



# Gender Dimensions of the Experience of the Burden of Epilepsy: An Example of the Manguissa Community in Cameroon

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## Abstract

This article examines the effects of gender in the experience of the burden of epilepsy in the Manguissa culture. This exploratory research combined a range of qualitative and quantitative techniques to meet the objectives. In-depth interviews and photo voice<sup>1</sup> were used to collect qualitative data, while quantitative data collection relied on SF12 Scale, ComQol and semi-structured questionnaire. Study findings highlight gender as affecting the level to which one feels the burden of epilepsy. The dichotomy between the sexes was seen in the relationship with family members and the community; intimacy or relationship with the opposite sex; perception of importance and satisfaction about life; and control over life and emotions. This study suggests that being female and having epilepsy in the Manguissa culture is better than being male and having the same condition. This is because females enjoy intimacy and are capable of procreating, so they are perceived as those who still have things to offer despite their condition. Although females are emotionally diminished as compared to males, they are more optimistic about the future than males. We recommend equitable attention and resource allocation at the family level as the first solution to the burden felt by people with epilepsy.

**Key Words:** DALY, culture, burden of disease, resource allocation, quality of life.

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## Résumé

Cet article examine les effets du genre dans l'expérience du fardeau de l'épilepsie au sein de la culture Manguissa. Cette étude exploratoire a combiné une gamme de techniques qualitatives et quantitatives pour atteindre ses objectifs. Les outils tels que les interviews approfondies et les « photo voices » ont été utilisés pour collecter les données qualitatives. Tandis que la collecte des données quantitatives s'est faite à l'aide de l'échelle SF12, le ComQol et un questionnaire semi structuré. Les résultats issus de cette étude nous ont montré que le genre est un facteur important d'acceptation des personnes atteintes d'épilepsie dans la communauté Manguissa. Ainsi, être une femme dans la communauté est mieux perçu qu'être un homme, car pour les femmes, cette maladie n'empêche pas d'entretenir des rapports intimes et la procréation contrairement aux hommes. Ce qui permet d'alléger le fardeau de la maladie chez elles. Cette situation contribue à rendre les hommes pessimistes quant à leur avenir par rapport aux femmes bien qu'émotionnellement diminuées. A l'issu de cette étude nous recommandons une attention et une répartition équitable des ressources au sein des familles ayant des membres atteints d'épilepsie.

**Mots clés :** DALY, culture, le fardeau de la maladie, la répartition des ressources, qualité de vie.

## Introduction

The experience of the burden of disease has been measured using the Disability Adjusted Life Years (DALY). Th is a composite measurement of the overall burden of disease due to losses from premature mortality and from healthy life resulting from disability (AbouZahr 1999; Anand and Kara 1997). However, this evaluation relies heavily on mortality although mortality is just one of the burdens of disease and cannot account for the entire experience of patients. Epilepsy as a disease is perceived differently across cultural boundaries and the experience of its burden is likely to match cultural perceptions.

In sub-Saharan Africa, particularly in rural regions, close family ties, communal living and traditional belief systems undoubtedly influence this experience (Baskind and Birbeck 2005). These belief systems lead to negative attitudes towards persons with epilepsy. In Nigeria for example, schoolchildren with epilepsy encounter social problems that are further compounded by the paucity of knowledge of epilepsy among teachers. This results in negative attitudes and beliefs despite high levels of

education in some areas (Ojinnaka 2002). It appears that in Khartoum State, Sudan, the level of knowledge and understanding of epilepsy needs community education to fill the gaps, clear the misconceptions and minimize social stigma. These efforts will lead to acceptance of persons with epilepsy (Sidig *et al.* 2009). In Cameroon, epilepsy has been reported to be highly stigmatised. Most persons with epilepsy faced high levels of discrimination irrespective of environment, gender or socio-economic status (Reidpath *et al.* 2001). Furthermore, those identified as persons with epilepsy in Cameroon have restrictions placed on them, which reduces their ability to perform traditional roles, affects their social value and excludes them from their communities (Allotey and Reidpath 2007).

On the other hand, gender is generally understood to be culturally constructed rather than a mere biological differentiation based on sex. Gender within the contemporary African context might in some aspects determine resource allocation. In Ethiopia, an evaluation of husband and wife assets indicates that variations across communities and ethnic groups may be larger than variations in the assets position of men and women within those groups (Quisumbing and Maluccio 1999). This implies that most African communities share the same assets ideas and that women are in a disadvantaged position.

