could directly affect policy decisions. Our finding that poor seizure control and cognitive impairment are the best predictors of school performance, demonstrate the necessity of improving access to anti-epileptic drugs for children. Prior research has attempted to intervene through stigma reduction programs(38–40). While stigma reduction programs are important, our study demonstrates that in Guinea, one of the world’s poorest countries, seizure control may be the driving factor leading to educational disparities for CWE. Based on our modeling, improved seizure treatment could be predicted to improve education outcomes for as many as 38 children—increasing the number of “high performing” students by approximately 33%. While it is recognized that, even with optimum seizure care, not all children would be capable of having fewer than 10 lifetime seizures, this result is useful for policy discussions around provision of adequate and consistent supplies of AEDs and showing the importance of improving access to anti-epileptics from an early age.

Additional strengths of our study include our relatively large sample size at 128 patients total and 113 children who had attended school for some period of time. This allowed us to examine more possible explanatory variables. As well, while other studies examining education and children have used either a historical diagnosis of epilepsy or a pediatrician’s assessment, our study had board-certified neurologists from both the United States and Guinea. Thus, the incidence of pseudo-seizures, exclusively febrile seizures, or alternative episodic diagnoses in our cohort is likely lower.
Summary and Conclusions

Overall our results show that there are significant barriers to achieving even a basic education for CWE in Guinea. We found that two major associations with poor educational outcomes for CWE in Guinea are poor seizure control and cognitive difficulties. While this is a cross sectional study, so causality cannot be established, one necessary important intervention for children would be early and aggressive seizure control in order to prevent both seizures and cognitive problems that arise from poorly controlled epilepsy. Based upon our model this could provide an improved outcome in as many as 1/3 of children. Future research should examine predictors of school drop-out longitudinally, as well as the barriers to taking AEDs.
Summary of Work

The burden of epilepsy is extremely high for children in low income countries, which has been shown to negatively affect their outcomes in school (8,9,21). CWE have higher rates of school drop-out and report negative experiences while in school. As most prior research is descriptive in nature, we sought to address this problem through a more systematic quantitative approach. We performed a cross-sectional study in Conakry, Guinea, examining associations with poor school performance (defined as dropping out of school or being held back) in CWE. We focused on four potentially modifiable factors—seizure burden, cognition, stigma, and household finances. These factors were chosen based upon a literature review on the effects of epilepsy on education in SSA.

In our sample, CWE had poor educational outcomes. Over 10% of the CWE in our study had never attended school, over 20% had dropped out of school, and over 40% of those who were still attending school had been held back at least one grade once. In multivariate analysis both a lower cognitive score and more lifetime seizures were significantly associated with a poor school performance. Neither stigma nor finances were significantly associated with a poor school performance while controlling for potential confounders. We performed modeling of the number of CWE who could become “high performing” if their seizures were treated to achieve a lifetime seizure burden of <10. Based upon our regression predictions, 38 additional CWE (33.6%) could become high functioning at school if all CWE were treated to the lowest lifetime seizure category of <10 seizures. This would bring the total percentage of the “high performing” children from 38.9% to 72.6%.

Overall our study showed that CWE in Guinea have significant barriers to education. In our analysis, lifetime seizures and cognitive score were significantly associated with school outcome. While our study was cross sectional, it does suggest that early and aggressive seizure control may be an extremely important factor to improve schooling outcomes for CWE. This is important for targeted future interventions.
References


Tables and Figures

Figure 1. Participant Flow sheet
Table 1. Baseline Characteristics of sample (n=128)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD)</td>
<td>11.6 (4.54)</td>
</tr>
<tr>
<td>Gender, %F (n)</td>
<td>48.4 (62)</td>
</tr>
<tr>
<td>On anti-epileptic drug, % on (n)</td>
<td>61.7 (79)</td>
</tr>
<tr>
<td>Loss of Consciousness with Seizure, % with (n)</td>
<td>80.5 (103)</td>
</tr>
<tr>
<td>Head Imaging, % with (n)</td>
<td>37.5 (48)</td>
</tr>
<tr>
<td>WNV median (25th, 75th percentile)</td>
<td>51 (32.25, 66.5)</td>
</tr>
<tr>
<td>Median age of first seizure (25th, 75th percentile)</td>
<td>4 (1, 9)</td>
</tr>
<tr>
<td>Median Age Diagnosed (25th, 75 percentile)</td>
<td>7 (4-12)</td>
</tr>
</tbody>
</table>

Table 2. Summary of AED use

<table>
<thead>
<tr>
<th>Value</th>
<th>% on (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of AEDs Used</td>
<td></td>
</tr>
<tr>
<td>Zero</td>
<td>40.6 (52)</td>
</tr>
<tr>
<td>One</td>
<td>51.6 (66)</td>
</tr>
<tr>
<td>Two</td>
<td>6.3 (8)</td>
</tr>
<tr>
<td>Three</td>
<td>1.6 (2)</td>
</tr>
<tr>
<td>Type of AED used*</td>
<td></td>
</tr>
<tr>
<td>Phenobarbital</td>
<td>17.2 (22)</td>
</tr>
<tr>
<td>Carbamazepine</td>
<td>19.5 (25)</td>
</tr>
<tr>
<td>Valproic Acid</td>
<td>19.5 (25)</td>
</tr>
<tr>
<td>Levetiracetam**</td>
<td>12.5 (16)</td>
</tr>
<tr>
<td>Diazepam</td>
<td>1.6 (2)</td>
</tr>
</tbody>
</table>

*Participants on multiple AEDs were counted once for each AED they were taking

**While Levetiracetam is not typically available in Guinea, we had brought levetiracetam during a prior trip. All participants on levetiracetam had received it from our group, with the exception of one participant who received it from relatives abroad.
Table 3. Reasons for dropping out of school or never going to school

<table>
<thead>
<tr>
<th>Reason</th>
<th>Never attended school (n=15)</th>
<th>Dropped out (n=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental pressure/decision</td>
<td>46.7 (7)</td>
<td>40.0 (12)</td>
</tr>
<tr>
<td>Pressure from teachers</td>
<td>6.67 (1)</td>
<td>40.0 (12)</td>
</tr>
<tr>
<td>Pressure from classmates</td>
<td>6.67 (1)</td>
<td>23.3 (7)</td>
</tr>
<tr>
<td>Fear of injury</td>
<td>20.0 (3)</td>
<td>46.7 (14)</td>
</tr>
<tr>
<td>School was too difficult</td>
<td>26.7 (4)</td>
<td>33.3 (10)</td>
</tr>
<tr>
<td>Needed to work or help at home</td>
<td>6.67 (1)</td>
<td>3.33 (1)</td>
</tr>
<tr>
<td>Behavioral problems</td>
<td>0.00 (0)</td>
<td>3.33 (1)</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>46.7 (7)</td>
<td>3.33 (1)</td>
</tr>
<tr>
<td>Other*</td>
<td>20.0 (3)</td>
<td>20.0 (6)</td>
</tr>
</tbody>
</table>

