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The Socioeconomic status of children with epilepsy in Zambia:

Implications for long-term health and well-being

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Summary

Epilepsy is a highly stigmatized disorder in Zambia. Adult studies indicated that adults with epilepsy in many regions have significantly lower socioeconomic status (SES) than their peers. We conducted a case-control study of Zambian children with epilepsy (CWE) to assess the SES of CWE. 98 child pairs were recruited (n=196), mean age 10.8 yrs, 59.7% male. The comparison group's medical conditions included asthma (54.0%), rheumatic heart disease (26.6%), type 1 diabetes (14.2%), and hypertension (5.2%). Compared to children with non-stigmatized chronic medical conditions, CWE have fewer educational opportunities, more environmental hazards, and poorer food quality and security (all p's<0.05). These deprivations may be related to lost maternal income from mothers who deferred employment so they could remain at home to care for the child. These early deprivations have long-term implications for health and well-being. Healthcare workers and child advocates need to be aware of the circumstances facing CWE in this region.

Keywords

nutritional status; education; stigma; deprivation; drowning; pediatrics; epilepsy; education; burns; socioeconomic status

Introduction

Epilepsy is the commonest neurological disorder worldwide and one of the most common chronic, non-communicable diseases among adults in resource-poor settings(1,2). Previous

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work among adults with epilepsy in Zambia found them to have significantly lower socioeconomic status than their peers with non-stigmatized chronic conditions. Adults with epilepsy had poorer food security, less personal safety, poorer housing quality, and lower levels of educational attainment. Women with epilepsy were less likely to access healthcare services for antenatal care (3). Whether deprivation for people with epilepsy is an adult-only phenomenon or extends to children is unclear, but early deprivation for children with epilepsy (CWE) would have long-term implications for their potential lifelong health and well-being.

In sub-Saharan Africa, the majority of the children who suffer from epilepsy do not consult medical doctors. Epilepsy is perceived as an “African” affliction due to supernatural effects of ancestral spirits or bad spirits (4). Consequently, the treatment gap is >90% (5) and epilepsy remains highly stigmatized (6-10). It is still regarded as highly contagious (11). Adolescents with epilepsy are stigmatized by fellow students (12) and teachers (13). In Nigeria >36% of children and 6% of adolescents with epilepsy have never attended school (14) and many who started school withdrew prematurely (15). Numerous studies have also documented problems in academic performance of children with epilepsy when compared with healthy children or children with other chronic conditions (16-19). Seidenberg et al found that academic underachievement was associated with longer duration of seizures, multiple seizure types and more refractory seizures (19).

Clearly school performance is negatively impacted by underlying epilepsy in sub-Saharan Africa, but we are not aware of any quantitative studies assessing the social economic status of children with epilepsy more broadly. We conducted a case-control study comparing the SES of children with epilepsy compared to children with a chronic, non-stigmatized health condition in Zambia.

Methods

Participating Sites

Four outpatient sites providing pediatric epilepsy care as part of primary and multi-specialty healthcare services were included in this study—2 urban (University Teaching Hospital Specialty Pediatric Clinic and Chainama Clinics in Lusaka), 1 rural (Chikankata Health Services Outpatient Department, Mazabuka) and 1 mixed (Monze Mission Hospital Outpatient Department, Monze). Each site provides care for children with epilepsy as well as the full-range of pediatric medical problems common in the region.

Instrument Development

The survey instrument was designed for use in structured interviews and included items regarding demographic characteristics, economic status. For education, we determined if the child with epilepsy was presently in school as well as the educational status of the sex sibling closest to them in age was assessed to provide an intra-household comparison in addition to the control group. For children not presently in school, parents/guardians were asked an open-ended question regarding why the child was not in school. The economic assessment included household-level measures of housing quality, food security, access to water, power source, waste management, and accumulated wealth. A composite score for housing quality was developed based on a ranked and then summed score for three housing features (materials used for walls, floor and roof). Food security inquiries included four standard questions regarding present food access as well as a question assessing food access during the hunger season.¹ Household food security as well as the child’s individual level of food security was assessed. To determine overall household wealth accumulation, a list of commonly owned items (*e.g.*

¹Generally February-April before crops are harvestable but when last season’s produce has been consumed.

number of poultry and cattle, bicycle ownership) was reviewed with the respondent and market values applied. Height, weight and mid-upper arm circumference were also measured in participating children.

