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Cognition, mood and quality-of-life outcomes among low literacy adults living with epilepsy in rural Kenya: A preliminary study

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ABSTRACT

Epilepsy is frequently associated with neurocognitive impairments, mental health, and psychosocial problems but these are rarely documented in low- and middle-income countries. The aim of this study was to examine the neurocognitive outcomes, depressive symptoms, and psychosocial adjustments of people with epilepsy (PWE) in Kilifi, Kenya. We evaluated the impact of these outcomes on health-related quality of life. Self-report, interviewer-administered measures of depression (Major Depression Inventory) and quality of life (RAND SF-36) were administered to 63 PWE and 83 community controls. Neurocognitive functioning was assessed using Raven's Standard Progressive Matrices, Digit Span, and Contingency Naming Test. The results show that PWE have poorer scores for executive function, working memory, intelligence quotient (IQ), depression, and quality of life than controls. Twenty-seven (27%) of PWE had depressive symptoms, which was significantly greater than in controls (6%); $P < 0.001$. Quality-of-life scores were significantly lower in PWE with depressive symptoms than in those without depressive symptoms (Mean QoL scores (standard deviation (SD)): 46.43 (13.27) versus 64.18 (17.69); $P = 0.01$. On adjusted linear regression models, depression affected total quality-of-life scores ($P = 0.07$) as well as individual health indicator domains touching on pain ($P = 0.04$), lethargy/fatigue ($P = 0.01$), and emotional well-being ($P = 0.02$). Our results show that epilepsy is associated with a significant burden of mental health and neurocognitive impairments in the community; however, community-based studies are needed to provide precise estimates of these disorders.

1. Introduction

Epilepsy, a common neurological disorder, accounts for a significantly high proportion of the global burden of disease [1]. Approximately 70 million people globally are living with the condition; 80% of which reside in low- and middle-income countries [2, 3]. The prevalence of epilepsy is higher in sub-Saharan Africa (SSA) than in other parts of the world although its estimates vary across regions [4]. In Kilifi, the prevalence of active convulsive epilepsy is estimated to be 7.8/1000, but this could double if nonconvulsive epilepsy is taken into account [4]. Over two-thirds of epilepsy cases in Africa present with focal features [5], which are important risk factors for neurological impairments and cognitive and mental health disorders [5–7].

Several studies have shown that epilepsy is associated with multiple neurocognitive impairments [8–12]. Similarly, adults living with epilepsy have been observed to present with poor mental health and psychosocial adjustment problems including unemployment, poor marriage prospects, and limited education [10,13–16].

However, most of the existing research evidence arises from data from high-income countries. To the best of our knowledge, we do not know of any study that comprehensively investigates the neurocognitive and mental health outcomes of adults with epilepsy in SSA. It is likely that these outcomes are poorer in adults with epilepsy in malaria-endemic areas in SSA such as Kenya since neurocognitive impairments persist in children who have had cerebral malaria [17], which is a risk factor for epilepsy in this region [3,17]. Data from other parts of the world cannot be extrapolated to guide interventions in Africa because of the differences in the proportion of symptomatic epilepsy, healthcare systems, access to medication, and formal and informal support systems among others. There is, therefore, an urgent need to investigate the long-term outcomes of epilepsy among adults in SSA.

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We set out to conduct a comprehensive study examining the neurocognitive outcomes, depressive symptoms, and psychosocial adjustments of adults with epilepsy in Kilifi, Kenya. Specifically, we aimed to answer the following research questions:

1. Do adults with epilepsy experience neurocognitive impairments, depressive symptoms, and psychosocial maladjustments compared with age-matched controls in the community?
2. Do cognitive impairment and depressive symptoms in people with epilepsy (PWE) impact their health-related quality of life?

2. Materials and methods

2.1. Study site and population

This cross-sectional study was conducted at the Centre for Geographic Medical Research, Coast (CGMRC-Kilifi, Kenya), which has unique facilities for the study of neuropsychological functioning. Particularly, the center established the Kilifi Health & Demographic Surveillance System (KHDSS) in 2000 and currently conducts a census three times per year of a population of over 260,000, allowing for accurate follow-up of study participants [18]. Also, the CGMRC hosts an epilepsy clinic with a database of around 2000 people. Within this unit, we have technicians and an assessment team trained to administer measures of neurological, cognitive, and mental health functioning.