In relation to epilepsy, the experience of its effects varies between men and women. As to the degree to which women suffer more than men, it is also understood that being a female and living with epilepsy, one faces several dangers with regard to reproductive activity. Anti-epileptic medications can reduce the effect of birth control pills and render epileptics vulnerable to pregnancy. While pregnant, the frequency of epileptic fits increases (Esprit *et al.* 1969; Bersjo 1971; Melin *et al.* 1974; Janz and Schmidt 1974; John, 1976; Kenyon 1982). In the cultural domain, Zambian women with epilepsy face the risk of breaking taboos as well as limitations in role fulfillment and extremes of social rejection by family and community (Gretchen *et al.* 2008). Therefore, the general outcry has always been that women are placed in a disadvantaged position relative to the culturally constructed concept of gender. Within the context of the present study, a reverse trend has been observed where a man living with epilepsy is in a disadvantageous position compared to a woman in the same situation.

The theoretical paradigm used in this work is the cognitive approach. Cognitive anthropology examines how people perceive the world around them. This paradigm relies on the notion that the world itself is chaotic and humans understand it through their own classification (Tyler 1969;

McGee and Richard 2004). In other words, people put the world in order by noticing some phenomena and ignoring others or by grouping some aspects together and excluding others. Accordingly, people perceive and organize phenomena – such as materials, events, behaviour and emotions – according to different patterns. Instead of attempting to search for universal laws that apply to all cultures, the cognitive anthropological approach reveals classification systems that are unique to each culture. This paradigm studies human conditions and especially ‘idea systems’ (D’Andrade 1995). Gender dimensions and their implications for the experience of epilepsy in the Manguissa community can best be grasped by using the theoretical paradigm that the importance of either male or female is culturally constructed.

### **The Manguissa People**

The Manguissa community is located about 80 kilometres north-west of Yaoundé, at latitude 4° 20’ north of the equator and between longitudes 11° 15’ and 11° 35’ east of the Greenwich Meridian. This community lies to the right of the main road linking Yaoundé and Bafoussam. The two subdivisions – Sa’a and Ebebda – are bordered to the west by Mbam and Inoubou Division, to the north-west by Mbam and Kim Division, to the East by Obala subdivision, and to the south by Monatele subdivision.

The history of settlement of the Manguissa people is not separate from that of the other Beti-Pahuin groups. Their migration coincided with the conquests of Usman Dan Fodio in the early 19th century. Under pressure from Fulbe (Fula) raiders, the Vute moved once more into Beti-Pahuin lands, and the Beti-Pahuin were forced to relocate once again. They moved south and west in a series of waves (Neba 1999; Ngoh 1996). Oral sources among the Manguissa people narrate that they crossed the Sanaga River moving southwards. The crossing of the Sanaga River was a mystical event that could be likened to a divine crossing. The narrative states that the people found something that was like a trunk of wood and crossed on it. This trunk of wood was a python.

The Manguissa people are patrilineal. The family is traced in two directions: the father’s relatives (*abus tsangwe*) meaning behind the father, and the mother’s relatives. Succession follows the father’s line of relatives. One can only succeed his father if the mother’s bride price was fully paid. This notwithstanding, the Manguissa people place a lot of importance and respect on the maternal uncle (*nyia ndome*) and the nephew. To them, the nephew has the right to claim anything in the uncle’s compound. The uncle on the other hand is respected and feared because he has the right and powers to curse. The highest level of social integration

is known as the *mbock*.<sup>2</sup> The head of the family or lineage has some religious powers over his subjects. There is no external control out of the sphere of influence of the *mbock*.

Empirical data show that the Manguissa people live in small, roadside villages of no more than a few thousand inhabitants. These villages are mostly linear, with houses parallel to the road and backed by the forest. The typical dwelling unit is constructed of dried mud placed on a bamboo frame and roofed with corrugated sheets. In some places, there are still a few dwellings roofed with palm fronds. In recent times, wealthier individuals have constructed their homes with concrete. In front of each dwelling is a hangar used for drying either cacao or foodstuffs. Most toilets are behind the dwellings, and further on there are some plantations. In some villages, the secondary forest is not at all far from the dwellings.

## Methodology

This exploratory research investigated the gender dimensions of the experience of the burden of epilepsy in Manguissa culture. The following methods were used: qualitative data collection relied heavily on observation, in-depth interviews, and photo voice, while quantitative data collection relied on semi-structured questionnaire, SF12 (Short Form Health Survey) and ComQol (Comprehensive Quality of Life) scales. The use of multiple methods permitted the triangulation of data to grasp all aspects of the study.

We observed the daily activities of persons living with epilepsy and they allowed us to take pictures of their activities. These activities were divided into two categories: those that they can do despite the disease and those that they cannot do because of the disease. In-depth interviews were conducted with persons living with epilepsy and with their relatives, considered in this study as significant others as they relate very much with persons living with epilepsy. These interviews were conducted at their homes. SF12<sup>3</sup> Scale measured activities and control over sickness while ComQol collected data on the respondents' life, satisfaction and importance domains. The semi-structured questionnaire collected data on respondents' history of epilepsy.

