

Household poverty, schooling, stigma and quality of life in adolescents with epilepsy in rural Uganda

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Abstract

Background

Epilepsy remains a leading chronic neurological disorder in Low- and Middle-Income Countries. In Uganda, the highest burden is among young rural people. We aimed to; (i) describe socio-economic status (including schooling), and household poverty in adolescents living with epilepsy (ALE) compared to unaffected counterparts in the same communities and (ii) determine the factors associated with the overall quality of life (QoL).

Methods

This was a cross-sectional survey nested within a larger study of ALE compared to age-matched healthy community children in Uganda. Between Sept 2016 to Sept 2017, 154 ALE and 154 healthy community controls were consecutively recruited. Adolescents recruited were frequency and age-matched based on age categories 10–14 and 15–19 years. Clinical history and standardized assessments were conducted. One control participant had incomplete assessment and was excluded. The primary outcome was overall QoL and key variables assessed were schooling status and household poverty. Descriptive and multivariable linear regression analysis were conducted for independent associations with overall QoL.

Results

Mean (SD) age at seizure onset was 8.8 (3.9) years and median (IQR) monthly seizure burden was 2 (1–4). Epilepsy was associated with living in homes with high household poverty; 95/154 (61.7%) ALE lived in the poorest homes compared to 68/153 (44.5%) of the healthy adolescents, $p = 0.001$. Nearly two-thirds of ALE had dropped out of school and only 48/154 (31.2%) were currently attending school compared to 136/153 (88.9%) of healthy controls, $p < 0.001$. QoL was lowest among ALE who never attended school ($p < 0.001$), with primary education ($p = 0.006$) compared to those with at least secondary education. Stigma scores [mean(SD)] were highest among ALE in the poorest [69.1(34.6)], and wealthy [70.2(32.2)] quintiles compared to their counterparts in poorer [61.8(31.7)], medium [68.0(32.7)] and wealthiest [61.5(33.3)] quintiles, though not statistically significant ($p = 0.75$). After adjusting for covariates, ALE currently attending school had higher overall

QoL compared to their counterparts who never attended school ($\beta = 4.20$, 95%CI: 0.90,7.49, $p = 0.013$). QoL scores were higher among ALE with \geq secondary education than those with no or primary education ($\beta = 10.69$, 95%CI: 1.65, 19.72).

Conclusions

ALE in this rural area are from the poorest households, are more likely to drop out of school and have the lowest QoL. Those with poorer seizure control are most affected. ALE should be included among vulnerable population groups and in addition to schooling, strategies for seizure control and addressing the epilepsy treatment gap in affected homes should be specifically targeted in state poverty eradication programs.

Introduction

Epilepsy is a leading chronic neurological disorder characterized by a propensity to recurrent unprovoked seizures [1], [2], [3]. This global health problem affects over 50 million people of all ages. Over 80% of people with epilepsy live in Low and Middle-Income Countries (LMICs) [4], [5], [6]. In these regions, populations in rural areas bear a greater burden of the disease: with an estimated median prevalence of active convulsive epilepsy of 12.7 compared to 5.9 per 1000 population in urban areas [7]. The annual mortality is high at a rate of 19.8 deaths (range 9.7–45.1) per 1000 people with epilepsy [8] with a standardized mortality ratio (SMR) of 7.2 (95% CI 4.4–11.6) [9].

The burden of active convulsive epilepsy varies across sub-Saharan Africa and differences in the prevalence of risk factors contribute to the variation in burden [10]. Although the relative contributions of the specific causes of epilepsy have not been fully investigated, the most important include birth trauma, childhood central nervous system (CNS) infections such as bacterial meningitis and cerebral malaria [11], [12], [13], [14], [15], onchocerciasis [9], [16], [17], cysticercosis [18], and traumatic brain injury [19]. Many of these etiological factors are more common in poorer communities suggesting that in poor countries, poverty is a major risk factor of preventable epilepsy.

