

# Family Environment and Influence on Children with Epilepsy

+Elwyn Chomba<sup>1</sup>, Alan Haworth<sup>2</sup>, Masharip Atadzhanov<sup>3</sup>, Edward Mbewe<sup>4</sup>, & Gretchen L. Birbeck<sup>5</sup>

## ABSTRACT

### Background

Epilepsy is a common, chronic childhood illness in Zambia and has adverse effects not only on children with epilepsy but on parents/guardians and siblings. In order to effectively understand and help children with epilepsy and their families, healthcare providers and advocacy groups must better understand the psychosocial, economic, and behavioural impact of epilepsy on the family unit.

### Methods

A series of focus group discussions involving the parents of children with epilepsy as well as youths with the condition were held in urban Lusaka and rural Mazabuka from 16<sup>th</sup> June to 9<sup>th</sup> October 2004

### Results

Key issues reported by families included parental fears regarding seizure-related injury with subsequent efforts to "protect" the child from such injuries. This negatively impacted parental work and educational opportunities, educational opportunities for the children were sometimes abbreviated to avoid school-related injury exposures and older children resented limitations placed upon them by their parents. Behavioral problems in the child with epilepsy resulted in social conflicts for the entire household, both among family members and with the greater community. Sometimes however, where residence was well established and assistance requested, neighbours were a source of support for some families. Conflicts between the parents also occurred frequently as a result of stressors related to the additional care burden. Dual usage of traditional healers and medical clinics was generally reported with healthcare costs notably higher among healers. Despite their limitations, children with epilepsy reported many age-appropriate life ambitions.

### Discussion

The presence of a child with epilepsy impacts the entire household. These issues need to be considered by healthcare providers, advocacy groups, and governmental bodies.

## INTRODUCTION

Epilepsy is the commonest neurological disorder with the highest morbidity in infancy, childhood and adolescents. (1, 2) Epilepsy prevalence rates are particularly high in Zambia with children disproportionately affected (3). In addition to the medical morbidity and mortality associated with a seizure disorder, childhood epilepsy exposes individuals to detrimental social and economic problems when they are at their most vulnerable. Potential factors affecting a child's development are complex and numerous. This qualitative, focus group discussion study was conducted to assess how the family environment is impacted by a child with epilepsy and the subsequent effects on children with epilepsy and the larger family.

## METHODS

Focus group discussions were held in rural Mazabuka and urban Lusaka. Groups included 10-15 participants each and consisted of children with epilepsy aged between 8- 15 years (2 urban, 1 rural), female caretakers of children with epilepsy (1 urban, 1 rural) and male caretakers of children with epilepsy (1urban, 1 rural). Participants in the rural regions were invited, based upon a random selection from a population-based epilepsy registry, with stratified sampling to avoid selection of more than one participant per village. Urban participants were selected via random selection from the 10 urban clinics managing children with epilepsy.

Urban meetings were conducted in the students lecture room within the Department of Paediatrics and Child Health. Rural discussions were held in the local high school's conference room. For each discussion, two local research nurses fluent in the local language (Tonga,

<sup>1</sup> University of Zambia School of Medicine,

<sup>2</sup> Chainama Hills College of Health Sciences,

<sup>3</sup> Michigan State University International Neurologic & Psychiatric Epidemiology Program (INPEP) & Director of Chikankata Health

\*Corresponding author

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Nyanja or Bemba) as well as English facilitated the discussion. Many of the facilitators were already experienced in focus group discussion facilitation, but a 1-day training symposium was held in Lusaka for all facilitators to assure a common understanding of the process and goals. The facilitators assisted in preparing a list of topics to be covered during the discussion. Consent was sought for participation as well as audio recording of the discussions, which were subsequently translated into English for content by a committee of 2-3 individuals including a healthcare worker and social worker. A co-investigator or the principal investigator was generally present at the discussions as an observer only.

The University of Zambia's Research Ethics Committee and Michigan State University's University Committee for Research involving Human Subjects approved this work.

## RESULTS

Several common themes emerged across discussions, which are delineated below.

### *Parental seizure worries*

Most family members were concerned about leaving children with epilepsy alone at home fearful that the child would sustain injuries during a seizure. Not only did the fear arise from injuries that might be sustained during an attack, but also many parents were especially concerned that if the child got burned during a seizure, she/he would never recover from epilepsy. This is a common belief in Zambia. Since many rural households and some urban ones have to use charcoal for most of their cooking, this further prevents an adolescent child from being able to help with cooking.

Guardians also worried that a child with epilepsy might not only cause injury to itself, but that they might cause harm to other children. This was particularly true for older youths with epilepsy who experienced an agitated post-ictal state.

Parental seizure worries often resulted in limitations imposed by the family on the physical environment of the child, which restricted the child's ability to participate in play and attend school and pursue other activities important for normal development and future employment. (3)

The heavy psychosocial burden of seizure worry imposed on parents of children with epilepsy often resulted in loss of employment and educational or training opportunities for the parent. Many parents never felt

free to participate fully in leisure activities away from home.

### *Child behavioural and mood problems*

Most parents complained that their child with epilepsy tended to be depressed and frustrated and older children with epilepsy reported frustration with the limitations imposed upon them by their parents' concerns.

Depression is a common feature in children with epilepsy and may be associated with loss of self-esteem as one the youth reported. (4, 5, 6, 7). Caretakers lacked knowledge regarding the behavioural consequences of seizures and anticonvulsant medications. Many parents interpreted their child's behaviour inappropriately, viewing the child as being "possessed".

Parents who felt that teachers needed to be aware of the child's condition and who sought conventional medicine from health institutions were often frustrated by the stigma their child encountered from peers. Sometimes stigma from other children was severe enough to result in a child having to withdraw from school.