## The Sample

This research was conducted using a total of 88 persons (44 with epilepsy plus 44 significant others within the social network).<sup>4</sup> As for persons with epilepsy, we had 22 males and 22 females. This gender division enabled us to gather enough data on the extent to which individuals of both sexes suffer differently from epilepsy.

The judgment sampling method was used in selecting respondents to represent each of the independent factors in each setting (i.e. sex and disease severity) and to ensure that the operationalisation of the disease conditions was consistent for all respondents. Informants were purposively selected to suit the disease conditions set out for the study. This is an appropriate sampling technique for the selection of a few cases for intensive study in life history research (Russels 1989).

With regard to data treatment and analysis, raw data in audio tapes were transcribed and saved as separate files. These were thematically analysed using Text Base Beta.<sup>5</sup> Quantitative data were analysed using Epi-Info. These data were later exported into SPSS Windows software for quantitative data analysis) and Microsoft Excel for better graphic presentation.

## **Results**

### *Family Life*

Family life in this study embodied two sub-concepts: affinal<sup>6</sup> and consanguinal<sup>7</sup> relations. Results show that both relationships are affected to varying degrees. For affinal relationships, we found that variables such as single life without children, single parenthood, strained relationship, and separation were very prevalent among persons living with epilepsy. For consanguinal relationships, variables such as importance of blood relationship, satisfaction with blood relationship, and support were also affected.

## **Affinal Relations**

### *Single Life without Children*

Of the forty-four informants, thirty-one were single without children. Eleven out of this number were female while twenty were male. The twenty males with epilepsy claimed that they did not have children due to epilepsy. This category was also of the opinion that they did not have children because women intimidate them whenever they make love advances towards them:

My sickness actually had an impact on my life because at this age I am not yet married. I do not have a woman. This is why I do not have children and I am very worried about this. This is because I am to some extent intimidated by the feminine gender. This is because I could not control my life at a certain time. I am living alone, I am still single. (E6m)<sup>8</sup>

Because when it happened like this, hum, all the girls with whom I was living went back to their parents. (E9m)<sup>9</sup>

Women in the Manguissa community are usually very proud of their male partners and it is culturally degrading to have one who is epileptic, considering the social stigma the disease carries in the community.

### *Single Parenthood*

There were eight single parents with epilepsy and all of them were female. Four of the single mothers had two children each and the other four had one child each. This is because females with epilepsy still have relatively greater access to sexual intercourse than their male counterparts do. They are left with children without fathers, as wayward men run away after making them pregnant. However, their status within the society is higher than that of their male counterparts without children.

Apart from the consideration that they continue to receive from the society as people who are still useful because of their capacity to procreate, females with epilepsy face the responsibility of children without fathers. One woman was abandoned because the father of one of her children discovered through gossip that she was suffering from epilepsy. Some do not know the whereabouts of their children's fathers. They have never been married before:

Married! I do not yet know. If the person who is the father of this child, if he wants to come, I am waiting. His sister was saying that I was going to go back with him. I do not know whether they are going to come again. (E3f)<sup>10</sup>

As I am seeing, the father of my first child ran away. He was saying that he cannot accept to marry a woman who is sick. He is ashamed. He is ashamed that people will say that his wife is sick. Therefore, he left; he abandoned me like that without any problem. Even the other one, when they were saying that I was sick, he was not accepting but when he saw me (having a fit), he could not (stand) it. (E12f)<sup>11</sup>

No! He is with his parents and does not want to write to me while he knows that I am pregnant. He is running away. There is nothing that I can do. I did not know that I was pregnant until my mother told me. He came and deceived me and ran away. (E22F)<sup>12</sup>

In general, the women say that they never really dated the men for long, but pregnancy came immediately they got into sexual contact with these men who then denied responsibility just because the women had epilepsy.

### **Separation**

Two men living in semi-urban centres of the region (Ebedda and Sa'a) had separated from their wives. They hold the opinion that their spouses separated from them because they were constantly sick and unable to provide for the family. According to them, their partners abandoned them simply because of epilepsy. All these men have children who live with their mothers. They feel stigmatised by their wives.