Epilepsy has devastating consequences on patient's wellbeing such as stigma, reduced likelihood of employment, as well as physical and psychological vulnerability [20]. In rural settings, large family sizes, poor financial returns from agriculture, low household incomes, parental unemployment, and stigma towards children with epilepsy (CLE) all affect families' capacity to address the basic needs of CLE. Moreover, the socio-economic status of homes, parental beliefs, education and household poverty have a negative impact on access to care, achieving seizure control and so, may be important drivers of the higher burden and severity of epilepsy in Africa and the increased attributable mortality [21], [22]. Childhood poverty remains highest in the Northern regions of Uganda [23].

Adolescence is an important transitional stage of life between childhood to adulthood [24]. Many life events during adolescence have the potential for long-term impact including psychosocial, overall earnings and socio-economic status [25]. Some national advocacy efforts for poverty

reduction have prioritized supporting livelihoods in youths below 35 years [26]. Most studies of epilepsy in Africa have also focused on young children and adults to examine the burden, features [27], risks factors [28], antiepileptic drug treatment [29] or clinical [19] and policy implications. To our best knowledge, there are almost no studies of epilepsy in adolescents or the impact of epilepsy on livelihood, achievement, and quality of life (QoL) in the region. Here, we describe schooling, socio-economic status and household poverty and the relationship of these with QoL of adolescents living with epilepsy (ALE) in rural Uganda compared to unaffected adolescents in the same communities. We hypothesized that QoL scores in adolescents with epilepsy differed by their level of formal schooling and household poverty.

Section snippets

Study design

This was a cross sectional study describing the socio-economic status, household poverty, attendance of formal education, and QoL of adolescents with epilepsy compared to age-matched normal community children in northern Uganda. The study was nested in a large project studying the pathogenesis and treatment of a devastating neurologic disorder in this region, the nodding syndrome, and *Onchocerca volvulus* associated epilepsy [30]. Ethical approval was provided by Makerere University School of

Demographics

Over one year from September 2016 to September 2017, 154 patients with convulsive epilepsy and 154 age-matched healthy community controls were recruited. One community control had incomplete assessments and was excluded. The mean (SD) age of participants with epilepsy and healthy controls was 15.5 (1.9) and 14.7 (1.9) years respectively. Three fifths (60.4%) of the ALE were male. The mean (SD) age at seizure onset was 8.8 (3.9) years and at the time of this study, the median (IQR) monthly

Discussion

This study aimed to examine schooling, household poverty and QoL of adolescents with epilepsy in rural northern Uganda. The study demonstrated that epilepsy in adolescents is associated with higher levels of household poverty and poorer QoL. To the best of our knowledge, this is the first such study to describe the relationship between household poverty, schooling status and QoL among adolescent with epilepsy in this region.

Study limitations

First, this baseline survey was cross-sectional in design therefore we were limited in inferring causal relationships between poverty, schooling and QoL in adolescent living with epilepsy. Secondly, some factors associated with regular school attendance, completion rates and QoL in adolescents such as type of and adherence to AED, injury severity (burns) were not controlled for. Despite these methodological gaps, to our knowledge we present the first evidence from Northern Uganda demonstrating

Implications for clinical practice and policy

Quality of life is a multi-dimensional measure of individual general wellbeing therefore clinicians should consider assessing and interpreting associations between clinical history and symptoms within the patients' social context. We demonstrated the relationship between epilepsy and household poverty. A plausible explanation that links long term poverty levels in this setting due to high school dropouts particularly among adolescents with epilepsy can be drawn. Adolescents living with epilepsy

Conclusions

Adolescents living with Epilepsy in this rural area are from the poorest households, are more likely to drop out of school and have the lowest QoL. Those with poorer seizure control are most affected. ALE should be included among vulnerable population groups and in addition to schooling, strategies for seizure control and addressing the epilepsy treatment gap, affected homes should be specifically targeted in state poverty eradication programs.

Declaration of Competing Interest

All authors report no conflict of interest.

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