*Reasons listed under “other” included, speech difficulties (n=2), embarrassment or trouble with seizures (n=4), shame and difficulty concentrating (n=1), difficulty walking (n=1), could not play (n=2)
<table>
<thead>
<tr>
<th>Variable</th>
<th>No School (n=15)</th>
<th>Low Performers (n=69)</th>
<th>High Performers (n=44)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, median, years (25th, 75th percentile)</td>
<td>7.9 (5.0-11.1)</td>
<td>12.24 (9.64-16.14)</td>
<td>9.91 (7.19-14.92)</td>
</tr>
<tr>
<td>Gender, %F (n)</td>
<td>40.0 (6)</td>
<td>47.8 (33)</td>
<td>52.3 (23)</td>
</tr>
<tr>
<td>WNV, median (25th, 75th percentile)</td>
<td>0.00 (0.00-18.50)</td>
<td>46.0 (30.0-57.0)</td>
<td>67.0 (51.0-77.0)</td>
</tr>
<tr>
<td>Lifetime Seizures, % (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10</td>
<td>6.67 (1)</td>
<td>5.8 (4)</td>
<td>29.5 (13)</td>
</tr>
<tr>
<td>10-50</td>
<td>13.3 (2)</td>
<td>17.4 (12)</td>
<td>27.3 (12)</td>
</tr>
<tr>
<td>50-100</td>
<td>0.0 (0)</td>
<td>17.4 (12)</td>
<td>11.4 (5)</td>
</tr>
<tr>
<td>&gt;100</td>
<td>80 (12)</td>
<td>59.4 (41)</td>
<td>31.8 (14)</td>
</tr>
<tr>
<td>Family Wealth Quintile</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First</td>
<td>20.0 (3)</td>
<td>23.1 (16)</td>
<td>11.4 (5)</td>
</tr>
<tr>
<td>Second</td>
<td>33.3 (5)</td>
<td>26.1 (18)</td>
<td>13.6 (6)</td>
</tr>
<tr>
<td>Third</td>
<td>13.3 (2)</td>
<td>15.9 (11)</td>
<td>25.0 (11)</td>
</tr>
<tr>
<td>Fourth</td>
<td>20.0 (3)</td>
<td>21.7 (15)</td>
<td>22.7 (10)</td>
</tr>
<tr>
<td>Fifth</td>
<td>13.3 (2)</td>
<td>13.0 (9)</td>
<td>27.3 (12)</td>
</tr>
<tr>
<td>Stigma scale score, mean</td>
<td>53.5 (14.1)</td>
<td>51.8 (14.9)</td>
<td>49.9 (14.0)</td>
</tr>
<tr>
<td>(standard deviation)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most recent Seizure:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24 hours</td>
<td>26.7 (4)</td>
<td>15.9 (11)</td>
<td>9.09 (4)</td>
</tr>
<tr>
<td>One week</td>
<td>40.0 (6)</td>
<td>28.9 (20)</td>
<td>6.82 (3)</td>
</tr>
<tr>
<td>One month</td>
<td>13.3 (2)</td>
<td>11.6 (8)</td>
<td>27.3 (12)</td>
</tr>
<tr>
<td>3 months</td>
<td>0.0 (0)</td>
<td>18.8 (13)</td>
<td>6.82 (3)</td>
</tr>
<tr>
<td>6 months</td>
<td>0.0 (0)</td>
<td>7.25 (5)</td>
<td>13.6 (6)</td>
</tr>
<tr>
<td>9 months</td>
<td>0.0 (0)</td>
<td>7.25 (5)</td>
<td>15.9 (7)</td>
</tr>
<tr>
<td>One year</td>
<td>0.0 (0)</td>
<td>2.90 (2)</td>
<td>9.09 (4)</td>
</tr>
<tr>
<td>&gt;1 year</td>
<td>6.67 (1)</td>
<td>7.25 (5)</td>
<td>9.09 (4)</td>
</tr>
<tr>
<td>Highest parental education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No school</td>
<td>20.0 (3)</td>
<td>20.3 (14)</td>
<td>2.27 (1)</td>
</tr>
<tr>
<td>Primary</td>
<td>13.3 (2)</td>
<td>4.35 (3)</td>
<td>4.54 (2)</td>
</tr>
<tr>
<td>Some secondary</td>
<td>6.67 (1)</td>
<td>10.1 (7)</td>
<td>4.54 (2)</td>
</tr>
<tr>
<td>Full secondary</td>
<td>6.67 (1)</td>
<td>5.80 (4)</td>
<td>4.54 (2)</td>
</tr>
<tr>
<td>High school</td>
<td>13.3 (2)</td>
<td>11.6 (8)</td>
<td>18.2 (8)</td>
</tr>
<tr>
<td>University</td>
<td>40.0 (6)</td>
<td>47.8 (33)</td>
<td>65.9 (29)</td>
</tr>
<tr>
<td>Anti-epileptic drug, % (n)</td>
<td>33.3 (5)</td>
<td>69.6 (48)</td>
<td>59 (26)</td>
</tr>
<tr>
<td>Age at first seizure, median (25th, 75th percentile)</td>
<td>0.75 (0.50-2.25)</td>
<td>6.0 (1.5-10.0)</td>
<td>4.0 (1.0-7.25)</td>
</tr>
<tr>
<td>Age diagnosed, median (25th percentile, 75th percentile)</td>
<td>3.0 (0.54-5.0)</td>
<td>9.0 (5.0-13.0)</td>
<td>7.0 (4.0-11.0)</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Low Performers (n=69)</td>
<td>High Performers (n=44)</td>
<td></td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-----------------------</td>
<td>------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>School Rank, % (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Top of the class</td>
<td>5.80 (4)</td>
<td>11.4 (5)</td>
<td></td>
</tr>
<tr>
<td>Above average</td>
<td>18.8 (13)</td>
<td>36.4 (16)</td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>31.9 (22)</td>
<td>36.4 (16)</td>
<td></td>
</tr>
<tr>
<td>Below average</td>
<td>26.1 (18)</td>
<td>6.82 (3)</td>
<td></td>
</tr>
<tr>
<td>Bottom of the class</td>
<td>17.4 (12)</td>
<td>0.00 (0)</td>
<td></td>
</tr>
<tr>
<td><strong>School Difficulty, % (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely difficult</td>
<td>40.6 (28)</td>
<td>6.82 (3)</td>
<td></td>
</tr>
<tr>
<td>Sometimes difficult</td>
<td>20.3 (14)</td>
<td>45.0 (11)</td>
<td></td>
</tr>
<tr>
<td>Average difficulty</td>
<td>13.0 (9)</td>
<td>15.9 (7)</td>
<td></td>
</tr>
<tr>
<td>Not very difficult</td>
<td>14.5 (10)</td>
<td>29.5 (13)</td>
<td></td>
</tr>
<tr>
<td>Easy</td>
<td>11.6 (8)</td>
<td>2.27 (1)</td>
<td></td>
</tr>
<tr>
<td><strong>Participates in Sports, % (n)</strong></td>
<td>54.4 (37)</td>
<td>72.7 (32)</td>
<td></td>
</tr>
<tr>
<td><strong>Teachers informed of epilepsy, % (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>73.1 (49)</td>
<td>53.4 (23)</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>13.4 (9)</td>
<td>32.6 (14)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>13.4 (9)</td>
<td>14.0 (6)</td>
<td></td>
</tr>
<tr>
<td><strong>Students informed of epilepsy, % (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>68.2 (45)</td>
<td>43.2 (19)</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>12.1 (8)</td>
<td>29.5 (13)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>19.6 (13)</td>
<td>27.3 (12)</td>
<td></td>
</tr>
</tbody>
</table>