Actually as I told you, I was planning to remain with a certain girl, the one I recently took, which I really wanted to take as my second wife. We had some problems just of recent. She does not respect at all. I think she is planning to leave. (E4m)<sup>13</sup>

I told you that I have exhausted my (strength) as (far as) this sickness is concerned. This is because my wife is no more with me. You know that with women when one does not have money again and is not in good health, they cannot support. She is no more with me. Our children are just like that. No matter what I am doing, I do no more have anything that can give me money apart from my work which I can no more do. (E10m)<sup>14</sup>

### **Consanguinal Relations**

Persons living with epilepsy expressed the importance and satisfaction they derive from their blood relations. Details of the relationships equally portray discrepancies in terms of gender, with the male sex experiencing strained relations and less support as compared to their female counterparts.

### **Importance of Blood Relationship**

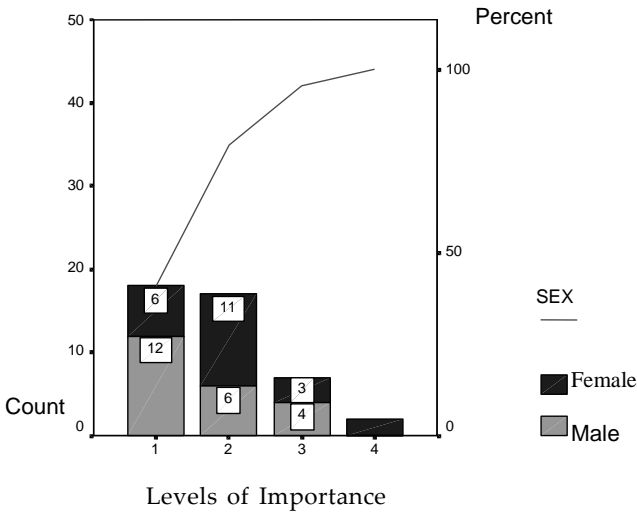
The Comprehensive Quality of Life Scales (ComQoL) produced a score that helped in assessing respondents' relationships with their families. One of the scores portrayed the importance of this type of relationship. Eighteen respondents out of forty-four declared that the relationship with their family members was 'very, very important'. On the other hand, seventeen respondents declared that this relationship was only 'very important'. Seven respondents declared that this relationship was 'somewhat important', meaning that they were indifferent, while two were of the opinion that their relationship was 'slightly important'. However, no epileptic was of the opinion that the relationship with his or her family members was not important.

Differentiation by sex shows that 67 per cent of those who accepted that their relationship was 'very, very important' were male as opposed to 33 per cent who were female. Females constituted 65 per cent of those who accepted that the relationship was just 'very important', while



males represented 35 per cent. In the indifference group, males constituted 57 per cent while females were 43 per cent. The two respondents who accepted that their relationship was ‘slightly important’ were female epileptics. On the whole, females tend to take the relationship with family members for granted.

**Fig. 1:** Sex Representation of Importance of Close Relationship with Relatives



In Figure 1 above, level 1 represents ‘very, very important’, level 2 ‘very important’, level 3 ‘somehow important’, while level 4 represents ‘slightly important’. It should be noted that no person with epilepsy chose level 5, which represents ‘not important at all’.

On the whole, both male and female respondents felt that their relationship with the members of their families was important. Here, females underestimated the importance of the relationship with family members while males overestimated the importance of the family.

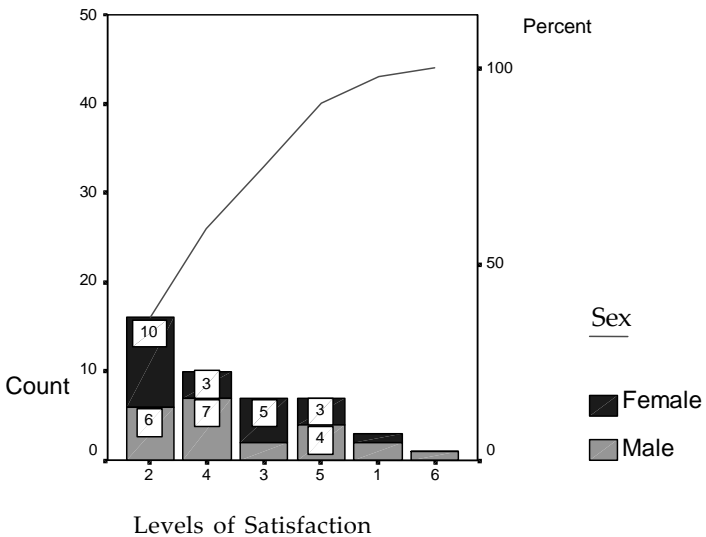
**Satisfaction with Blood Relationship**

Again, a score from the ComGol scale helped in assessing the satisfaction of respondents with their family members. Respondents of both sexes expressed their satisfaction level with relatives. Only three respondents were delighted with the relationship while sixteen respondents were pleased with the relationship. On the other hand, seven respondents were mostly satisfied while ten were indifferent. There were also seven respondents who were mostly dissatisfied with this relationship. Only one patient was unhappy with the family relationship – see Figure 2

below on how satisfied people living with epilepsy are with their close relationships at family level.