Subject Selection and Interviews

Enrollment and interviews were conducted at each of the four sites between September 1-December 31, 2005. Research staff were comprised of local healthcare workers fluent in both English and the applicable local languages (Bemba, Tonga or Nyanja). All research staff received one week of intensive training together as a group to decrease inter-site variability. Potential cases included: children less than 18 years of age, seeking care for an established diagnosis of epilepsy accompanied by a parent or guardian who was able to answer questions regarding the child's household. At each site, clinical staff registering patients for outpatient visits as well as healthcare workers in the clinic alerted potential participants regarding the study, their possible eligibility, and where the research office could be found. The parent/guardian of potential study subjects who presented to the research staff were given further details regarding participation, eligibility was assessed, and written consent and assent were sought. For each enrolled case, research staff provided outpatient clinic staff and care providers with the gender and age range needed for a matched control. Inclusion criteria for controls, matched on gender, age (+/-6 months), and site of care, included care-seeking for an established chronic condition NOT thought to be associated with stigma (specifically asthma, rheumatic heart disease, hypertension or type 1 diabetes mellitus). Patients suffering with AIDS or HIV-related problems, severe malnutrition, or tuberculosis were excluded. Potential controls identified by clinic staff and healthcare providers were referred for screening. Clinical staff notified the parent/guardian of each potential control regarding the study until a qualifying control presented to the research team, consented/assented and completed the enrollment interview. Participants were given K10,000 (~\$2) for participation. Interviews were conducted in a private location and no identifying data was collected.

Data Management

Answers to interview questions were recorded on paper copies of the instrument along with study identification numbers. Names were not recorded on the instrument, but clinic staff made note of who had already been referred to the study team to avoid duplicate interviews. Completed surveys were copied and copies stored in the central study office at Chikankata. Using the original hardcopies, data were double-entered into Microsoft Access before importation into EPI INFO 3.2.2 for analysis. Nutritional parameters including age-adjusted z-scores were calculated using NUTSTAT available in the EPI INFO program.

Analysis

Two-tailed comparisons between cases and controls were made using student's t-test, the Mantel-Haenszel chi-square test or the Kruskal-Wallis test when applicable. A threshold of $p < 0.05$ was considered statistically significant. The open ended question regarding why a child was not in school was post-coded by the group into selected categories.

Due to concerns that the hypertension may be associated with higher SES, a sensitivity analysis was conducted omitting case-control pairs where the control had hypertension.

Human Subject Protection

This study was approved by the University of Zambia's Research Ethics Committee and Michigan State University's Committee for Research involving Human Subjects.

Role of Funding Source

The sponsor of this study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all data in the study and had final responsibility for the decision to submit for publication.

Results

Results

98 child pairs were recruited (n=196), mean age 10.8 yrs, 59.7% male. The comparison group's medical conditions included asthma (54.0%), rheumatic heart disease (26.6%), type 1 diabetes (14.2%), and hypertension (5.2%).

Demographic and SES comparisons between CWE and the control group are illustrated in Table 1. Children did not differ on age, birth order, sibling numbers, or household composition (all p 's >0.05). CWE however were less likely to be in school relative to the comparison group (62.2 vs. 87.8%, $p=0.0001$) and compared to their nearest age, same sex sibling (62.2 vs. 67.3%, $p=0.05$). The educational status of the control group did not differ from the control group's siblings (87.8 vs. 85.7%, $p=0.15$). The most common reason reported for CWE not being in school was parental/guardian concern that the child would have a seizure while the child was attending school.

Although the fathers' job classification was not different between the two groups, mothers' of CWE were more likely to stay at home without outside employment (57.1 vs. 44.9%, $p=0.03$). Mean wealth from material goods was \$292 for households of CWE vs \$532 ($p=0.01$). Households with CWE were less likely to have running water (13.3 vs 30.6%, $p=0.005$), electricity (25.5 vs. 44.9%, $p=0.01$), or toilets/pit latrines (79.6 vs. 88.8%, $p=0.002$).