*One low performer did not respond about sports participation, 2 low performers and 1 high performer did not respond about informing teachers of epilepsy, and 3 low performers did not respond about informing classmates of epilepsy.
Table 6. Odds ratios, 95% confidence intervals, and p-values for all variables included in the four primary models

<table>
<thead>
<tr>
<th>Model</th>
<th>OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Seizures: &lt;10 (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-50</td>
<td>0.244 (0.821-15.0)</td>
<td>0.105</td>
</tr>
<tr>
<td>50-100</td>
<td>6.56 (1.44-35.8)</td>
<td>0.020</td>
</tr>
<tr>
<td>&gt;100</td>
<td>8.81 (2.51-37.4)</td>
<td>0.001</td>
</tr>
<tr>
<td>Age</td>
<td>1.11 (1.01-1.23)</td>
<td>0.041</td>
</tr>
<tr>
<td>Wealth Quintile</td>
<td>0.736 (0.531-1.00)</td>
<td>0.057</td>
</tr>
<tr>
<td>Model 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WNV</td>
<td>0.954 (0.926-0.977)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age</td>
<td>1.14 (1.00-1.31)</td>
<td>0.051</td>
</tr>
<tr>
<td>Parental education: none (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>0.040 (0.001-0.823)</td>
<td>0.047</td>
</tr>
<tr>
<td>Some Secondary</td>
<td>0.249 (0.008-4.13)</td>
<td>0.350</td>
</tr>
<tr>
<td>Full Secondary</td>
<td>0.108 (0.003-2.15)</td>
<td>0.162</td>
</tr>
<tr>
<td>High School</td>
<td>0.056 (0.002-0.597)</td>
<td>0.034</td>
</tr>
<tr>
<td>University</td>
<td>0.074 (0.003-0.571)</td>
<td>0.033</td>
</tr>
<tr>
<td>Most recent seizure: 24 hours (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One week</td>
<td>5.37 (0.620-59.0)</td>
<td>0.141</td>
</tr>
<tr>
<td>One month</td>
<td>0.718 (0.098-5.24)</td>
<td>0.740</td>
</tr>
<tr>
<td>3 months</td>
<td>4.12 (0.540-37.0)</td>
<td>0.181</td>
</tr>
<tr>
<td>6 months</td>
<td>0.635 (0.069-5.63)</td>
<td>0.680</td>
</tr>
<tr>
<td>9 months</td>
<td>1.08 (0.130-9.15)</td>
<td>0.942</td>
</tr>
<tr>
<td>One year</td>
<td>0.082 (0.004-1.13)</td>
<td>0.074</td>
</tr>
<tr>
<td>Greater than one year</td>
<td>1.77 (0.160-21.4)</td>
<td>0.641</td>
</tr>
<tr>
<td>Model 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stigma</td>
<td>0.993 (0.957-1.03)</td>
<td>0.693</td>
</tr>
<tr>
<td>Age</td>
<td>1.11 (0.990-1.26)</td>
<td>0.078</td>
</tr>
<tr>
<td>Parental education: none (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>0.135 (0.004-1.03)</td>
<td>0.178</td>
</tr>
<tr>
<td>Some secondary</td>
<td>0.340 (0.011-5.66)</td>
<td>0.461</td>
</tr>
<tr>
<td>Full secondary</td>
<td>0.239 (0.008-4.44)</td>
<td>0.339</td>
</tr>
<tr>
<td>High school</td>
<td>0.096 (0.005-0.691)</td>
<td>0.061</td>
</tr>
<tr>
<td>University</td>
<td>0.109 (0.0991-1.26)</td>
<td>0.497</td>
</tr>
<tr>
<td>WNV</td>
<td>0.966 (0.944-0.985)</td>
<td>0.001</td>
</tr>
<tr>
<td>Total Seizures: &lt;10 (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-50</td>
<td>5.11 (1.09-30.1)</td>
<td>0.049</td>
</tr>
<tr>
<td>50-100</td>
<td>5.64 (1.03-37.9)</td>
<td>0.055</td>
</tr>
<tr>
<td>&gt;100</td>
<td>7.48 (1.72-40.7)</td>
<td>0.011</td>
</tr>
<tr>
<td>Model 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wealth Quintile</td>
<td>0.845 (0.586-1.21)</td>
<td>0.364</td>
</tr>
<tr>
<td>Age</td>
<td>1.01 (0.989-1.23)</td>
<td>0.086</td>
</tr>
<tr>
<td>Parental education: none (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>0.268 (0.008-5.11)</td>
<td>0.395</td>
</tr>
<tr>
<td>Some secondary</td>
<td>0.275 (0.010-4.22)</td>
<td>0.360</td>
</tr>
<tr>
<td>Full secondary</td>
<td>0.176 (0.006-2.97)</td>
<td>0.236</td>
</tr>
<tr>
<td>High school</td>
<td>0.133 (0.006-1.14)</td>
<td>0.102</td>
</tr>
<tr>
<td>University</td>
<td>0.147 (0.007-1.01)</td>
<td>0.096</td>
</tr>
<tr>
<td>Total Seizures: &lt;10 (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-50</td>
<td>3.74 (0.907-18.4)</td>
<td>0.081</td>
</tr>
<tr>
<td>50-100</td>
<td>6.32 (1.32-36.5)</td>
<td>0.027</td>
</tr>
<tr>
<td>&gt;100</td>
<td>8.77 (2.39-39.6)</td>
<td>0.002</td>
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</tbody>
</table>
Appendix 1: English Translation of Surveys; for review purposes only