Sex representation of these data produces the following results. It was observed that most of the females with epilepsy were satisfied with their relationship with the rest of their family members as compared to their male counterparts. The majority in the indifferent group, right up to the unhappy group, are male epileptics (Figure 2). This satisfaction level has a direct relation with the shabby treatment they receive from their family members.

**Fig. 2:** Sex Representation of Satisfaction with their Close Relatives at the Family Level



In the above figure, level 1 stands for ‘delighted’, level 2 ‘pleased’, level 3 ‘mostly satisfied’, level 4 ‘indifferent’, level 5 ‘mostly dissatisfied’, level 6 ‘unhappy’. No person living with epilepsy was found at level 7, which represents ‘feeling terrible’.

**Support from Close Blood Relatives**

Twenty-four of the forty-four respondents were receiving material, financial, moral and physical support from their family members. Twenty-two of them are females. This support varies from family to family. Financial support usually comes from first-degree family members (father/mother). Brothers and sisters were equally prominent as main agents for physical and moral support. They help respondents when they move out of home, go to the bush, the market, to church, and so on. Most re-

spondents were assisted by their mothers in looking for treatment. The following statements illustrate the range of help:

No! It has not affected our family life and the whole family has really fought very hard to restore my health. This is why for the moment I am now with my grandmother because my mother is almost blind. (E17f)<sup>15</sup>

They are still as they were before when I was not yet sick. They have not changed. They assist me with food, clothes and many other things. (E2f)<sup>16</sup>

Some people living with epilepsy who receive material, financial, moral and physical support from family circles instead tend to undermine the importance of the family. They take the support they receive from their families for granted, in contrast to those who receive little or no support.

### **Effects of Epilepsy on Intimacy**

The social milieu of people living with epilepsy is characterised by the distortion of intimacy. Respondents experienced this in relation to their sex life: no sexual relations at all, decrease in the frequency of sexual relation, and no effect on sexual relations.

#### ***No Sexual Relations at All***

Nineteen respondents have completely stopped sexual relations and fourteen of them are male. There are several reasons why there are many more males than females in this category. Where sexual relations are concerned, male respondents suffer more from social stigmatisation than females since women in this community are proud of their male partners. No woman can boast of a male partner living with epilepsy, since epilepsy is stigmatised. This is best explained by the following excerpt.

I have no friend in this village. I do not easily go out. If I need a friend, then I am forced to go to Yaoundé where people do not know me as an epileptic. In Sa'a, our main town here, I cannot easily have a partner because I am already known there as an epileptic and all the women run away from me. (E6m)<sup>17</sup>

Many of these respondents were very depressed, being people who would have liked to have friends of the opposite sex.

#### ***Decrease in the Frequency of Sexual Relations***

Twenty-two persons living with epilepsy said they are experiencing a decrease in their sexual relations due to epilepsy. These are people who had very good friends before falling sick. There are others who have developed coping strategies for concealing the disease from their part-

ners. There are more females in this category than males. One major reason why there are more females than males in this category is that women retain their sexual partners despite the disease whereas their male counterparts are rejected by women when they are categorised as epileptics. The following are statements by two female epileptics on how they are treated by their former friends:

Yes, what can I tell you? You know that when you are living with a man, you do not know that one day you will have this type of a disease. As for me, the type of life that I was leading with him is not the same that I am leading now. I can say that I am now just as a pendulum. I am a thing that can be balanced by men at will. (E16f)<sup>18</sup>

It is due to this sickness, because the father of my child is looking at me from a distance. He cannot even pay drugs for my sickness. He can only take the child to the hospital when it is sick. He will like to be dealing with me in hiding. (E14f)<sup>19</sup>

Most of these men visit their former friends in the night and have sex with them but would not like the general public to believe that they live together. The women believe that it is due to epilepsy that men are treating them like this. Despite everything, their friends are no longer zealous in their relationships and they can compare life before and after the beginning of the sickness.

Males who continue to have sexual relations with their partners are those who live in semi-urban villages and whose partners reside in urban areas such as Yaoundé.

### *Sexual Life not Affected*

Among the forty-four persons living with epilepsy, there were three whose intimacy was not affected by epilepsy. This happens because of two factors. Firstly, marriage is a stabilising factor in epilepsy, as those whose intimacy is not affected are married. Secondly, the ability to conceal the disease within the society protects intimacy. This is true as female members of the community interact sexually with males with epilepsy whose nature of disease is not known.

