Brief Communication

Community perceptions of developmental and behavioral problems experienced by children living with epilepsy on the Kenyan coast: A qualitative study

Amina Abubakar [a,b,c,*], Symon M. Kariuki [a,d], Judith Dzombo Tumaini [a], Joseph Gona [a], Khamis Katana [a], Jacqueline A. Phillips Owen [e], Charles R. Newton [a,f]

[a] KEMRI-Wellcome Trust Research Programme- Centre for Geographic Medicine Research (Coast), Kenya
[b] Department of Culture Studies, Tilburg University, Netherlands
[c] Department of Psychology, Lancaster University, UK
[d] Nuffield Department of Medicine, University of Oxford, Oxford, UK
[e] Institute of Psychiatry, Kings College London, UK
[f] Department of Psychiatry, University of Oxford, UK

ABSTRACT

Childhood epilepsy is common in Africa. However, there are little data on the developmental and behavioral problems experienced by children living with epilepsy, especially qualitative data that capture community perceptions of the challenges faced by these children. Identifying these perceptions using qualitative approaches is important not only to help design appropriate interventions but also to help adapt behavioral tools that are culturally appropriate. We documented the description of these problems as perceived by parents and teachers of children with or without epilepsy. The study involved 70 participants. Data were collected using in-depth interviews and focus group discussions and were analyzed using NVIVO to identify major themes. Our analysis identified four major areas that are perceived to be adversely affected among children with epilepsy. These included internalizing and externalizing problems such as aggression, temper tantrums, and excessive crying. Additionally, developmental delay, especially cognitive deficits and academic underachievement, was also identified as a major problematic area. There is a need to supplement these findings with quantitative estimates and to develop psychosocial and educational interventions to rehabilitate children with epilepsy who have these difficulties.

© 2015 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

1. Introduction

Epilepsy is a common neurological disorder in resource poor settings, where it is often caused by brain insults, including infectious disease and perinatal complications [1,2]. It is estimated that nearly 70 million people live with epilepsy worldwide; of these people, 10 million live in the African continent [3]. Epilepsy in children is associated with cognitive impairments [4–6], academic underachievement [7,8], and behavioral and emotional problems [9]. However, most of the evidence arises from studies carried out in Western countries, and there is paucity of data from Africa. Differences in formal health systems, underlying risk factors and social support available for people with epilepsy (PWE) in Africa compared with those in the West, imply that evidence from the West cannot be extrapolated to formulate or implement intervention programs for PWE in Africa [10,11]. There is, therefore, a need for

more African-based mental health studies among PWE so as to provide an evidence base that can be used to develop appropriate interventions.

The impetus for this study is provided by three interlinked factors. First, there are few studies from Africa such as those by Kariuki et al. [9], Lagunju et al. [12], and Burton et al. [13], all of which used quantitative standardized methodologies to demonstrate an increased prevalence of behavioral problems in children with epilepsy compared with controls. While the earlier approaches allow for the quantification of the problem, they did not provide information on the community's perceptions of the behavioral and developmental challenges faced by children with epilepsy. In studying aspects related to behavioral outcomes among children, inclusion of community voices is especially important since there are observations showing contextual and cultural differences in the way people present and express mental health symptoms. Qualitative data are important in capturing cross cultural nuances in understanding ill-health and its consequences whenever it exists.

Second, Africa lacks culturally appropriate and standardized measures for use in evaluating childhood developmental and behavioral problems. The literature provides many examples to show that the simple

* Corresponding author at: Centre for Geographic Medicine (Coast), KEMRI-Wellcome Trust Programme, Box 230, Kilifi, Kenya.
 E-mail address: AAbubakar@kemri-wellcome.org (A. Abubakar).

translation of measures for childhood outcomes from the West into local languages may not be an adequate approach and that, very often, researchers have to make significant adaptations to these measures to ensure their adequacy [14–16]. Qualitative research is useful in ensuring that study materials, questions, idioms, and stimuli are both contextually relevant and culturally appropriate [17]. Qualitative studies provide additional information that is useful in designing studies and in adapting methods and questionnaires for use in large-scale epidemiological surveys [18]. Therefore, as a first step in carrying out a large community survey aimed at quantifying the burden of behavioral problems in children with acute seizures, we carried out this study to understand, in part, the idioms and phrases that can be used to define behavioral problems in this area while adapting and validating the Child Behavior Checklist (CBCL) and the Strength and Difficulties Questionnaire (SDQ) [19].

Third, the inclusion of community voices in understanding the challenges of chronically ill children is important in providing ecological validation of quantitative data and in developing appropriate interventions. In the context of psychological assessment, ecological validity refers to the extent to which 'deficits' observed during controlled assessments can be replicated or observed in the day-to-day function of a person across different settings [20].