**Parent of Patient Survey**

Directions: Survey will be administered by a trained evaluator and questions will be read to the patient in the patient's preferred language. The evaluator administering the survey will write in the response. This survey is intended to be answered by the parents of patients who are too young to answer themselves. *All questions are in relation to the child.*

Name of Patient: ____________________________  Patient #: __________

Name of Parent/Guardian: ____________________________

Relationship to patient: ____________________________

Date of Evaluation: _____/_____/______ (day/month/year)  Name of Evaluator: -

Village: ____________________________  District: ____________________________

Tel/mobile: ____________________________

Age (years): _______  Date of birth: _____/_____/______ (day/month/year)

Gender (circle one):  Male  Female

Highest education level completed (circle one):  no school  primary school  secondary school  high school  university

Religion of child/family (circle all that apply):  Muslim  Christian  Other: ____________________________

Occupation: ____________________________

Was your child born preterm (early)?  Yes  No

Was your child born in a healthcare facility?  Yes  No

Was your child born as a twin?  Yes  No

Was your child delivered vaginally?  Yes  No

Was your child admitted to the ICU after birth?  Yes  No

Age at crawling (months): ______________

Age at walking (months): ______________

Age at first words (months): ______________

How old was your child at the first seizure (years): __________

Was your child diagnosed with epilepsy?  Yes  No

• If yes, how old was your child when diagnosed (years): __________

• If yes, who diagnosed your child with epilepsy? (circle all that apply)

  medical doctor (western/modern)  traditional healer  other: ____________________________
Which of the following characterizes your child’s seizures? (check all that apply)

□ loss of consciousness
□ falling to ground with stiffening and shaking of body
□ falling to ground, no shaking
□ uncontrollable shaking of one part of the body
□ staring spells
□ unusual behavior or acting strangely
□ unusual sensory events (vision hearing touch smell taste)
□ tongue biting
□ urinary incontinence
□ salivation
□ grunts/shouting/noises of some form
□ other: __________________________________________

How many seizures has your child had total?: _________________________________

How many seizures has your child had in the past month?: _________________________________

What is your child’s longest seizure free interval? _________________________________

When was your child’s last seizure? (check one)

□ within the last week  □ within the last month
□ within the last 3 months  □ within the last 6 months
□ within the last 9 months  □ within the last year
□ over 1 year ago

Do any of the following trigger your child’s seizures? (check all that apply)

□ infections/fever  □ lack of sleep  □ flashing lights  □ stress
□ forgetting to take medications  □ other: __________________________________________

Has your child ever had a seizure lasting for longer than 5 minutes?     Yes     No

Seizure Treatment

Has your child ever taken medication for epilepsy (AEDs)?     Yes     No

Is your child currently taking medications for epilepsy (AEDs)?     Yes     No

If not, why did he or she stop taking the medication ____________________________

• When did your child start treatment for seizures? (Age, in years): _______
• Does your child take his or her medications regularly?  Yes  No
If no, explain: ______________________________________________________________

• Which medications or treatments? (check all that apply and complete questions)
  □ Phenobarbital  Dose: _______________  □ Currently taking  □ Not anymore
  □ Phenytoin    Dose: _______________  □ Currently taking  □ Not anymore
  □ Carbamazepine Dose: _______________  □ Currently taking  □ Not anymore
  □ Sodium Valproate Dose: _______________  □ Currently taking  □ Not anymore
  □ Levetiracetam  Dose: _______________  □ Currently taking  □ Not anymore
  □ Clonazepam   Dose: _______________  □ Currently taking  □ Not anymore
  □ Clobazam     Dose: _______________  □ Currently taking  □ Not anymore
  □ Diazepam     Dose: _______________  □ Currently taking  □ Not anymore
  □ Other: ___________________________  □ Currently taking  □ Not anymore

• List any side effects from medications: ____________________________________________
  __________________________________________________

Has your child ever used non-AED treatments for seizures?
  □ Special diet   Explain: _______________  □ Currently taking  □ Not anymore
  □ Traditional treatments Explain: __________  □ Currently taking  □ Not anymore
  □ Prayer         Explain: _______________  □ Currently taking  □ Not anymore
  □ Other: ___________________________  □ Currently taking  □ Not anymore

Has your child ever had:
  □ head CT   Results: __________________________________________________________
  □ MRI       Results: __________________________________________________________
  □ EEG       Results: __________________________________________________________

Family & Past Medical History

Does anyone else in the family (blood relatives) have seizures?  Yes  No
If yes, does more than one family member have seizures?  Yes  No

Has your child ever had a head injury with loss of consciousness?  Yes  No

Has your child ever had a stroke?  Yes  No
Has your child ever had a brain infection?  

Yes  
No

Has your child ever been diagnosed with neurocysticercosis?  

Yes  
No

What other medical problems does your child have?  

________________________________________________________________________________________________________

________________________________________________________________________________________________________

Is your child on any other medications or treatments?  

________________________________________________________________________________________________________

________________________________________________________________________________________________________

Has your child ever had any injuries related to seizures? (check all that apply)  

☐ Burns  
☐ Breaking bones/fractures or bone dislocation  
☐ Head injury  
☐ Car accidents  
☐ Skin injury (scratches, cuts)  
☐ Other:  

________________________________________________________________________________________________________

Education

The following questions are meant to better understand your and your child’s experience with formal education in Guinea. These questions all refer to the formal schooling in Guinea and not to religious schools or alternative forms of education. There are no correct answers. We want to understand more about your experiences attending school with epilepsy.