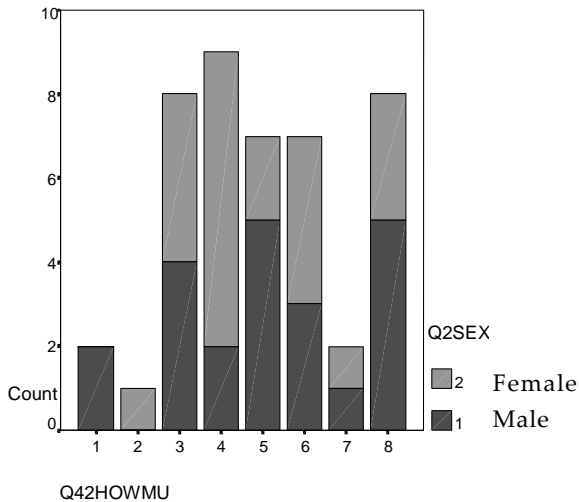
### **The Effects of Epilepsy on Quality of Life**

Respondents expressed the effects of epilepsy on their quality of life in terms of control over factors not stated life, optimism, self-esteem, and material well-being.

### Control

Control over life with epilepsy was measured on a scale from 1 to 10 where 1 represented no control at all while 10 stood for complete control. Many persons with epilepsy had lost control over their lives due to the disease, some drastically. None of them had a control level higher than 8. Instead, 4 per cent of them declared that they had control over their lives at level 1. Nineteen per cent of them had control over their lives at level 8. Four per cent of them had it at level 7, while 16 per cent had it at level 6. Another 16 per cent had control at level 5, 20 per cent and 19 per cent had control at levels 4 and 3 respectively, while 2 per cent had it at level 2 (Figure 3).

**Fig. 3:** Control over Life with the Sickness



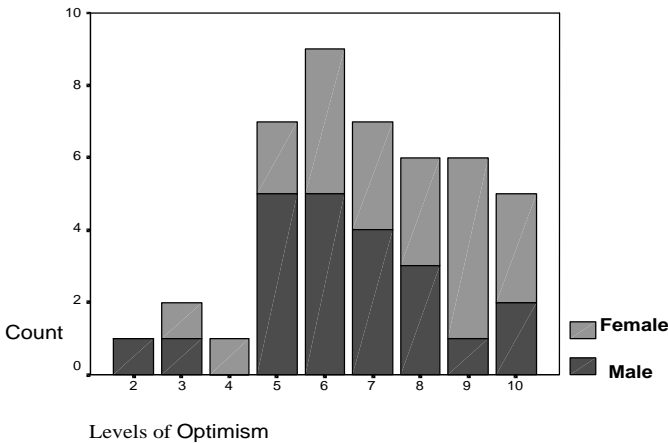
In Figure 3 above, 1 represents no control at all, while 10 represents complete control. Levels 5 and 6 are on the border line between those who had control and those who did not.

The data show that some females with epilepsy have relative control over their lives compared with their male counterparts because at the lowest control level, only males with epilepsy were found. The qualitative data show that female epileptics are better treated socially than their male counterparts are. Due to social isolation and neglect, male epileptics face psychological problems and can be overwhelmed by the disease.

## Optimism

The way persons with epilepsy feel about their future was expressed on the SF-12 health survey scale and complemented with data from in-depth interviews. The SF-12 health survey scale runs from 1 to 10. Each point represents a level of measurement. Responses about optimism for the future were concentrated at levels 5 and 7, representing 16 per cent of the sample each. Levels 8 and 9, which fall among the highly optimistic levels, each had a score of 15 per cent. Level 6 was the only exception, registering the highest score of 21 per cent. It should be noted that levels 5 and 6 were at the dividing line in the middle of the scale, representing those who were not certain about their future at all. They were neither too optimistic nor pessimistic. They constituted 37 per cent of the sample. Those who stood at points 2, 3 and 4, were very pessimistic about their future and represented 9 per cent of the sample, meaning that persons with epilepsy were generally not pessimistic about the future. It is notable that females living with epilepsy are relatively more optimistic about their future than their male counterparts are.

**Fig. 4:** Optimism about the Future



In Figure 4 above, level 1 stands for 'completely disagree about being optimistic', while 10 stands for 'completely agree'. The outcome of this measurement varied with sex, with females more optimistic about their future than male epileptics are. This provides further confirmation of the outcome of qualitative data on how male epileptics face greater discrimination within the family than their female counterparts do.

