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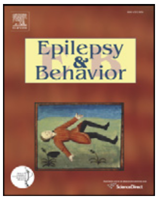

The reasons for the epilepsy treatment gap in Kilifi, Kenya: Using formative research to identify interventions to improve adherence to antiepileptic drugs

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ABSTRACT

Many people with epilepsy (PWE) in resource-poor countries do not receive appropriate treatment, a phenomenon referred to as the epilepsy treatment gap (ETG). We conducted a qualitative study to explore the reasons for this gap and to identify possible interventions in Kilifi, Kenya. Focus group discussions (FGDs) were carried out of PWE and their caregivers. Individual interviews were conducted of PWE, their caregivers, traditional healers, community health workers and leaders, nurses and doctors. In addition, a series of workshops was conducted, and four factors contributing to the ETG were identified: 1) lack of knowledge about the causes, treatment and prognosis of epilepsy; 2) inaccessibility to antiepileptic drugs; 3) misconceptions about epilepsy derived from superstitions about its origin; 4) and dissatisfaction with the communication skills of health providers. These data indicated possible interventions: 1) education and support for PWE and their caregivers; 2) communication skills training for health providers; 3) and improved drug provision.

1. Introduction

Over 69 million people worldwide have epilepsy, of which 62 million live in resource-poor countries (RPCs) [1]. More than 500 million people are indirectly affected by epilepsy as parents, relatives and friends [2]. The World Bank has prioritized epilepsy as a highly cost-effective condition to treat [3] since relatively inexpensive antiepileptic drugs (AEDs) are very effective in controlling seizures: with up to 75% of those treated will become seizure free [4]. Despite this fact, over 90% of the people with epilepsy (PWE) in RPCs do not receive appropriate treatment for their condition [5–7], a phenomenon that has been called the 'Epilepsy Treatment Gap (ETG)'. The International League Against Epilepsy (ILAE) has defined ETG as the difference between the number of people with active epilepsy and the number of people whose seizures are being appropriately treated [8].

In response to the diverse factors involved in the effective treatment of PWE in RPCs, several researchers have tried to instigate affordable community-based interventions. Previous interventions at community the level have met with some success in Nakuru, Kenya [9], Ecuador [10], Malawi [11] and India [12,13]. Recent directives from the World Health Organization (WHO) state that health care delivery will increasingly have to move away from acute illness episodes and concentrate more on treatment adherence, client self-management and quality-of-life issues [14].

The characteristic of most successful interventions is integration within community health care delivery and community involvement in the planning and implementation processes. Community-based interventions have been used with some success in several conditions. For example, in Nigeria, community-designed and community-administered treatment programs have been successful in the control of onchocerciasis [15], and in Bangladesh, community health workers (CHWs) have successfully identified tuberculosis (TB) and increased adherence to treatment in their own villages [16].

Most commentators highlight the need for good anthropological or community-based data on practices and perceptions for behavioral interventions to succeed [17]. In Kilifi, there is some evidence that

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Abbreviations: PWE, people with epilepsy; ETG, epilepsy treatment gap; FGDs, focus group discussions; RPCs, resource-poor countries; AEDs, antiepileptic drugs; CHWs, community health workers; CWE, children with epilepsy; THs, traditional healers.

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bio-medical treatment regimens for children with epilepsy (CWE) are in conflict with local perceptions [18]. Parents may have a ‘health’ versus ‘sickness’ model that influences their perceptions of treatment. Occasional seizures may be placed in the ‘health’ sphere, making the recommendation of regular and continued medication illogical for what is perceived to be a generally healthy child. If regular seizures persist beyond a certain age, the child may be placed in the ‘sickness’ sphere, suggesting that the child is incurable and treatment attempts are futile. El Sharkawy and colleagues also found that belief in ‘external’ causes (such as witchcraft, contact with certain animals/birds) of epilepsy was commonly held, and that treatment choices favored external treatments, such as wearing charms or pouring liquid on the child's body [18]. These findings are similar to those of Hausmann-Muela and colleagues, who investigated what they termed as ‘medical syncretism’ in Tanzania [19]. They found that in the case of malaria, biomedical knowledge is blended with indigenous concepts [19]. These examples fall under Helman's description of ‘externalising’ belief systems, which concentrate on etiologies arising outside of the sick child's body [20]. If the cause of an illness is believed to be found in the natural, social or supernatural worlds, biomedicine may be sought for symptomatic relief only, but the cure and explanations about the causality are sought from traditional healers (THs) [20].