Please circle the highest of level of education for the parents of the child

Mother: no school  primary school  lower secondary  upper secondary  university  unknown

Father: no school  primary school  lower secondary  upper secondary  university  unknown

For each of your other children, please list:

1. Age
2. Highest level of education (no school, primary, lower secondary, upper secondary, university)
3. Whether they are currently in school
4. Whether they have epilepsy
How far away (in kilometers) is the nearest school from your residence?

How did/do your children travel to school (i.e. bus, foot, etc.)?

How long (in minutes) does it take your children to travel to school?

What is the cost of school for each child, if any?

How much do you pay for school for your child with epilepsy?

Is your child with epilepsy currently attending school? If yes, how often?

   How many days of school has he/she missed in the last month?

   How many days of school has he/she missed in the last month because of seizures or epilepsy?

What class [grade] is your child with epilepsy currently in?

Has your child with epilepsy ever been held back/failed a class/grade?

How does/did your child with epilepsy do in school?
   □ Top of his/her class
   □ Above average
   □ Average
   □ Below average
   □ Bottom of his/her class

Do/did your child with epilepsy find school difficult?
   □ Very difficult
   □ Sometimes difficult
   □ Average
□ Not very difficult
□ Easy

**Do/did your child with epilepsy participate in sports at school?**
□ Yes
□ No
□ If you answered no, please explain why: ________

**If your child with epilepsy is no longer in school, why did they leave? Please check all that apply:**
□ Pressure from parents
□ Pressure from teachers
□ Pressure from classmates
□ Could not pay
□ Feared injury during seizure
□ Found schoolwork too challenging
□ Needed work and/or help at home
□ Other: ____________

**Do your child’s classmates know they have epilepsy?**
□ All
□ Some
□ None
□ Not sure

**Did you inform your child’s teachers that they have epilepsy?**
□ All
□ Some
□ None

If you did not inform your child’s teacher that they have epilepsy, please explain why below:

**Do you feel that your child’s school would know how to take care of your child if they had a seizure?**
□ Very well
□ Well
□ Average
□ Not well
□ Not at all

---

**Economics**
The following questions are designed for us to understand more about your financial situation, as this can affect the medical care that individuals are able to access. When asked for a monetary value please answer in Guinean Francs.

Is there a head of the household? If so, what is their relation to the child?
What is the highest education of the head of the household:
no school primary school lower secondary upper secondary university unknown

How many people are there in your household: ________

Number of adults 18 and over: ______
Number of adults who are working: ______
Number of adults who are not working: ______
Number of children: ______
Number of older (non-working) adults: ______

How much money have members of your household earned in the past month? ______

In a typical month, how much money does your household spend to cover all expenses including housing, food, schooling, and household goods? ______

In a typical month, how much does your household spend on food? ______

In a typical month, how much does your household spend on schooling? ______

In a typical month, how much does your household spend on treatment for epilepsy, including medications, visits to doctors, and traditional therapies? ______

Cost of Anti-epileptics ______
Cost of visits to doctors ______
Cost of traditional therapies ______

What is the marital status of the head of the household?
☐ Married or living together
☐ Divorced or separated
☐ Widowed
☐ Never married

Is the child’s mother currently alive?
☐ Yes
☐ No

Is the child’s father still alive?
☐ Yes
☐ No

Where is the water supply?
☐ In own dwelling
☐ In own yard/plot
☐ Elsewhere
How long does it take you to go there, get water, and come back?
Minutes: ________
[ ] Don’t know

What is the main source of drinking water for members of your household?

- [ ] Piped water (tap water)
  - [ ] Piped into dwelling
  - [ ] Piped into yard/plot
  - [ ] Piped into neighbor
  - [ ] Public tap/standpipe
- [ ] Tube well or borehole
- [ ] Dug well
  - [ ] Protected well
  - [ ] Unprotected well
- [ ] Water from spring
  - [ ] Protected spring
  - [ ] Unprotected spring
- [ ] Rainwater
- [ ] Tanker truck
- [ ] Cart with small tank
- [ ] Surface water (rivers/dams/lakes/ponds/rivers/canals/irrigation channel)
- [ ] Bottled water
- [ ] Other: ________

What is the main source of water used by your household for other purposes such as cooking and handwashing?

- [ ] Piped water (tap water)
  - [ ] Piped into dwelling
  - [ ] Piped into yard/plot
  - [ ] Piped into neighbor
  - [ ] Public tap/standpipe
- [ ] Tube well or borehole
- [ ] Dug well
  - [ ] Protected well
  - [ ] Unprotected well
- [ ] Water from spring
  - [ ] Protected spring
  - [ ] Unprotected spring
- [ ] Rainwater
- [ ] Tanker truck
- [ ] Cart with small tank
- [ ] Surface water (rivers/dams/lakes/ponds/rivers/canals/irrigation channel)
- [ ] Bottled water
- [ ] Other: ________

In the past two weeks, was the water from this source not available for at least one full day?

- [ ] yes
- [ ] no
- [ ] I don’t know
Do you do anything to the water to make it safer to drink?
- □ yes
- □ no
- □ I don’t know

What do you usually do to make the water safer to drink? Please check all that apply
- □ Boil
- □ Add Bleach/Chlorine
- □ Strain through a cloth
- □ Use water filter (ceramic/sand/composite/etc)
- □ Solar disinfection
- □ Let it stand and settle
- □ Other ______________
- □ Don’t know

What kinds of toilets to members of your household typically use?
- □ Flush or pour flush
  - o Connected to piped sewer system
  - o Connected to a septic tank
  - o Connected to a pit latrine
  - o Connected to something else
  - o I don’t know what it’s connected to
- □ Latrine
  - o Ventilated improved pit latrine
  - o Pit latrine with slab
  - o Pit latrine without slab/open pit
- □ Composting toilet
- □ Buckets
- □ Hanging toilet/Hanging latrine
- □ No toilets/bush/field
- □ Other: ______________

Do you share this toilet with other households?
- □ Yes
- □ No

Including your own household, how many households use this toilet facility?
- □ Number of households __________
- □ More than 10
- □ Not sure

Where is this toilet facility located?
- □ In own dwelling
- □ In own yard/plot
- □ Elsewhere

Does anyone in your household have a bank account?
- □ Yes
- □ No

Please check the box if you do have the following items in your household:
- □ Electricity
- □ Radio
- □ Television
☐ Non-mobile telephone
☐ Computer

Please check the box if any member of your household owns the following:
☐ watch
☐ mobile phone
☐ Bicycle
☐ motor cycle or motor scooter
☐ Animal drawn cart
☐ Car or truck
☐ Boat with a motor

Does your household have any mosquito nets?
☐ yes
☐ no

How many mosquito nets does your household have?

