



Beliefs of people living with epilepsy in the Accra Metropolis, Ghana

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ARTICLE INFO

Keywords:

People living with epilepsy
Beliefs
Ghana

ABSTRACT

Purpose: The study aimed at describing the beliefs that People Living with Epilepsy (PLWE) have about the disease.

Methods: A descriptive-exploratory qualitative design was employed to guide the study. Thirteen (13) participants living with epilepsy in the Accra Metropolis were purposively sampled. Face-to-face in-depth interviews were conducted and data were analysed using the content analysis approach.

Results: The themes that emerged from the data were beliefs about signs and symptoms, causes, consequences and beliefs about cure and control of epilepsy. Participants believed epilepsy was a disgraceful illness. Most participants believed epilepsy was due to spiritual causes. Seizures resulted in injuries and were believed to have affected the education, work and relationships of the PLWE.

Conclusion: The results suggest that the false beliefs about the causes of epilepsy were an indication of knowledge gap on the causes of epilepsy among the PLWE. Health care professionals should intensify health education campaigns on epilepsy to demystify traditional beliefs about epilepsy and promote greater understanding and acceptance of PLWE.

1. Introduction

Epilepsy is a chronic brain disorder that briefly interrupts the normal electrical activity of the brain to cause seizures [1]. Roughly 50 million people worldwide suffer from epilepsy, which accounts for 0.5% of the global burden of disease [2]. Epilepsy directly affects around 10 million people in Africa [2], with its highest prevalence in poor countries including countries in sub-Saharan Africa [3]. The incidence of epilepsy in Ghana is believed to be high as compared to the sub-Saharan African region [4].

The disease continues to be an often misunderstood and stigmatizing condition that affects the quality of life of the people living with epilepsy (PLWE) [5]. Among the symptoms to manifest are loss of consciousness [6] and uncontrolled musculoskeletal movements [7]. Hence a person living with epilepsy is usually unaware of the happenings around him or her [8] during and/or after an episode.

In many primitive societies, including in Africa, epilepsy is believed to be a result of sin and demonic possession [9]. The traditional African belief system, which attributes epilepsy to witchcraft and blames the victim, offers the ideal environment for stigma to flourish [10]. Epilepsy is sometimes attributed to mental illness [11] due to ignorance on the part of the society [9]. Although brain injuries, space occupying

lesions and infections have been found to cause epilepsy, the causes of most epilepsies remain unknown [11].

A clinical diagnosis of epilepsy often carries a silent social stigma [12]. Some PLWEs experience actual discrimination (enacted stigma) in the form of termination or refusal of employment [13], avoidance or rejection by society [12] and rejection from actual or prospective life partners. Some people avoid PLWEs for fear of contagion [11].

Despite these unfortunate outcomes of epilepsy, some PLWEs eventually gain some form of control over the condition when they come to terms with the condition and accept it as a part of their lives [14]. Some affected persons express hope for a better outcome and develop some confidence and sense of control when placed on Anti-Epileptic Drugs (AEDs) [15]. Other PLWEs believe the condition made them tough survivors [16].

In Ghana epilepsy is a highly stigmatised condition [17] and is also attributed to spiritual causes [18]. Existing literature on the beliefs about epilepsy in Africa may not represent that of PLWEs in Ghana, due to socio-cultural differences. This study sought to explore the epilepsy beliefs among PLWEs within the Accra Metropolis in Ghana, such as the causes, signs and symptoms, consequences, cure and control of epilepsy.

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2. Methods

2.1. Design

The study employed a descriptive-exploratory qualitative design to explore detailed descriptions of beliefs of PLWEs. This design is appropriate in assessing beliefs of a phenomenon from the participants' perspective [19].

2.2. Sample and Sampling

Participants were recruited through the community mental health units of one polyclinic and two general hospitals within the Accra Metropolis, using the purposive sampling technique. Thirteen PLWEs without co-morbid mental retardation and psychiatric illness in the age group 18–40 years of age, and who could speak and understand English or “Twi” were purposively selected for the study. The staff at the three community mental health units served as contact persons for the identification and recruitment of participants for the study. Written consent was sought from the participants after which interview sessions were arranged with them.