The current study was set out to answer the following question: What are the developmental and behavioral problems experienced by children with epilepsy in Kilifi as perceived by parents and teachers of children with epilepsy and of those without epilepsy?

2. Methods

2.1. Study site

The study was undertaken in Kilifi County, Kenya. Kilifi County is one of the poorest counties in Kenya, with more than 67% of the people living below the poverty line (living on less than a dollar a day), indicating limited access to essential food and nonfood items [21]. Most of the people in Kilifi depend on subsistence farming, but frequent failure of rainfall has resulted in insufficient farming products, compromising food access in the general population. Epilepsy is common in children living in Kilifi, with an adjusted prevalence of lifetime and active epilepsy as 41/1000 (95% confidence interval (CI): 31–51) and 11/1000 (95% CI: 5–15) and an incidence of active epilepsy of 187 per 100,000 per year (95% CI: 133–256) in children 6–12 years of age [22]. We have found that behavioral problems are very common in children with epilepsy [9]. At the Kilifi County Hospital, there is a clinic dedicated to the care of people living with epilepsy. The clinic provides assessment including electroencephalography, antiepileptic medication (phenobarbital, phenytoin, carbamazepine, and/or sodium valproate), outpatient services, and counseling for people living with epilepsy and their caregivers.

2.2. Study participants and sampling

For mothers of children with epilepsy and of those without epilepsy, the sampling was based on databases at the KEMRI-CGMRC. Two sets of databases were used. For parents of children with epilepsy (n = 40), we used the data for children in a cohort with epilepsy [22]. We made a list of all parents who have children with epilepsy ≤12 years of age. We identified 40 parents of children without epilepsy ≤12 years of age from the Kilifi Demographic Surveillance Data [23]. These families were visited at home and recruited to join either the focus groups or the in-depth interviews based on availability for either. Recruitment was carried out until we had reached a point of saturation where no more new data were being collected during the interviews. For the sample of teachers, we conveniently selected two schools from Kilifi and randomly selected teachers from these schools who teach children in the lower primary classes (since most of them will be less than 12 years of age) to participate in either the focused group discussions or the individual in-

Table 1
Participants' characteristics.

Group	Participants' median age in years (IQR)[a]	In-depth interviews	Focus group discussion	Total
Parents/caregivers of children with epilepsy	35.0 (28.5–39.3)	10	3 FGDs N = 7 N = 6 N = 4	27
Parents of children without epilepsy	23.0 (20.5–26.0)	11	2 FGDs N = 6 N = 7	24
Teachers	32.0 (27.0–41.0)	5	2 FGDs N = 7 N = 7	19
Total	30.5 (23.7–37.2)	26	44	70

IQR = interquartile range.
[a] Age range reported for the participants who provided us with this information. Some (33%) participants did not provide us with this information.

depth interviews. Only teachers who were available at the time of the appointments participated (See table 1 for details on the participants).

2.3. Data collection

Data were collected using in-depth interviews and focus group discussions. All interviews and focus group discussions were audio-taped. Each interview and focus group discussion took approximately 1 h. The interviews were guided by a standard set of questions to ensure standardization. Probes and clarifications were sought as deemed necessary. Participants were asked to express themselves in the language in which they were most comfortable; thus, sessions were conducted in both Kiswahili and Kigiriama interchangeably.

2.4. Interview tool

A checklist of questions was developed by the research team through discussions and consensus. Through initial interviews and discussions of the initial transcripts among the study team, the questions were modified. The items were clarified through an iterative process, involving the first few FGDs and in-depth interviews; this was carried out to ensure clarity in the questions presented and in the responses received.

2.5. Data management and analysis

The final transcripts used for analysis were generated from the audio-taped materials. Data were analyzed using the NVIVO 10 software program through content analysis [24,25]. This process was completed based on prior defined themes of interest. Based on five randomly selected transcripts, the first author (AA) and the fourth author (JG) independently generated coding schemes and identified themes. Three of the authors (AA, JG, and JTD) then met to discuss the coding and generated themes. Based on this process, an agreed-upon coding scheme was generated and AA coded all the remaining transcripts. After coding the transcripts, AA and JG discussed the coding item-by-item with a view to ensuring consistency in coding. Direct quotes from the transcripts are presented to support the identified themes. Three of the authors – AA, JG, and JTD – checked for the accuracy of the translations and interpretation of the quotes presented.

2.6. Ethical considerations

The Kenya Medical Research Institute National Scientific and Ethical Committees approved the study. Written informed consent was obtained from all study participants prior to participation.