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Stigma and functional disability in relation to marriage and employment in young people with epilepsy in rural Tanzania

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ABSTRACT

Purpose: To assess the impact of childhood epilepsy on social transitioning outcomes for young people with epilepsy (YPWE) living in Tanzania, and to explore influences on these outcomes.
Methods: At six years from baseline, we followed up 84 YPWE and 79 age- sex- and village- matched controls recruited into a case-control study of childhood epilepsy in rural northern Tanzania. Data were collected from interviews with young people and their carers using a structured questionnaire. Perceived stigma was evaluated using the Kilifi Stigma Score and functional disability using the Barthel Index (BI). The effects of age, gender, functional disability and stigma on selected markers of social transitioning (education, employment and relationships) were estimated using multivariable modelling.
Results: Fewer YPWE than controls were in an intimate relationship (42.3% vs. 76.9%) or in education or paid employment (33.3% vs. 91.1%) and they reported elevated perceived stigma scores (27.4% vs. 3.8%). Among YPWE, a positive education or employment outcome was predicted by a lower seizure frequency (adjusted OR 3.79) and a higher BI score (adj. OR 12.12); a positive relationship outcome was predicted by a higher BI score (adj. OR 45.86) and being male (adj. OR 8.55).
Conclusion: YPWE were more likely to experience adverse employment, educational and relationship outcomes in the transition to adult life than controls, with the greatest disadvantage experienced by females, those with greater functional disability and those with poorer seizure control. Markers of social transitioning should be included in any prospective evaluation of interventions designed to support these groups.

1. Introduction

Epilepsy is one of the most common childhood neurological disorders affecting 33 million children, 85% of whom live in low and middle-income countries (LMICs) [1,2]. The prevalence of epilepsy in sub-Saharan Africa (SSA) is estimated at 9.39 per 1000, compared to 5.8 per 1000 in Europe [3]. The reasons for the higher prevalence in SSA include suboptimal ante- and perinatal care, the high burden of infectious diseases affecting the central nervous system, and traumatic head injury [4]. The problem is compounded by the absence of universal access to antiepileptic drugs (AEDs) [5,6].

In many parts of SSA, epilepsy is a highly stigmatised condition. The aetiology is often thought to be supernatural and the misconception that it is contagious is prevalent [7,8]. The resulting stigma, especially in rural areas, continues into adulthood and so the rates of marriage and employment are significantly lower amongst people with epilepsy (PWE) compared to the general population [9,10].

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Stigma can be separated into two distinct but related concepts: enacted stigma refers to acts of discrimination against the person, performed solely because of their condition, whereas perceived stigma is the stigma that a person feels that they experience and their anticipation of discrimination [11]. Recent research suggests that perceived stigma may have at least as important an effect on health outcomes as enacted stigma [12]. Very high levels of perceived stigma associated with epilepsy have been reported in Ethiopia (81%), Benin (69%) and in adults in Tanzania [13–15]. The Kilifi Stigma Scale (KSS), which can be used to quantify the perceived stigma experienced by PWE, has been validated for use in SSA [16].

PWE are also known to have a higher level of functional disability than their background populations [17]. The Barthel Index (BI) is a commonly used tool to assess functionality by scoring the ability of the subject to complete everyday activities [18].

Both stigma and the disability associated with epilepsy are likely to influence the social transition from childhood to adulthood. Successful social transitioning is often defined in terms of social and economic outcomes [19] and despite the fact that in resource-poor settings seizure remission can be achieved in up to 75% of people with epilepsy, given access to adequate treatment and follow-up, around half of all PWE remain disadvantaged in terms of social outcomes [20].

We compared social (relationship status and marriage expectations) and economic (educational achievement and initiation into vocation/employment) outcomes in adolescents with and without epilepsy living in rural Tanzania and examined associations between perceived stigma and disability on these outcomes.