2.3. Data collection

A semi-structured interview guide was used to conduct face-to-face in-depth interviews with the participants. Nine of the interviews were carried out in the community psychiatric units of the selected health facilities, and the remaining four were conducted in the participants' own home environment. Each interview session lasted between 45 and 90 min. The interview guide had two sections: Section “A” was on demographic data, and Section “B” comprised guiding, open-ended questions with probes on beliefs about epilepsy.

The open-ended questions aided in seeking clarification by probing the issues arising from the interview [20]. These questions assessed respondents' beliefs about epilepsy, the signs and symptoms of epilepsy they experienced, how they felt about epilepsy and the effect of epilepsy on their lives. The interviews were all audio recorded and field notes were also taken from observations made during each interview session.

2.4. Transcription

The interviews were transcribed verbatim. Interviews done in “Twi” were translated into English by a “Twi” expert, whilst ensuring confidentiality in the process. Transcription and analysis were done after each interview.

2.5. Data Analysis

The principles of content analysis involving preparation, organisation and reporting of results [21] were applied in the analysis of transcripts from the interviews. Transcribed data were read through several times to get the real meaning of each transcript. Coding was then carried out by identifying similar words, phrases, sentences and ideas, which were highlighted in similar colors. These were then grouped together to form themes and subthemes.

Data from field notes were also analyzed and added to the results to enhance the meaning of the information gathered. Reports on the themes and sub-themes were supported with verbatim quotes of participants from the transcribed data. In place of participants' real names, identification codes were used in reporting findings in order to ensure anonymity. The second and third authors verified findings to ensure that the true beliefs of the respondents were fully represented.

2.6. Rigour

Methodological rigour was ensured by applying the trustworthiness criteria of Lincoln and Guba [22]. Pre-testing the interview guide enhanced the credibility and dependability of the study [23]. Co-coding and assessment of the findings were done by the second and third authors to ensure the study findings and conclusions drawn are supported by the data. An in-depth exploration of the phenomenon under study and clarification of all information provided were done to ensure confirmability. This was transcribed immediately after each interview to portray the exact meaning of each interview.

2.7. Ethics

Ethical approval was granted by the Institute of Statistical, Social and Economic Research, University of Ghana (ECH 079/ 13-14), and permission sought from the Greater Accra Regional mental health unit coordinator of the community mental health unit in the Greater Accra Region to collect data.

3. Results

This study explored beliefs about epilepsy among PLWE in Ghana. Thirteen PLWEs were interviewed by the principal investigator. The age range of the participants was from 18 to 40 years. One was below 20 years, two were between 20 and 30 years and ten were from 30 to 40 years. Seven of the participants were males and six were females. Seven of them attained basic education and six had attained secondary education. Ten of them were not married, two were married and one was divorced. Five of them were self-employed and three were private employees. However, four were unemployed and one was a student. Only one was a Muslim. The remaining 12 were Christians. Seven of the participants have lived with epilepsy for 20 years and below, four have lived with epilepsy for 21 to 30 years and two have lived with epilepsy for 31 to 36 years (Table 1).

Accounts of the beliefs of PLWEs about epilepsy have been grouped into four themes, namely: beliefs about signs and symptoms, beliefs about causes, beliefs about consequences and beliefs about cure and control of epilepsy.

3.1. Beliefs about signs and symptoms of epilepsy

The beliefs of the signs and symptoms of epilepsy of the participants are what they experience, including falling down during a seizure episode and loss of consciousness. They either realised they had a seizure after waking up to see themselves dirty and bruised or were told by relatives and/ or friends who witnessed these seizure episodes.

“At first when the seizure attack occurs, it causes me to fall down” (M5).

“When I fall, I don't even know that I have fallen to the ground ... I will sleep for a long time and only realize that I got injured when I wake up” (M6).

A few of them believed they passed urine and soiled themselves during seizure episodes, although this was not a regular occurrence:

“Sometimes I urinate in my pants ...” (M1).

“Usually when it happens, before I realise, I would urinate on myself. Sometimes the urine drips on me without my control” (F2).

These signs and symptoms occur in church, mosque, market and school in the full glare of the public, including friends and unsuspecting persons. As a result of this, the PLWEs believe epilepsy is a shameful illness.

“... Sometimes at church it happens, I get the attack and it disgraces me” (M5).

“I have seizures when I go to school it (epilepsy) disgraces me ...The

Table 1
Demographic characteristics of participants [n = 13].