Household food security based upon kilograms of mealie meal purchased per person per month was the same in the two groups (9.3 vs 11.0 kg, $p=0.22$). Despite this, CWE received fewer high protein meals per month (9.3 vs. 11.0, $p=0.04$) and were more likely to subsist on fewer than three meals a day (32.9 vs. 9.2%, $p=0.0007$). Z-scores on weight: height did not differ in the two groups, but height comparisons bordered on significance for the two groups (134.4 vs. 131.4 cm, $p=0.07$) and on gendered stratified analysis, was substantially different for boys (114.0 vs. 131.0, $p=0.009$).

None of the statistical findings from the primary analysis were altered in the sensitivity analysis excluding the case-control pairs with hypertension in the control group.

Discussion

In this Zambia-based case-control study, CWE have fewer educational opportunities, less food security and live in homes with increased risk for accidental injury or death related to burns and/or drowning. Household level-deprivation may explain why the siblings of CWE appear to have fewer educational opportunities relative to siblings of children in the control group and is likely related to the mother's employment status. Mother's of CWE often report discontinuing work to remain home and care for the child (20). Particularly concerning is evidence that even within the relatively deprived household, the CWE is disproportionately affected in terms of access to food and education. The stunting with preserved height-to-weight ratios identified among male CWE suggests chronic food insecurity (but without overt acute malnutrition) relative to the control group. Such physical deprivation has long-term implications for their health and well-being.

A key limitation of this work is that the cross sectional design cannot provide data to disentangle the critical temporal nature of events--Does being born into a relatively more deprived home in Zambia increase a child's risk of developing epilepsy? Or is the poverty differential identified here simply a result of parental income loss through mothers who are staying at home to care for a CWE? Certainly there are exposures associated with poverty that might result in increased risks for epilepsy-e.g. poorer antenatal services, more infectious exposures. Longitudinal studies are needed to answer such questions. If the cycle of poverty resulting from early deprivation followed by lack of education and chronic malnutrition is to be broken, there is need for more human and material resources to better manage these children.

Interventions to improve the situation for CWE require a multifaceted approach aimed at families, educators, and the healthcare sector. Improvements in the household SES would likely benefit the children to some extent, but to more fully understand the relative intra-household deprivation found, in-depth qualitative studies are needed to better understand the familial dynamics. For example, are nutritional deprivations a result of enforcing prohibitions against consuming foods that traditional beliefs hold are related to seizures? A poor appetite among CWE? Or unequal food distribution? Educational opportunities for CWE should also be improved if the goal is to break the vicious cycle of poverty. Levels of education and schooling rates might be improved by simply increasing household income or wealth. However, prior research in the region indicates that even when parents wish to send their children to school, teachers are often very reluctant to have such pupils in their classroom(20). A knowledge, attitudes and practice survey of Zambian teachers found that teachers with some prior personal contact with someone with epilepsy exhibit more knowledge and tolerance for the condition (21). Educational programs aimed at teachers in Zambia are presently being developed and implemented in four of nine provinces and repeated measures of educational access and attainment among CWE in these provinces is planned.

Improving access to treatment and more optimal quality of medical care are also needed.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1
Demographic and SES Comparisons between CWE and Controls²