2. Methods

This study was part of the long-term follow-up of a cohort of YPWE living in the Hai district of northern Tanzania, which was initially recruited in 2009 and 2010 [21]. We employed both cross-sectional and case-control designs.

2.1. Setting

Tanzania is one of the world's poorest countries, with 46.6% of the population living on less than $1.90 a day (2011 Purchasing Power Parity) [22]. The rural Hai district is located in the north of the country, on the southern side of Mount Kilimanjaro, where the vast majority of the population is engaged in subsistence farming. Cash crops including coffee and tomatoes are also grown to generate additional income. Part of the district was established as a health and demographic surveillance site in the early 1990s [23] and each village has at least one enumerator, who is responsible for collecting census data and liaising with the community with regards to on-going research.

Government-funded healthcare in the district is provided by village dispensaries, one health center and one district hospital. There are also numerous private and church-run dispensaries and a Lutheran mission hospital as well as a large tertiary referral hospital where neurology services are available.

In Tanzania, children start primary school at the age of seven and leave at fourteen. At this stage, they must take an entrance exam to go on to secondary school where they undertake a further four years of education and graduate at 18 years of age. Primary education is 'free, compulsory and universal' whereas secondary education often incurs fees [24].

2.2. Baseline data collection

Children aged six to 14 years (inclusive) with active epilepsy were initially identified in 2009 during a door-to-door prevalence study [25]. A total of 112 children with epilepsy were diagnosed by a paediatrician with a special interest in neurology (KB) using criteria recommended by the International League Against Epilepsy (ILAE) [26]. One hundred and thirteen controls without epilepsy were simultaneously recruited from the background population. For pragmatic reasons pair-wise matching of cases with controls was not attempted, although controls were frequency-matched by age, sex and village to ensure that the groups were broadly comparable.

2.3. Six-year follow-up

2.3.1. Study variables

Demographic data were collected for YPWE and controls, and disease-specific data (e.g. AED use, seizure frequency, last seizure) were collected for YPWE. All study participants aged over 15 years were asked about their relationship status and whether they anticipated getting married and having a family. Participants younger than 15 years were excluded from this outcome measure as local health-care workers advised us that asking about relationships in this group would be culturally insensitive (16 YPWE (19.0%) and 19 controls (24.1%) were younger than 15 years). Those who were not currently in a relationship but thought it likely that they would get married in the future were classed as "expecting to get married".

Participants were classified as 'currently at school', 'completed secondary school', 'never started' or 'did not complete secondary school'. The reasons for not starting or completing secondary school were coded as: epilepsy-related, financial hardship, poor academic performance or due to marriage or employment. For those who had left school, information was gathered on their current occupational status. To answer these study variables, JG, SS, WG and RW composed questions based on prior experience of working in this population and designed them to be simple and unambiguous.

Functional disability was measured using the Barthel Index (BI), a tool which assesses functional independence in ten activities of daily living [18]. The BI is quick to complete, can be answered by the primary carer, and is disease and culturally non-specific, making it a useful tool for comparisons with disability levels worldwide. It has been previously used in SSA, including within the Hai population [27–29]. One minor modification was necessary for use in Hai: since almost all buildings are single-storey the ability to climb stairs was replaced with the ability to walk up a steep hill. For analysis, scores were divided into groups by severity of impairment: no/mild (19–20), moderate (15–18) and severe (<15) functional disability [30].

Perceived stigma was measured using the Kilifi Stigma Scale (KSS) [16]. The scale has 15 items, scored as 'not at all' (scored 0), 'sometimes' (scored 1) and 'always' (scored 2). A higher score suggests a greater level of perceived stigma. The scale has been validated and shown to have high internal consistency ($\alpha = 0.91$) and test-retest reliability ($r = 0.92$). Internal consistency scores did not change whether a PWE or their caregiver answered the questions [16]. We were advised by local health workers that asking the KSS questions to those younger than 15 would be culturally inappropriate.

The final questionnaire included the questions developed by the authors followed by the modified BI and KSS.