Identification Code	Age (Years)	Sex	Education	Marital Status	Employment Status	Religion	Duration of Illness (Years)
M1	28	Male	Basic education	Single	Unemployed	Christian	23
F1	38	Female	Basic education	Single	Self employed	Christian	18
F2	36	Female	Basic education	Divorced	Self employed	Muslim	20
M2	36	Male	Basic education	Single	Self employed	Christian	21
F3	29	Female	Basic education	Single	Unemployed	Christian	19
M3	40	Male	Secondary education	Single	Self employed	Christian	36
F4	18	Female	Basic education	Single	Student	Christian	11
M4	34	Male	Basic education	Single	Private employee	Christian	11
F5	36	Female	Secondary education	Married	Private employee	Christian	22
M5	40	Male	Secondary education	Married	Self employed	Christian	14
M6	38	Male	Secondary education	Single	Self employed	Christian	30
M7	34	Male	Basic education	Single	Unemployed	Christian	32
F6	35	Female	Secondary education	Single	Private employee	Christian	20

other day my mother sent me to the market and it disgraced me at the market” (F4).

“I think it (epilepsy) is a bad illness that wants to disgrace me just like that ... It is a disgraceful illness” (F4).

Some of the participants believed that the symptoms of their epilepsy would be of a short duration, while others were unable to tell how long their seizures would last.

“I know now that it (epilepsy) will not last for a long time” (M3).

“At the beginning I thought the seizures will not last. However, since the year 2009 up till now I am still not totally cured from my epilepsy” (M4).

“As for this I don’t know how long it (epilepsy) will last because this thing started since 1994 up till now” (F5).

3.2. Beliefs about causes of epilepsy

Belief about causes of epilepsy included physical, spiritual and unknown causes. A few of the participants attributed their epilepsy to physical causes such as hunger and starvation.

“I could remember that in the evenings, during my childhood I don’t eat. At times I could even eat once in a day and I think that has caused this epilepsy” (M6).

The majority of the participants believed that their epilepsy had a spiritual cause. Others believed that it was someone with evil intentions against them who was indirectly afflicting them with epilepsy spiritually, due to envy for their bright future.

“As for me I think that it is a bad spirit that caused this sickness” (M1).

“I used to live with a certain girl. She put some medicine inside my food and after I ate the food, I began to have seizures” (M7).

Some consulted spiritualists and pastors who proclaimed that their epilepsy was caused by evil spirits. Some participants, however, had no idea about the cause of their condition:

“They took me to one medicine man (spiritualist). Then they said that it is a bad spirit” (F2).

“...I really can’t point out that the actual cause of this illness” (F3).

3.3. Beliefs about consequences of epilepsy

Beliefs about the consequences of epilepsy were described in the form of physical injuries, effect on work, effect on education, stigma, disgrace, restrictions from general activities, effect on relationship with family and effect on love relationships.

Some of the PLWEs believed they fell into gutters and on the ground and sustained bruises whilst others got burnt by fire, which was evident by the scars on their bodies, as a result of their seizures. One woman

believed she aborted her pregnancies repeatedly as a result of injury from seizures:

“Some time back, I even fell into a gutter ... I got injured and had a lot of bruises” (M2).

“This is the scar from the burns I had [Shows burns scars on right arm and right thigh]. “It is on my arms and my legs. They said I fell into fire” (F3).

“Because of this illness ... anytime I get pregnant I lose it” (F2).

Most PLWEs believed they were restricted by relatives and friends to protect them from sustaining more injuries from the seizures. Some were restricted from cooking or getting close to sources of fire, handling electrical gadgets and from social gatherings such as parties.

“My father does not even allow me to handle electrical gadgets. Even if I had to heat water to bath, another person does it for me” (F3).

“My brothers do not allow me to go for any party because of this sickness. They are afraid that I will have a seizure episode outside” (M1).

Moreover, repeated seizure episodes were believed to have disrupted the work and school activities of some of the PLWEs. Others believed they had to stay at home for treatment and to avoid getting injured at work or in school from seizures. Some believed they were sacked after they had seizures at work, whilst others could no longer cope with learning at school.

“At first, I was working at the airport and I had an attack there so they sacked me. I went to another company and the same thing happened” (F5).

“Sometimes it happens in school. It happens on the way to school. That is why my mother stopped me from going to school” (M1).