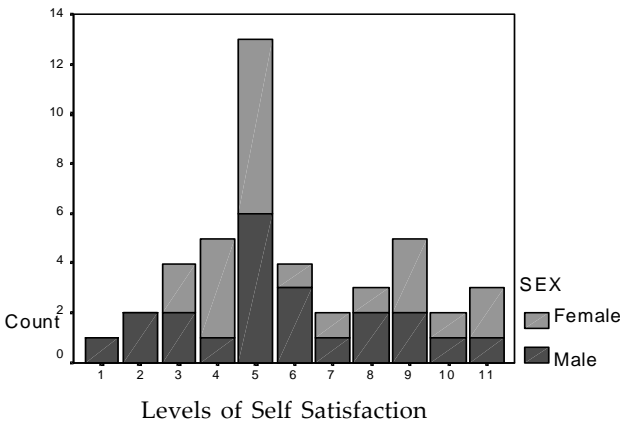
### Self-esteem

The SF-12 health survey scale produced a score that permitted assessment of self-esteem as a component of quality of life. This scale was graded into 11 points and each point represented a measurement level. Level 1 represented a position where they ‘strongly disagreed’ while level 11 stood for ‘strongly agreed’.

The highest single score for self-esteem was at level 5, situated on the border line between those who were not satisfied with themselves and those who were satisfied – 29 per cent of the sample was situated at this point. They neither totally disagreed nor agreed. The second highest frequency was at level 9, which represented 12 per cent of the sample. On the whole, a majority of them agreed that they were to some extent satisfied with life.

In relation to sex, the trend shows that those who had the lowest levels of self-satisfaction (at points 1 and 2) were all males with epilepsy. On the other hand, the majority of respondents at points 10 and 11 Levels of Optimism were female, indicating how female respondents are much more confident about themselves than their male counterparts. The explanation for this difference in perception about oneself can be found in the social milieu where female epileptics are treated better than their male counterparts.

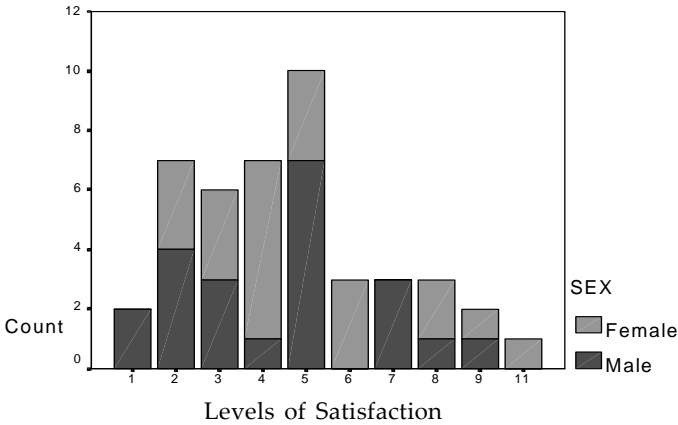
**Fig. 5: Self Satisfaction**



In Figure 5, level 1 stands for ‘strongly disagree’ while 11 stands for ‘strongly agree’. In terms of feeling good about themselves, the highest frequency of scores on the SF-12 scale was again at level 5, which was the border line between those who were not feeling good about themselves and those who were feeling good. They represented 22.7 per cent of the

sample and were situated from level 4 down to 1. At level 1, only male respondents were found, while at level 11 only female epileptics were found.

**Fig 6:** Feeling Good about Oneself



This again illustrates gender differences in the perception of self-esteem.

## Discussion and Conclusion

Gender determines the extent to which one is either rejected or accepted within family circles and the community. When gender dimensions are considered in the assessment of people's attitudes to respondents with diseases that carry stigma, compassion seems to be more common among women than men (Ndinda *et al.* 2007). Traditionally, girls and women are believed to have more psychological problems than boys and men (Nolen-Hoeksema and Girgus 1994). However, contrary to this traditional gender perspective, males with epilepsy in the Manguissa community experience more psychological problems than females with the same condition. A majority of those who did not have children among persons living with epilepsy in the Manguissa community were males. These male members of the community were considered useless, as they have nothing to offer. In this situation, family resources are diverted away from them. They see themselves as different from the rest of the family, and so develop depressed behaviour, which then makes them look even physically different from others and strengthens stigmatisation. They develop 'felt stigma',<sup>20</sup> which is really the habit of learning to become an epileptic. It is a vicious cycle as stigmatisation strengthens their position as a different class of people. This is why males with epilepsy are known as mad men.



This perception and treatment of males with epilepsy within the Manguissa community stems from their consideration of the female child as the window of the family or better still as the ambassador of the family. Female children are perceived as those who would one day leave the family and unite with other families. Better treatment helps them look good and thereby become better family ambassadors. This perception is therefore translated into the more favourable attention given to epileptic females.