Identifying the cultural context, values, beliefs and community norms of target groups through qualitative research is the key to the design and implementation of successful interventions [21]. Akogun and colleagues comment that their experience of working with a Nigerian community to implement a behavioral intervention suggests that within certain parameters, the structure of interventions may be less important than the process through which they are introduced, in terms of acceptability and sustainability [15]. Building upon the work of El Sharkawy and colleagues [18], we aimed to carry out a qualitative investigation to develop alternative intervention strategies based on the expressed needs and perceptions of the stakeholders. While El Sharkawy and colleagues focused on the effect of attitudes and practices on service utilization for children with epilepsy [18], we specifically conducted this descriptive research as part of preliminary work to develop an intervention to address the ETG in both adults and children with epilepsy, within the broader community of Kilifi District, including traditional medicine. Our research questions were:

1. What are the stakeholders' (PWE, their families and service providers) attitudes and beliefs relating to PWE and how do they affect the utilization of the traditional and biomedical services offered to this population group?
2. What are the specific needs of PWE and their families?
3. Using techniques such as participatory workshops, can a consensus be reached with key community members on an intervention that will reduce the ETG and improve the quality of life of PWE in Kilifi?

2. Methods

2.1. Study setting

This qualitative study was conducted in the Kilifi Health Demographic Surveillance System (KHDSS) located in Kilifi District on the coast of Kenya. It comprises 15 locations with 40 sub-locations sub-divided into 187 enumeration zones that can be easily located using digital maps of homesteads. It covers an estimated area of 891 km^2 with 233,880 residents in 28,000 homesteads. The residents are mainly Mijikenda, a Bantu grouping of nine tribes with Giriama (45%), Chonyi (33%) and Kauma (11%) dominating. The average per capita income is about Ksh.700 (10 US dollars) per month, and about 55% of the population is considered poor. The majority (80%) depend on subsistence farming which is limited by the low productivity of the land since only 19% of the land is arable. Literacy levels are low: only 45% of the people can read and write [22].

2.2. Sample

Families from different educational backgrounds and with different experiences of AED treatment were purposively selected using the baseline information recorded on the KHDSS. The criteria for selection are outlined in Table 1. The target age group was anyone with epilepsy — adult or child. The selection criteria were treatment status, educational background and severity of epilepsy. Once appropriate participants were identified, convenience sampling was used, influenced by willingness to participate, geographical distribution and time constraints.

Service providers (CHWs, in the case of the FGDs) were identified from lists of active community health worker groups held by the local Ministry of Health. Community health workers are members from the community who have volunteered or have been selected by the village leaders to receive extra training about health matters. They often do this on a voluntary basis but receive some payment, for example, when attending seminars on health. Initial pools of participants for individual interviews and participatory workshops were elicited from FGD participants, using a snowballing technique. Final selection and participation were again based on convenience and voluntary informed consent. The composition of key informant groups is described in Table 2.

2.3. Procedure

The study included a combination of strategies for data collection – FGDs, individual interviews and participatory workshops – to enhance

Table 1
Criteria for sample selection for focus group discussions.

Key informant group	Selection factors	Method of identification
Children with epilepsy (14–18 years)	• Have/have never received available treatment • Have received and rejected available treatment • Attending school/not attending school	• Identified from KHDSS
Adults with epilepsy	• Have/have never received available treatment • Have received and rejected available treatment • Less educated[a]/more educated[b]	• Identified from KHDSS
Parents of children with epilepsy	• Child has/has never received available treatment • Child has received and rejected available treatment • Less educated[a]/more educated[b]	• Identified via the child's record on the KHDSS
Other family members of children living with epilepsy	• Grandmothers of children with mild and severe epilepsy • Siblings (aged 14–18 years) of children with mild and severe epilepsy	Identified via the child's record on the KHDSS

Severe epilepsy was defined as more than one seizure per week; mild epilepsy was defined as less than one per month;KHDSS: Kilifi Health Demographic Surveillance System.

[a] Less educated residents indicated 8 years or less of schooling.

[b] More educated residents indicated more than 8 years of schooling.