“At first, I was intelligent in school ... but now I have noticed that when they teach, I am not able to understand it well” (F4).

Stigmatizing attitudes in the form of disrespect and mockery were experienced by the participants. Others believed people avoided them due to fear of contracting epilepsy. However, some family members showed concern and drew closer to offer their support.

“My husband’s relatives don’t respect me and they talk to me anyhow” (F2).

“They don’t even allow me to touch anything belonging to someone ... I was even asked to buy my own cup and bucket to use” (F3).

“All my relatives are free with me and they all get close to me. No one rejected me” (M5).

Furthermore, epilepsy is believed to have affected the love life of some of the PLWE. Two of the women with epilepsy got impregnated by their lovers but they believe the men refused to marry them due to their epilepsy. One woman got thrown out of her matrimonial home by her in-laws.

“I have a son, and his father run away from us. His father went for another woman” (F3).

“My husband’s sisters asked me to park out of the house ... My marriage is now over” (F2).

For the male participants, they believed their lovers quitted the love relationship after finding out they had epilepsy.

“The ladies I proposed marriage to later got to know about my epilepsy and they refused to accept my marriage proposal. At least two ladies have come and left” (M3).

3.4. Beliefs about cure or control of epilepsy

Participants’ belief about cure and control represented their expectations of recovery from seizures as they tried to control their seizures. The participants expressed hope and believed in God for cure. Others were confident that their medications had put their seizures under control. One participant opined that not all sicknesses were curable and had no expectations for total cure.

“As a result of the prayers and the medicines I take, I believe that God can heal me completely” (F4).

“I will say I have been able to deal with this illness (epilepsy) and put it under control ... The severity and frequency of the seizures have reduced” (M5).

“Not all sicknesses are curable. Maybe they are only helping me to cope with it (epilepsy) or just to prevent it to some extent” (M4).

4. Discussion

Study findings on beliefs about signs and symptoms of epilepsy revealed that the PLWEs believed they fell unconscious during seizure episodes. Seizures associated with loss of consciousness are usually termed generalized seizures and are usually accompanied by tonic-clonic movements of the limbs [7]. However, due to a disturbance of consciousness from seizures [6], the PLWEs were not always aware of their seizures and the signs and symptoms of the seizure episodes they experienced. This confirms the findings of Hoppe et al. [8] in Germany where PLWEs were unaware of some of their seizure episodes.

Having seizures in full view of the public is humiliating for the PLWEs. Hosseini et al. [12] posited that PLWEs feel a sense of indignity and low self-respect when onlookers stare and make contemptuous glances at them when having an epileptic seizure. Some participants soiled themselves with urine during some seizure episodes, which may be linked to loss of voluntary muscle control due to the nature of epilepsy [24]. The shameful experience of having seizures in public was associated with the belief that epilepsy is a shameful illness. This confirms the finding of Rätty, Larsson, Starrin and Wilde-Larsson [25] where the identity linked to epilepsy was shame.

Epilepsy was believed to be due to physical, spiritual and unknown causes. Although hunger was believed to be a physical cause of epilepsy, hunger and starvation may lead to malnutrition which may indirectly be a cause of epilepsy due to micronutrient deficiency [26]. However, hunger and starvation may be consequences of epilepsy due to stigmatizing attitudes against PLWEs [27].

Most of the participants approached spiritual healers due to the belief that epilepsy was a spiritual affliction placed on them. This depicts certain Ghanaian cultural beliefs where chronic illnesses such as epilepsy are attributed to spiritual causes such as acts of witchcraft, sorcery and the devil [18,10]. This situation is also common in many primitive societies, including in Africa, where epilepsy is attributed to sin and demonic possession [9]. On the other hand [11], posited that the causes of most cases of epilepsy are unknown. This may explain why a few of the participants could not link their epilepsy to any specific cause.

Despite beliefs of the PLWE about the signs and symptoms and causes of epilepsy, some had expectations for cure. This may be because early on they believed epilepsy was a short-term illness, but after years of treatment without complete cure, they could not predict how long the seizures would last. This suggests that with time, the reality of the chronic nature of epilepsy tends to dawn on the sufferers, which might make some lose hope [14]. This confirms the finding of Rätty et al. [15] where PLWE later came to the realisation of their epilepsy as a lifelong illness.