On the other hand, since females with epilepsy do not completely lose intimacy, their status within the family and the community is not completely lost. As childbearing is traditionally the measurement of success in life within the Manguissa community, epileptic females who have children are not classified among those who have failed; the Manguissa consider childlessness or barrenness as failure. Despite the presence of epilepsy in their lives, affected women are considered as still having something to offer. This results in high self esteem, which is directly translated into high quality of life. This consideration has enabled females with epilepsy to escape being considered "mad".<sup>21</sup> This corroborates the findings of Guralnik *et al.* (2009) on the reduced midlife physical functioning among never married and childless men, where for men, marriage and parenthood protect against functional decline in midlife. Therefore, in our context, living with epilepsy and being able to procreate strengthens one's position in the community. As females with epilepsy are capable of having sexual relations with community males, they are better than their male counterparts who have lost their sexual partners.

This notwithstanding, it is not simple for a woman with epilepsy to play the role of a mother. Despite the high status that children confer on females with epilepsy in this society, taking care of these children is another burden. Many single parents with epilepsy complain bitterly about the future of their children. Some of them are even worried that their children might be taken away from them for security purposes, sometimes without their consent. This is the ambivalence of being female and having epilepsy in the Manguissa community. You are given a better status due to procreation and at the same time, you carry a burden of child bearing.

Although most males with epilepsy confirmed that the relationship with their blood relatives is very important, they receive poorer treatment from family members than their female counterparts receive and are not satisfied with such relationships. Most males with epilepsy have

been abandoned to fend for themselves. On the other hand, females underestimate the importance of family relationships, but are very satisfied with such relations. Again, the fact that males with epilepsy are not satisfied with their blood relationships leads to depression in many more instances as compared to their female counterparts. Females within this cultural context are considered ambassadors of the family and in order to reduce shame and disgrace, these ambassadors should be treated well. This finding contradicts the traditional 'gender-divide' literature where most often, family finances are oriented more to the benefit of male children than of females, as the Indian case shows (Asfaw *et al.* 2009). This treatment of female children within the Manguissa family context could be considered as a kind of equity as females within this cultural context do not inherit landed property. We are dealing with a very powerful patriarchal society where succession rights are bestowed only on males. Therefore, giving better treatment to the female child while she is still residing within the family may be considered normal.

Perceptions of control over life among people with epilepsy were fairly evenly spread. However, only males with epilepsy were found at the lowest control level. This is a pointer to the fact that males with epilepsy receive shabby treatment from the social milieu. Females with epilepsy are optimistic and have high self-esteem as compared to their male counterparts. Control over life is a measure of quality of life. Having no control means that your decisions are not taken into consideration by anybody and you are reduced as a person. A study on the relation between stigma, depressed mood, low self-esteem, and low quality of life in respondents with schizophrenia spectrum disorders revealed that association of insight with depression, low quality of life, and negative self-esteem are moderated by stigma as patients with good insight do not perceive much stigmatisation (Staring *et al.* 2009). Due to social isolation and lack of attention, males with epilepsy in our context develop psychological problems and are overwhelmed by the disease. This is one of the causes of low self-esteem and consequently low quality of life. From the evidence, being female and able to procreate are conditions for a higher quality of life. Therefore, the experience of epilepsy in the Manguissa community depends on gender. Being a male with epilepsy in this community means you have to fend for yourself most of the time, while having the same condition as a woman does not necessarily lead to the same situation.

## Notes

1. A technique that enables the compilation of images generated by participants and interrelated to gain in-sights to qualitative interviews.
2. 'Mbock' in the Manguissa community is a tribe. It is controlled by the eldest person in the family.
3. A health survey scale mostly used by health psychologists.
4. 'Significant others' partner in an intimate relationship or very important close family relations.
5. A computer software used in analysing qualitative data.
6. Relationship by married.
7. Blood relationship.
8. Interview conducted in June 2000 at Mbilmana.
9. Interview conducted in June 2000 at Mbilmana.
10. E = Epilepsie, 3 = Numéro, f = femelle. Interview conducted in April 2000 at Nsan-Mendouga.
11. Interview conducted in April 2000 at Nsan-Mendouga.
12. Interview conducted in April 2000 at Bikogo.
13. E = Epilepsy, 4 = Number, m = male. Interview conducted in June 2000 at Nkol-Nguben.
14. Interview conducted in June 2000 at Nkol-Nguben.
15. Interview conducted in July 2000 at Mbenega.
16. Interview conducted in July 2000 at Mbenega.
17. Interview conducted in May 2000 at Mbilmana.
18. Interview conducted in May 2000 at Mbilmana.
19. Interview conducted in July 2000 at Ebomzout.
20. This refers to the individual's own attitude about their condition and how they expect others will react on learning of it. Felt stigma has also been referred to as self-stigmatisation and as fear of stigma.
21. Those who suffer from frequent loss of memory.

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