With a population of about 1.2 million people, 36% of the inhabitants of Kilifi County lack formal education, and only 52% have attained at least primary school level of education [19]. Majority of the residents are poor, earning a living either through subsistence farming or fishing [18]. The prevalence of epilepsy is high in the community [4]; about 62% do not access treatment [20].

2.2. Selection of study participants

This was part of a larger study conducted to evaluate the feasibility, acceptability, and reliability of using a mobile-based cognitive measure to assess and monitor chronically ill adults in Kilifi, Kenya. In this larger study, adults of low literacy were specifically targeted based on the assumption that they were more likely to experience challenges being assessed using mobile-based technology. It was envisaged that measures that can be used with the less literate populations will work with those who are better educated. As such, study participants were limited to only those with a primary level of education (up to class 8 in the current Kenyan education system).

2.2.1. Participants living with epilepsy

Stratified random sampling was used to recruit 100 adults, based on standard psychometric guidelines where a sample size of at least 100 participants is needed for one to carry out internal consistency tests and get stable estimates [21]. Eligible participants were randomly selected from the Epilepsy database, followed in their rural homes, and included based on the following: i) if they had a confirmed epilepsy diagnosis; ii) they were aged 20 to 50 years; iii) they had no more than primary level of education; iv) they were able to provide informed consent together with a caregiver where needed; v) they were fluent in Swahili language; and vi) they had no symptoms of acute illness on the day of assessments.

2.2.2. Control subjects

Controls were randomly selected from the KHDSS database, later approached at home, and requested to take part in the study. Those agreeing were referred to the clinic for assessment. All had to satisfy similar inclusion criteria as the cases apart from the epilepsy diagnosis.

2.3. Procedures

After giving consent, every participant underwent a detailed medical examination and neuropsychological assessment. Five-day training was given by the principal investigator, a research psychologist, to orient data collectors and supervisor on the measures to be used and the objectives of the study. Questionnaires were checked for completeness and consistency by the supervisor and principal investigator (Flowchart 1).

2.4. Measures

Consent forms, questionnaires, and tests were all translated to Swahili and back-translated and pretested before administration in the study.

2.4.1. Cognitive functioning

Cognitive measures assessed three domains: executive functioning, working memory, and intelligence quotient (IQ). Three measures that have previously been used in Kilifi were administered: i) Raven's Standard Progressive Matrices (RSPM) [22], which is a nonverbal standardized measure of intelligence; ii) Contingency Naming Test (CNT), which taps the processing speed, attention shift, and response inhibition aspects of executive functioning and requires naming the color or shape of a series of stimuli according to different rules [23]; iii) Digit Span Backwards, which is a test of memory span having a list of random numbers which are read aloud to the participant who is then required to recall the items in a reverse order [24].

2.4.2. Depressive symptoms

Major Depression Inventory (MDI) is a self-report measure of moods experienced in the past 2 weeks aimed at investigating depressive symptoms [25]. It has 12 items; however, during scoring, only 10 items were considered since items 8 (a) and (b) and items 10 (a) and (b) were collated into two items. The measure is scored on a 6-point Likert scale with '0' being at no time and '5' at all the time. As a severity measure, the tool's score ranges from 0 to 50. Mild depression was interpreted as an MDI total score of 20–24. Moderate depression was equated to an MDI total score of 25–29, and severe depression for scores of 30 or more. This measure has been adapted and yielded reliable psychometric properties among young adults in Kilifi [26].

2.4.3. Quality of life

The RAND 36-Item Health Survey 1.0 is a generic measure of health-related quality of life. It assesses eight health domains namely physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, emotional well-being, social functioning, energy/fatigue, and general health perceptions [27]. Scoring the tool is a two-step process. Firstly, precoded numeric values are converted to percentages using a predetermined scoring key with a high score defining a more favorable state of health. Secondly, items in the same scale are averaged together to create the 8 different scale scores.

2.4.4. Socioeconomic status (SES)

A 13-item asset index, which is used reliably to assess SES over time in studies conducted in this rural setting, was administered to adults with and without epilepsy [28,29]. The asset index items screen for the ownership of a list of disposable assets by participants (or their family) such as radio, television, bicycle, and motorbike. A single index score of SES was generated, with a higher score indicating a higher SES.

2.5. Clinical characterization of PWE

Epilepsy-related features including semiology (focal versus generalized seizures), frequent versus infrequent seizures, electroencephalogram (EEG) recordings, and antiepileptic drug (AED) treatment were