In this study, the PLWEs believed they sustained injuries such as burns and bruises due to falls from seizures. This confirms the findings of Kariuki et al. [28] where PLWEs in Africa were found to experience burns and head injuries from their seizure episodes. Usually, seizures result in injuries because they happen so quickly and the person has no warning to protect him or herself from falling [29].

One woman who suffered pregnancy losses due to seizures may have suffered severe physical trauma during seizure episodes. This is likely to cause fears concerning childbearing among women of fertility age living with epilepsy. In Zambia, such fears among women living with epilepsy went beyond losing their pregnancy to fears of the child being taken away from them after birth [30].

Attempts, by family and friends, to protect the PLWEs from severe injury in the event of a sudden seizure episode were in the form of restrictions from sources of fire and electrical gadgets. This confirms the finding of Gauffin, Flensner and Landtblom [31] that seizures impose further restrictions on PLWEs. Some could not attend social gatherings for fear of sustaining injuries from seizures in public. A similar response to seizures was reported by Hills [32], where PLWEs became socially withdrawn and avoided taking part in social events.

Seizure episodes at work not only disrupted activities in the workplace, they also resulted in discrimination against the PLWEs. These revelations are consistent with the findings of Scambler [13] that PLWEs face problems such as being rejected by an employer or discrimination in the form of actual termination or refusal of employment. Consequently, disruptions from work and other activities due to continuous seizures are likely to make PLWEs depend on others and become a burden to the family and the community at large [12], which is likely to affect their quality of living.

The education of the PLWEs was not immune to the negative effects of the seizures. This affected their cognitive function, which can be linked to the finding of Mung’ala-Odera et al. [33] where most (65%) children with epilepsy had cognitive impairment. This explains the lack of formal education noted among some PLWEs [28].

Participants experienced various stigmatising attitudes in the form of mockery and disrespect to them by family members, friends and neighbours. This is described by Jacoby [34] as enacted stigma and tallies with the findings of Hills [32] where people mocked, gossiped, avoided the company of PLWEs. Some of the PLWEs in the study experienced social isolation, which confirms the findings of Adjei et al. [17] that epilepsy is a highly stigmatised condition in Ghana. This is mainly due to ignorance on the part of society [9].

On the other hand, the experience of living with epilepsy rather strengthened the relationship between some PLWEs and their families, which serves as a social support for PLWEs and improves their quality of life [35]. Contrary to this, findings from Wang et al. [36] revealed that Chinese patients with epilepsy reported less family cohesion and less emotional support from their family. In Zambia, some women with epilepsy had supportive families whilst others were rejected [30].

However, the effect of living with epilepsy is believed to have negatively affected the love relationship of a majority of the participants with some men denying responsibility for children born to them by some women with epilepsy. This showed that although the men enjoyed having sexual relations with the women, they were not willing to commit themselves to a marital relationship with them. This is not different from the situation in Zambia where women with epilepsy found it difficult to have a life partner and some married ones were

eventually abandoned by their husbands [30]. One woman was maltreated by her in-laws, which finally led to the dissolution of her marriage. This depicts enacted stigma against PLWEs [13] where they are displaced or discriminated against due to unacceptable differences placed on them by the society.

The use of a small sample size in this study limits generalization of the findings to PLWEs in Ghana, however, it provided deep insight into the phenomenon under study – a hallmark of qualitative studies [37].

5. Conclusion

Seizure episodes were believed to be shameful due to the undignified fashion in which seizures manifested. Although epilepsy is believed to be caused by physical factors, superstitious beliefs about epilepsy still exist. The attribution of epilepsy to unnatural causes is an indication of a knowledge gap on the causes of epilepsy among PLWEs. This underscores the need for intensified health education to demystify traditional concepts about epilepsy among Ghanaians. The people living with epilepsy had their daily activities, including school, work and social life, interrupted by the seizures. Despite the chronic nature of epilepsy, most PLWEs still have hope for a cure. Future studies should aim at assessing the quality of life of people living with epilepsy in Ghana and the development of a community care model to improve the quality of life of people living with epilepsy.

Declaration of Competing Interest

The authors have no conflict of interest regarding this study.

Acknowledgements

This work was supported by an MPhil dissertation grant from the Christian Health Association of Ghana (CHAG) through the Office of Research, Innovation and Development (ORID), University of Ghana, Legon in the year 2015. The authors declare that the source of funding never affected the research process nor the write up of this manuscript.

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