How many months ago did your household get the mosquito nets?
☐ months: _____
☐ more than 36 months ago
☐ not sure

Did anyone from your household sleep under the mosquito net(s) last night? If so, who?

Where did you get your mosquito net from?
☐ Government health facility
☐ Private health facility
☐ Pharmacy
☐ Shop/market
☐ Religious institution
☐ school
☐ other
☐ don’t know
Appendix 2: Surveys Given to Participants in French

**Questionnaire pour parent de patient**

Directives : le questionnaire sera fait par un enquêteur entrainé et les questions seront lues dans la langue du choix du patient. L’enquêteur va écrire les réponses recueillies. Ce questionnaire doit être répondu par des parents de patients trop jeunes pour répondre eux même. Toutes les questions sont relatives à l’enfant.

Nom du patient: ____________________________________________________________  Patient N°: ____________

Nom du parent/tuteur: ________________________________________________________

Relation avec le patient: ____________________________________________________

Date d’évaluation: _____/_____/______ (jour/mois/année)  Nom de l’enquêteur: ____________

Village: __________________________

District: _________________________________________________________________

Téléphone: ______________________________

Age (années): ____________  Date de naissance: _____/_____/______
(jour/mois/année)

Sexe (encercler un):  Masculin  Féminin

Niveau d’éducation complété le plus haut (encercler un):

Non scolarisé  Ecole primaire  Collège  Lycée  Université

Religion de l’enfant/famille (encercler tout ce qui s’applique):

Musulman  Chrétien  Autre: ____________________________

Profession: ______________________________

Votre enfant est-il né prématuré (tôt) ?  Oui  Non

Votre enfant est-il né dans un centre de santé ?  Oui  Non

Votre enfant est-il jumeau ?  Oui  Non

Votre enfant est-il né par voie basse ?  Oui  Non

Votre enfant a-t-il été admis en réanimation après la naissance ?  Oui  Non

Age auquel votre enfant a rampé (mois) : ________________________

Age auquel votre enfant a marché (mois) : ________________________

Age auquel votre enfant a parlé (mois): ________________________

Quel était l’âge de votre enfant au moment de sa 1ère crise (années): ______________

Votre enfant a-t-il été diagnostiqué épileptique?  Oui  Non

• Si oui, quelle était l’âge de votre enfant au moment du diagnostic (années): ______________

• Si oui, qui a posé le diagnostic? (Encercler tout ce qui s’applique)

   médecin  guérisseur traditionnel  autre: ____________________________
Comment caractériseriez-vous les crises de votre enfant ? (Cochez toutes les cases applicables) ?

☐ perte de conscience
☐ chute avec enraidissement et secousses du corps
☐ chute sans secousses
☐ secousses incontrôlables d’une partie du corps
☐ regard figé
☐ comportement inhabituel ou bizarre
☐ événements sensoriels inhabituels (vision ouïe toucher odorat gout)
☐ morsure de la langue
☐ incontinence urinaire
☐ salivation
☐ grognement/cris/toute autre forme de bruit
☐ Autre: ___________________________________________________

Combien de crises votre enfant a-t-il fait au total ? ____________________________________________

Combien de crises votre enfant a-t-il fait le mois passé ? __________________________________________

Quel est l’intervalle le plus long sans crise pour votre enfant ? _____________________________________

Quand est ce que votre enfant a-t-il eu sa dernière crise? (cochez un)

☐ la semaine passée ☐ au cours du mois passé
☐ au cours des 3 derniers mois ☐ au cours des 6 derniers mois
☐ au cours des 9 derniers mois ☐ au cours de l’année passée
☐ il y a plus d’un an

Est-ce que l’un ou l’autre de ces éléments favorisent les crises de votre enfant ? (Cochez tous les choix applicables)

☐ infections/fièvre ☐ manque de sommeil ☐ flash lumineux
☐ stress ☐ oublì de prendre son médicament. ☐ Autre: ______________________________

Votre enfant a-t-il une fois eu des crises qui ont duré plus de 5 minutes ? Oui Non

Traitement des crises

Votre enfant a-t-il une fois pris un médicament antiépileptique ? Oui Non

Prend-il actuellement un médicament antiépileptique ? Oui Non

Si non, pourquoi a-t-il arrêté le traitement ____________________________________________

45
- Quand est-ce que votre enfant a commencé le traitement des crises ? (Age, en années): ____

- Votre enfant prend-il régulièrement ses médicaments ?  
  
  Oui  Non  
  
  Si non expliquez: ________________________________________________________________

- Quel médicament ou traitement? (cochez tous les choix et complétez les questions)

  □ Phenobarbital  
  Dose: ____________  □ Traitement actuel  □Traitement arrêté

  □ Phenytoin  
  Dose: ____________  □ Traitement actuel  □ Traitement arrêté

  □ Carbamazepine  
  Dose: ____________  □ Traitement actuel  □ Traitement arrêté

  □ Valproate de Sodium  
  Dose: ____________  □ Traitement actuel  □ Traitement arrêté

  □ Levetiracetam  
  Dose: ____________  □ Traitement actuel  □ Traitement arrêté

  □ Clonazepam  
  Dose: ____________  □ Traitement actuel  □ Traitement arrêté

  □ Clobazam  
  Dose: ____________  □ Traitement actuel  □ Traitement arrêté

  □ Diazepam  
  Dose: ____________  □ Traitement actuel  □ Traitement arrêté

  □ Autre  
  ________________________________________________________________  □ Traitement actuel  □ Traitement arrêté

- Listez tous les effets secondaires des médicaments: ______________________________________

- Votre enfant a-t-il déjà utilisé un traitement autre que les médicaments antiépileptiques?