Characteristics	Epilepsy	Controls	p-value
Age (mean yrs)	10.7	11.1	0.27
Birth order	3.6 (3)	3.5 (3)	0.36
# sibs alive (mean, median)	4.7 (5)	4.8 (5)	0.70
# sibs dead (mean, median)	0.63 (0)	0.61 (0)	0.17
# adults in household (mean, median)	3.6 (3)	3.5 (3)	0.83
# children in household (mean, median)	4.8 (4)	5.1 (5)	0.05
# (%) presently in school			
-Subject	62.2 (61)	87.8 (86)	0.0001*
-Subject's nearest age, same sex sibling	67.3 (66)	85.7 (84)	0.001*
	Compared to closest sib p=0.05	Compared to closest sib p=0.15	
Mom Job status (%)			0.03*
-missing	12.2 (12)	4.1 (4)	
-housewife	57.1 (56)	44.9 (44)	
-student	0	2.0 (2)	
-full time salaried	9.2 (9)	21.4 (21)	
-piece work	6.1 (6)	7.1 (7)	
-self-employed	5.1 (5)	12.2 (12)	
-farmer	6.1 (6)	2.0 (2)	
-seeking work (was employed)	0	2.0 (2)	
-seeking work (never employed)	0	2.0 (2)	
-retrenched	1.0 (1)	0	
-retired	1.0 (1)	0	
Dad's job status (%)			0.38
-missing	13.3 (13)	16.3 (16)	
-housewife ^o	1.0 (1)	1.0 (1)	
-student	0	3.1 (3)	
-full time salaried	25.5 (25)	34.7 (34)	
-piece work	16.3 (16)	9.2 (9)	
-self-employed	10.2 (10)	11.2 (11)	
-farmer	22.4 (22)	21.4 (21)	
-seeking work (was employed)	2.0 (2)	1.0 (1)	
-seeking work (never employed)	0	1.0 (1)	
-retrenched	2.0 (2)	0	
-retired	2.0 (2)	2.0 (2)	
Housing quality score (mean)	8.4	8.5	0.33
Water source (% , n)			0.005*
-Running in home	13.3 (13)	30.6 (30)	
-pump	20.4 (20)	26.5 (26)	
-tap	49.0 (48)	25.5 (25)	
-well	8.2 (8)	9.2 (9)	
-stream/river	9.2 (9)	8.2 (8)	
Waste management (% , n)			0.002*
-missing	0	1.0 (1)	
-toilet in dwelling	13.3 (13)	29.6 (29)	
-toilet nearby	0	6.1 (6)	
-pit latrine	66.3 (65)	52.0 (51)	
-bush	20.4 (20)	11.2 (11)	
Electricity in dwelling (% , n)	25.5(25)	44.9 (44)	0.01*
Cooking source (% , n)			0.001*
-missing	1.0 (1)	1.0 (1)	
-electric stove	21.4 (21)	41.8 (41)	
-wood	44.9 (44)	44.9 (44)	
-charcoal	32.7 (32)	12.2 (12)	
Lights (% ,n)			0.003*
-electric	26.5 (26)	44.9 (44)	
-generator	0	1.0 (1)	
-kerosene/gas/paraffin	27.6 (27)	32.7 (32)	
-candles	36.7 (36)	19.4 (19)	
-fire	9.2 (9)	2.0 (2)	
Wealth (mean kwacha, dollars)	1,314,000	2,396,000	0.01*
Meals per day for child	\$292	\$532	0.0007*
-missing	1.0 (1)	0	
-one	2.0 (2)	0	
-two	29.6 (29)	9.2 (9)	

Characteristics	Epilepsy	Controls	p-value
-three or more	67.3 (66)	90.8 (89)	
# meat, poultry, or fish meals per month child eats	9.3 (8)	11.0 (10)	0.04*
Kg of mealie mealie purchased by household/person/month ³ (mean, median)	11.3 (8.3)	9.1 (8)	0.22
Low middle upper arm circumference # (%)	17 (17.3)	7 (7.1%)	0.03*
height ⁴	122.4 (130)	131.4 (133)	0.07
Mean ht:age z-score	-3.30	-1.96	0.24
Mean wt:age z-score	-1.55	1-.79	0.47
Mean wt:ht z-score	-3.05	0.09	0.87
Mean muac:ht z-score	-1.22	-0.76	0.48

² p<0.05

* indicates p<0.05

⁵ Indicates dad staying at home while wife is employed outside the home

³ Adjusted for number of adults and children within the household

⁴ Z-scores for weight:height were not significantly different (p=0.25)

Table 2

Explanations provided as to why CWE was not in school (n=30)

Reason	Number
Seizure worries	17
Associated disabilities (intellectual disability)	3
Stigma (others laugh at them, etc.)	4
No money for school	2
No school available	2
Not applicable (too young to attend school)	2