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 ≥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

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