  □ Régime spécial  
  Expliquez: ________________  □ traitement actuel  □ traitement arrêté

  □ Médicaments traditionnels  
  Expliquez: ____________  □ traitement actuel  □ traitement arrêté

  □ Prière  
  □ traitement actuel  □ traitement arrêté

  □ Autre  
  Expliquez: ________________  □ traitement actuel  □ traitement arrêté

- Votre enfant a-t-il déjà réalisé:

  □ Scanner cérébral  
  Résultats: ________________________________________________________________

  □ IRM  
  Résultats: ________________________________________________________________

  □ EEG  
  Résultats: ________________________________________________________________
**Antécédents personnels et familiaux**

Y a-t-il quelqu’un dans la famille (lien de sang) qui fait des crises ?  
- Oui  
- Non  

Si oui, est-ce que plus d’une personne fait des crises?  
- Oui  
- Non  

Votre enfant a-t-il une fois eu un traumatisme crânien avec perte de conscience?  
- Oui  
- Non  

Votre enfant a-t-il une fois fait un AVC?  
- Oui  
- Non  

Votre enfant a-t-il déjà eu une infection cérébrale?  
- Oui  
- Non  

Votre enfant a-t-il une fois eu la neurocysticercose?  
- Oui  
- Non  

Quel autre problème de santé a votre enfant ? __________________________________________________________________________________________________________

Votre enfant prend-il d’autres médicaments ou traitement? __________________________________________________________________________________________________________

Votre enfant a-t-il déjà eu des blessures lors des crises ? (Cochez tous les choix)  
- Brulures  
- Fractures/luxations  
- Traumatisme crânien  
- Accidents de la voie publique  
- Blessures cutanées (égratignures, coupures)  
- Autre: __________________________________________________________________________________________________________

**Education**


Veuillez encercler le niveau d’éducation le plus élevé des parents de l’enfant  
- Mère: non scolarisée  
- école primaire  
- début collège  
- fin collège  
- lycée  
- université  
- je ne sais pas  

- Père: non scolarisé  
- école primaire  
- début collège  
- fin collège  
- lycée  
- université  
- je ne sais pas
Pour chacun de vos enfants, veuillez lister:

5. L’âge
6. Le plus haut niveau d’éducation (non scolarisé, école primaire, début collège, fin collège, lycée, université)
7. S’ils sont actuellement à l’école
8. S’ils sont épileptiques

A quelle distance (en kilomètres) se trouve l’école la plus proche de votre domicile?

Comment se rend votre enfant à l’école (c.a.d. bus, à pied, etc.)?

Combien de temps (en minutes) votre enfant met-il pour se rendre à l’école?

Quel est coût de la scolarité de chaque enfant, s’il y en a ?

Combien payez-vous pour la scolarité de votre enfant épileptique ?

Votre enfant épileptique va-t-il actuellement à l’école ? Si oui, à quelle fréquence ?

Combien de jours d’école a-t-il raté le mois passé ?

Combien de jours d’école a-t-il raté le mois passé à cause des crises ou de l’épilepsie ?

En quelle classe [niveau] votre enfant épileptique est-il ?

Votre enfant a-t-il du retard/a-t-il redoublé une classe ?

Comment ça s’est passé/se passe pour votre enfant épileptique à l’école?

☐ le meilleur de sa classe
☐ Au-dessus de la moyenne
☐ Moyen
☐ En dessous de la moyenne
☐ le dernier de la classe

Votre enfant épileptique a-t-il trouvé/trouve-t-il l’école difficile ?

☐ Très difficile
☐ Parfois difficile
☐ Moyen
☐ Pas très difficile
☐ Facile
Votre enfant a-t-il participé/ participe-t-il aux sports à l’école ?
□ Oui
□ Non
□ Si non, veuillez expliquer pourquoi: ____________________________

Si votre enfant épileptique ne part plus à l’école, pourquoi a-t-il quitté ? Veuillez cocher tout ce qui s’applique:
□ Pression des parents
□ Pression des enseignants
□ Pression des camarades de classe
□ Ne peut pas jouer
□ Crainte de blessures au cours des crises
□ Trouve l’école difficile
□ Besoin d’aide/travail à domicile
□ Autre: ____________________________

Est-ce que les camarades de classe de votre enfant savent qu’il est épileptique ?
□ Tous
□ Quelques-uns
□ Aucun
□ Pas sur

Avez-vous informé les enseignants de votre enfant qu’il est épileptique ?
□ Tous
□ Quelques-uns
□ Aucun

Si vous n’avez pas informé les enseignants de votre enfant qu’il est épileptique, veuillez expliquer pourquoi ci-dessous:

Pensez-vous que l’école de votre enfant saurait bien s’occuper de lui s’il a une crise ?
□ Très bien
□ Bien
□ Moyennement
□ Pas bien
□ Pas du tout

Aspect financier

Les questions suivantes ont été élaborées pour nous permettre de mieux comprendre votre situation financière, puisque ceci peut affecter les soins médicaux auxquels l’on peut avoir accès. Lorsqu’on vous demande une valeur monétaire veuillez répondre en Francs Guinéens.

Y a-t-il un chef de famille chez vous ? Si oui, quelle est sa relation avec l’enfant ?

Quel est le niveau d’éducation du chef de famille ?

Non instruit  école primaire  début secondaire  fin secondaire  université  je ne sais pas

Veuillez encercler le niveau d’éducation le plus élevé de l’accompagnant de l’enfant:

Non instruit  école primaire  début secondaire  fin secondaire  université  je ne sais pas
Combien de personnes y a-t-il dans votre maison? ________
   Nombre d’adultes âgées de 18 ans ou plus: ________
   Le nombre d’adultes qui travaillent: ________
   Le nombre d’adultes qui ne travaillent pas: ________
   Le nombre d’enfants: ________
   Le nombre de personnes âgées (qui ne travaillent pas): ________

Quel montant les membres de votre famille ont-ils gagné au cours du mois passé? ________

Au cours d’un mois typique, de quel montant votre famille a-t-elle besoin pour couvrir tous ses besoins y compris le loyer, la nourriture, la scolarité, et d’autres effets familiaux? ________

Au cours d’un mois typique, quel montant votre famille dépense-t-elle pour la nourriture? ________

Au cours d’un mois typique, quel montant votre famille dépense-t-elle pour la scolarité? ________

Au cours d’un mois typique, quel montant votre famille dépense-t-elle pour le traitement de l’épilepsie, y compris les médicaments, les consultations médicales et les traitements traditionnels? ________
   - Cout des antiépileptiques ________
   - Cout des consultations médicales ________
   - Cout des traitements traditionnels ________

Que est le statut matrimonial du chef de votre famille?
   - Marrié ou vivant en couple
   - Divorcé ou séparé
   - Veuf (ve)
   - Jamais marié

Est-ce que la mère de l’enfant est vivante?
   - Oui
   - Non

Est-ce que le père de l’enfant est vivant?
   - Oui
   - Non

Où se trouve l’approvisionnement en eau?
   - Dans votre propre habitation
   - Dans votre propre cour/terrain
   - Ailleurs

Combien de temps vous faut-il pour y aller, puiser l’eau et revenir?
   - Minutes: ______________
   - je ne sais pas
Quelle est la principale source d’eau à boire pour les membres de votre famille ?