Parents also feared that the child with epilepsy would disrupt classroom if allowed to go to a normal school. This was especially true for parents who reported that their child exhibited aggressive behaviour or were labelled as "mad" by the community. Children's outbursts were frequently destructive.

### *Care Seeking*

Most parents had sought advice and treatment from traditional healers.

Fathers generally indicated that it was the mother who made the decision to take a child to a traditional healer, while many mothers felt that their husbands were not doing enough in caring for these children. Financial burdens associated with care seeking add to marital stress.

Traditional healers' charges ranged from \$6 to \$100 depending on what the parents could afford and not on the service offered (compared to health centres' fees which for under 5's are free. However costs are incurred from transport which varies widely about \$4 to \$8 dollars in the urban and transportation in the rural areas is limited to use of bicycles or by foot. The public health sector also lacks antiepileptic drugs and the cost of these from private pharmacies is beyond the reach of most parents, as drugs are required to be taken regularly over a number of years whereas the healers usually charge

just for the one visit. Healers' recommendations also barred children with epilepsy from eating many of the more nutritious foods available to them—, fish, pork, eggs and chicken.

Care seeking was the responsibility of mothers many relying upon their husbands for funds required to seek help from traditional healers. Attendance at the health institution was also a responsibility of the female caretakers.

Many caregivers complained that the government was not doing enough in procuring drugs for CWE.

### ***Marital Conflict***

Strife in the home was common. In addition to the financial pressures of caring for a child with epilepsy, couples accused each other for not doing enough for the child. Close relatives may advise the couple to divorce believing or accusing each other's family of witchcraft.

### ***Local Community***

In the urban areas, close neighbours were very willing to help CWE by accompanying them to school or seeing to it that they are not injured during a fit.

This worked well if;

- the parent had disclosed that the child had epilepsy
- the child had lived in the same area for a long time

The two above greatly reduced stigma in the neighbourhood and benefited the child.

A right attitude towards neighbours also facilitated improved care of CWE.

Sometimes, neighbours were accused of playing a role in the development of epilepsy in the child. A father of a four-year-old for example reporting the wife's accusation that the neighbours bewitched their child was because he (the father) was the only one with a regular job.

### ***Children's' Ambitions***

Children with epilepsy who had well-controlled fits were ambitious about their future and anxious to continue their education. Career goals ranged from telephone operators to becoming a lawyer. Some children did report school performance problems and the group seemed to acknowledge that this might negatively impact future ambitions.

## **DISCUSSION**

The complexities of development in a child with epilepsy are similar to those in any child. However, the home and family environment will impact either positively or negatively on child development and the child's condition with its associated financial and emotional stressors placing a heavy burden on the entire household. The interpersonal relationships between father and mother of a child with epilepsy play a big role on the child's development. Parental anxiety related to seizure worry may negatively impact the child with loss of self-esteem, lack of autonomy, and a consequent inability to function normally. This relationship between maternal anxiety and the quality of life for children with epilepsy has been previously described by William et al. (3). The impact of epilepsy on the child is manifold. The child who screams the whole day ends up by being chased from the school. There is a lot of frustration, misery and anger exhibited by the children and the whole family. This leads to great destabilisation and a feeling of hopelessness among family members. From our FGD the male contribution to care of the CWE was minimal. However this is not just a reflection on caring for a CWE but is characteristic of most the Zambian families which expect the woman to care for the family whether the man is in employment or not. (9) In a chronic illness such as epilepsy male CWE would require support from their fathers/male guardians especially when they exhibited violent behaviour, which might have been directed against their mothers.

Complex psychosocial problems are also evident among older children. These may result from poor seizure control, cultural beliefs and the family dynamics. The cited reason for this was multi-factorial. Some may be due to the epilepsy itself, others to the loss of autonomy especially in older children and others from over protection by the family.

The economic impact of having a child with epilepsy were many, costly consultations from traditional healers, giving up employment in order to look after a CWE, and staying at home with the child rather than look for food to feed the family.

Lack of drugs within the public health structure had a very severe impact on the family dynamics, not only was the children disruptive because of poorly controlled fits but the parents were extremely frustrated and anxious about the future of their children leading to psychosocial maladjustment within the family.

From the clinician's review of the notes taken during the focus group discussions it was found that children who had well controlled fits or nocturnal fits performed better and thus were well adjusted socially. Some of these children were depressed more from the limitations imposed on them than the epilepsy it self.

Eklund and Siveberg found that seizures, limitations on social activities, side effects from the drugs placed particular strains on the adolescents (4). Gus et al in their study on adolescents found that that the stereotypes and attitudes can cause more pain than the seizure. (1) It was also evident that the lack of drugs in the government institutions was adding to the frustration of the guardians. The lack of sufficient explanation to the caretakers subjected them to further hardships beyond those arising from drug shortages. There was insufficient knowledge on behavioural changes, which may result in a child suffering from epilepsy. Educating parents on epilepsy should be put in place as anxiety and depression experienced by parent's impact negatively on the CWE. In this study it is quite clear that CWE should be prioritized in the acquisition of drugs in order to control their epilepsy as it has been clearly shown in other studies that children whose fits are well controlled are likely to lead productive lives in future. Setting up adolescent clinics/clubs for CWE would help to improve behavioural, social, emotional and educational attainment, as these would offer support to these children in this vulnerable period. These clubs would be used for education on epilepsy.

There is need for health care providers and advocacy groups to have an integrated approach in managing CWE by understanding the impact, which a child with epilepsy has on the family dynamics.

#### **Limitation of the study**

Because of the small sample size there is need to do much larger studies. However this study provides insights into experiences of children with epilepsy within a family environment as most qualitative work it is difficult to know whether those involved in the focus groups provide a representative view.

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