- [ ] Eau courante ( robinet)
  - o Canalisé dans l'habitation
  - o Canalisé dans la cour / terrain
  - o Canalisé dans le voisinage
  - o Robinet public/colonne montante
- [ ] Puits tubulaire ou forage
- [ ] Puits creusé à la main
  - o Puit protégé
  - o Puit non protégé
- [ ] Eau de source
  - o Protégée
  - o Non protégée
- [ ] Eau de pluie
- [ ] Citernes
- [ ] Carton avec des bidon, canettes,
- [ ] Eau de surface ( rivièrè/barrage/lac/ étang/conduit)
- [ ] Eau en bouteilles
- [ ] Autres: ___________

Quelle est la principale source de l’eau utilisée dans votre maison pour les autres besoins tels que la cuisine et la lessive?

- [ ] Eau courante ( robinet)
  - o Canalisé dans l'habitation
  - o Canalisé dans la cour / terrain
  - o Canalisé dans le voisinage
  - o Robinet public/colonne montante
- [ ] Puits tubulaire ou forage
- [ ] Puits creusé à la main
  - o Puit protégé
  - o Puit non protégé
- [ ] Eau de source
  - o Protégée
  - o Non protégée
- [ ] Eau de pluie
- [ ] Citernes
- [ ] Carton avec des bidon, canettes,
- [ ] Eau de surface ( rivièrè/barrage/lac/ étang/conduit)
- [ ] Eau en bouteilles
- [ ] Autres: ___________

Au cours des deux dernières semaines, est que cette eau a été indisponible pour au moins une journée entière ?

- [ ] Oui
- [ ] Non
- [ ] Je ne sais pas
Est-ce que vous faites quelque chose à cette eau pour la rendre plus sûre pour la consommation ?

☐ Oui
☐ Non
☐ Je ne sais pas

Que faites-vous généralement pour rendre l’eau plus sûre pour la consommation ? Veuillez cocher tout ce qui s’applique

☐ Bouillir
☐ Ajouter du javel
☐ Décanter avec un tissu
☐ Usage de filtre (ceramique/sable/composite/etc)
☐ Désinfection solaire
☐ Laisser décanter
☐ Autre ________________
☐ Je ne sais pas

Quels types de toilettes les membres de votre famille utilisent généralement ?

☐ WC à chasse automatique ou manuelle
   o Connecté à un égout
   o Connecté à une fosse septique
   o Connecté à un égout ouvert
   o Connecté à autre chose
   o Je ne sais pas à quoi est-ce connecté
☐ Latrine
   o Latrines améliorées
   o Latrines auto-aérées
   o Latrines ouvertes
☐ Toilette à compost
☐ Bassines (pots)
☐ Latrines/toilettes suspendues
☐ Pas de toilettes/ dans la brousse/ champs
☐ Autres: ________________

Partagez-vous ces toilettes avec d’autres familles ?

☐ Oui
☐ Non

Combien de familles utilisent ces toilettes, la votre y compris ?

☐ Nombre de familles __________
☐ Plus de 10
☐ Pas sur

Ou sont situées les toilettes ?

☐ Dans votre propre habitation
☐ Dans votre propre cour/terrain
☐ Ailleurs
Y a t il une personne dans votre famille possédant un compte bancaire?
☐ Oui
☐ Non

Veuillez cocher si vous avez les éléments suivants dans votre maison :
☐ Electricité
☐ Radio
☐ Télévision
☐ Téléphone fixe
☐ Ordinateur

Veuillez cocher si un membre de votre famille possède les choses suivantes :
☐ Montre
☐ Téléphone mobile
☐ Bicyclette
☐ Moto ou scooter
☐ Carosse
☐ Voiture ou camion
☐ Bateau à moteur

Avez vous une moustiquaire dans votre maison?
☐ Oui
☐ Non

Combien de moustiquaire y a t il dans votre maison?

Cela fait combien de temps que vous avez ces moustiquaires?
☐ mois: ______
☐ Plus de 36 mois
☐ pas sur

Quelqu’un a t il dormi sous moustiquaire la nuit dernière? Si oui, qui est-ce?

Ou avez vous eu votre moustiquaire ?
☐ Structure sanitaire gouvernementale
☐ Structure sanitaire privée
☐ Pharmacie
☐ Boutique/Marché
☐ Institution religieuse
☐ Ecole
☐ Autre
☐ Je ne sais pas
### Appendix 3: Logistic regression of association of wealth with school drop out

<table>
<thead>
<tr>
<th>Variable</th>
<th>OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wealth Quintile</td>
<td>0.549 (0.336-0.853)</td>
<td>0.011</td>
</tr>
<tr>
<td>Age</td>
<td>1.163 (1.038-1.317)</td>
<td>0.012</td>
</tr>
<tr>
<td>Parental Education: none (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>2.124 (0.076-30.696)</td>
<td>0.598</td>
</tr>
<tr>
<td>Some Secondary</td>
<td>0.688 (0.094-4.903)</td>
<td>0.707</td>
</tr>
<tr>
<td>Full Secondary</td>
<td>0.253 (0.010-2.708)</td>
<td>0.295</td>
</tr>
<tr>
<td>High School</td>
<td>1.105 (0.185-6.472)</td>
<td>0.911</td>
</tr>
<tr>
<td>University</td>
<td>1.118 (0.264-4.894)</td>
<td>0.879</td>
</tr>
<tr>
<td>Total Seizures: &lt;10 (ref)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-50</td>
<td>0.285 (0.029-2.219)</td>
<td>0.236</td>
</tr>
<tr>
<td>50-100</td>
<td>1.444 (0.240-9.655)</td>
<td>0.690</td>
</tr>
<tr>
<td>&gt;100</td>
<td>1.996 (0.493-10.344)</td>
<td>0.360</td>
</tr>
</tbody>
</table>